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Telehealth and Citizen Involvement

by
Valerie Gideon

Graduate Program in Communications
McGill University, Montreal
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of Doctor of Philosophy

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Abstract

Telehealth is defined by Jocelyne Picot as "the use of communications and information technology to deliver health and health care services and information over large and small distances" (Telehealth Industry 1). Current research in telehealth focusses on the evaluation of applications and projects, on the competitiveness of the telehealth industry, and on its role in international development. In contrast, this dissertation contextualizes telehealth in social history and theory. In so doing, it adopts an analytical, cultural studies approach rather than an empirical one. It also studies the extent of citizen involvement in current telehealth initiatives in Canada. More specifically, the dissertation examines whether the forms of involvement promoted by telehealth initiatives *empower* Canadian citizens. The examination is conducted through a five-step process. The first four steps involve an overview of the following: (1) histories of medical technology; (2) critiques of medical technology; (3) history and critique of the Canadian health care system; (4) critiques of information and communications technology and policy. The fifth step consists in mapping out the current state of telehealth development in Canada, including policy, applications and projects, as well as distinguishing the main roles of citizens in such initiatives. In closing, ways of achieving citizen empowerment through telehealth are suggested, whether it is found to be achieved in recent initiatives or not. Theoretical frameworks with the aim of positioning new technology in order that it may accomplish social change and citizen empowerment are put forward as an innovative means of evaluating current telehealth applications and projects in Canada.

Résumé

La télésanté est définie par Jocelyne Picot comme étant "l'utilisation des technologies de l'information et des communications pour offrir des services, des soins et de l'information en matière de santé, sur de grandes et courtes distances" (L'industrie de la télésanté 1). La recherche actuelle portant sur la télésanté est axée sur des évaluations d'applications et de projets, des études sur la compétitivité de l'industrie de la télésanté, ainsi que des études sur ses débouchés en développement international. Présentant un nouvel éclairage, cette dissertation mettra plutôt l'emphase sur le contexte historique et social de la télésanté. Pour ce faire, une approche analytique fondée sur les études culturelles sera adoptée plutôt qu'une approche empirique. De même, les moyens de participation des citoyens, établis dans le cadre d'initiatives courantes en télésanté entreprises à travers le Canada, seront étudiés. Plus spécifiquement, cette étude évaluera si ces moyens de participation accroissent le pouvoir des citoyens. Pour procéder à cet examen, cinq étapes seront suivies. Les quatre premières présentent un aperçu global sur les sujets suivants : (1) l'histoire de la technologie médicale ; (2) la critique de la technologie médicale ; (3) l'histoire et la critique du système de soins de santé canadien ; (4) la critique des technologies de l'information et des communications et de leur politique. La cinquième étape décrit l'état actuel de la télésanté au Canada, considérant les politiques, les applications et les projets. De même, on fait la distinction entre les principaux rôles des citoyens au sein d'initiatives de télésanté. En conclusion, des moyens visant à augmenter le pouvoir des citoyens par l'entremise de la télésanté sont suggérés, moyens réalisés dans le cadre d'initiatives actuelles ou non. En s'appuyant sur des modèles théoriques visant à déployer la nouvelle technologie de façon à ce qu'elle

amène des changements sur le plan social et qu'elle augmente le pouvoir des citoyens, cette dissertation permet d'élaborer une méthode novatrice, ainsi que de nouveaux critères d'évaluation des applications et des projets de télésanté.

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To Sebastien and my parents, for their love.

INTRODUCTION

Telehealth is most commonly defined as "the use of communications and information technology to deliver health and health care services and information over large and small distances" (Picot, Telehealth Industry 1). There has occurred a remarkable amount of activity in the field of telehealth since I was first introduced to it in 1996. However, telehealth itself is not new. Experimental projects began as early as the nineteenth century when the telegraph was used to transmit communications between physicians, and to assess patients at a distance. Since then, telehealth in Canada has generally been implemented through pilot projects, relying on government funding, that were rarely sustained. More recently, the federal government has demonstrated an interest in financing pilot projects to evaluate the best conditions for implementation and use of telehealth. It has also launched national telehealth initiatives, primarily geared toward the development of health information networks for the purpose of public health, health promotion/prevention, clinical research and evidence-based decision-making. As well, many provincial and territorial governments are in the process of establishing their own health information networks that will incorporate a wide range of applications, ranging from telemedicine[1], electronic patient records, research networks and information management.

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[1]Telemedicine is more narrowly defined as the delivery of medical services at a distance.

Since the main obstacle to further telehealth development is the lack of sustained funding, research relating to telehealth has focussed on evaluations of the efficiency, clinical and technical effectiveness of pilot projects and applications.[2] It is assumed that if the outcomes of these evaluations are positive, support for telehealth will increase. As well, taking into account that the primary funding source of health care services in Canada is the state, telehealth must be proven to accommodate health care reform measures of cost containment and rationalized administration. The emphasis, therefore, is on building an adequate business case for telehealth initiatives. As Field confirms, ". . . sustainable telemedicine programs require attention to organizational business objectives and strategic plans that is not always evident in current applications" (3). Lately, much attention has indeed been paid to the formulation of a standard framework for telehealth evaluation, including a set of guiding principles and best practices. In addition, studies of the telehealth industry, commissioned by the state, promote the competitive edge of Canadian excellence in high-quality medical care and in information technology and telecommunications, hoping to foster a domestic and international market for telehealth products and services. Lastly, Canada's active role in foreign aid and global politics has prompted studies on the potential of telehealth in international development.

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[2]Notwithstanding, Marilyn J. Field has determined that most of these evaluations address feasibility and technical integration, rather than health outcomes, the process of health care, access to services and cost-benefits. Few peer-reviewed studies and a melting pot of divergent approaches and areas of study have impeded replications and cross-validations according to Field.

While I recognize that these approaches to the study of telehealth are fundamental to its growth, I am also aware of the lack of analysis of the wider context of telehealth, that is, its integration in social history and theory. Except in the evaluative approaches mentioned above, linear, descriptive histories of telehealth innovations, and discussion papers pertaining to relevant medico-legal issues, the implications of telehealth as a new technology, as a new mode of health care delivery, as a new industry, as a new professional specialty, as a new research interest etc., on Canadian history and society have not been considered. It is for this reason that I have chosen to undertake a dissertation on telehealth development in Canada that adopts an analytical, cultural studies approach rather than a descriptive or empirical one.[3] Nevertheless, my intention is not to dissociate this dissertation from the more prominent evaluations of telehealth initiatives. Preferably, I wish to inform these evaluations by contextualizing the planning, implementation and operation of telehealth initiatives. Taking into account that telehealth was born of the confluence of information and communications technology, health care and medical technology (Picot, Telehealth Industry 2), I will be framing telehealth development within the history and research of medical technology, the history and policy of Canadian health care, and the research and policy of information and communications technology. It is my contention that knowledge of the larger historical and social context of telehealth can influence the formulation of evaluation criteria and the interpretation of research outcomes. At the end of this dissertation, I will precisely

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[3]The place of cultural studies in the history of critiques of information and communications technology will be outlined in Chapter Four.

demonstrate how this materializes.

The dissertation also deals with citizen involvement in telehealth. I became interested in this particular topic after noticing a recent trend in Canadian public policy documents in which the potential contribution of telehealth to public empowerment is promoted. Most notably, the Advisory Council on Health Info-structure has proposed public empowerment as the first strategic goal of the Canada Health Infoway. As previously intimated, due to the emphasis on cost-containment in current health care reform, every additional target area for government investment must be justified on grounds that are politically, socially and morally acceptable and desirable. Therefore, the grounds on which the health info-structure, or other applications of telehealth, are being justified by public policy bodies offer a unique opportunity to discuss and challenge the assumptions that are made about the power of new technology to reform social institutions such as the health care system, including their power to change the knowledge and behavior of citizens. Simply put, the assumption that the health info-structure, or other applications of telehealth, can empower the public is one that, I believe, must be contextualized in history and theory, tested in practice, and either accepted or rejected in policy. Hence, the research question raised in the dissertation is as follows: "*Can telehealth empower citizens?*"

The dissertation is divided into five chapters. In Chapter One, I define technology for the purpose of this dissertation, undertake a brief overview of approaches to the

history of technology, and bring forth social histories of medical technology. The importance of taking into account the social dimensions of technology, both in its definition and its history, is established. The historical material on medical technology is organized according to four topics: the medical gaze, the medical profession, the medical institution and medical decision-making. How medical technology, including telehealth, has been influenced by, and has influenced, these topics is detailed. In Chapter Two, I concisely outline the main theoretical approaches to the critique of technology: critical theory, social constructivism, actor-network theory, feminism, postmodernism and social anthropology. Analytical concepts hereby introduced are applied to critiques of medical technology presented later in the second chapter. Critiques of medical technology, representing the various theoretical perspectives to technology, are brought forth: medicine as technoscience, medicine as Technopoly, cyborg medicine and medicine as Superpanopticon. These are followed by two critiques closely examining two particular technological artifacts: the electronic medical record and reproductive technology. The goal of these two chapters is to establish a historical and an analytical framework according to which the implications of telehealth as a new medical technology can be deciphered, such as its implications for health care providers, for the scientific discipline of medicine, and for the physician-patient relationship.

In Chapter Three, I provide a history of the Canadian health care system and the role of citizens and communities in this system. A preamble first explores the various meanings of the concept of community in the context of health care. The chapter is then

divided into two parts: a study of the Canadian health care system and a review of Canadian health care reform. In the first section, I introduce a brief history of the Canadian health care system, highlighting the advent of state health insurance, in order to identify the main structures and ideologies of its policy. I analyze the main paradigms directing the allocation of health care resources and the models of accountability instituted in health care management and delivery, underlining the intricacies of the community model. In the second section, I profile the federal/provincial/territorial strategies and initiatives carried out in health care reform during the 1990's. Once again, the objectives and critical assessments of regionalization initiatives are more extensively construed. The study of health care reform revolves around three issues: the impact of reform on community-based health care, the focus of reform on evidence-based decision-making and the role of technology in reform.

Chapter Four is also divided into two parts. Because of the central role of information and communications technology (ICT) in telehealth development, I begin by quickly surveying the main theoretical approaches to the study of this technology and Canadian government policies and initiatives relating to the development of ICT. The review of theoretical critiques contextualizes the cultural studies approach adopted in the dissertation, in addition to introducing concepts relating to the phenomenon of virtuality crucial to an analysis of citizen involvement in ICT and, correspondingly, in telehealth. Manifestly, it follows that I next contemplate the extent of citizen and community involvement in ICT development. Since Chapters One and Two deal with the

implications of telehealth as a medical technology, Chapter Four is geared toward elucidating the implications of telehealth as an information and communications technology. It is observed that different sets of knowledges, practices and policies are tied to each specific technic. In the second section, I contribute an overview of telehealth development in Canada, dealing with telehealth public policy and initiatives, categories of applications and examples of projects.

Lastly, in Chapter Five, I identify the roles in which citizens are positioned in telehealth initiatives. Substantiated by reported experiences in current applications and projects, I demonstrate if and why these roles are empowering to citizens. Why I have chosen to use the designation of citizen – as opposed to patient, consumer, user, client etc. – and the meaning of the term "empowerment" is addressed. The objective of Chapter Five is to interpret the political implications of telehealth, as a medical technology, a health care delivery mechanism and an information and communications technology. In this context, the term "political" should not be understood as it pertains to parliamentary or bureaucratic procedures. In contrast, it refers to the assertion of power in leadership, in governance, in the possession of a voice and a capacity in participation. The political stakes can range from control/power/participation in the *medical* (in the physician-patient relationship, in health care institutions, in personal health management), in the *institutional* (in health care public policy-making, in community-based health care governance, management and delivery) and in the *technical* (in design, use and implementation of the technology). To conclude, I further suggest how to achieve citizen

empowerment in telehealth, whether this is found to be accomplished in present applications and initiatives or not. Theoretical frameworks describing alternative technological models, alternative health/medical models and alternative citizen/community participation and governance models are delineated. The convergence of the reflections surfaced in these frameworks allows me to formulate an alternative model of telehealth development. This model is put forward as an "object-to-think-with"[4] used to evaluate the political implications of telehealth applications and initiatives, and to achieve citizen empowerment.

The dissertation was completed by referring to five main sources of information. First, I contacted experts in the relevant fields of research in order to identify key references.[5] Second, I read through all articles of health-related journals of the social sciences and humanities library[6] of the University of Ottawa published over a ten year

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[4]Object-to-think-with is a concept advanced by Sherry Turkle to designate "the social appropriability of a given theory", that is, its ability to "move beyond intellectual circles" (77).

[5]For instance, I contacted Margaret Lock of the Department of Social Studies of Medicine, McGill University, for references on the history of medical technology. In addition, Jocelyne Picot of the Graduate Program in Communication, McGill University, has frequently pointed me to many interesting sources in the field of telehealth.

[6]The journals reviewed explore the social/political/economic dimensions of health and should be differentiated from those located at the health sciences library of the university that have a clinical focus. There are a total of 20 journals (Canadian Bulletin of Medical History, J of Health and Social Behavior, Healthcare Management Forum, J of Health Politics, Policy and Law, Health and Canadian Society, J of Medical Systems, International J of Health Care Quality Assurance, Health Affairs, J of Healthcare Finance, Evaluation and the Health Professions, International J of Health Services, J of Healthcare Management, Hospitals and Health Networks, Health Progress, Hospital Topics, Inquiry,

period (1988-1998) that address the issues of citizen/community involvement in health care and in telehealth, the use of telehealth for outcomes research and evidence-based decision-making, the history of Canadian health care and the history of medical technology. Third, I collected materials on Canadian telehealth initiatives from several workshops and conferences.[7] Fourth, I conducted searches on the Internet (mainly government websites and telehealth information exchanges) and in prominent on-line databases such as MEDLINE. Finally, federal/provincial/territorial government policy documents were analyzed. Tables are used throughout the chapters in order to simplify the material and bring out its main points. While some tables were directly reproduced from others found in particular works, others were created for the purposes of this dissertation.

World Hospitals, Marketing Health Services, Hospital Outlook, Health Management Technologies).

[7]These include, but are not restricted to, Medicine 2001 (Montreal, June 96), Partnership for Health Informatics/Telematics (Montreal, Oct. 97), Ensuring Privacy and Confidentiality on Canada's Health Iway (St-John's, Oct. 97), Health Care Transitions: Integrated Systems, Enabling Technologies & the Community (Ottawa, Oct. 97), the National Conference on Health Info-structure (Feb. 98), Marketing Telehealth (Toronto, Feb 98), African Telemedicine Project: Spring Workshop (Ottawa, Mar. 98), Ottawa's Life Sciences and Environmental Industry (Ottawa, Apr. 98), Telepractice 2000 (Toronto, May 98), G7 Sub-Project 4 Forum on Interoperability in Telemedicine, Interactive Health (Fredericton, Oct. 98).

CHAPTER ONE : HISTORY OF MEDICAL TECHNOLOGY

Preamble: Meanings of Technology

In an attempt to clarify the terminology used in this dissertation, I will outline in the preamble to the first chapter, a few common understandings of the terms *technology* and *technics*. I will then state the specific definitions of these terms that will be used for the purposes of this dissertation. In defining the term technology, many authors simultaneously reveal their theoretical approach and orient their readers to the scope of their subject matter. This is due to the fact that the term technology has been used to determine various objects/artifacts, time periods, mindsets, practices/disciplines etc. In 1973, Jacques Guillerme claimed to have collected over 600 definitions of the terms "technologia", "technologie" or "technology" with little possibility of achieving consensus among them. Generally, the French, German and Slavic languages utilize two terms, "technique" and "technologie", to distinguish between the operative and the discursive, theoretical level. According to Jan Sebestik, " 'technics' refer to sequences of operations, to material production, to machinery, whereas 'technology' means the description and analysis of these operations, i.e. technological science" (26). In other words, technology or technological science consists of "the systematic reflexion *(sic)* on tools, crafts and industrial production as a specific branch of human knowledge" (Sebestik 25).[8] However, in a French literature review conducted in 1984, Maurice

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[8]Based on a literature review of the works cited by Guillerme and Sebestik in Thalès (1966), François Sigaut identifies four main traditions of thinking about technology: technology as engineering (study of optimization of technics), descriptive technology (study of the knowledge inside technics), theoretical technology (study of symbolization

Combarnous pinpointed the second meaning of technology as a group of technics. While he contends that the first meaning is more consistent with etymology and traditions, he argues that the second meaning came about in the 1950's under Anglo-American influence.[9]

Consistent with Sebestik's approach, Jacques Ellul, a French political thinker, has defined "technique" as "any complex of standardized means for attaining a predetermined result" (Technological Society vi) and as "the totality of methods rationally arrived at and having absolute efficiency in every field of human activity" (Technological Bluff vi). In defining technique in such a way and technology as the study of technique, Ellul differentiates both concepts from the machine. He thus broadens the meaning and impact of the technical from its origins in the strictly mechanical. He emphasizes the context of the material and its dependency on the socio-technical. As Ellul states:

> It is a mistake to continue with this confusion of terms, the more so because it leads to the idea that, because the machine is at the origin and centre of the technical problem, one is dealing with the whole problem when one deals with the machine. Technique has now become almost completely independent of the

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of technics through axioms) and technology as "technique de l'usage calculé des techniques" (systems analysis, operational research). For a more detailed description of each conceptual tradition, refer to Sigaut.

[9]A third meaning has indeed been recognized by Sigaut. It defines technology as the scientific equivalent of technics. This definition is problematic since it does not specify how to distinguish non-scientific from scientific technics. It also promotes an artificial distinction between science and technology (defined as a group of technics) that will not be retained in this dissertation.

machine . . . (Technological Society 4)

Ellul's conception of the "technical problem" will be discussed in Chapter Two. First and foremost, Ellul sees technique as the means of rationally integrating the machine into society in the name of efficiency. Hence, in its function as integrator, technique transcends the machine, "because it remains in close touch with the human order" (Ellul, Technological Society 5). Nonetheless, Ellul insists that the technological system, in spite of its role as the locus of social control and structuring, remains but a *constituent* element of society. Society retains other components that remain external to the technological system including ideology, tradition, history etc. These external attributes are assumed by Ellul to be potential sources of resistance that the technological system must strive to overcome.

Ellul's view of technique is shared to some extent by Bryan Pfaffenberger whose work in the social anthropology of technology has led him to stress the role of culture, versus nature, in determining technical necessity. Pfaffenberger defines technique as "the system of material resources, tools, operational sequences and skills, verbal and nonverbal knowledge, and *specific* modes of work coordination that come into play in the fabrication of material artifacts" ("Social Anthropology" 497). Pfaffenberger opposes this definition to the Standard View of technology[10]; a modernist view summarized with the phrases "Necessity is the mother of invention" and "Form follows function" ("Social Anthropology" 494). According to Pfaffenberger, the Standard View betrays an

[10]It is presumed here that Pfaffenberger understands technology as a group of technics.

ambivalence towards technology. It depicts technological progress as purely rational, cumulative and unilinear. However, despite Pfaffenberger's attempt to contextualize the role of technique in human adaptation and the social shaping of technique itself, his definition remains restricted to, what he calls, "merely technical" activity ("Social Anthropology" 497). Along with Ellul's definition, it, therefore, corresponds to one of two common understandings of technology identified by Martin Heidegger: the *instrumental* view of technology[11], or, technique as means.

In order to account for the social dimension of technology, Pfaffenberger supplements his definition of technique with a second, broader definition of the *sociotechnical system*: ". . . the distinctive technological activity that stems from the linkage of techniques and material culture to the social coordination of labor" ("Social Anthropology" 497). The sociotechnical system is a concept first advanced by Thomas Hughes following his study on the evolution of modern electrical power systems. A more complete description of the sociotechnical system, its use as an analytical tool in actor-network theory and the social anthropology of technology, will be brought forth in the second chapter. Once again, Pfaffenberger's definition of the sociotechnical system can be tied to Ellul's conception of the technological system. Both authors have sought to contextualize technique within society so that technique may encompass what Ursula Franklin describes as "structures as well as the act of structuring" (14). However,

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[11]Once again, it is presumed that Heidegger understands technology as a group of technics.

Franklin includes the strictly technical and sociotechnical facets under the umbrella term of technology. She defines technology as "*practice*", as "*system*", as "*ways of doing something*", as involving "organization, procedures, symbols, new words, equations, and, most of all, a mindset", as "an agent of power and control", and, as "a multifaceted entity . . . [that] includes activities as well as a body of knowledge . . ." (11-14). A similar approach to Franklin's is adopted by Raymond Williams. R. Williams details the process by which a technical invention becomes a technology as follows:

> . . . a technical invention as such has comparatively little social significance. It is only when it is selected for investment towards production, and when it is consciously developed for particular social uses – that is, when it moves from being a technical invention to . . . an available *technology* – that the general significance begins. These processes of selection, investment and development are obviously of a general social and economic kind, within existing social and economic relations, and in a specific social order are designed for particular uses and advantages. (129-130)

Here, R. Williams defines technology as technics with an added socio-economic dimension. Ellul, Pfaffenberger, Franklin and R. Williams thus address the second common understanding of technology identified by Heidegger: the *anthropological* view of technology or technology/technological system as human activity.

In taking technology or a technological system to be a form of activity/practice, these authors directly link technology to culture because, as Franklin argues, "culture, after all, is a set of socially acceptable practices and values" (15). Having established this direct link to culture, these authors and many critical theorists envision technology as beyond the embodiment of pure rationality. As Andrew Feenberg posits, in critical theory, technology is regarded as embedded in a value-governed action system that renders the integration of technique in society a process of negotiating normative consensus through the formation of various *social* and technical codes. The technical code of productive efficiency no longer automatically constitutes the bottom line of societal adaptation to technique. In seeing the technological system as a conceptual framework of social and technical practices/activities, Feenberg concludes the following:

> . . . the democratization of technical change reflects potentialities contained in the nature of technology itself. Coupling the technical design process to aesthetic and ethical norms and national identities through new and more democratic procedures is no utopia. (14)

Hence, in relating how critical theory and social anthropology define technology, the conceptual framework of technology is broadened in order to encompass the social dimension of technics that becomes relevant in the design and integration of technology in society. This conceptual framework will inherently allow for the possibility of resistance to the purely technical adaptation of society grounded in rational judgement and productive efficiency, and for the democratization of technical integration grounded in aesthetics, identities, culture, ethics etc. Compared with the Standard View of

technology, this conceptual framework is, therefore, much more relevant to the study of technology and citizen empowerment undertaken in this project.

To summarize, for the purposes of this project, I will retain the instrumental definition of technics as operations/processes/methods, material production and machinery. I will then define technology as a group of technics that also takes into account the social dimensions of technics, that is, that will include both context (historical, cultural, political, economic etc.) and content/object. I will, therefore, view "technology as a spectrum, with ideas at one end and techniques and things at the other with design [and development] as a middle term" (Edwin Layton, Jr. 37-38). Moreover, the term technology will incorporate, not only technical objects, human and technical practices and activities, but also knowledge. This understanding of technology differs from that espoused in the conventional model of science-technology relations, adopted foremost by historians of science. The latter model restricts technology to technics and asserts its singular role in applying knowledge generated from science.[12] It distinguishes between science and technology in Platonic terms, according to the two concepts of "epistēmē" (knowledge) and "technē" (art). As Edwin Layton, Jr., elaborates:

> From this point of view it would be absurd to think of knowledge flowing from technology to science. But if one sees the difference in social terms, as values held by different communities, the result is a symmetric model of science-technology interaction. There is no contradiction involved in assuming that

[12]For a more detailed critique of this model, refer to Layton Jr. on page 35.

> knowledge might flow from a community that values doing to one that values knowing. (40-41)

Similarly, Combarnous argues that the sole difference between science and technics is that the scientist must act in order to know and that the technician must know in order to act (Sigaut 118).

Dealing with technology as knowledge has become a trend in contemporary historiography according to Layton, Jr. He suggests that this trend has first led to an intellectual history of technology. Second, he posits that it has placed much emphasis on the role of technology in social change. In both cases, technological development must be understood in context, that is, in its relation to other evolving social practices and organizations. And, as Layton, Jr. concludes: "Paradoxically, a concern for knowledge serves to emphasize the importance of social history for the history of technology" (41). In this dissertation, I will take into account this implication of the definition of technology as objects, practices and knowledge when undertaking a study of the history of technology, and more specifically, of Western medical technology. I will, correspondingly, emphasize the social history of Western medical/health technology following the example of such authors as Stanley Reiser, Joel D. Howell and Michel Foucault. For instance, Howell, in his study of technology in the hospital during the early twentieth century, identifies three levels of meaning of technology: as physical artifact, as activity and as knowledge. According to Howell, the first level, adopted alone, provides a standard model that portrays the invention and dissemination of technology solely as a

function of its efficacy. The first level, thereby, corresponds to the Standard View of technology described by Pfaffenberger. Howell argues that such an approach restricts the understanding of technological development to that of a logical expression of scientific and clinical reality. Such an understanding blinds historians to why technologies fail and why they are opposed. As Howell relates, "Indeed, the reasons given for *not* using a particular technology, even one as ultimately successful as the x-ray machine, may provide insights into the process by which communities make decisions about how to practice medicine" (11). To conclude, defining technology as a multi-dimensional spectrum will enable me to focus on the historical process of integration of Western medical technology, including: the process of negotiation amongst various stakeholders, the changing nature of the medical profession, the related changing view of patients, sources of resistance, and the emergence of new social and technical codes. However, I will begin by reviewing various approaches to the history of technology, stressing that of the social history of technology, an approach consistent with my chosen definition of technology.

Section 1: Histories of Technology

According to Derek de Solla Price and Eugene S. Ferguson, among others, the first contributors to the field of the history of technology were technicians, collectors or curators and economic historians, until it was marked in the late 1950's by the publication of the five-volume A History of Technology edited by Charles Singer. E. Ferguson traces back the beginnings of the field as a separate academic discipline to January 1958, when

Melvin Kranzberg, professor of history at the Case Institute of Technology, attended a meeting in Cleveland, Ohio, of the Advisory Committee for Technology and Society. Kranzberg then founded the journal Technology and Culture. However, American college courses in the history of technology were initially formulated to suit the interests of engineering students and offer them some degree of socially related curricula. Hence, historical materials were substantially developed within technical studies and, therefore, were organized around the cumulative success of technological innovations.

As already indicated, the history of technology should not be limited to a set of progressive discoveries. It should also shed some light on resistance to technics, the process of adaptation, failures, revivals, that is, "phenomena that cannot be represented without inserting technology into general history" (Redondi 2). Lucien Febvre was the first, according to Pietro Redondi, to consider in depth the idea of a *social history of science and technology*[13], initially proclaimed in 1931 at the Second International Congress of History of Science and Technology in London. In 1935, Febvre published his "Reflections on the History of Technology" in the sixth volume of the Annales d'histoire économique et sociales. In his brief article, Febvre acknowledges the need for a history of technology that would include three chapters: (1) the role of technology in the organization and coordination of labor (whether labor is executed by humans or

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[13]It should be noted, however, that the phrase "critical history of technology" was first published in the following footnote in the first volume of Karl Marx's Das Kapital: "A critical history of technology would demonstrate how small a role one individual, alone, could have played in any particular invention" (qtd. in Redondi 1).

machines);(2) the inter-relationship between science and technology; (3) the role of technology in general history and the role of general history in technological development, i.e. a social history of technology. The main objective of the social history of technology, as further described by Redondi, is ". . . to see technology through its relationship to history by placing it at the centre of historical perspective as a variable that is autonomous without being independent of the state of society" (2).

Since Febvre, several historians have contributed to a theoretical framework of the social history of technology.[14] Notwithstanding, there continues to be important discrepancies in this social, historical approach. Trevor Pinch and Wiebe Bijker raise two central problems: the continued profusion of descriptive historiography and the asymmetrical focus of analysis. With regards to the second problem, Pinch and Bijker cite a literature survey which found that only 9 articles out of 25 volumes of Technology and Culture highlighted failed technological innovations (Staudenmaier). Subsequently, Pinch and Bijker suggest that this deficiency reflects "the implicit adoption of a linear structure of technological development" (405). The authors point to new approaches to the social history of technology that, they believe, will succeed in breaking away from the "old" history of technology. These include the systems approach and studies of the effect of labor relations on technological development (Pinch and Bijker 406).

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[14]Among them, E. Ferguson names the following: Lynn White, Carlo Cippola, Sigfried Giedion, Eric J. Hobsbawm, John A. Kouwenhoven, Lewis Mumford, Elting Morison, Nef, Herbert Sussman, E. P. Thompson etc. E. Ferguson also refers to an analytical summary provided by John H. Weiss in Technology and Social History, a guide published by the Harvard University Program on Technology and Society.

Published almost a decade after the article by Pinch and Bijker, Bijker and John Law provide a more detailed account of the social history of technology. They contend that its strength lies in its relatively unsystematic character and that its value stems from its attempt to deal with technological heterogeneity. Still, the authors question whether any generalization across studies is possible. They argue that a general model or theory would inevitably take the form of a general statement of priorities, reducing methodology to a set of shared principles and assumptions. Concurrently, Bijker and Law propose the principles and assumptions outlined in Table 1. They also profile three, at times, overlapping theoretical approaches: systems theory, actor-network theory and the social constructivist approach. Exponents of the first approach, such as Thomas Hughes, postulate that the success of technological innovations depend, not only on their technical character, but also on their social, political and economic contexts. A similar approach with a different focus, actor-network theory seeks to develop a neutral vocabulary to describe the actions of heterogenous technicians and monitor the evolving boundaries drawn between machines and people. The manner in which technicians, boundaries, and other sociotechnical elements are combined, constituted and shaped by technological networks is the main object of these studies, such as that undertaken by Michel Callon. Lastly, the social constructivist approach derives from recent research in the sociology of scientific knowledge. Researchers concentrate on the process of closure, the process through which conflicts are resolved and technologies are stabilized.

In their historiography of gender and technology studies, Lerman et al demonstrate the important contribution of these studies to a social history of technology. They trace back the introduction of historians of technology to feminist critiques of science and technology, to the late seventies and early eighties. As Lerman et al infer: "Earlier work sought to restore women to the historical narrative, focussing on women in male-dominated domains or acknowledging women's undervalued activities" (17). For instance, in 1976, Ruth Schwartz Cowan identified the home as a crucial site of technological activity and women as important technological actors. Initial feminist collections and literature reviews were put together by Martha Moore Trescott and Judy McGaw. McGaw sought the integration of labor history in feminist histories of technology, including discussions on skilling and de-skilling, as well as consideration of consumption as a significant phase in technological development. However, it was the interdisciplinary, scholarly collection published by Joan Rothschild in 1983 that called for a complete change in the very approach to the history of technology, an approach that, as later presented by Joan Scott, would position gender theory as the central organizing paradigm. Just prior to Scott's article entitled "Gender: A Useful Category of Historical Analysis", sociologists Donald MacKenzie and Judy Wajcman edited a collection of works in the history and sociology of technology. MacKenzie and Wajcman thus promoted cross-fertilization amongst the two disciplines, all the while offering gender and technology studies as a prime example of such interdisciplinary scholarship by including papers by Cynthia Cockburn and Cowan. Independently, several feminist authors influenced historians of technology by devoting their research to re-examining

conventional approaches to technological knowledge and interpretations of technological activities (Lerman et al 16).[15]

In conducting a literature review of gender and technology studies published from 1987 to 1997, Lerman et al conclude that more recent work "focuses on gender relationships, both men and women, and asks questions about cultural practices and social systems" (17). Both fields of gender studies and technology studies separately emphasize the social contextualization of technological development and contemplate issues related to cultural and social practices. Lerman et al identify three main trends in approach and subject matter: (1) technological actors/actor-network theory; (2) artifacts; (3) separate spheres. The first approach has adopted two principal strategies: to document the role of women as innovators and actors, and to reframe the home as a site of technological activity. This approach calls for a broader definition of technological actor to encompass workers and users in addition to inventors, engineers and designers. The second approach studies all phases of technological development, including production and consumption. Research has highlighted imaging technologies (media and medical), reproductive technologies and technologies of identity (cosmetics, genetics, etc.). Hence, this approach recognizes the body as a meaningful site of technological activity. Finally, the third approach deals with the gendered construction of labor and skill.

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[15]Lerman et al identify the following authors: Evelyn Fox Keller, Sandra Harding, Helen Longino and Donna Haraway (16).

Section 2: Histories of Medical Technology

According to Redondi, the pursuit of a "confrontation and collaboration" between an external or social history and an internal history of technology is driven by the present need to "master technological instruments" (4). Redondi explains:

> Technology is the most powerful instrument of the will to power. Up to now, it has served this will in the pursuit of the mastery of nature. Today, it is the mastery of the technological instruments by technology itself that constitutes the crucial problem. . . .For technology, the necessity to understand its own past is no longer just the requirement of an erudite curiosity. This comprehension is becoming a condition for putting its present in perspective, for envisioning a responsible coordination between the natural sciences, the humanities and social sciences, and the applied sciences of today. (4)

I agree with Redondi – although I am unsure of exactly what he means when he refers to the "mastery of technological instruments" – and, therefore, I feel it necessary to briefly review the history of technology in medicine in order to study the present development of telehealth in Canada. Having established the importance of taking into account the social dimensions of technology, both in elaborating its definition as well as its history, and taking into account that the intent of this dissertation is not to conceive a unique history of medical technology, I have chosen to draw mainly from three authors who have undertaken a social history of medical technology. That is, the authors have conducted histories on the process of integration of medical technology into society, instead of adopting the Standard View of technological development as a cumulative process of

spontaneous innovations. These authors and their works are: Michel Foucault's The Birth of the Clinic: An Archaeology of Medical Perception (first translated in 1973), Stanley J. Reiser's Medicine and the Reign of Technology (1978) and Joel D. Howell's Technology in the Hospital: Transforming Patient Care in the Early Twentieth Century (1995). For his part, Reiser admits that several factors influence medical care and the use of technology, such as philosophy, religion, economic and political systems, socio-cultural values etc. In addition to his definition of technology – reviewed in the preamble to this chapter – that encompasses its social dimensions, Howell also recognizes that to understand clinical applications of technology, the meaning of medical technology within a specific socio-political context must be considered. Howell accomplishes this in his study for the expressed purpose of subverting the premise that only scientific validity (or truth) determines clinical use of medical technology. In outlining a brief history of medical technology, I will not treat the works of these three authors separately, but rather, I have chosen to organize the material according to four key topics: (1) the medical gaze; (2) the medical profession; (3) the medical institution; (4) medical decision-making. I will attempt to demonstrate how medical technology has influenced, and has been influenced by, each of these topics.

2.1 The Medical Gaze: From Subject to Object

It is reported by Joseph Bronzino, Vincent Smith and Maurice Wade that around 2725 B.C. a physician practised in Ancient Egypt named Imhotep, "he who cometh in peace". He apparently received training at temple schools in the acts of interrogation,

inspection and palpation, and also occupied the positions of high officer, pyramid builder and astrologer. Deified as the god of healing, he is often compared to the ancient Greeks' god of healing, Asclepius. Beginning in Ancient Greece in the sixth century before Christ, health sanctuaries were established, named Asklepia, that featured thaumaturgic (dream therapy) medicines. The popularity of the Cult of Asclepius (in Latin, Aesculapsius) was revived in Rome after 291 B.C. Ancient Greek medicine mostly originated from the Pythagorean system and its Empedoclean principle of the four elements of fire, air, water and earth. The Pythagorean geometric conception of the world led to the concept of basic atoms shaped like triangles and squares. In addition, the mystical view of the sphere of Pythagoreans as the perfect figure inspired a spherical vision of the earth and of heavenly bodies. Correspondingly, Plato posited that the divine, rational soul of man must reside in the head since it too is spherical.

Contrary to the approach adopted by Plato, it is generally believed that Hippocrates (c460-c360 B.C.) was the first physician to distinguish medicine from philosophy and religion and to define the physician as an independent practitioner. Continuing the work of Alcmaeon of Croton[16], the cornerstone of Hippocratic medicine is the Theory of the Four Humors.[17] Based on the Empedoclean principle, it defines the

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[16]Alcmaeon was most likely the first known physician to conceptualize health as a state of equilibrium of the body, balancing consistent fluids with specific qualities and causal properties.

[17]This theory is not attributed to Hippocrates but to his son-in-law Polybus. It is written in the Hippocratic treatise Nature of Man ascribed to Polybus by Aristotle in his Historia animalium.

four constituent humors as phlegm, blood, yellow bile and black bile. The Hippocratic Corpus is a collection of approximately sixty medical treatises, composed by various scholars in the name of Hippocrates and some perhaps by Hippocrates himself[18], the majority of which are conventionally dated to the late fifth and early fourth centuries before Christ. While the treatises are united by "the rational spirit of medicine freed from all traces of magics," Jacques Jouanna discerns many heterogeneities in the corpus, such as differences in vocabulary, contradictions among doctrines, diversity in origins of the written texts, the readership targetted by various texts, and diversity in the date of composition of these texts (56). While admittedly implying some oversimplification of the evolution of the corpus, Jouanna uncovers three main origins of the Hippocratic treatises: the core collection authored by the school of Cos during the Hellenistic period (such as Epidemics and Airs, Waters, Places consisting of the recording by itinerant physicians of seasonally prevalent diseases in given places; Prognostic, Regimen in Acute Diseases, and The Aphorisms on medical practice); those included in Erotian's list during the reign of the Roman Emperor Nero issued by the school of Cnidus (such as nosological and gynecological treatises that reflect a more traditional approach to medicine); and lastly, others of unknown origin diffused in medieval manuscripts (such as Fleshes and

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[18]During the twentieth century, historians recognized their inability to confirm that Hippocrates had any direct connection to the Corpus. Jody Rubin Pinault accepts that it is impossible to write a credible biography of Hippocrates since there is not enough contemporary evidence to determine without a doubt that a physician by that name, an Asclepiad, was ever associated with the school of Cos and known in Athens. References to Hippocrates, Pinault recognizes, are essentially limited to two references by Plato and one by Aristotle. Furthermore, Pinault despairs in the five hundred year gap that exists prior to the publication of the first surviving biography of Hippocrates.

Regimen that reflect a more philosophical orientation). The Hippocratic Oath specifies both the duties of the medical student-teacher relationship and a brief summary of medical ethics. Once again, historians have revealed many inconsistencies in the oath, including its prohibitions on abortion, suicide and surgery that ran counter to the norms and practices of ancient Greek society. They have also traced back the dogma elaborated in the oath to the philosophical orientation of Pythagoreanism and concluded that the oath may indeed be a non-Hippocratic document that was reappropriated by Christianity.[19] Despite Hippocratic medicine's intent to dissociate medicine from its religious overtones, it is due to this distortion and reappropriation that the Hippocratic Oath, with its religious subtext, has been retained for centuries.

The significance of Hippocratic medicine is explained by Bronzino, Smith and Wade as follows:

Because he viewed the physician as a scientist rather than a priest, Hippocrates

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[19]Around 500 A.D., the oath was incorporated into the Hebrew oath. Despite the fact that the oath harmonized well with Judeo-Christian morality, it is not a Christian document since it calls on the worship of pagan gods. The oath states: "I swear by Apollo Physician, by Asclepius, by Health, by Panacea and by all the gods and goddesses, making them my witnesses, that I will carry out . . ." (qtd. in Temkin App. 1). Owsei Temkin has studied "whether Hippocratic medicine was inseparably bound to a religion of nature" and whether this affected its incorporation into Christian society (189). He admits that political and social developments also influenced the practice of Hippocratic medicine in Christian rule. He points out that the oath makes no mention of philanthropy and patriotism but instead establishes worldly success and failure as the proper reward and punishment of physicians. However, in other Hippocratic treatises (like Precepts) and in Plato's account of Hippocratic medicine, Temkin finds that compassion is specified as a main obligation of the physician, an obligation further reinforced by Christianity. Thus, Temkin concludes: "The many faces of Hippocrates correspond to the plurality of potential relationships of Hippocratic physicians to Christianity" (252).

> instilled an essential ingredient into the realm of medicine: the scientific spirit. . . .Instead of blaming disease on the gods, Hippocrates taught that disease was a natural and rationally comprehensible process and that symptoms were reactions of the body to disease. The body itself, he emphasized, possessed its own means of recovery, and the function of the physician was to aid these natural processes. (3)

Practitioners of Hippocratic medicine are described as agonistic and preoccupied with articulating a logical, step-by-step approach to guide the physician from the nosological causes of disease and conceptual framework of human physiology to the curative process. The mechanical and causal principles outlined by Hippocratic medicine strongly differ from those of the old theory of sympathies characterized by correspondences and homologies. Continued interest in Hippocratic texts is due, in no small part, to the enthusiasm of Claudius Galen (c130-c200) whose works and commentaries are credited with having transmitted the knowledge of ancient Greek medicine to Renaissance scholars. Six centuries after Hippocrates, Galen's treatises comprehensively documented medical theory and practice at the height of the Roman Empire[20], including his own findings in anatomy, physiology and therapeutics. These findings were built upon a

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[20]While medicine occupied a less privileged position in Rome than it had in Greece, Roman medicine comprised of three main fields: practical medicine undertaken by the head of the family using home remedies (based on agriculture); Etrusian medicine practised by the state religion (e.g. hepatoscopy: reading divine signals in animal livers); and, Greek medicine practised by private physicians who were often freed, Greek slaves. In addition, the Roman Empire regarded health as interrelated to daily life and to government. As such, it placed much importance on public health and made significant advances in sanitation engineering. Some historians believe that this emphasis can be attributed to the influence of the Hippocratic treatise on Airs, Waters, Places.

paradigm that incorporated the atoms and the four elements of the Pythagorean School, the ideal, divine universe of Plato, Aristotle's fifth essence of "pneuma", and Hippocratic medicine's four humours. Compared with Hippocratic medicine however, Galen promoted the study of philosophy in medical training. As well, although he was not Christian, his research reflects a belief in a Supreme Being. Furthermore, Galen's writings portray the body as an instrument of the soul. Consequently, Galen's pervasive influence can also be attributed, to some degree, to his acceptance by Christianity, as well as by Arab and Hebrew scholars.

Galenic physiology is rooted in the fundamental principle of life called pneuma (air, breath), introduced by Aristotle[21] as a fifth, quintessential element to Plato's four, ideal bodies (appropriated from Pythagoreanism). According to this physiology, there are two types of blood, the venous and the arterial, with distinct pathways and functions relating to the three chief body centres: the liver (responsible for nutrition and growth), the heart (vitality), and the brain (sensation, reason and movement). His detailed physiology, encompassing 300 anatomical observations, was grounded on the dissection of animals, primarily the Barbary ape, and was, consequently, inaccurate. Nonetheless, due to the comprehensiveness of his studies, Galenism remained the foundation of Western medical thought and practice for nearly 1500 years until it was sympathetically challenged by Andreas Vesalius (1514-1564). Vesalius was a Renaissance humanist who published, in 1543, the first complete textbook on human anatomy entitled The Fabric of

[21]Aristotle also proposed three forms of soul: vegetative, animal and rational/human.

the Human Body. A classicist by education and humanist at heart, Vesalius sought to resurrect the ancient anatomy presented by the Alexandrian School of medicine[22] and by Galen. Famous for his dissection-lectures, he sought to supplement ancient theory with present practice, that is, with direct observation through dissection.[23] While Vesalius successfully challenged Galen's anatomy, Galenic physiology remained intact.

Prior to the contribution of Renaissance physicians such as Vesalius and Ambroise Paré (c1510-1590)[24], practitioners of the high Middle Ages firmly distrusted human perception, primarily due to its variability. As well, they distrusted the material world. Rather, they asserted the centre of all truth and experience in God, reverting to a medicine grounded in religious creed. While historians of science admit that it is difficult

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[22]In the fourth century before Christ, the dominant centre for Greek medical knowledge and research was a museum established by Alexander the Great and governed by a dynasty deriving from his general, Ptolemy. Located in Alexandria, the museum enjoyed much notoriety. Its two principal contributors were Herophilos of Chalcedon, who recognized the diagnostic value of the pulse, and Erasistratos of Iulis, who described in detail the anatomy of the brain.

[23]Contrary to popular belief, autopsies were not completely censored during the Middle Ages. They were resorted to when investigating suspicious deaths, plagues, and even the special "gifts" of saints. During the thirteenth and fourteenth centuries, many medical university faculties in Southern Europe were authorized to conduct human dissections within certain parameters. Dissection manuals were published, most notably Mondino de Luzzi's (c.1275-c.1326) Anatomy (1316). It should be noted that such manuals, including de Luzzi's, sought to confirm the findings of ancient texts rather than challenge them.

[24]Paré defended the dignity and value of surgery. During the Middle Ages, medicine had been assigned a privileged position and, subsequently, distanced from empirical and mechanical practice, such as that conducted by surgeons. Paré's primary contributions to the advancement of surgical technics stemmed from experience in the battlefield.

to pinpoint the exact moment when a shift in attitude and a revival of classical medicine occurred in European society, they do suggest that the introduction of humanism in the fourteenth century and writings of Leonardo Da Vinci (1452-1519) were critical. Da Vinci reinstated the value of human perception, and more specifically, of human vision in determining the forms and colors of the universe. That is, he positioned the human eye, and thus, human experience, as the single point from which all parts of the universe are combined. In doing so, he encouraged the extension of human vision through instrumentation for the purposes of art and science. Da Vinci illustrated perfectly the cross-fertilization that occurred during the Renaissance amongst the fields of anatomy, mathematics, optics, art and medicine. He was led to perform dissections of animals and humans by his interest in art. Both artists and physicians of the period sought accurate anatomical knowledge. In addition, refinement of artistic technics enabled improved anatomical illustrations.

To conclude, Renaissance anatomists, in seeking to revitalize Greek medical knowledge, subverted it by challenging Alexandrian and Galenic physiology with neo-Aristotlelian approaches to the study of nature. These approaches emphasized human vision and experience through dissection, and thus, distanced medical research from essentialist and religious doctrine. Notwithstanding, there was a conflicting trend in Renaissance medicine that, following the recovery of the Corpus Hermeticum – a group of treatises supposedly written in Ancient Egypt by Hermes Trismegistus – and other more mystical texts, emphasized the role of natural magic in defining the relationship of

man (microcosm) to macrocosm. This current of medical thought turned to mystical knowledge and to chemistry (grounded in previous work in alchemy). For instance, Paracelsus (1493-1541) rejected anatomical and humoral pathology in favour of chemical pathology. In other words, he theorized that the body's physiology depended on the equilibrium of an alchemical force called "archaeus". He, therefore, excelled in developing pharmacology as the main form of therapeutics.

Major contributions to medical knowledge and instrumentation were made by great names of the Scientific Revolution (1450-1630), such as Francis Bacon (1561-1626) and Galileo Galilei (1564-1642). For his part, Bacon advocated a more practical approach to medicine and the study of nature. He encouraged physicians to rely on empirical data as opposed to ancient theories. Similarly, Galileo's mechanical philosophy, as argued by Bronzino, Smith and Wade, ". . . encouraged the use of experimentation and exact measurement as scientific tools that could provide physicians with an effective check against reckless speculation" (7). For instance, Sanctorius Sanctorius (1578-1657), a pupil of Galileo, completed several comparative studies of human temperature and pulse using devices introduced by his teacher, including the thermoscope, pendulum and telescopic lens. Moreover, Sanctorius pioneered quantitative experimental medicine and is known as the "Father of Metabolism" having first documented the quantitative metabolic phenomena of body weight. Building on Vesalius's anatomy, William Harvey (1578-1657), a graduate of Padua where Galileo lectured in 1592, applied Galileo's laws of motion and mechanics to measure blood

circulation but without the aid of the microscope. Harvey went further than Vesalius by directly challenging Galenic physiology.

It was during the seventeenth century, amidst many controversies in medicine, science, religion and politics, that clinical medicine emerged hand in hand with botanical taxonomy. Using the microscope, Anthony van Leeuwenhoek (1623-1723) found that plant and animal tissues were composed of cells; he also discovered bacteria, protozoa, ameobas etc.[25] In addition to Leeuwenhoek's work, John Parkinson published his Theatrum Botanicum in 1640, an influential work in the advancement of botanical taxonomy. The point of contact between the classification of plants and that of diseases came in 1676 when Thomas Sydenham (1624-1689) first advocated the botanical method in the study of diseases.[26] A disciple of Paracelsus, Sydenham, known as the "English Hippocrates", reacted against the established, speculative medicine in favor of a clinical medicine grounded in observation and experience at the patient's bedside. However, the greatest progress in botanical and medical taxonomy was reached after Sydenham.

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[25]While Leeuwenhoek is often called the inventor of the microscope, compound microscopes – those using more than one lens – were invented around 1595. Other scientists such as Robert Hooke and Jan Swammerdam had built such microscopes prior to Leeuwenhoek. However, Leeuwenhoek did succeed in improving their technology. As opposed to past microscopes that magnified objects to 20 or 30 times their natural size, Leeuwenhoek built microscopes that magnified over 200 times, with clearer and brighter images. Leeuwenhoek's research is also distinguished by the great variety of his subject matter (plants, animals, minerals and fossils) and by his diligence in documenting all his observations, through written texts and illustrations.

[26]Thomas Sydenham is accredited by Foucault as being the "initiator of classificatory thought" (Clinic 22).

Notably, in 1763, Karl von Linné (1707-1778), a Swedish botanist and physician, categorized all living creatures according to their morphological relations to each other in his Genera Morborum. The Linnean classification system identified 325 different kinds of diseases and defined an order of abstract relations among them denominated by various terms, such as species, genus (kind), family, class etc.

The botanical, taxonomical model had two major implications for medical knowledge, distinguished by Foucault as follows:

> First, it made it possible to turn the principle of the analogy of forms into the law of the production of essences; and secondly, it allowed the perceptual attention of the doctor . . . to communicate with the ontological order – which organizes, from the inside, prior to all manifestation – the world of life; the same structures govern each, the same forms of division, the same ordering. (Clinic 7)

The *classificatory rule* defines a specific configuration of disease, whereby, disease is organized in a set of hierarchical relations (species, families, genera) before it is treated. As Foucault resolves, "The space of *configuration* of the disease and the space of *localization* of the illness in the body have been superimposed . . ." (Clinic 3). Notwithstanding, early exponents of classificatory, clinical medicine, thought of the localization of disease as a "subsidiary problem", second to identifying the disease as species by recognizing its difference, similarity, subordination, to others (Foucault, Clinic 5). Sydenham writes: "Nature, in the production of disease, is uniform and consistent; so much so that for the same disease in different persons the symptoms are for the most part

the same; . . ." (qtd. in Lester S. King 112).

According to Foucault, the knowledge and practice of classificatory medicine reflects the following guiding principles. First, it privileges historical knowledge at the expense of the philosophical. It describes disease chronologically as a set of signs, revealed one after the other with the emergence of symptoms. Comparatively, philosophical knowledge would seek to determine the origins and causes of the disease. While conducting his studies of nosology, François Boissier de Sauvages de la Croix (1706-1767) maintained that the theory of medicine must be sharply differentiated from its practice. He insisted that, while the theory of medicine rests on the cause of disease, such cause cannot be utilized as the basis for classification of diseases because it is a matter of inference and not of direct observation. Second, classificatory medicine uses analogies to define the essence of the disease; the disease is assessed according to its degree of resemblance to a predelimited category. Third, this degree of resemblance reveals the rational order of the disease (its progression, symptoms etc.). Lastly, this ordering and categorization of disease portrays disease in its natural and ideal state. The classificatory medical gaze must abstract the patient to discover the essential truth of the disease; there is no room for variability and individuality. Sydenham expresses this quite simply in the quote stated above. Hence, the classificatory gaze is not directed at the patient, at the body, but rather at signs that will serve to identify the disease. As Foucault appropriately concludes: "It is not the pathological that functions, in relation to life, as a *counter-nature*, but the patient in relation to the disease itself" (Clinic 8).

The findings of classificatory medicine were widely disseminated in the eighteenth century through teaching clinics. Here, according to Foucault, "the clinic must form, constitutionally, a structured nosological field" (Clinic 59). The clinical gaze perceives the patient as an "accident" of the disease, and as Foucault further describes, as "the transitory object that it happens to have seized upon" (Clinic 59). Compared to the hospital that happens to treat this or that person, the proto-clinic operates according to a process of quantitative and qualitative selection in search of ideal cases. While, in the hospital, the patient is a subject of the disease (a "case"), in the clinic, the patient is an object of the disease (an "example"). The clinical gaze does not *examine* a patient, but *deciphers* a disease; it does not *discover* but *demonstrates* (Clinic 60-61). This implies a standardization and reproducibility of the patient's experience that allows for a "plurality of observations" to arrive at "a progressive, theoretically endless convergence . . ." (Clinic 97). Foucault analyzes the clinical gaze by discerning the "codes of knowledge" that bind the gaze and the field of practice. Foucault identifies two major forms of such codes: the linguistic structure of the sign and the aleatory structure of the case (Clinic 90). These codes are summarized by Foucault in Table 2, along with the principal stages of the clinical gaze.

As the clinical gaze evolved, it sought to clarify the definition of disease through autopsies and the use of medical instrumentation, once again raising the importance of personal observation such as previously done by Renaissance artists (Da Vinci) and scientists (Galileo), and the early advocates of clinical medicine. In 1761, Giovanni

Battista Morgagni (1682-1771) published a critical work in pathological anatomy entitled The Seats and Causes of Diseases. A professor at the University of Padua, Morgagni based his nosology on detecting morphological changes in organs post-mortem. In other words, by conducting over 600 dissections, he established correlations between symptoms of disease and post-mortem findings. Also in 1761, Leopold Auenbrugger (1722-1809) published a brief, 20-page account of chest percussion, a new diagnostic technic. This technic relied on the perception of differences in the sounds emanating through air and fluid from the chest cavity, after thumping on the chest of the patient. This technic, when popularly adopted, revolutionized physical examination of the patient that, until then, had been restricted to limited evaluation of the pulse. Hence, during the nineteenth century, the diffusion of pathological anatomy, auscultation and other diagnostic technics required that the medical practitioner and the patient be in close proximity while, previously, diagnosis by letter had been feasible since it mainly relied on the patient's narrative. In fact, the fee for rendering such diagnosis, at the time, was greater than the fee for an office visit.

While both Morgagni's and Auenbrugger's works are celebrated as monumental in the history of medicine, they were set aside by practitioners of the eighteenth century until they were rediscovered by Marie-François Xavier Bichat (1771-1802) and Jean Nicholas Corvisart (1755-1821) respectively. Foucault attributes forty years of inattention to these works to the rise of the clinic, where historical versus geographical knowledge of symptomatology was of interest. Foucault hypothesizes: "First the

medicine of classifications and then the clinic had detached pathological analysis from this regionalism [the linking of certain species of diseases with certain anatomical regions] and constituted for it a space at once more complex and more abstract, concerned with order, successions, coincidences, and isomorphisms" (Clinic 127). In 1801, Bichat published his General Anatomy Applied to Physiology and Medicine, whereby, he identified tissues, classified into 21 types, as the core elements of the organs. According to his pathological anatomy, diseases were rooted in damages to tissues, reflected in a certain set of symptoms. Compared to Morgagni, Bichat extended his post-mortem observations to living patients (Reiser, Medicine 19). Where Morgagni sought to penetrate organ densities that would, ultimately, specify the nature of the disease, Bichat aimed at reducing organic volumes to wide-ranging, homogeneous surfaces of tissues. And thus, Foucault characterizes "Bichat's eye [as] a clinician's eye, because he gives an absolute epistemological privilege to the *surface gaze*" (Clinic 129). As such, Foucault concludes that Bichat, in seeking to become the central figure in the clinical method, does not rediscover the "geography of organs", but rather the "order of classifications" (Clinic 130). Foucault writes: "Pathological anatomy was *ordinal* before it was *localizing*" (Clinic 130). So Bichat did rediscover nosology stemming from bodily analysis, but in doing so, he continued to define disease as an order of analytical classes; however, these classes were now grounded in pathological decomposition. Hence, the clinical gaze evolved from abstract perception into empirical, physical reality. In its restructuration of epistemic knowledge, the *anatomo-clinical gaze* adopted new rules of observation and analysis, identified by Foucault and summarized in Table 3. Fundamentally, Foucault

observes that, compared with early classificatory and clinical medicine where the structure of gaze measured disease against the background of *nature*, the anatomo-clinical gaze measures it against the background of *life*. In other words, while disease was previously perceived as counter-nature, it is now positioned as the pathological form of life. As Foucault succinctly declares, "[i]t is not because he falls ill that man dies; fundamentally, it is because he may die that man may fall ill" (Clinic 155).

In 1808, Corvisart published a translation and commentary of Auenbrugger's work. The revival of chest percussion by Corvisart prompted René Théophile Hyacinthe Laënnec (1781-1826) to proclaim the value of direct and indirect auscultation, the latter mediated by the stethoscope introduced by Laënnec in 1816. While, according to the Foucault, it had been natural for clinical medicine to reject technology that would artificially present signs where no symptoms had yet appeared, the increasing acceptance of localized pathological anatomy encouraged the adoption of technology that could bring to the surface a lesion hidden within organs/tissues *before death*. With the aid of medical instrumentation, the anatomo-clinical gaze became multi-dimensional, with each dimension corresponding to a different sensorial field (touch, hearing, sight). Furthermore, Foucault concludes: "The structure, at once perceptual and epistemological, that commands clinical anatomy, and all medicine that derives from it, is that of *invisible visibility*" (Clinic 165). The stethoscope also attained wider acceptance by the fact that it relieved the physician-patient relationship from the impropriety of physical contact. It paved the way for the physical examination to become the key to diagnosis between 1819

and 1850, a diagnosis that could no longer be subject to the idiosyncrasies of patients. Reiser does report some resistance to the technology on the part of physicians and patients alike. Physicians feared their potential inability to master a new technology, as well as their possible lack of physical ability (good hearing). In addition, they feared being associated with surgeons, who were thought of as mere craftsmen. Patients feared the instrument itself, partly due to the general association of instrumentation with operations/surgeries. While the stethoscope acquired popular support in the 1820's despite initial resistance, Reiser recognizes that it was more the physician's skills in auscultation, rather than the instrument itself, that were considered crucial for its success.

The invention of the stethoscope was later followed by the inventions of the ophthalmoscope in 1850 and the laryngoscope in 1857. Reiser describes the significance of both instruments as follows: "Before [their] invention . . ., internal disorders in patients were not visible to the eye, unless the body's surface were violated through surgery. Vision now competed with sound as the physician's main sensory probe of the human interior" (Medicine 55). The prominence of visual, medical instrumentation reduced the importance of direct physical examination by the medical practitioner. As early as the 1850's, Reiser claims that there was talk of replacing subjective evaluation of the patient by the physician in favor of a visual patient record. The prominence of visual aids in diagnosis grew with the invention, during the 1860's, of several instruments to illuminate the stomach, bladder, rectum and vagina. Reiser suggests that the rapid diffusion of such instruments was partly due to the popularity of photography, a momentous achievement

of the nineteenth century.

The prominence of visual instrumentation grew exponentially when, on November 8, 1895, Wilhelm Conrad Roentgen (1845-1923) discovered the x-ray. His invention was rapidly distributed due to its initial low-cost and the simplicity of its technic. The fluoroscope enabled an instant view of the body, including the body in motion. Physicians, at first, resisted implementation of the technology in their daily practice. They feared the technology would render them increasingly susceptible to malpractice suits by potentially serving to discredit their subjective evaluations of the patient. Notwithstanding, the significance of physical examinations, and even the need for the physical presence of the patient during the evaluation process, were greatly reduced as the role of the x-ray in the clinical method increased. The x-ray challenged the use of touch in diagnosis, including the use of direct and indirect auscultation. It was found that the x-ray could generate more accurate information on the internal organs than previous technics. The x-ray was also celebrated as a means of further protecting the privacy of patients, particularly women. As Howell argues:

> The x-ray image could be used to objectify the body. Using it, one could look at the body without being overtly sexual; one could look at the body as a scientist, without having to deal with emotions. . . .The x-ray image thus helped to bring the meaning of the body out of the social sphere. (167)

These objectification and neutralization effects of the x-ray had, according to Howell, important implications for gender politics in medicine. "The emphasis on the x-ray

image as a privileged way of knowing may be part of a male dominance of the whole entreprise of scientific medicine," Howell writes, "along with a diminution of the importance of an affective understanding of illness which has traditionally been the realm of female understanding" (167-168). To support his allegation, Howell points to the common use of the x-ray during the mid-1920's to diagnose pregnancy, that is, to further distance women from their traditional role in pregnancy and childbirth. Additional feminist critiques of medical technology, including reproductive technology, will be brought forth in Chapter Two.

During the nineteenth century, medical instrumentation emerged that, not only increased the physician's ability to view the anatomy of the body, but also its physiology. The first efforts to define the modern physiology of the body and its pathological phenomena can be traced back to, what Foucault has coined, the "crisis of fevers". As Foucault points out, Bichat and his followers had not succeeded in resolving two main issues: how diseases came about (their "being") and how they become related to lesional phenomena; and second, how to explain non-lesional diseases (Clinic 174-175). Since diseases were not determined by the lesions themselves but by a prior order of classification, there was room for non-lesional diseases in the anatomo-clinical method. Non-lesional diseases included neuroses and essential fevers, the latter having been commonly understood as a sign of the body's resistance to disease. In fact, Carl Wunderlich went so far as to theorize that fevers were not diseases at all, but rather a symptom of physical health. During the eighteenth century, the concept of "fever"

evolved into that of "fevers". The various species of fevers were categorized according to the circulatory system involved, the inflammatory organ, the resulting quality of excretions, or their specific form and evolution. However, in 1808, François Joseph Victor Broussais (1772-1838) published his Histoire des phlegmasies chroniques in which he grounded his study of fevers on particular forms of inflammation of tissues. Broussais's study prompted a reorganization of the anatomo-clinical gaze from its prioritization of the localization of disease and its regard of the visibility of the disease as secondary phenomena. This reorganization enabled medical practitioners to detect diseases, especially physiological diseases, that caused hardly perceptible alterations to the body. According to this reorganization, the localization of the disease is inferred by the perception of symptoms, and not determined after the lesional phenomena has been seen. "Disease exists *in space*," Foucault summarizes, "before it exists *for sight*" (Clinic 188). In other words, the first step in this restructured anatomo-clinical method is to determine which organ is sick, rather than what disease is present. And hence, Foucault declares: "The medicine of diseases has come to an end; there now begins a medicine of pathological reactions . . ." (Clinic 191).

A new emphasis on the study of physiology promoted new technology, developed to portray and monitor functional actions of the body by inscribing them on graphs and measuring them through quantification. This technology, hereby, transformed bodily processes into objective phenomena. It included the spirometer (1846), the sphygmometer (1835), the sphygmomanometer (1876), the manometer (1896, 1905), the

electrometer (1872) and its more advanced version the electrocardiograph (1887), and the thermometer (from Galileo to Gabriel Fahrenheit to Wunderlich in 1868). When these instruments were introduced, some of their innovators and supporters believed they would act as equalizers of diagnostic skills. Julien Hérisson, inventor of the sphygmometer, trusted that the reliability of its readings would enable the physician to further distance himself from his patients by delivering accurate diagnoses by letter. In his monumental treatise entitled On the Temperature of Diseases (1868), Wunderlich argued that, in the case of thermometry, the ability to register the temperature of the patient could be dissociated from the ability to interpret the results. Thus, the physician could delegate the former responsibility and hold on to the latter. This argument reflects an ongoing objective of the medical profession to separate the scientific expertise of the physician from manual and instrumental manipulation, this despite the increasing convergence of medicine and surgery that began in the eighteenth century with the advent of the anatomo-clinical gaze and medical instrumentation.

While the expansion of the anatomo-clinical gaze incited the development and acceptance of a wide range of medical instrumentation that emphasized anatomical and physiological imagery, it also prevented other technics, most prominently in microbiology and chemistry, from advancing until the middle of the nineteenth century. Foucault explains: "The only type of visibility recognized by pathological anatomy is that defined by everyday vision: a *de jure* visibility that envelops in temporary invisibility an opaque transparency, and not (as in microscopic investigation) a *de natura* invisibility that is

breached for a time by an artificially multiplied technique of the gaze" (Clinic 166-167). Bichat's refusal to use the microscope when developing histology is due therefore to limitations imposed by the gaze itself. Its scope limits possible knowledge and, in doing so, limits the use of technics focussing on problems of measurement, substance or composition at the level of invisible structures, despite the fact that some of these technics had been used in the past (Clinic 166-167). Regardless of the accomplishments in microbiology of Leeuwenkoek and Giovanni Bonomo, anatomists continued to resist the microscope, blaming errors on the instrument itself. Skepticism was reduced during the 1840's after several anatomists who had adopted the microscope in their research were appointed as professors in medical faculties throughout Europe. The restructuration of the anatomo-clinical gaze that occurred during the "crisis of fevers", its emphasis on the physiology of pathological phenomena, also contributed to the legitimation of invisible structures as an object of study. Important milestones that fuelled the advancement of microbiology during the nineteenth century include Rudolf Virchow's Cellular Pathology (1958), Louis Pasteur's (1822-1895) and Joseph Lister's (1827-1912) studies of putrefaction, and Robert Koch (1843-1910) who established a causal relation between microorganisms and disease.

Chemistry had first been deployed by Western medicine in the sixteenth century in the context of uroscopy and Paracelsus's push for the chemical analysis of urine. During the nineteenth century, chemistry began to play a role in pathological anatomy and in the clinical method, beyond its previous, restricted contribution to the clarification of

physiology.[27] While blood chemistry was impeded with the end of blood-letting therapy, technology was developed to analyze small amounts of blood.[28] This technology led to unparalleled progress in diabetic research during the 1910's. During the 1880's, the diagnostic laboratory was established for two main purposes identified by Reiser: to integrate new knowledge of biology and disease into new diagnostic and therapeutic technics; and, to provide diagnostic services for physicians. The laboratory evolved into three basic types: the research laboratory, the clinical laboratory (research and patient care), and the ward laboratory (patient care). Parenthetically, the prominence of diagnostic laboratories significantly increased with the success of the Wasserman test for syphilis released in the early 1900's.

To conclude, during the nineteenth century, the anatomo-clinical gaze integrated several branches of medical research that had been previously neglected – physiology, chemistry and microbiology – with the help of new medical technology to further the study of gross and microscopic anatomy. However, Lois N. Magner contends that the introduction of these new technics in the clinical method did little to improve therapeutics.[29] For instance, in the case of microbiology, she writes:

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[27]Examples include Richard Bright's albumin test (1827) and Gabriel Andral's Pathological Hematology (1943). Technology was created to integrate chemistry in medical diagnosis, such as the haemacytometer invented by William Gowers in 1877 and the hematokrit introduced by Sven Hedin in 1889.

[28]Contributions of Ivan Christian Bang and Otto Folin (1867-1934) are notable.

[29]According to Magner, the greatest contribution to therapeutics came from studies of immunology in the late nineteenth and early twentieth centuries. For an introductory

> The major public health benefit of germ theory was the guidance provided in stopping the spread of waterborne diseases like typhoid fever and cholera through improved sanitation and rational public health measures, such as the purification of drinking water, proper sewer systems, food inspection, and pasteurization. (336)

The public health movement will be discussed later in this chapter as the impact of medical technology on the medical institution is addressed. At the turn of the twentieth century, rapid advances in applied sciences gave way to intense cross-disciplinary fertilization and significant improvements in diagnostic and therapeutic technics. After the Second World War, clinical medicine was greatly influenced by new technologies developed in pursuit of military strategies.[30] During the 1960's, the integration of the computer in medical research provided quantitative analysis tools that facilitated increased precision and improved organization of experimental data. Computers also served to automate information management and medical decision-making. The impact of such automation will be dealt with later in this chapter. Of course, the twentieth century is momentous for remarkable new technology in medical imaging, including computed tomography (CT/scanners) and magnetic resonance imaging (MRI). As we will later see, new medical technology in the twentieth century led to the institutionalization of medical care, its centralization in hospitals and clinics. It further

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account of such studies, refer to Magner (344 ff.).

[30]For instance, innovations in electronics enabled the mapping of the electrical behavior of the neuron. Other innovations include pulse monitoring, nuclear medicine and diagnostic ultrasound based on sonar technology.

distanced the physician from his/her patient in several ways: by reducing the prominence of the subjective evaluation of the patient by the physician; by reducing the importance of the physical examination and direct manipulation of the patient by the physician (i.e. through touch); by fragmenting patient care across medical disciplines (from family physicians to a team of specialized practitioners) and across institutions (physician's office, hospital departments, emergency and operating rooms, ICU, clinic, laboratory).

The further distanciation of the physician from his/her patient is most evident with the integration of telecommunications in medical practice, often referred to as telemedicine. Because the history of telemedicine is populated with a series of discrete and fragmented experiments using the telegraph, telephone, television, satellite, and other communications media, a list of its main developments is provided in Table 4. As revealed in this list of events, pioneers of telemedicine include members of the military, medical practitioners, educators and NASA. The evolution of clinical telemedicine was partly driven by the need to provide access to medical services for remote and rural populations. While there occurred a proliferation of telemedicine projects from the 1960's to the 1980's, the large majority of these projects were not sustainable due to several factors, identified as follows by the Committee on Evaluating Clinical Applications of Telemedicine: the failure to link projects to organizational strategies; poor planning; high transmission costs; inappropriate and outdated technology; low patient volume; lack of physician support; and, limited insurance coverage (public and private) (Field 42). The resolution of some of these issues, as well as the advent of health

care reform and other factors, prompted an important surge in telemedicine activity during the 1990's. Projects dating from 1990 and their conditions for success will be looked at in Chapter Four.

2.2 The Medical Profession: From the Doctor to the Specialist

The anatomo-clinical gaze was significant to the organization of the medical profession in that it provided a scientific, ideological foundation, and the practical means, through the development of precise medical instrumentation, for the specialization of medical practitioners. In 1915, there were 34 recognized medical specialties. In 1929, one out of four medical practitioners in the US was a full-time specialist. Forty years later, that number rose to three out of four (Reiser, Medicine 144-145). The decline in family physicians corresponds, to some extent, to the decline in the number of physicians practising in rural areas. Specialization of medical practice has been resisted by patients who fear the fragmentation of patient care and the lack of understanding of their personal situation. According to Reiser, specialization proliferated hand-in-hand with the establishment of interdependent and cooperative practice in North America. Both specialization and cooperative practice were driven by the need to master the constant proliferation of medical knowledge, to reduce the expense of new medical technology and to achieve efficiency. Cooperative practice was viewed as a means to integrate the interrelationship among physician, patient and technology. Reiser describes as follows the emergence of cooperative specialism:

The growth of cooperative specialism was aided by the support of physicians who

> had served in World War I, and of their patients; both had become accustomed to the organized delivery of medical care in the armed services . . . .Cooperative specialism also reflected the tendency in medicine toward group effort that characterized industry and various social entreprises in early twentieth century society. (Medicine 151)

Cooperative practice was formalized in hospitals and private group practice. The chief model of the latter is the well-known Mayo Clinic founded in the 1880's by the Mayo brothers, William and Charles. The brothers sought to practice medicine and surgery in Rochester, Minnesota. Initially, cooperative practice was resisted by patients due to the following: a fear of abuse of the vulnerability of the patient by ordering superfluous tests; fear that medicine would be turned into a business and result in an impersonal atmosphere and the systematic "processing" of patients ("department store" medicine); a fear that it would weaken personal ties and diffuse accountability (Reiser, Medicine 156).

The control of new medical technology was often perceived of as a means to obtain professional power. For instance, upon the introduction of the x-ray, many physicians attempted to distinguish themselves as specialists in the production and interpretation of x-ray images. However, due to the fact that patients never directly contacted the radiologist compared with the physician and surgeon, the role of the radiologist in the health care team was not as widely appreciated. Radiologists then came to understand that their situation would improve if they were not portrayed as providers of an x-ray plate (such as a seller of photographs), but rather as an expert offering a

consultation. To reinforce their control over this "privileged way of knowing", radiologists became the exclusive observers of x-ray images, refusing to allow patients to view the images themselves. Consequently, professional power was acquired through the x-ray due to differential access to the technology, as opposed to technical complexity. Now that the profession of radiologist is well established, the public has regained access to its x-ray images, such as in the common case of fetus ultra-sound.

A similar situation occurred in the case of blood technics. Initially, new blood technics threatened the role of the pathologist by providing objective data used for diagnoses before death. Pathologists, therefore, delayed the popularization of blood tests; they were still not commonly executed even well into the twentieth century. In seeking to achieve a status equal to physicians and surgeons, pathologists affirmed their exclusive right to draw blood from patients. Eventually, they were overwhelmed by massive demand. Alternatively, they recognized that it was more practical and profitable to act as supervisors of blood technicians and as independent consultants.

2.3 The Medical Institution: From the Home to the Hospital

The precursor model to the modern hospital came about during the reign of Constantine I in 335, the first Roman Emperor to embrace Christianity. Pagan temples of healing were closed. While physicians continued to practise primarily in the home, Church hospitals were built in every cathedral city to serve the poor and travellers, as well as to provide palliative care. Hospitals were notorious for crowding, unhygienic

conditions and high death rates among patients and attendants. The modern hospital was first secularized by Henry VIII when he suppressed the monastery system in the early sixteenth century. A network of private and nonprofit hospitals were established and administered on a voluntary basis by physicians and medical students. During the seventeenth century, several hospitals were built in London following increased demand. Two such hospitals, St-Bartholomew's and St-Thomas adopted a policy that prescribed the exclusive admission of *curable* patients. Other noncurables were sent to asylums, prisons or almshouses.

In France, during the eighteenth century, the medical profession acquired a political prestige when it was reorganized to represent a "collective consciousness of pathological phenomena" (Foucault, Clinic 28). Prior to such reorganization, Sydenham's classificatory medicine had identified two different forms of constitution of disease that differed according to their scale: sporadic and epidemic. Epidemic constitutions are said to be characterized by constant and homogeneous pathological phenomena. Their "historical individuality", it was told, requires a complex process of observation and a "multiple gaze" to perceive their peculiar, spontaneous and unpredictable qualities (Foucault, Clinic 25). It was recognized in the eighteenth century that the medicine of epidemics needed to incorporate a policing function to supervise, qualify/quantify and control casualties, tainted areas, nutrition and sanitation etc. The medicine of epidemics was institutionalized during the period 1775-1780 with the advent of the French Société royale de médecine. The purpose of this institutionalization is

interpreted by Foucault as follows:

> . . . [here] medical space can coincide with social space, or, rather, traverse it and wholly penetrate it. One began to conceive of a generalized presence of doctors whose intersecting gazes form a network and exercise at every point in space, and at every moment in time, a constant, mobile, differentiated supervision. (Clinic 31)

According to Foucault, just before and just after the French Revolution, two great myths were intertwined with medical practice: the myth of a national medical profession whose members would be involved in every aspect of individual and population health, acting as the "priests of the body" (Clinic 32); and, the myth of the total alleviation of disease. The democratic and humanitarian movements that took hold of France and America during the eighteenth century influenced the medical profession in such a way that it advocated, as a primary condition for the state of health of the population, the liberation of the individual. As Foucault argues, the political power of the medical profession lies in its vision of what constitutes a healthy man, an ideal model that takes on a normative force. "In the ordering of human existence it [the medical profession] assumes a normative posture," Foucault writes, "which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives" (Clinic 35).

In its new position as protector of individual and population health, the medical profession emphasized the role of the family as key to a natural healthy environment. It

offered the hospital as a sanctuary to those unfortunates who did not dispose of the natural comfort of family and pressured the state to fulfil its social duty by providing them with assistance. In 1911, the Comité de Mendicité of the National Assembly of France, under the influence of physicians and economists, recommended the abolishment of hospital foundations in favor of a decentralization and redistribution of assistance under the guardianship of the "doctor-magistrate". In such a role, the physician's task is first and foremost of a political/moral/economic nature, as opposed to a medical one.

The reform of medical practice that reflected the democratization of society and the advent of the welfare state increased the prominence of the hospital as a socio-political institution. The deterioration of the hospital, that resulted after secularization, began to be rehabilitated during the nineteenth century, following the reform of nursing and the influence of Florence Nightingale in improving the sanitation and architecture of the hospital ward, the introduction of antiseptic technics in surgery by Joseph Lister in 1867, and the findings of Robert Koch who linked bacteria to disease in 1882. In America, most hospitals were opened much after the settlement of colonies. For example, the Massachusetts General Hospital was established over 200 years after the founding of the city of Boston. American hospitals retained the British practice of admitting only the sick poor. According to Howell, in 1873, over half of all American hospitals did not admit patients with contagious diseases, and many did not admit patients who were assessed as incurable. At the turn of the twentieth century, with the influence of the medicine of epidemics and the humanitarian movement, hospitals were designed

for long-term care, as orphanages or nursing homes. Whether or not a hospital was highly regarded depended on the technological sophistication of its amenities, that is, of the laundry rooms, kitchens and telephone system. Since voluntary hospitals were supported by business owners, investment in new amenities was aimed at attracting patients with access to private funds.

From 1900 to 1925, the number of US hospitals dramatically increased. They became central to medical education. At the same time, Howell contends that technology became central to hospital care. Medical technology was more strictly defined in terms of technology used directly on or around the patient. By 1925, Howell describes US hospitals as "actively and self-consciously" based on science (2). However, what constituted science was fairly broad and extended beyond applied sciences to Taylorism and scientific management. While new medical technology was used to attract middle-class patients, the new influx of private money increased the demand for technics of business management, not to mention recent demands made by physicians to be reimbursed for services and tests rendered. New hospital boards were composed of leaders in industrialization; these boards were instrumental in integrating technics of cost accounting and medical management technology (adding machines, punch cards, typewriters) into daily hospital practice. As well, new record-keeping and management technics, in reorganizing the hospital's functions and information, resulted in the further standardization and fragmentation of patient care. With the standardization of forms, patient records could be filled out by various individuals. They could include greater

amounts of information. Moreover, new administrative units were created to fulfil the requirements of scientific management and they also issued their own unique forms.

Howell goes so far as to argue that increased attention to hospital organization encouraged the rise of surgery. As previously mentioned, surgery had occupied a less privileged position than medicine for the greater part of its history, characterized as a craft versus a science. Howell posits that the modern hospital was crucial to the rise of surgery for several reasons: due to the importance of the operating room; due to the increased availability of aseptic technics; and, due to the hospital's new organizational framework. The latter facilitated an increased volume of procedures at a more rapid pace. The routine use of x-rays also depended greatly on a new hospital structure. While Howell reports that, in 1900, all major American hospitals had x-ray machines, it was not until 1920 that most patients were x-rayed while they were hospitalized. Howell trusts that such an increase resulted from the following: changes in the type of patients hospitalized (higher class, more routine patient care); the number of medical personnel that earned experience with the technology during the First World War; and, the new hospital organization (forms and reimbursement schedules).

2.4 Medical Decision-Making: The Notion of Evidence

Technology has impacted medical decision-making in two fundamental ways. First, there has been concern and criticism during the past forty years relating to the alleged overdependence of medicine on technology. Second, medicine is increasingly

scientistic to the point that human error in decision-making has become unacceptable. As a result of this process of scientism, medical technology has been developed to standardize and automate medical practice. These two impacts of technology on medical decision-making will be discussed in this last section on the history of medical technology.

Technology was designed to automate the processing of medical tests, which, in turn, allowed testing to expand. For instance, in 1956, L.T. Skeggs, Jr. introduced the automatic analyser that could execute ten separate laboratory procedures from one biological substance and perform tests on 5,000 specimens on a daily basis. Automation enabled tests to be grouped and packaged together as Chem 6, Chem 8, Chem 12 etc. According to Reiser, the automation of medical testing produced an excessive diagnostic inquisitiveness, which he defines as the routine use of technology without a clear ordering of thought (Medicine 161). Reiser believes that overdependence on technology is rooted in the presumption that medicine becomes scientific by its very use of technology. He states that many physicians consider medical practice to be as scientific as the proportion of quantitative measures of illness available versus qualitative measures. Reiser posits that excessive testing was also driven by patients – their enthusiasm stemming partly from fascination and partly from their threat of malpractice suits – as well as by the public and private insurance systems. Reiser concludes that, by the 1970's, diagnostic decision-making had become no longer an intellectual, deductive act but rather a managerial act of choosing what tests to order and what specialists to consult.

Reiser acknowledges some resistance to overdependence on medical technology grounded in the following observations: the physician has become more of a biologist than a caregiver, an intermediary between patients and technicians; the physician does not possess enough knowledge of laboratory science to subject test results to medical scrutiny; medical technology is used as a means to shield the physician from distressing situations – critical illness and death – where he/she is faced with his/her limitations and failures (Medicine 166-173). Reiser points to Sir James Mackenzie (1853-1925) who, early on, attempted to distinguish between the art and science of medicine. Mackenzie defines the art of medicine as the ability to understand the needs of the patient and use this knowledge to improve treatment. He sought to reinstate the patient in the diagnostic process and he argued that direct patient evaluation was as reliable as technologically-derived evidence since both were subject to human interpretation. Mackenzie, therefore, advocated the use of prognosis. According to Mackenzie, technology should be deployed until the physician learns to obtain the same knowledge without it. However, as Reiser recognizes, the qualitative practices of medicine that Mackenzie deemed as part of the art of medicine, have since been re-appropriated as part of the science of medicine by psychiatry and sociology.

Automation served, not only to expand medical testing, but to standardize medical practice. The increasing role of science in medicine emphasized the need for constancy in the interpretation and the recording of pathological phenomena. During the twentieth century, medical research uncovered significant variation and error in human observation

and interpretation attributed to the following factors: flaws in the personality of the physician; carelessness; lack of experience; untactful behavior with patients; faulty medical education; shortcomings in medical knowledge and technics; changing physiological constitution of the patient due to weather, digestion, emotion, work etc. (Reiser, Medicine 183).[31] Variation was especially troubling in the case of laboratory technicians. It was found that due to the fact that lab technicians are far removed from the patient, they had a less direct sense of accountability. Furthermore, their lower status rendered them susceptible to overwork and poorer training. The integration of computers into medicine elucidated the issue of variation and error in medical decision-making.[32] Reiser recalls:

> As computer experts applied their knowledge of data-handling to medicine, they demonstrated that medical diagnosis and decision-making often occurred in the face of incomplete evidence; that because of the limits on the amount of data the mind could hold, the memory could recall, and the intellect could analyse, giving more pertinent information to the doctor did not necessarily diminish the uncertainty under which he acted. (Medicine 204)

In order to compensate for the limited ability of the physician to process the ever-

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[31]It was determined that arriving at a precise diagnosis depends on the following: the intrinsic accuracy of the method of measurement; constant phenomena; and, the ability of observer. In the 1950's, studies on variation and error in medical decision-making were discouraged because they were thought to disturb morale.

[32]In 1959, the Conference on Diagnostic Data Processing held at New York's Rockefeller Institute was dedicated to the future of using computers in medicine. In 1960, computers were capable of storing 100 items of information on one patient for a total of 50,000 patients on one real of magnetic tape.

mounting quantities of information available through new technology, some strategies were suggested, most notably the further specialization and standardization of practice and the automation of medical decision-making itself.

The standardization of medical practice was two-fold. It implied the standardization of patient data collection and the standardization of medical practice through clinical practice guidelines (CPGs). As early as 1915, many stakeholders – such as new professional associations, researchers, litigants, clinicians and hospital review boards – had demanded improvements in medical data collection. During the 1950's, standard forms were developed to gather quantitative and qualitative (check-list) patient data. Concerns were raised that these forms would discourage any individuality on the part of physicians and prevent the documentation of the unique circumstances surrounding each case. While there were initial efforts to create a unified patient record in the early 1900's, the patient record has remained fragmented to this day.[33] Comparatively, clinical practice guidelines have been sanctioned by most professional associations and health care institutions since the 1960's. They are advocated as a means to ground medical decision-making on universal scientific principles. However, while they have been found to be effective and generate accurate decisions, they privilege certain types of patients and social contexts.

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[33]In 1907, a unified patient record was introduced at St Mary's Hospital operated by the Mayo brothers. The record was improved by the Presbyterian Hospital in 1916.

During the 1960's, research aimed at automating the diagnostic process undertook an intensive study of the logic that underlies such a process. Two approaches to this study were formulated. The first approach sought to replicate the mental steps followed by physicians to come to a diagnosis. The second approach argued that diagnostic strategies appropriate to the computer should be developed regardless of human reasoning. Researchers found that physicians reached diagnoses by evaluating illness according to yardsticks that were based on their own experiences and values. While some researchers proposed that this variable and hybrid form of reasoning was representative of the art of medicine, others believed that it could be measured mathematically through symbolic logic. Toward the end of the decade, most researchers reverted to the second approach and several sets of computer directives, based on Thomas Bayes's mathematical theorem (1763), were created to diagnose diseases in various parts of the body (heart, glands, blood, bones and brain) in patients who had already received a specialist consultation. While the computer's accuracy rivalled that of the physician, it did not have the capacity to select relevant patient history and depended on historical, patient data to be inputted manually by the physician. Once the information was entered, the computer could then evaluate the probability of different diseases. However, Bayes's theorem required mutually exclusive categories of diseases and mutually independent symptoms which were not always the case. Other difficulties hindered the use of the computer in medical diagnosis. First and foremost, the main concern was whether diagnosis should be based on probabilities at the expense of knowledge of the total clinical situation. For instance, the most probable diagnosis could involve the most perilous therapy.

Other technology was more successful in automating medical decision-making but with a much narrower focus. The Cornell Medical Index was introduced during the Second World War to process military recruits more rapidly by automatically obtaining, processing and storing their patient histories. While it was revealed that the Index was as efficient as the physician, it depended heavily on the ability of the patient to relate the information through a literate, inflexible format. During the mid-1950's, the cytoanalyser could detect abnormal human cells by scanning pictures and graphs and transmitting the medical images to a computer. Other programs similarly quantified electronic impulses obtained from scanning x-ray images. In 1972, an evaluation of such programs, published in Hospital Tribute, found a greater accuracy with computer analysis (72 per cent) than radiologist interpretation (62 per cent) in the diagnosis of rheumatic heart disease ("Radiology"). In conclusion, the automation of medical decision-making is seen as favorable because it may free physicians to spend more time with their patients, because it brings out the value of patient history and examination, because it reestablishes patient experiences at the forefront of medical diagnosis and the physician's knowledge as the main focus of evidence in clinical medicine. Notwithstanding, it has been indicated that the computer undermines the physician's authority and human relationships within medicine, and that it may dominate medical practice.

The history of medical technology, undertaken in the context of this project, has sought to reveal the influence of technology on the evolution of the medical gaze, the medical practitioner, the medical institution and medical decision-making. As Reiser

confirms: "Techniques influence the relationship of the patient with the physician; they influence the doctor's image of himself as a decision maker; they influence the association of physicians with each other, and thus the manner in which the institutions of medical practice are organized" (Medicine 227). As reviewed, the scientific spirit was first introduced in medicine under Hippocratic influence, whereby, mechanical and causal principles were distinguished from those of correspondences and analogies espoused by the old theory of sympathies. Reviving Hippocratic medicine, Renaissance anatomists reestablished the value of human versus divine perception and experience. Their contribution was furthered by the dominance of empirical thought during the Scientific Revolution that produced several key innovations in medical technology. During the seventeenth century, the classificatory-clinical gaze separated the practice from the theory of medicine. Institutionalized in the proto-clinic, it was first to advocate the standardization and reproducibility of medical evidence. Further supported by autopsies and medical technology, clinical medicine required greater physical proximity of the physician from his/her patient. A product of medical technology, the anatomo-clinical gaze emphasized the multi-dimensionality of the gaze and studied pathological anatomy as it is viewed before death.[34]

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[34]To recapitulate, each phase of the medical gaze has its own distinct emphasis, summarized as follows: (1) the classificatory gaze emphasizes the *essence* of disease; (2) the clinical gaze emphasizes the *frequency* and *probability* of the manifestation of disease; (3) the anatomo-clinical gaze, during its first phase of development, emphasizes the *seat* of disease (Bichat's tissue analysis tied to postmortem visibility) and, in its second phase, emphasizes the *cause* of disease (Broussais's reorganization with the crisis of fevers highlighting the acceptance of artificial eyes/instrumentation).

During the nineteenth century, anatomo-clinical medicine integrated physiology, biology and chemistry. Its medical technology, which later came to include computers and telecommunications, transformed bodily processes into objective phenomena and distanced the physician from his/her patient in several ways: by separating patient examination, that is the registering of symptoms, from the interpretation of symptoms and reducing the importance of direct patient observation; by reducing the importance of the subjective evaluation of the patient by the physician; and, by fragmenting and standardizing patient care across specialized medical disciplines and health care institutions. New technology enabled physicians to acquire professional power through differential access. And, it enabled modern hospitals to privilege certain professional disciplines (surgery). Reiser disbelieves that new technology will enable the physician to spend more time with his/her patients. "Machines inexorably direct the attention of both doctor and patient to the measurable aspects of illness," Reiser contends, "but away from the 'human' factors that are at least equally important" (Medicine 229). To the contrary, he trusts that new technology will continue to estrange the physician from his/her patients and his/her own judgement. Instead, he favors a decentralized environment for physicians to practice away from specialists and technology in order that they may trust their own judgement and conduct a more personalized practice (Medicine 231). He also stresses the importance of reducing the isolation of rural areas for patient and practitioners alike.

CHAPTER TWO: CRITIQUE OF MEDICAL TECHNOLOGY

Section 1: Critiques of Technology

In the same fashion that I earlier reviewed the manner in which different theoretical perspectives define technology and approach the history of technology, I will now briefly outline how the following theoretical, analytical perspectives critique technology, its design, development and social impact: critical theory (including, but not limited to, the Frankfurt School), social constructivist theory, actor-network theory, feminist theory, postmodern theory, and social anthropology theory. In so doing, I will introduce several theoretical concepts that are applied in critiques of medical technology brought forth later in this chapter, in critiques of information and communications technology discussed in Chapter Four, and in critiques of telehealth detailed in Chapter Five. Critiques that address citizen involvement in technological design, implementation and evaluation will be emphasized.

1.1. Critical Theory

In Technics and Civilization, Lewis Mumford undertakes a social history of technological development. That is, he presents technological development as one element in human culture and assesses its socio-cultural impact. He traces back the underlying, driving force of Western, modern technology to the natural philosophy of the seventeenth century formulated by Bacon, René Descartes, Galileo, Sir Isaac Newton (1642-1727) and Blaise Pascal (1623-1662). During what he calls, the Eotechnic phase

of technological development, a mechanical conception of the universe dominated research and application, and gave way to the experimental method in science. This new scientific method provided a theoretical and practical framework for the advancement of the physical sciences and technology. It is also during this period that the *technological imperative* originated, described by Mumford as follows:

> The point is that invention has become a duty, and the desire to use the new marvels of technics, like a child's delighted bewilderment over new toys, was not in the main guided by critical discernment: people agreed that inventions were good, whether or not they actually provided benefits, just as they agreed that child-bearing was good, whether or not the offspring proved to be a blessing to society or a nuisance. (53)

Mumford argues that the technological imperative was reinforced by a desire for order, regularity and certainty. Technology was seized upon as a definite finality on which one could depend in the midst of political and economic crises experienced throughout Europe.[35] He compares the compulsive urge toward mechanical development to religious fanaticism. However, Mumford points to a gradual rise in the skepticism of society with regards to technological development, deriving from the realization that the machine constitutes a potential force in the destruction of organized society and that it perpetuates subordination of human activity to capitalist entreprise. As will later be discussed,

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[35]These include important challenges to growing state power in England, France and Spain in the 1640's, the last wars of religion merged with wars relating to commercial expansion and the overthrow of governments, natural disasters caused by weather, famine and plagues, a prolonged economic depression in mid-seventeenth century etc.

Illich's critical review of iatrogenic medicine is a case in point.

Ellul offers an even more extensive account of technological development and criticizes Mumford for restricting his notion of "technics" to the machine. He claims that Mumford's history of technology, divided into periods defined according to the various modes of exploiting energy, is inadequate unless technology is understood solely in terms of the machine. Alternatively, Ellul recapitulates the historical development of technology in order to distinguish the new characteristics of modern technology from those of traditional technology. The main currents of technological progress recognized by Ellul are described in Table 5. He concludes from this recapitulation that the evolution of the characterology of technology can only be perceived by closely observing the changing nature of the social dimensions of technology, as opposed to its technical dimensions (such as the ways in which it exploits energy). That is, "[i]t is not, then, the intrinsic characteristics of techniques which reveal whether there have been real changes," Ellul argues, "but the characteristics of the relation between the technical phenomenon and society" (Technological Society 63). In brief, Ellul specifies the following characteristics of traditional technology: its application in limited areas; its localism; its subordination to social relations; its relative unimportance compared to the skill of the worker; its gradual perfection through pragmatism; its slow evolution; its concession of the possibility for human choice. Comparatively, the technical phenomenon of the twentieth century is circumscribed by two essential features, its rationality and artificiality, the former depicted by Ellul as follows:

> . . . a rational process is present which tends to bring mechanics on all that is spontaneous or irrational. This rationality, best exemplified in systematization, division of labor, creation of standards, production norms, and the like, involves two distinct phases: first, the use of "discourse" in every operation . . . .Second, . . . the reduction of method to its logical dimension alone. (Technological Society 79)

In addition to identifying rationality and artificiality as the defining parameters of the current relation between the technical and social realms, Ellul recognizes several new characteristics of modern technology: the automatism of technical choice, self-augmentation, monism, universalism and autonomy. Each characteristic is described in greater detail in Table 6. According to Ellul, modern technology is no longer positioned as a "means" or as an "intermediary", but rather as an "independent reality" to which society is confronted (Technological Society 63).

In his One-Dimensional Man, Herbert Marcuse contrasts pre-technological from technological thinking as follows. Pre-technological thinking privileges the dialectical relation of opposites. It positions the subject as an agent in history, whereby his/her identity is constructed through, and against, historical and social reality. Dialectical thought presupposes a critical consciousness in that its object, concrete reality, is defined by the subject's intuitive judgement (grounded in his/her perception of how an object clearly appears). It contends that the subject's immediate perception and experience is a "false" experience – in the sense of different from concrete reality – and that the meaning

of this experience is determined by historical contextualization. Contradiction is inherent to the meaning of the object by the very fact that the object is defined by what it is not. Comparatively, technological thinking, originating in Aristotle's formal logic, is realized through abstraction, indifference and decontextualization. It is foremost characterized by its rationality/instrumentality, operationalism and containment of social change. Marcuse defines *technological rationality* as the methodology, organization and treatment of matter as instrument. He argues that Aristotle's formal logic neutralizes the material content, or concreteness, of reality by claiming that contradiction is the outcome of incorrect thinking. Furthermore, it categorizes concepts according to their adherence to an organized system of logic, isolating and marginalizing the erred "subjective" conceptual dimension.[36] Objective concepts are reduced in meaning to their corresponding set of operations/functions. Marcuse posits that such *discursive operationalism* – previously mentioned by Ellul as the first phase of technological rationality – gives way to a particular social and political behaviorism by closing off other potential uses of the object. For instance, the increased use of abbreviations and acronyms reveals a tendency to recognize concepts that are institutionalized; their meanings are fixed, sanctioned and unambiguous. As Marcuse concludes:

> This language of one-dimensional thought imposes *images* and it impedes

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[36]There are clear parallels between technological thinking, as depicted by Marcuse, and the rules of classificatory medicine brought forth in Chapter One: the privileging of historical rather than philosophical knowledge; reliance on direct observation and analogy (resemblance to a predelimited category); specification of a rational order of matter/disease; and, abstraction (or neutralization) of reality/patient in order to preserve knowledge of the matter/disease in its abstract/ideal form.

> conceptual thinking. Abridgement of the concept in fixed images; arrested development in self-validating hypnotic formulas; immunity against contradiction; identification of the thing (and of the person) with its function – these tendencies reveal the one-dimensional mind in the language it speaks. (Man 97)

William Leiss distinguishes technological rationality from its scientific counter-part. While science is assigned a broad, social imperative directed to the mastery of nature, he suggests that technology links the mastery of nature to the mastery of man. According to Leiss, science's increased capability to master nature has escalated the instances of social conflicts due to several consequences of its actions, including: the inequitable distribution of needed natural resources, the gap in scientific knowledge and ability amongst nations, the rising material expectations of populations, the symbolic struggles over needs and aspirations etc. Leiss concludes: "Political mastery over human nature in all its diverse cultural forms is sought in response to the intensified social conflict which in turn depends in part on a growing mastery over external nature" (159). He trusts that technology is well positioned to facilitate such political mastery since it can respond more directly to human needs and its social tasks are not mediated by reflexive thought. Thereby, Leiss identifies as the main distinguishing feature of technological rationality its role in social integration achieved through a system of domination over human nature. Later to be elaborated upon, medicine – a system that increasingly depends on technology – serves as a mechanism of social integration by asserting and maintaining regulatory control over the human body. For instance, it determines the

body's status as healthy or ill and, subsequently, has the power to segregate ill bodies from society.

Likewise, Marcuse identifies two major consequences of technological thinking: the establishment of a system of domination that is embodied and reproduced in a technological apparatus; and, the containment of social change through this system of domination. Marcuse contrasts pre-technological domination, which was sustained by personal dependence in the master/slave relationship, from technological domination, persisting thanks to dependence on the objective order/system of logic. Critical theorists have proposed different ways in which technological rationality has created structures of domination. Others conceive of technological rationality as a form of liberation. Most notably, Marx claimed that the application of science to production would release workers from exploitation and alienation by substituting scientific knowledge for labor. In so doing, in automation, economic value inevitably becomes disassociated from the amount of labor invested in production. It is assumed that Marx believed in the beneficent value of science because he held on to Enlightenment assumptions that linked science to reason, the subject, idealism, man and mind, and because he privileged these values at the expense of unreason, the object, materialism, nature and body. Neomarxist authors of the Frankfurt School later sought to analyze the relation between science and industry independent of such dualistic thought.

In Dialectic of Enlightenment, Theodor Adorno and Max Horkheimer subvert science's claim to a unique connection to reason, as well as science's rejection of ideology in the forms of religion, intuition, superstition, tradition etc. They, instead, argue that scientific epistemology is grounded in the domination and objectification of nature that, when applied to the "culture industry", serves to dominate the spectator/receiver of communication and transforms science into ideology itself. Mark Poster, however, points out the authors' neglect of the conditioning effects of the structures of communication/media that are also part of the system of domination – structures in which technology, as the application of scientific epistemology, plays a much greater role – claiming that they only deal with the content of socio-cultural discourse. For his part, Axel Honneth discounts their work for not considering the collective struggle over identity, meanings and values, that is, for not explaining how structures of domination are determined, not just by instrumental control, but by consensually adopted norms.

The normative foundations of technological society are explored by another Neo-Marxist scholar, Jurgen Habermas. In accordance with Max Weber, Habermas argues that instrumental reason leads to domination from its cultivation and legitimation within institutions. Weber more narrowly contends that instrumental reason is institutionalized in the form of bureaucracy; it is then transformed into domination. Weber envisions a bureaucracy that is both rational and irrational. It is rational because it imposes instrumental action upon individuals; and, it is irrational because it is not itself subjected

to rational critique. Weber maintains that rational critique must be based on theory, and theory must be premised on rationality as its basis for action. It follows that, since the credo of bureaucracy is rationality, then theory cannot critique its own foundation. Weber's analysis, in any event, is not so privileged as to be beyond critique. As Poster remarks, while he established science as the guiding epistemology of bureaucracy, he did not regard science as politically biassed.

Comparatively, Habermas extrapolated from Weber and found that capitalism enabled instrumental rationality to be extended from science to most other societal institutions (including health, education, military etc.). The actions of these institutions are legitimated to the individual by the fact that they are rational and undertaken by institutions that reject more traditional forms of domination. Nonetheless, Habermas notes that, in the late nineteenth century, the rise of interventionist actions by the state in economic matters exposed deficiencies in the self-regulating nature of the capitalist market that rendered it vulnerable to political manipulation. In order to depoliticize its actions, the interventionist state resorted to science as a means to legitimation. Habermas explains that if the state was perceived as acting in accordance with scientific principles, its political actions were neutralized. Thus, Habermas does not concur with Weber's neutral view of science and, in fact, concludes that scientific rationality became a political form of domination. To briefly illustrate, in Chapter Three, I will discuss how Canadian health care reform is advocating the use of evidence-based decision-making throughout the health care system for the purpose of rationalizing services – that is, to contain costs –

and to improve the quality of care. It can be inferred that evidence-based decision-making will provide the means through which the state can mask its direct accountability for measures taken in the context of reform under a veil of scientific credibility.

Subsequent to the politicization of science, Habermas seeks to define a new means to legitimation of institutional action: from instrumental action to symbolic rational interaction. Habermas locates social integration and the formation of individuality in the independent communicative sphere. He extends understanding of communication beyond the technical control of discourse, such in the case of discursive operationalism. He identifies several key conditions for communicative exchange, for the *ideal speech situation*: the acceptance of the subjectivity of the Other; the norms of sincerity and truth as regulators of the exchange; the role of agreement vs. control; the role of common ideologies; the role of identity; social integration and rational consensus achieved through discussion and media of money and power. Both Honneth and Poster object to Habermas's retention of the Enlightenment notion of reason that, de facto, reflects his continued belief in the neutrality of technological rationality. In fact, Habermas is not against the expansion of the technological system, but rather advocates for an increased role of normative regulation in the legitimation of institutions. Typical of critical theory of the Frankfurt School, he continues to aspire to a distanced objectivity of the observer and, in doing so, obscures power relations within the critical position itself. He, along with Adorno, Horkheimer and Marcuse, in retaining some concepts of

the Enlightenment, exposes critical theory to technological thinking.[37]

Foucault ascertains how the production of discursive truths, on which Enlightenment concepts rely, is achieved by, and reinforces domination. His argument ostensibly draws parallels with Marcuse's analysis of the one-dimensionality of technological thinking, its discursive operationalism. Foucault considers discourse as a language formation that reveals the operation of power, not only in the statements that it selectively validates, but also in the rules that govern the formation and the system that validates it. In the case of scientific discourse, Foucault attempts to decipher the language patterns, as well as the practices to which they are associated, including the production of norms. He then links these practices to the structures of domination that they legitimate. For instance, I earlier brought forth his analysis in The Birth of the Clinic that outlined the structures of the medical gaze. As they evolved, the structures of the gaze shaped the physician-patient relationship, defined the non-sick and sick, the normal and the pathological, according to various norms, and established the codes and rules of medical knowledge (Tables 2 and 3); they also served to legitimate the proto-clinic, the clinic and later the hospital. In Discipline and Punish, Foucault demonstrates how the norm that defines prisoner from non-prisoner is enforced through a technology of power

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[37]To illustrate, in an Essay on Liberation, Marcuse projects that the emergence of different goals and values will enable the "rational utilization of technical and technological forces" of advanced capitalism and socialism on a global scale to end poverty and scarcity in the near future (4). Hence, he retains the concept of a rational society, distinguishing between instrumental and emancipating/enlightened rationality, the latter based on norms of justice, peace and happiness reminiscent of the French Revolution.

called the Panopticon. The *technological micropolitic* of the Panopticon dominates a collection of separated individualities through a state of conscious and permanent visibility. These individualities are produced and repressed through disciplinary training, involving hierarchical observation, normalization of judgement and highly ritualized examination (objectification, documentation and standardization). Power is effected through a concerted distribution of docile bodies whose internal mechanisms fix in scope the relations in which individuals are implicated. Such distribution involves the technics of enclosure, partitioning, the establishment of functional sites and the interchangeability of units (or ranks). Foucault describes as follows how the hospital is organized as a functional site for the distribution of those designated as "sick":

> Gradually, an administrative and political space was articulated upon a therapeutic; it tended to individualize bodies, diseases, symptoms, lives and deaths; it constituted a real table of juxtaposed and carefully distinct singularities. (Discipline 144)

The hospital is characterized as an "administrative and political space" by Foucault because it directly relates medical supervision of pathologies to other structures of domination, such as the military, the administrative management of treatments, the financial management of medical commodities etc. While Foucault successfully links the production of institutional norms to structures of domination, Feenberg criticizes his analysis for reducing individuality to a reflex of bodily training. Even though Foucault insists that scientific discourse contributes to social domination versus the domination of nature, Feenberg reminds him that he has lost the "social", especially the idea of social

struggle, in his presentation of technological micropolitics.

In order to consider the contingency of social struggle, technological domination cannot be understood as solely involving the instrumentalization of passive human labor. This conceptualization does not allow for any resistance to power beyond a complete reversal of who possesses the means of technological control or a total expulsion/destruction of technology. Rather, Honneth recognizes the need to demonstrate how technological domination and rational consensus are intertwined. That is, technological rationality must be conceived of as co-determined by norms and moral viewpoints – the products of communicative understanding (Habermas) and/or disciplines (Foucault) – that are introduced and adopted within technological development itself. Hence, Honneth speculates that class formation depends on the implicit content of collective action in consensus formation and includes those actions determined by technological choices. Technologies are adorned with normative (and not just behavioral) prescriptions that converge in the conscious form of group value orientations. These orientations serve to stabilize social groups and to provide a basis for coordinated action, and also for a system of domination. Honneth's insight mirrors Foucault's conception of disciplinary technologies and their role in social integration, as well as Ursula Franklin's notion of prescriptive technologies to be further described in Chapter Five.

Marcuse alleges that the perpetuation of the technological system of domination relies on its ability to integrate society by establishing a rational consensus, that is, "to reconcile the forces opposing the system and to defeat or refute all protest in the name of the historical prospects of freedom from toil and domination" (Man xii). This containment of social change – nominated by Marcuse as the greatest achievement of technological domination – is manifested politically in bipartisan policy, the convergence of the warfare and welfare state under the imperative of a National Purpose such as anti-communism, global competitiveness, nationalism etc. According to Marcuse, it is manifested socially in the behavior of the working class whose resistance has been weakened by their inclusion in a consumer society. The welfare state, Marcuse explains, raises the standard of living to the extent that it suffocates those needs and aspirations that require liberation from a technological society. It substitutes affluence and consumer choice for self-determination and free choice. In Canada, the welfare state, in instituting public health insurance, offers consumer choice among health care providers, but offers no such choice among ideological models that dictate health and health care. It imposes the system of iatrogenic medicine, whose critique by Illich will later be discussed.

Likewise, Ellul posits that the technical system of domination is reinforced by a rational consensus that takes the form of "a new religion of a rational and technical order" in order for man "to justify his work and to be justified in it" (Technological Society 324). He maintains that since the primary objective of the technical order is yield (production) then "this yield can only be obtained by the total mobilization of human

beings, body and soul, and this implies the exploitation of all human psychic forces" (Technological Society 324). Human technics, according to Ellul, are implemented for the purpose of achieving this total mobilization. They do so in three ways: by making superhuman demands on man; by instituting changes in the human environment (through the modification of space and time); and, by altering sociological structures (the creation of a mass society and the disappearance of community). In order to successfully perform, they must be applied generally (across all subjects), objectively (regardless of personal situation) and permanently. While Ellul identifies medicine as a human technic, he is careful to point out that human technics are potent only when interrelated with the state. He believes that medical technic is of little interest to the state since its widespread practical application as a means of population control presents many challenges.

Faced with the perpetual propagation of a technological system of domination, Marcuse proposes an interactive, but vague, strategy for change that is grounded in a reevaluation of aesthetics as the source of new needs and of a new practice of freedom. For example, if a concept such as beauty could be understood as an objective criterion[38], then Marcuse trusts that the entire normative basis of the technological system could be revolutionized. Perhaps the ethical could be instituted as the foundation for technological development. Marcuse, thereby, moves away from past models of critical thought that advocated a complete rejection of technology (the Great Refusal), but instead aims at

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[38]Here we see another example of how Marcuse retains the Enlightenment concept of objectivity.

changing the course of technological development. He suggests that any successful opposition to the technological system must come from the margins (minorities, students, developing countries).

Other critical theorists and, as will later be dealt with, constructivists and feminists have argued that resistance is inevitably implied in the internal contradictions of the technological system. For instance, Foucault recognizes the subversive power of subjugated knowledges, that is, local perspectives that reveal how the dominated perceive social reality. Hence, these theorists refer to the adversative potential of technological micropolitics whose stakes are control of the design and implementation process. According to Feenberg, subversive technological micropolitics "involves forms of concrete political protest that aim to transform particular technologies or technical systems through pressure from users, clients, or victims" (38). Contrary to Marcuse, many authors suggest that subversive technological micropolitics do not necessarily originate from the "margins" of society as he understands them, but rather, as pointed out by Feenberg, "[t]he emergence of technical micropolitics testifies to the fact that marginality is potentially an aspect of everyone's condition in a technological society" (40).[39] Next, I will address the work of social constructivists, actor-network theorists, (especially Bruno Latour's on delegation), and that of feminists which have greatly contributed to arriving at a clearer understanding of the normative aspects of

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[39]Feenberg cites several case studies from the field of electronic communications to illustrate subversive technological micropolitics including the Internet, initially designed as an international research network, and Teletel, a French national videotext network.

technological domination. These works make room for the possibility of subversive technological micropolitics, fuelled by flaws in the technocratic consensus that render it susceptible to protest and revision.

1.2 Social Constructivism

Based on three stages of theoretical analysis proposed by the Empirical Programme of Relativism (EPOR), Pinch and Bijker outline a methodology for the Social Construction of Technology (SCOT). For its part, the EPOR seeks to demonstrate the social construction of scientific knowledge in the "hard" sciences. It posits that science does not occupy a privileged epistemological position, but counts as one of many knowledge cultures. Dating back fifteen years, the article by Pinch and Bijker attempts to define the embryonic field of SCOT, as well as its main stages of analysis, by targetting EPOR's methodology as a starting point and by extrapolating from several case studies. The authors describe SCOT as a multi-directional model that understands the development of technological artifacts as an alternating process of variation and selection. The model resists more conventional, linear accounts of technological development espoused by innovation studies and histories of technology. The role of the *relevant social group* is key to the multi-directional development of technology. Members of this group are brought together by the shared set of meanings that they attach to a specific artifact. A group may consist of institutions or companies and may be organized or unorganized. The group mainly contributes to technological development by identifying problems with specific technologies. According to Pinch and Bijker, the relationship

established between technologies and relevant social groups brings out several conflicts pertaining to the following: conflicting technical requirements needed by different groups (e.g. speed versus safety); conflicting solutions to one problem; and, moral conflicts (416). As Pinch and Bijker remark, resolutions to these conflicts are not solely found within the realm of the technological, but also in the judicial, economic, moral etc. As technological development progresses in accordance with the SCOT model, researchers can observe varying degrees of *stabilization* of technologies. In other words, researchers aim to map the process by which technologies reach or fail to reach a stable interpretation in social interactions between and within relevant social groups.

Pinch and Bijker identify three stages to be undertaken in the SCOT. The first stage consists of demonstrating the *interpretative flexibility* of the technological artifact.[40] That is, technologies are culturally constructed and interpreted; there is flexibility in how they are designed, conceived, utilized, implemented and evaluated. While there are many approaches to unearthing this flexibility, one way is to correspond varying meanings of one technology to its different social contexts. For instance, in Chapter Five, I will specify how citizens are involved in telehealth to a lesser or greater extent depending on the different contexts in which it is implemented, and subsequently, how they are positioned relative to it. These differing degrees of involvement are a direct result of whether or not telehealth is perceived as a "thing" or as a "place".

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[40]Interpretative flexibility with respect to technological artifacts is a concept that derives from David Bloor's principle of symmetry applied to the sociology of scientific knowledge.

The second stage consists of an attempt to map out the mechanisms implicated in the stabilization, and eventual closure, of the technology. Here, the process of consensus formation is the focus. It is generally necessary for researchers to observe many degrees and mechanisms of stabilization at work in more than one relevant social group. Pinch and Bijker identify two principal closure mechanisms: rhetorical closure and closure by redefinition of the problem. In both cases, closure results from a perceived consensus within the group that a solution to all problems has been negotiated and/or imposed. Finally, in the third stage, the content of the technology is related to the wider sociopolitical context. While the structure of the SCOT analysis presented by Pinch and Bijker is useful – including its concepts of interpretative flexibility, stabilization and closure, and relevant social group – it does little to elucidate how conflicts among and within groups are negotiated, especially in cases where one group is dominant over another. However, in a later analysis, Bijker speculates on how these negotiations may take place and on their potential political implications. He does so within the context of actor-network theory. The SCOT approach also does not address how the technology itself partly determines/influences the negotiation process.

1.3 Actor-Network Theory

Similarly to social constructivism, actor-network theory (ANT) is aimed at moving away from inadequate models of innovation that present technological development as a natural lifecycle beginning with pure research and ending with adoption/implementation. Bijker and Law, in fact, argue that "the *pretense* of a natural

trajectory and the concealment of contingency behind legal and organizational barriers were central ploys in the process of *creating* a successful technology" ("Do Technologies" 18). Notwithstanding, social constructivism and actor-network theory differ in the way in which they discern the concepts of the "social" and "technological". Social constructivism adopts the interactive view based on three assumptions: what divides the social from the technological is stable and matter-of-fact; the social shapes the technological; and, reciprocally, the technological shapes the social (Bijker and Law, "What Next" 201). On the other hand, ANT prefers the seamless web view, foremost characterized by the fact that it does not see the distinction between the social and the technological as matter-of-fact.[41] Rather, the distinction which takes shape in a network of heterogeneous elements is depicted as a process or an achievement versus a permanent structure. The seamless web or network of social and technological elements (or *sociotechnologies*) is broken under varying circumstances in order to establish boundaries between the inside and outside of technologies and social actors. In other words, these boundaries are the products of interaction among heterogeneous elements rather than the determinants of the network. Indeed, the social is interpreted as a circulating entity, a trajectory that alternates from the individual (actor, agency) to the societal (structure, system). As Latour elaborates:

> Actor and network . . . designate two faces of the same phenomenon, like wave and particles, the slow realisation that the social is a certain type of circulation that can travel endlessly without ever encountering the micro-level – there is never an

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[41]Harding refers to a similar approach as *co-constructivism*.

> interaction that is not framed – nor the macro-level – there are only local summing up. ("On Recalling ANT" 18-19)

In the same manner that ANT advances the term sociotechnology to describe the entanglement of the social and technological, it proposes a new unit of analysis, the *sociotechnical ensemble* to overcome consideration of science, technology and society as three distinct entities. The concept of the sociotechnical system corresponds to Callon's principle of general symmetry that extends Bloor's principle of symmetry formulated in the sociology of scientific knowledge. According to Callon's principle, the construction of science and technology and the construction of society should be studied using the same conceptual and theoretical framework. Table 8 demonstrates how Bloor's principle of symmetry is interpreted by social constructivism compared to its interpretation by ANT.

Callon's principle is applied by actor-network theorists, such as Latour and Madeleine Akrich, in such a way as to assign agency to objects as well as to social actors. Such theorists do not pay much attention to the distinction between nonhuman and human *actants*, and instead focus on the chain along which competences and actions are distributed, simply referred to as the *setting*. "Students of technology are never faced with people on the one hand and things on the other," Latour acknowledges, "they are faced with programs of action, sections of which are endowed to *parts* of humans, while other sections are entrusted to parts of nonhumans" ("Missing Masses" 254). The role of

the student is, therefore, to report on the programs of action of certain actants in settings and their relations to one another. Actantiality is defined by Latour as "not what an actor does . . . but what provides actants with their actions, with their subjectivity, with their intentionality, with their morality" within the "circulating entity" ("On Recalling ANT" 18). For clarity, Latour distinguishes the actant – "whatever acts or shifts actions, action itself being defined by a list of performances through trials [from which] are deduced a set of competences with which the actant is endowed" – from the actor – "an actant endowed with a character (usually anthropomorphic)" ("Missing Masses" 259). Anthropomorphic qualities are assigned to nonhuman actors by ANT on the following three grounds: (1) on the basis that they are originally made by humans; (2) because they act as substitutes, or permanent delegates, for the actions/positions of humans; (3) because they shape human action by prescribing certain behaviors (Latour, "Missing Masses" 235). However, in considering human and nonhuman actors, ANT assumes what Callon has evoked, as the radical indeterminacy of the actor. In so assuming, the actor's specific characteristics, whether his/her/its physical and psychological constitutions, motivations, reservations etc., are not outlined; the actor remains anonymous and his/her/its account vague. Callon warns that this indeterminacy is problematic in that it raises significant concern over the relativism of ANT.

In addition to presenting its main analytical concepts, the scope and methodology of ANT will be considered in brief. Akrich identifies two fundamental questions raised by ANT researchers that I had previously noted are lacking in the SCOT approach: (1) to

what extent does the composition of the technology constrain the relations of the actants to the technology and to each other; (2) what is the character of these actants and their associations, to what extent can they reshape the technology and the ways in which it is used. ANT researchers seek to reveal the *script*: the innovator's perspective (beliefs, intentions etc.) inscribed in the content of the technology that predetermines settings. The script sketches the delegations attributed to a technology, that is, the competencies that will be delegated to the technology as opposed to human actors. For instance, professional competencies are delegated to medical technologies like decision support systems (delegation of the diagnostic process) and prescription drugs (delegation of the treatment process). Moral delegation is implied when technologies are designed to control the moral behavior of human actors, some through rewards and punishments. Through de-scription, the researcher undertakes an inventory and analysis of the ways in which the form and content of the technology are established. He or she does so by outlining the technology's *frame*: a set of heterogeneous concepts, technics and resources deployed by a relevant social group, that may include cultural values, organizational constraints, artifacts, networks of relations etc. The technological frame acts as a bridge between the structure of a technology and the action of a social group, that is, between the technological and the social. The heterogeneity of the technological frame is the main reason why actor-network theorists believe that the process of stabilization of a technology is not irreversible.

In de-scription, the researcher takes on a different approach depending on whether or not the technology is stabilized. If the technology is not yet stabilized, he or she will observe negotiations between relevant social groups.[42] Once a technology is stabilized, or "black-boxed", he/she will find prescriptions in users' manuals, advertisements, contracts etc. When the process of stabilization is ongoing, the researcher can disclose power relations involved in and among technological frames. Power relations can be made evident semiotically – their role is to fix the meanings of the technology – and/or in technological micropolitics. Micropolitics are characterized by continuous interactions among relevant social groups. Bijker has developed a configuration model to guide the researcher in deciphering the potential maps of sociotechnical change, summarized in Table 9.

ANT pinpoints the stabilization process in the naturalization effect that comes about when the technology is totally integrated in the social fabric. It recognizes the political implications of technology at the moment when it is stabilized, when it becomes an instrument of knowledge. As Akrich comes to find:

> This is why it makes sense to say that technical objects have political strength. They may change social relations, but they also stabilize, naturalize, depoliticize, and translate these into other media. After the event, the processes involved in

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[42]Telehealth is an example of a technology that is not yet stabilized. Consequently, this dissertation is following the recommended process by looking at negotiations undertaken in public policy frameworks, other government initiatives, current research findings and reported experiences in projects etc., not to mention contextualizing these negotiations in history and theory.

building up technical objects are concealed [depoliticization]. (222)

Likewise, Feenberg has demonstrated how the technocratic technical code – the cultural assumptions designed into the technology on which delegations are based – has particularly important political implications when it is found in public service organizations. According to Feenberg, such organizations restructure public services according to technological mediations that impose centralization, control, hierarchy and communicative rationality. In the case of modern medicine, he declares:

> Vast bureaucracies now mobilize the labor of physicians and through them patients' bodies; these bureaucracies draw their power not from their role in healing, but from control of buildings, instruments, and financial tools such as accounting systems and computers. The redefinition of treatment as a form of technical intervention alters the role of physicians and patients. The delegation of communicative or "caring" functions to drugs is a particularly significant consequence of these changes. (88)

1.4 Feminist Theory

The feminist critique of scientific knowledge originated in the British and American women's health movement that surfaced in the 1970's. Initially, members of the movement sought to reappropriate knowledge and control of their bodies, and campaign for issues relating to sexuality and fertility. Harding sums up the development of gender analysis by stating that it evolved from asking the "woman question" in science to asking the more radical "science question" in feminism (qtd. in Wajcman 4). Wajcman

recognizes four main trends in feminist critiques of science. First, feminist historians of science studied the nature/culture dichotomy and how it was parallelled to metaphors of the feminine/masculine. Second, in the 1980's, eco-feminism focussed on the positive, rather than the negative, consequences of women's affinity with nature to the extent that eco-feminists proclaimed women's ability to liberate the earth. Third, feminists informed their approach to scientific knowledge by drawing from psychoanalysis, and more specifically, from the object-relations school of thought. For instance, Evelyn Fox Keller argues that women's exclusion from science has led the masculine mindset, characterized by detachment and mastery, to be institutionalized in scientific principles and methodology. Contrary to eco-feminists, Keller proposes an alternative conceptual framework that accommodates a gender-neutral science undertaken by androgynous individuals. Fourth, feminist critique has extended labor theory and the Marxist critique of bourgeois science. The Marxist critique denounces the diffusion of alienated and abstract, scientific knowledge, a form of knowledge that is a product of the split between manual and mental labor, imposed by capitalist production. The feminist critique, such as undertaken by Hilary Rose, has also considered the impact of the gender division of labor on science.

According to Wajcman, feminist critiques of technology are more recent and, therefore, less theoretically developed. To illustrate this point, in 1983, Joan Rothschild conducted a survey of articles in Technology and Culture, the leading journal on the history of technology, to reveal the number of articles that chose gender as a subject of

analysis. Four articles out of 24 years of publications were found. Wajcman cautions that trends in feminist critiques of technology that she has identified should not be viewed as coherent positions in a debate, but rather as strands of thought and argument. Obviously, in response to the lack of contemplation of women's position in the history of technology, feminists seek to distinguish the roles of women in technological development. A second trend identified by Wajcman is an essentialist one that runs somewhat parallel to the work of eco-feminism in the critique of science. Also emerging during the eighties, this perspective studies the gendered character of technology. Such authors as Cynthia Cockburn speculate that, because technology is an embodiment of patriarchal values, women actively resist participating in its development despite the rise in liberal equal opportunity policies. A third trend applies class analysis to technology. Here, technology is understood as a means to control capitalist production. Authors such as Cockburn, Maureen McNeil, Wendy Faulkner and Erik Arnold hypothesize that women are marginalized due to the gender division of labour and the male dominance of skilled trades in capitalist production.

Lastly, Wajcman has found that feminist theorists have extended findings of the SCOT approach. This approach dictates that technology, a historical and socio-cultural construction, is an object of conflict amongst relevant social groups who wish to shape technological design. However, the feminist critique notes how the SCOT approach has neglected to study the gender issues at play. It is concerned not just with technology as a social construction, but more specifically, with technology as a masculine construction, as

a "culture that expresses and consolidates relations amongst men" (Wajcman 22). It stresses the need to consider the exclusion of certain relevant social groups, such as women, as indicative of the mobilization of gender interests. As well, feminist authors include other spheres of social activity in which technology and women play a defining role that have previously been neglected by social constructivists: reproduction, consumption, unpaid household production, and Third World production.

Over the past twenty years, Wajcman has observed two general approaches to feminist critiques of science and technology described as follows. The first approach was advocated during the earlier phase of second-wave feminism. Liberal in character, it demands equitable access to scientific and technological programs, resources and knowledge, and the breakdown of gender stereotypes.[43] This approach retains the idea of science as empirical and gender neutral. It expresses faith in the capacity of strict adherence to scientific methodology to overcome the social biases integral to existing power structures. Comparatively, in the late 1970's, a more radical approach called for the cultivation of a feminist epistemology in scientific inquiry. The cultural, feminist approach emphasizes gender difference in order to celebrate feminine qualities and *savoir-faire*. Hence, exponents of this approach seek to regenerate a science and a technology that are based essentially on feminine values. It should be noted that many

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[43]This approach is still alive and well in Canada. In August 1999, the Women's Internet Campaign was launched for equal access, equal participation and an equal voice in information and communication technologies (http://www.womenspace.ca). The campaign is funded by Status of Women Canada as part of the project "Women and the Internet: Policy and Practice" .

feminist authors who support the idea of a science incorporating women's values, strongly object to radical feminist essentialism. These authors point out that concepts such as "masculine" and "feminine" are historically and culturally constructed and, therefore, are constantly evolving. To distinguish these authors, Sandra Harding proposes that they are supporters of *feminist standpoint epistemology* versus a "feminine" science. In so doing however, Harding recognizes in feminist standpoint epistemology the difficulty of not assuming a privileged position from which science and technology can be assessed, that is, a "woman" from whose perspective it can be evaluated. Instead, Harding suggests that feminist standpoint epistemology must contend with "fractured identities of women" (qtd. Wajcman 11). Moreover, Wajcman insists that the adoption of a feminist method in science would not necessarily change current scientific practices without drastic reorganization of existing power structures.

Donna Haraway also acknowledges the inevitability of fractured identities of women that feminism must address. She suggests that the "unity" in feminism should be sought for in affinity versus identity. To support her argument, she brings forth Chela Sandoval's analysis of the formation of a new political voice called "women of colour". Sandoval posits that "women of colour" exposes a political, postmodern identity constructed out of an oppositional consciousness, the perspective of the Other. Haraway interprets Sandoval's analysis as follows:

> This identity marks out a self-consciously constructed space [of otherness] that cannot affirm the capacity to act on the basis of natural identification, but only on

the basis of conscious coalition, of affinity, of political kinship. (156)

According to Haraway, the feminist struggles against "unity-through-domination" or "unity-through-incorporation" has, not only subverted patriarchal political myths and grand narratives/epistemologies, it has also weakened any claim to an organic or natural standpoint (157). Therefore, Haraway stresses the importance of *situated knowledges* as "marked" knowledges from which maps of consciousness can be produced for those who have been "marked" by inclusion in categories of race and sex (111). Situated knowledges "re-mark" or subvert the great "maps" drawn from masculine experiences in capitalism and colonialism (Haraway 111). Feminist objectivity in situated knowledges is a partial perspective that does not seek to transcend nor to divide the subject/object, but rather privileges contestation, deconstruction, the transformation of systems of knowledge and experience. Haraway cautions that experience is nothing more than a constructed imagery/narrative; it can be re-constructed, re-marked, re-membered. From the feminist, partial perspective, the object of knowledge consists of the actor/agent. The body of the subject is viewed as a material-semiotic actor, an agent of knowledge versus a resource for exploitation.

I have chosen to discuss Haraway's work in Simians, Cyborgs and Women because she attributes much importance to uncovering the social relations of science and technology. She sees this uncovering as a critical project in the reconstruction of socialist-feminist politics. Haraway conceptualizes science and technology as formalizations and instruments that enforce meanings. Science and technology are both

myth and tool that mutually constitute each other. She declares that the union of the political and physiological has long been impelled to justify domination by naturalizing differences. Sex, seen as a scientific problem, provides a physiological basis for therapeutic claims, the latter deployed as a means to assert control over women's lives. Haraway strongly emphasizes the role of domination in the theory and practice of contemporary sciences, including medicine, and sees the recognition of such a role as the first step to deciphering the content and social functions of science. However, she recognizes the greatest challenge in feminist critique to be the development of a *successor science project*, proposed by Harding. For Haraway, it is not sufficient to demonstrate the constructivism of patriarchal myths and tools, or to present radical, historical contingencies, feminists must strive to affirm and diffuse an improved account of history and society. What is at stake in the successor science project are ethics and politics more so than epistemology. Haraway describes the particular challenge of achieving this project as follows:

> . . . "our" problem is how to have *simultaneously* an account of radical historical contingency for all knowledge claims and knowing subjects, a critical practice for recognizing our own "semiotic technologies" for making meanings, *and* a no-nonsense commitment to faithful accounts of a "real" world, one that can be partially shared and friendly to earth-wide projects of finite freedom, adequate material abundance, modest meaning in suffering, and limited happiness. (187)

In addition to these ambitious objectives, Harding insists upon preserving the postmodern notions of irreducible difference and radical multiplicity of local knowledges (qtd. in

Haraway 187) through the adoption of concepts such as *strong objectivity* and *robust reflexivity*.

1.5 Postmodern Theory

The successor science project draws many parallels with Jean-François Lyotard's analysis of postmodern science as multiple narratives. Lyotard maintains that postmodernism is marked by the crisis of legitimation: legitimation is no longer tied to truth and other metanarratives, such as progress, emancipation, rationality and scientific objectivity, in part because they do not account for cultural difference. In the postmodern era, knowledge, in its two main functions in research and the circulation of learning, has been subjected to technological transformation. Lyotard argues that the computer determines, through a set of prescriptions, which statements are to be regarded as "knowledge" statements (4). The process of learning is quantified, that is, it is assessed according to the quantities of information acquired. Lyotard also speculates that knowledge will be commodified as its exchange value becomes indispensable in commercial production. Knowledge will be distributed such as money; its educational and political value will be substantially weakened. Hence, since Lyotard positions technology in such a way that it determines the operativity of knowledge in postmodernity, and since technology has no relevance for deciding truth and justice, legitimation must come from knowledge itself, from its own pragmatics or *language games*. The result, invoked by Lyotard, is the "atomization of the social into flexible language games" (17). These languages games are defined by institutions and reflect

structures of domination. They impose boundaries on what and how statements will be expressed and sanctioned within an institution.

Following the breakdown of narrative strategies of legitimation, Lyotard proposes two approaches adopted by postmodern institutions to recover their legitimacy: *performativity* (the pursuit of efficiency) and *paralogy* (the pursuit of originality). He explains that scientific knowledge formerly relied on narrative for legitimation, that is, on a form of knowledge that is not scientific. More precisely, it relied on the narratives of progress, truth and education. Scientific knowledge is the result of a consensus among peers. Such a consensus will be reached if scientific statements are found to be true. As well, a consensus depends on the approval of a group of persons that are regarded as equally competent, hence the importance of education in formulating scientific knowledge. Lyotard identifies the properties of the pragmatics of scientific knowledge and compares these to the pragmatics of narrative knowledge, as succinctly transcribed in Table 7.[44] Once modern science began to deploy technology in the production and evaluation of facts, it required additional resources provided by public and private funding. Private corporations and the state are not motivated to invest in science by its truth, but rather by the efficiency it facilitates. Consequently, Lyotard concludes that technology has transformed the critical value of science from truth to performativity. The language game of evidence-based decision-making promoted by Canadian health care

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[44]Poster suggests that Lyotard's distinction mirrors the distinction between myth and Enlightenment posited in Adorno and Horkheimer's Dialectics of Enlightenment.

reform, described in Chapter Three, demonstrates the use of scientific method to increase the health system's efficiency and justify cost-cutting measures undertaken by the state. It is clear that, in this context, science is valued for its performativity more so than its truth.

Comparatively, paralogic legitimation is achieved through originality, innovation and difference. It encourages the coexistence of a multiplicity of language games. Interpreting Lyotard, Feenberg writes: "Paralogy is a micropolitics that rejects totalization [through performativity] and favors the specific and the local. It represents a new type of resistance" (131). Lyotard envisions postmodern technology as ambivalent in the sense that it can reflect multiple rationalities and adopt both the performativity and paralogy criteria for legitimation. To illustrate this ambivalence, Lyotard brings up the computer that can be deployed to extend the efficiency of bureaucratic organizations, and therefore, as a means of population control. Alternatively, the computer is seen by Lyotard as a way to give the public free access to information and databanks, ergo, as a way of empowering the population. It could be argued, following Lyotard's characterization of the computer, that both applications, one geared toward performativity and the other paralogy, are implemented in Canadian health care reform and in telehealth initiatives As I will demonstrate in Chapter Three and Four, health care reform drives the computerization of population health information and patient records for the purposes of evidence-based decision-making in the name of efficiency, improved fiscal responsibility, and accountability in management. Concurrently, health care reform policies encourage the

use of computers, and foremost the Internet, to increase public access to health information and to increase self-care. Nonetheless, it is debatable whether public access and self-care are supported in order to empower Canadian citizens. Instead, it could be argued that self-care is viewed as a means to reduce the financial burden of the health care system by shifting some responsibility onto the individual. This argument will be presented in greater detail in Chapter Five. Succinctly, the lesson learned from computerization in health care reform is that whether or not a technology has the potential (or ambivalence) to sustain the performativity or paralogy criteria depends on the general "setting" (in the social constructivist sense) in which it is implemented.

Lyotard noted an important discrepancy in his theory of postmodern politics that I will only briefly address. He, along with Foucault, Gilles Deleuze and Félix Guattari, and Ernesto Laclau and Chantal Mouffe, have described postmodern politics in terms of multiple sites of power and a complicated understanding of the "social". For his part, Lyotard stresses the postmodern multiplicity of language games, but must recognize that his assertion constitutes a metanarrative of sorts used to legitimate the proliferation of discourse. Lyotard addresses this dilemma by introducing the concept of the *Differend* defined as an incompatible difference. The Differend cannot be resolved because there is no rule of judgement that can be satisfactorily applied to both conflicting statements. Lyotard classifies the political as the Differend; the political resists being incorporated within knowledge, especially within the latter's commodification. Since postmodern politics retain an incompatible difference, there is no central source of power and the

"social" is not perfectly integrated and coordinated within one language game.

1.6 Social Anthropology

Echoing thoughts of Lyotard, Pfaffenberger reckons the politics of technological innovation to be a force legitimated, or transformed into an authority, by the symbolic discourses of myth and ritual. Thus, while Lyotard argues that legitimation is asserted through language games, Pfaffenberger proposes the "ideal-typical model" of the *technological drama* to describe how the *affordance* of technological artifacts – the property that suggests their prospective uses – is socially sustained. The technological drama is a technological form of political discourse, that is, as Pfaffenberger clearly affirms: "Technology is not politics pursued by other means; it is politics constructed by technological means" ("Technological Dramas" 282). Thus, Pfaffenberger's analysis differs from that of Lyotard principally by emphasizing symbolic media[45] over linguistically-encoded knowledge, and by putting forward the political implications of technology at the front end of the analysis.

Pfaffenberger defines technological activity "as a process of technological communication in which each new technological act is interpreted in terms of acts already performed, as well as in terms of the reciprocal reaction it engenders on the part of the political addressee. These statements and their subsequent interpretations constitute

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[45]It should also be noted that Pfaffenberger prefers to use the term drama instead of text to highlight the performative character of technology.

social relations as a polity" (Pfaffenberger, "Technological Dramas" 285). This polity-building process is represented in the concept of technological drama, defined as a set of statements and counterstatements that reflect the three redressive technological activities of *regularization*, *adjustment* and *reconstitution*. That these activities are characterized by Pfaffenberger as redressive demonstrates his belief in the "discursive nature of resistance to technological domination" ("Technological Dramas" 285). Resistance can be made evident in technological regularization. The latter involves the innovation, appropriation or modification of a part of the technical design by a certain constituency (or relevant social group) for the purpose of inscribing a political aim in some technical feature. The political aim can be directed toward the re-allocation or subversion of power. Pfaffenberger cautions that it can be cloaked in myths of unusual power but can also be subject to several different interpretations, including open or implicit challenges to the dominating discourse. These challenges can be undertaken through technological adjustment and/or reconstitution. Impact constituencies – those who have suffered a loss following the introduction of new technology – use adjustment strategies to compensate for this loss, such as *counterappropriation* to gain access to the technology or the design process, *countersignification* to substitute a more favorable frame of meaning (such as through conspiracy theories), or *counterdelegation* to subvert the coercive function of a technical delegate, at times, through technical modifications on a small scale. On the other hand, technological reconstitution attempts to reverse the implications of new technology through *antisignification*, a symbolic inversion process that can lead to the creation of *counterartifacts*. In reconstitution, countercontexts and counterregularization

strategies are then developed to reintegrate counterartifacts into society. A key element in technological regularization is context-fabrication. To signal the pervasiveness of context-fabrication to his readers, Pfaffenberger formulates a comprehensive typology of regularization strategies, condensed in Table 8.

Pfaffenberger denounces the view of technological design as a "conduit through which preexisting political values can be transmitted without being affected or altered" ("Technological Dramas" 290). He insists that the technological artifact is *reciprocally* regulated within a particular social context through symbolic media that mystify and constitute its political aims ("Technological Dramas" 294). As well, he observes that technological regularization can allow for areas of interpretative flexibility, ambiguity and contradiction from which redressive social processes can arise. As he estimates, interpretative flexibility increases as the heterogeneity of the ideologies used to unite the design constituency increases. "To the extent that even the agents of domination must resort to adjustment strategies," Pfaffenberger explains, "the coherence and logic of domination are undermined, and the pathways for redressive action becomes clear" ("Technological Dramas" 297). The goal of uniting the design constituency surpasses that of maintaining the logical consistency of the regularization ideology. In addition, Pfaffenberger has noticed that the more heterogeneous the ideology, the greater its force in uniting the constituency. He attributes the ambiguity and heterogeneity of the overall regularization ideology to its origins in "root paradigms": cultural models for behavior that do not prescribe exactly how to act but rather facilitate the interpretation of social

relations in terms of cultural beliefs and worldviews. In fact, Pfaffenberger concludes that a culture's root paradigms are "discontinuously reproduced" in reciprocal interaction with technological regularization and counterregularization strategies ("Technological Dramas" 307). That is, a technology is appropriated by one constituency thanks to its adoption of certain root paradigms, while a counter-technology is later presented by another constituency as a means of solving the problems having surfaced upon this appropriation. This counter-technology is created based on these same root paradigms. Root paradigms are, therefore, discontinuously reproduced in reciprocation to technological activities.

Section 2: Critiques of Medical Technology

Having introduced the main analytical concepts generated by various theories on technology, I will now illustrate how some of these concepts are utilized to critique medical technology specifically. The first four critiques brought forth consist of general critiques of medical technology: medicine as technoscience (critical and constructivist theories), medicine as Technopoly (critical theory), cyborg medicine (critical, feminist and postmodern theories) and medicine as Superpanopticon (critical theory). The last two critiques focus on particular technological artifacts: the Electronic Medical Record and reproductive technology. In all, the critiques were selected because they represent a wide range of approaches to medical technology, that is, they refer to concepts presented by all theoretical perspectives outlined in the first part of this chapter, except for the social anthropology of technology. Due to the fact that the latter perspective addresses more

emphatically means of resistance to technology, it is more pertinent for critiques that are based on its theoretical framework to be introduced in the second section of Chapter Five, entitled "Exploring Alternatives" (mainly, Berg's study of Computer-Supported Cooperative Work).

2.1 Medicine as Technoscience

Critical and constructivist theories have questioned the axiomatic truth of scientific knowledge in medicine, and, in so doing, have found an effective means of tracing the relations of power in medicine. Power structures in medicine are mediated in and through scientific medical knowledge.[46] The latter is constructed, in large part, through its application in medical practice, such as in the development and use of medical technology. According to Michael Menser and Stanley Aronowitz, the term *technoscience* – just like its sister-concept technoculture – "forces us to realize that the technological is not so easily distinguished from the 'human', since it is within (medical technology, processed foods), beside (telephones), and outside (satellites). Sometimes we inhabit it (a climate-controlled office space), or it inhabits us (a pacemaker)" (9). Hence, identifying medicine as an illustrative form of technoscience implies that medicine's scientism and its technological applications have important consequences for the social. To shed light on the concept of scientism, Postman demarcates its four characteristics, reflected in medical practice: the misapplication of technics such as quantification; the

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[46]For further development, refer to The Problem of Medical Knowledge: Examining the Social Construction of Medicine edited by Peter Wright and Andrew Treacher.

confusion of material and social realms of human experience; the application of objectives and methodologies of natural sciences to social phenomena; the assumption that science can provide an objective answer to questions relating to the meaning of life.

Monica Casper and Marc Berg pinpoint three interrelated aspects of medical practice that render it unique as the "dominant cultural terrain . . . where we suffer (or relish) technoscience directly and deeply" (400). The first aspect is the role of medical practice in the construction and reconstruction of human bodies. As previously seen in the history of medical technology, the body, in its normal and pathological forms, has gone through various classifications and interpretations, each grounded in a specific practice of medicine. The increasingly technologically mediated practice of medicine has produced different bodies, different approaches to viewing and defining the body, different means of intervention and different physician-patient relationships. Referring to Reiser's study, Postman recalls how the emergence of the stethoscope prompted the detachment and estrangement of the physician from his/her patient and personal judgement. He comes to the following conclusions: technology is not a neutral element; technology establishes a wide-ranging social system to reinforce its imperatives; technology changes medical practice by redefining the role of the worker and their approaches to patients and disease (105).

The second aspect of medical practice as technoscience, distinguished by Casper and Berg, is the transformation of "lived" categories of health, illness, pain, death etc.

(401). Foucault's analysis in The Birth of the Clinic, previously brought forth, revealed how the political power of the medical profession primarily emanated from its normalizing function in defining "health" and "life". In addition, Foucault demonstrated how the anatomo-clinical gaze reconceptualized death, following its renewed use of autopsy, as a series of multiple, pathological events and a moment of revelation of the form and meaning of life. Lastly, the third aspect is the role of medical practice as a "crucial site of *control over* bodies and lives" (Casper & Berg 402). Ivan Illich's concept of iatrogenic medicine attempts to clarify the power structures that have enabled medical practice to achieve social control.

According to Illich, iatrogenic medicine adopts an engineering model based on its ability to subject man to technical manipulation, ergo, it espouses technological rationality. Illich argues that iatrogenic medicine is a political apparatus that reinforces the capitalist system by portraying health as a commodity, an individual consumer product and a capital good for society. He contends that medical practice, including medical technology, is used for the purpose of achieving industrial versus personal growth. In other words, Illich claims: "Iatrogenic medicine reinforces a morbid society in which social control of the population by the medical system turns into a principal economic activity" (Limits to Medicine 42). The welfare state, Illich reveals, has played a crucial role in promoting a passive, consumerist culture that cultivates individual dependence on the medico-industrial complex.

Illich recognizes three main forms of iatrogenic medicine. *Clinical iatrogenesis* refers to the damage inflicted by physicians on patients with the intent of curing the patient. It also includes any defensive actions intended to prevent malpractice, for instance, any elaborate, costly and painful preventive measures (diagnostic tests or surgeries such as mastectomies or hysterectomies). Illich delineates *social iatrogenesis* as "designating all impairments to health that are due precisely to those socio-economic transformations which have been made attractive, possible, or necessary by the institutional shape health care has taken" (Limits to Medicine 40). Illich lists the following outcomes of social iatrogenesis: the expropriation of health (including birth, death and illness at home), the denial of the right to self-care, a reduced tolerance for pain, the creation of new painful needs, an increase in stress, the standardization of health care, and over-hospitalization. Thirdly, *cultural iatrogenesis* renders people incapable of dealing with their own health, weakness and unique conditions independently and personally. Illich suggests several political countermeasures to iatrogenic medicine: the self-sufficient production of remedies and services, support for alternative views and services, an increase in resources for population and environmental health, and public licensing of professionals to prevent monopolies of medical guilds and associations. However, he recognizes that political resistance has been thwarted by socio-economic conditions that create stress, alienation and certain practices of leisure, that is, conditions that generate an environment detrimental to health. Postman forecasts that the computerization of medical practice will further strengthen bureaucratic institutions, such as the medico-industrial complex, and suppress "the impulse toward significant social

change" (116). Computers used in the management of medical practice as "invisible technology", Postman explains, standardize the decision-making process and blur accountability of the decision-maker (or medical practitioner) (123). Postman compares perception of the authority of the computer to that of God's will.

2.2 Medicine as Technopoly

While technoscience emphasizes the interwovenness of scientific knowledge and power structures within medical practice, the view of medicine as a domain of the Technopoly considers the role of medical information as a product of, and means to, the continued deployment of medical technology. Postman defines the Technopoly as "the submission of all forms of cultural life to the sovereignty of technique and technology" (52). The main drive of the Technopoly, he declares, is the production and access to ever proliferating amounts of information. In the context of the Technopoly, information is disconnected, ahistorical, without direction or purpose, characteristic of what Postman calls a "peek-a-boo" world (70). The over-satiation of the Technopolist market for information has strained technology's own control mechanisms. The Technopolist solution, Postman exposes, is resorting to the development of new technology. He describes three main technics serving to control the flow of information within the Technopoly: the bureaucracy; experts; and, technology, including invisible technologies common to management (intelligence testing, polling, decision support systems). The bureaucracy's impact has been to rationalize the use of information in the name of efficiency. Postman believes that the bureaucracy has grown into an autonomous and

self-serving meta-institution, aided by several historical developments: industrial growth, advances in transportation and communications, the advent of the welfare state and government centralization (86). The initial scope of practice of bureaucrats has evolved into one that encompasses, not only technical information, but also ideological, that is, moral, social and political information (Postman 86).

Postman's analysis of the Technopoly can be applied to medicine, for instance, by referring to Kenneth Warren's article on "Health Information Technology for the Third Millennium". Prior to Warren, Derek de Solla Price had shown that since about 1830, the proliferation of scientific literature had reached the point of absurdity. It was during the nineteenth century, in fact, that abstract journals surfaced as a means of simplifying access to scientific texts. Of course, abstracts and citations are now widely available in electronic format. Warren's approach to the evolution of scientific, and especially, medical publications is rather original in that he considers this phenomena from the perspectives of Charles Darwin's principle of natural selection, Charles Babbage's analytical engine and Adam Smith's theory of supply and demand. He argues that, surprisingly, medical information has been published at a rate that grossly controverts Darwinian evolution. He finds that over half of all published medical information is uncited, unread and unprofitable (130). Nonetheless, Warren forecasts how Babbage's invention will revolutionize the organization of this information. With computerization, the library, acting only as a conduit to the customization of information based on need, markets electronic information on the basis of speed and efficiency. Its reigning motto is

clearly spelled out by Warren: "the most information for the least amount of time". Babbage's technology, according to Warren, positions Darwin's principle at the core of the diffusion of medical knowledge by facilitating the selectivity of information. Warren points out that Smith's theory of supply and demand has helped those who believe that health care can be improved with increased exposure to medical information to understand that exposure depends on whether information-retrieval is transformed into a profitable activity. Acquiring knowledge is generally perceived as a cost item. However, some argue that knowing the cost-effectiveness of various treatment options is one example of the added-value (in financial terms) of medical information. Hence, Warren deduces that medical information has become a commodity and its proliferation must be tied to regulated, reimbursement protocols. These protocols can be regarded as mechanisms controlling the flow of information instituted by government and corporate bureaucracies. To conclude, in Warren's study, the three main technics for controlling information flow in the Technopoly are reflected in the distribution of medical information: bureaucracy (government, insurance companies, libraries), experts (librarians and technicians such as webmasters), and technology (databases, web servers etc.).

2.3 Cyborg Medicine

Haraway has gone beyond Postman in describing medicine, not solely as a form of information control, but as a form of communications control. She argues that the main focus of the life sciences has shifted since the First World War from organic and

functionalist bodies to bodies as texts, as cybernetic systems. That is, life sciences have been transformed from sciences of human engineering to those of communications engineering. As Haraway elaborates:

> Organic form, with its hierarchical and physiological co-operation and competition based on "natural" domination and division of labour, gave way to systems theory with its control schemes based on communications networks and a logical technology in which human beings become potentially outmoded symbol-using devices. (45)

Within sociobiology, a new form of life sciences, individuals are themselves structured flows of information instructed by genes. Haraway introduces the *cyborg* as "a cybernetic organism, a hybrid of machine and organism" prominently cultivated in modern medicine (149). Cyborg medicine, in Haraway's view, has as its fundamental paradigm the notion of difference: the dualism of recognition and misrecognition of the self and the Other, of the normal and the pathological.[47] In modern medicine, the body is both subject and object. As object, the body epitomizes the Cartesian mechanism; as subject, the body comprises of a legal and moral entity. Hence, the subject/object distinction is normalized in the nature/culture dichotomy. However, in cyborg medicine, there is no such dichotomy. Nature is already social by the very fact that it is defined in science and in medical practice. The body and mind are produced and constructed within medical

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[47]Immunology is the central biomedical discourse on recognition/misrecognition. The immune system is an iconic, mythic object, a mapping of difference, from which the body's reading practices can be deciphered. Difference, i.e. the body's boundaries, is constructed in social interaction.

practice, and as Haraway deduces, they can be viewed as texts. The textualization of nature forms a certain culture called "nature". Feenberg, in interpreting Haraway, finds that the cyborg image may evolve in two ways: it may incorporate all aspects of the subject and object into textual technologies of control, such as into genetic engineering or automation; or, technology and body can coexist harmoniously through a prosthetic extension of human capacities.

The biotechnical body, Haraway claims, can be conceived from two approaches: according to the rationalist paradigm of language and embodiment; or conversely, according to the *Generator of Diversity (G.O.D.)*. G.O.D. is a counter-rationalist or hermeneutic/situationist/constructivist perspective advanced by Haraway. Context plays a role in G.O.D. that surpasses background or surroundings, but acts as co-structure or co-text. The body – a strategic, meaning/difference-generating constituent of the social/communication system – is materialized within, and in turn, materializes, social reality through communication. Disease is reconceptualized by Haraway's G.O.D. as a subspecies of information malfunction, or communication pathology. For its part, language is a technical construct, composed of coded systems of recognition, reflected in computer networks or immune systems. It provides ID markers for instance, or behavioral/genetic instructions.[48] Haraway, in her concept of cyborg medicine, locates medical ethics and politics at the initial stage of the production of medical knowledge.

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[48]Here, Haraway's concept of language mirrors Latour's concept of delegation in technological artifacts.

Medical knowledge is produced by normatively regulated communication and technical entreprise, and ethics and politics play a defining role in establishing these norms. Feenberg, therefore, suggests that any reform of cyborg medicine must take hold at the level of legitimation of medical discourse.

2.4 Medicine as Superpanopticon

As previously brought forth, Foucault has satisfactorily linked language patterns and their corresponding practices, including the production of norms, to structures of domination. For instance, he demonstrated how the sick and non-sick norms were woven by the strands of judgement of the medical gaze, as well as the prisoner and non-prisoner norms by the strands of vision of the Panopticon. Expanding on Foucaultian theory, Poster comes to see that present communication patterns have given way to a *Superpanopticon*, "a system of surveillance without walls, windows, towers or guards" (Mode of Information 93). Technological advances, foremost being electronically mediated communication, are not the only contributors to this "qualitative change in the microphysics of power" (Poster, Mode of Information 93). These have prompted the widespread adoption of a new consciousness, one that has been disciplined to accept surveillance as a general state of being. By filling out forms, applying for services, safeguarding his/her multiple IDs, the individual is, at once, "the source of information and the recorder of the information" (Poster, Mode of Information 93). According to Poster, this change is not economic, but political involving "the reciprocal control of the population by itself" (Mode of Information 93).

As the main technology of power of the Superpanopticon, so named by Poster, the database enforces rigid fields of information-retrieval that restricts meaning and reduces knowledge to encoded bits of data. In addition, it creates relationships among bits of information that do not exist outside virtual discourse. Poster concludes that multiple identities of the individual are formulated by the databases' manipulation of these pieces of data. He sees this identity constitution as a new form of population control, of biopower, proper to the *mode of information*. The latter is a historical category introduced by Poster that is defined by the current form of symbolic exchange and characterized by the fetishism of information. It somewhat recalls the concept of Technopoly proposed by Postman. It will be further described in Chapter Four.

2.5 The Electronic Medical Record

The Electronic Medical Record (EMR), a prominent component of telehealth networks, can serve to demonstrate all four critiques of medical technology presented above.

2.5.1 Medicine as Technoscience

Berg and Geoffrey Bowker attribute to the EMR "a core role in the production of a *body politic*" because of the fact that it is implicated in the performance of the patient's body, as well as of medical practice and the medical institution. They proclaim that the EMR is not merely representative, but also constitutive, of three principal dimensions of medical organization: institutional (legal and insurance arrangements), work practice and processes of professionalization. From an institutional perspective, the EMR is a legal

document that establishes the physician as core decision-maker. It affirms a rational reconstruction of patient history and ensures that the diagnostic and treatment processes are rational deductions derived from collected data. The EMR, according to Berg and Bowker, first came about following the recognized need for a means to support the certification and accreditation of medical practitioners and institutions. Second, Berg and Bowker identify several ways in which the EMR determines the body politic of the clinic: by reproducing the institution's temporal structure, by organizing medical practice according to an extensive and intensive division of labor, by mapping a geography of the institution, by reproducing hierarchies between these geographical components, and by legitimating the organization's design.

Third, the EMR contributes to defining the status of medical practitioners as a group. For this reason, during the 1990's, it became an issue of contestation for professional nursing. Berg and Bowker bring forth Iowa University's School of Nursing's Nursing Interventions Classification (NIC) system to demonstrate how the EMR has been presented by this group as a means to increase the autonomy of the nursing profession. Compared with most EMR models, the NIC – the product of a technological adjustment strategy of counter-appropriation –includes codes such as "Hope Installation – 5310", "Humor – 5320", along with codes that relate to more obvious clinical acts ("Bleeding Reduction – Nasal – 4024"). The NIC is aimed at recognizing and preserving non-specific, indirectly clinical responsibilities that are regarded as special virtues of the nursing profession. The Iowa School argues that

standardization and modernization of nursing interventions will contribute to the production of a scientific body of knowledge about nursing. However, Berg and Bowker rightly point out that the NIC, in providing the foundation for such a body of knowledge, promotes the integration of nursing into the medical establishment, that is, its conformity and reappropriation within the present hierarchy, and in so doing, they conclude, the NIC contributes to the further marginalization of nursing.

The EMR is deployed by the medical establishment, generally, to supply the building blocks for a wide-reaching research infrastructure. In the context of this venture, Berg and Bowker assert that "the fashioning of medical records into infrastructural tools guaranteeing interoperability involves a series of organizational alignments of great political and ethical importance" (529). In order to achieve a national, or even global, medical research infrastructure, patient information must be interoperable at three main levels of integration: local (within the hospital, clinic etc.), vertical (between affiliated institutions or offices), and horizontal (among associations and institutions). Integration within, between and among institutions involves, at some point, the adoption of standards. The negotiation of standards at the national and global levels inevitably addresses the politically charged debate between private interest (professional and corporate) and public good.[49] A key point in this debate is the claim by female physicians

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[49]In Canada, this negotiation is being led by the Canadian Institute for Health Information (CIHI) through its Partnership for Health Informatics/Telematics initiative launched in March of 1996. One of the initiative's four main objectives is " to create the basis for longitudinal electronic health records" (Alvarez). All of the Partnership's working groups actively participate in fulfilling this objective by addressing the key standard

that conventional EMR codes quantify the work of physicians in such a way that their particular contribution is perceived as less productive due to the fact that they, on average, tend to spend more interpersonal time with their patients. In brief, standards serve to underwrite the alignment of organizations, and according to Berg and Bowker, "a key feature of this alignment is the evanescent ideal of the scientific operation of medicine" (532).

2.5.2 Medicine as Technopoly

In another article, Berg analyzes the EMR as a formal tool and looks at its impact on medical practice. In so doing, he demonstrates how technological advances in the recording of patient information aim to increase access to this information, to increase the amount of information recorded and to improve the efficiency of its organization. He thus introduces the EMR as a means of controlling the flow of patient information. Berg delineates formal tools as those that "operate on circumscribed input elements using sets

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domains of the (1) Health Information Model, (2) Privacy, Confidentiality, Data Integrity and Security, (3) Data Content and (4) Interoperability. Other Canadian organizations active in standards development in telemedicine are the Canadian Coordinating Office for Health Technology Assessment (CCOHTA), the Canadian Standards Association (CSA), the Canadian Health Informatics Association (COACH), the Telecommunications Standards Advisory Council of Canada (TSACC). Canada also cooperates with other international bodies, such as the International Organization for Standardization (ISO), the International Medical Informatics Association (IMIA), the International Telecommunications Union - Telecommunications Standardization Sector (ITU-T), the World Health Organization (WHO), and the Inter-American Telecommunications Commission (CITEL). Finally, Canada is an active participant in the G7 Global Healthcare Applications Subprojects that are directed toward, for instance, working Towards a Global Public Health Network (SP 1) and Enabling Mechanisms for a Global Healthcare Network (SP 5), the International Harmonization of the Use of Data Cards in Healthcare (SP 6), and constructing a Multilingual Anatomical Database (SP 8). Canada hosted the first meeting of the G7 SP 4, "International Concerted Action on Collaboration in Telemedicine", that was held in May 1998 to discuss the issue of interoperability.

of prefixed rules or formulas" ("Of Form" 404). Rules then delimit abstract "models" of the workplace for which formal tools are designed (Berg, "Of Form" 404). These models map out the tasks to be performed, professional responsibilities, and, in the case of the EMR, the body of the patient as well. Berg compares two common interpretations of formal tools. First, formal tools are preferred by naive formalists because they are believed to be more scientific or rational. Conversely, others recognize that formal tools are limited to modellings of the extrinsic aspects of the empirical, and for this reason, they will never be truly representative of its essence. Berg notes that both interpretations reinforce the formal/empirical dichotomy, picturing the former as the "map" and the latter as the "terrain" ("Of Form" 406).

Many authors argue that the interlocking of the map with the terrain gives rise to a certain generative power that can bring about, for instance, new competences, higher levels of complexity in work tasks, new coordination in time and space of activities etc. The map itself comprises of a "chain of re-representations", that is, it models a previous model (patient information in paper-based form) that modelled another past model (physicians' personal log), and so forth (Berg, "Of Forms" 409). This process of re-representation indicates to Berg "the intricate codevelopment of map and terrain" from which arises the generative power of the EMR. The EMR successfully organizes medical practice because the latter had already been structured to fit the patient information form. Procedures that came about as a direct result of the recording of patient information – such as urine containers, prefabricated blood and infusion bags etc. – are perfected with

the EMR, a tool that allows for automated 24-hour monitoring of fluid levels. Hence, map and terrain converge following a series of mutual adaptations. As Berg explains, the map models a task that involves several actors (nurse, physician, patient, formal tool), each aware of only one or two of its composite partial procedures. The relations between the actors are "non-transitive"; no one actor, human nor technological, controls the organization of the task (Berg, "Of Form" 419). Each human actor must also adapt his/her work around the limitations of the formal tool. He/She performs a "balancing act" that transforms the map through its use. Berg opposes the terms "repair" and "appropriation" since these imply that the technology-in-use is returned to an original state without having evolved in any way. Instead, he concludes the following:

> The networks [between tool and human actors] develop in piecemeal fashion, through complex interplay of driving forces, and partly in and through the ongoing balancing acts that occur wherever networks intersect. The work performed and its formal rendering, then, are the *outcome* of historical and real-time processes. ("Of Form" 428)

2.5.3 Cyborg Medicine

An observation of Foucault, medical knowledge is produced through the recording of individual cases and the accumulation of such experiences. Berg and Bowker, in using Latour's term, relate how a "cascade of inscriptions" engenders the means of knowing in medicine (514). Ergo, the authors reason that the body of the patient acquires a specific medical ontology through a network of embodied, materially heterogeneous practices that include technological artifacts. The EMR mediates the relations within this network – the

relations that it organizes – and the bodies that it also configures (or reconfigures). In a separate article, Berg and Bowker state that the EMR produces a patient with a medical history, an anatomical geography and a bureaucratic format. The patient's time is structured in order to fit with the measurement units of the financial administration, that is, in concurrence with the shifts of medical practitioners. The patient's geography is intervened upon according to how it is mapped out in the medical record. The patient's history is categorized in terms of professionally recognized medical events, such as examinations, prescriptions etc. While some reconfigurations of the patient's body by the medical record occur at the level of professional readings, others materially reconfigure the body by changing its natural cycles of sleep and eating, by changing its posture during X-ray exams etc. Consequently, Susan Leigh Star and Bowker proclaim a convergence between the body and its representation.

Consistent with Haraway's concept of cyborg medicine, Berg and Bowker view the body's ontology as acquired through a process of communication engineering (that is, the network of medical practices). This engineering produces a cyborg body through the interplay between the human and the technical (or text), between social reality (the body) and fictional discourse (its representation). In addition, Berg and Bowker assert the role of the EMR in configuration of the patient's body by recalling Foucault, as follows:

> . . . the medical record is fundamental to the everyday production of that contemporary body whose archaeology Foucault describes (a body that hides the essence of the disease in the pathological processes taking place in its tissues,

> where the symptom and signs attest to a reality that is never completely accessible in life) . . . (514)

By elaborating on the Foucaultian depiction of the body retained by Berg and Bowker, it can be understood that the body transformed into text by the EMR reveals the set of symptoms that then become signs, and therefore, reveals the disease extrinsically. The textualized nature of the disease, thereby, is grasped solely within the culture of medical knowledge.

2.5.4 Medicine as Superpanopticon

The title of Berg and Bowker's article, "The Multiple Bodies of the Medical Record", presents the EMR as a perfect example of how Poster's Superpanopticon applies to medicine. The authors acknowledge that the reconfigurations of the body by the EMR do not come together into a "single coherent and transparent patient's body", but, in truth, the EMR generates "multiple histories" (520). The medical establishment does not successfully discipline the body in a uniform and consistent manner. Its efforts are fragmented, situational and historical which again stresses the importance of a historically-sensitive, constructivist approach to the analysis of medical technologies.

2.6 Reproductive Technology

I have chosen to single out critiques of reproductive technology for the following reasons: their prominence, the importance of the context of implementation of this technology, and because many critiques draw strong parallels with the critique of medicine as technoscience. The context of implementation of reproductive technology is

unique because of three conditions: patients are uniformly women; patients are generally not ill; and, the male-dominated medical profession can not lay claim to personal expertise in the subject area. In the latter case, it has been argued by feminists that male physicians seek to legitimate their obstetric expertise by controlling access to new technology. During the 1730's, forceps were introduced and were exclusively controlled by physicians and surgeons. The medical profession's practice of midwifery was instantly differentiated by its technical aspect. In the early twentieth century, women's support of anaesthesia during labour, while initially opposed by physicians, precipitated the transition of the birthing process from a home event to a medicalized and institutionalized condition.

The implementation of reproductive technology reflects the arguments of the technoscience critique by demonstrating the principles of scientism, as well as illustrating the various forms of iatrogenic medicine identified by Illich, as succinctly explained in Table 10. Wajcman finds three main approaches to the feminist critique of reproductive technology. The first approach views reproductive technology as a means of liberating women from their oppressive roles in childbirth and motherhood.[50] The second approach does not regard childbirth or motherhood as a burden, but rather as a privilege.[51] It

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[50]A prominent advocate of this approach is Shulamith Firestone who published The Dialectic of Sex in 1970.

[51]In 1984, the Feminist International Network for Resistance to Reproductive and Genetic Engineering (FINRRAGE) was formed, represented by authors such as Gena Corea, Jalna Hanmer, Renate D. Klein, Maria Mies and Robyn Rowland.

denounces the advancement of medical technology into the domain of reproduction as a patriarchal system of domination. Theorists presenting arguments included in Table 10 espouse this second approach. Lastly, Wajcman points to a third, more neutral approach that trusts technology's ambivalence and judges reproductive technology according to how it is used (or abused). The local/situational context of implementation, as opposed to the technology itself, is problematized. Here, researchers recognize that reproductive technology may have different implications for Third World countries.

In these last two chapters, I have contextualized technology within medicine. In this chapter particularly, I introduced several critiques of technology, as well as several critiques of medical technology. In so doing, I have established the following with regards to technology. There is an inextricable link between technological phenomena and society. The technological and the social form a seamless web or sociotechnical ensemble. Modern and postmodern technological phenomena are characterized by their rationality, reflected in the one-dimensionality of technological thinking (or discursive operationalism) and in the performativity of its "language games". Technological rationality facilitates the social integration of technological phenomena by establishing a system of domination. This system of domination relies on the widespread adoption of a rational, normative consensus. However, the potential of subversive technological micropolitics is recognized, traced back to the interpretive flexibility of technological artifacts. That is, the subversion of the system of domination is rendered possible by the fact that technology is culturally constructed and interpreted. In other words, the

technological frame that acts as a bridge between the artifact and the actions of relevant social groups is heterogeneous. By de-scripting technological dramas, the discursive nature of resistance to domination is revealed, that is, the root paradigms of the dominant ideology can be identified and challenged. Finally, I have also established the following with regards to medical technology: medicine has promoted the political misuse of scientific knowledge and technological applications to extend the power of the medical profession; it has instituted bureaucratic, expert and technological mechanisms to control the flow of ever-proliferating amounts of general medical and patient information; it has furthered the state of general surveillance of the population by generating these increasing amounts of patient information; ethics and politics play a crucial role at the forefront of the production of medical knowledge, and subsequently, of medical technology.

The contextualization of technology within medicine has allowed me to decipher the role of medical knowledge and practice in influencing the course of technological adoption, implementation and use. In the next chapter, I will attempt to contextualize technology within health care, and more specifically, Canadian health care. While the dominant groups in medicine are the medical profession and medical institutions, the dominant group in Canadian health care is the state. Its role in the adoption, regulation and implementation of technology is crucial to establishing a background for the development of telehealth technology.

CHAPTER THREE: CANADIAN HEALTH CARE

Preamble: Meanings of Community in Health Care

Bruce Spitz raises the issue of how to define the term "community" in health care policy. He acknowledges that the difficulty lies not in finding a definition of community, but rather on settling for one such definition when there are many currently in use. From designating a group of individuals with shared characteristics, or living in a shared space, or involved in a shared activity or profession, or sharing a language, resources, worldviews, rights, obligations, institutions etc., Spitz concludes: "The problem is that – depending on the definition – each one of us is a member of an infinite number of communities. Which of these communities then should participate in making decisions about the health care system?" (1042-1043). Mark Schlesinger chooses to answer this question by retaining classical sociological definitions of community formulated by Weber and Ferdinand Tönnies. These definitions emphasize geographic proximity instead of shared personal characteristics or experiences. Schlesinger supports this emphasis for the following reasons. First, there is an important historic precedent in health policy. In my own research, I have also found this definition to be the most common in health policy documents and research literature. Second, since many health policies point to the influence of social and environmental factors on the health of the population, they inevitably sustain the significance of geographic proximity in determining community health. Third, Schlesinger recognizes the privileged status of local communities in American culture and morality. I believe there to be such sentiment

in Canadian ideology, although perhaps to a lesser extent. It is generally accepted amongst communitarian writers that a common territory lays the foundation for a shared identity among its inhabitants.

While Schlesinger strongly justifies his choice of defining community in terms of geographic proximity, he warns that researchers must take into account what this excludes.[52] I agree with Schlesinger and have chosen to follow this definition as well. In order not to disregard any alternative connotations of community, I will use the term "interest group" to designate a group bound together by common health needs, and "professional body" to refer to an association of medical or other practitioners. Instead of the commonly used term "medical community", I will name the panoply of health care professions and institutions (including management and support personnel) "health care providers" to avoid any confusion.

Section 1: Canadian Health Care

This chapter will be presented in two parts: (1) the Canadian health care system; and, (2) Canadian health care reform. To introduce the first section of Chapter Three, I will begin with a brief history of the Canadian health care system, paying special attention to the advent of state health insurance as related by Donald Swartz. This introduction

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[52]Most notably, the meaning of community may revolve around shared personal characteristics or experiences, a meaning advanced by Sherry Turkle in her study of virtual communities and Pauline Vaillancourt Rosenau in her postmodernist view of health politics (discussed in Chapter Five) among others.

will outline the structure and ideologies intrinsic to Canadian health public policy. Subsequently, I will analyze the main parameters at play in the allocation of health care resources, followed by the models of accountability existent in the Canadian health care system. The community health model of accountability will be more extensively construed. In the second section, I will profile the strategies, positions and federal/provincial/territorial initiatives that have been undertaken in the context of Canadian health care reform during the 1990's. I will especially consider the objectives and evaluation of regionalization initiatives. Finally, I will address three specific issues: the impact of health care reform initiatives on consumers; the focus of health care reform on Evidence-Based Decision-Making (EBDM); and lastly, the role of technology in health care reform.

In his article entitled "The Politics of Reform: Public Health Insurance in Canada", Swartz dispels the presumption that state health insurance arose out of an inclination of the Canadian state toward socialism, and instead argues that it resulted from the struggles of the industrial working class. Unions or friendly societies negotiated arrangements for organized insurance funds, managed by the unions themselves or by employers. Employers agreed to such arrangements on the grounds that they contributed to the recruitment of workers in remote locations or in hazardous positions, that they increased labor efficiency and that they muffled worker resistance. However, these arrangements were unable to provide comprehensive coverage because of the great financial capacity this would have required. Consequently, Schwartz characterizes them

as "paternalistic plans, designed to blunt the expression of employee discontent by offering benefits to 'loyal' employees" (218). While Saskatchewan and Alberta adopted an extensive municipal doctor plan to attract physicians to rural areas, Swartz claims that launching provincial initiatives was not seriously considered until resistance to private, corporate arrangements increased. In addition, widespread industrial unrest combined with the dawn of socialist ideology threatened the stability of the labor force. According to Swartz, architects of state health insurance saw it as a means of containing working-class insurgence by bringing it more in line with the capitalist system, that is, as a means to protect the status quo.

During the early 1940's, the federal government began to support a universal health insurance plan. This support was prompted by the failure of British Columbia to promulgate legislation passed to provide state health insurance to employed workers earning less than $1800 annually. Ian Mackenzie, a Liberal from British Columbia, joined the W. L. Mackenzie King cabinet in 1939 and began to advocate for federal action. Such action had also been called for in Albert Edward Grauer's report of the Royal Commission on Dominion-Provincial Relations (Rowell-Sirois Commission) in light of the British Columbia experience. In 1941, a government committee chaired by Dr. John Joseph Heagerty, Deputy Minister of Health, was established. By 1943, the committee had drafted a model bill in cooperation with the Canadian Medical Association (CMA). According to Swartz, the bill outlined a more comprehensive state health insurance plan than is implemented in any province as of today, exceptionally

valuing disease prevention and public health measures. King lent support to the bill because, as Swartz reports, he foresaw the implications of the rising popularity and militancy of industrial unionism, and of an expected post-war recession. Despite strong political support, the bill was plagued by federal-provincial disputes.[53] In addition, King became vulnerable to mounting opposition from the private sector. While business was initially against state health insurance on the grounds that it reduced the importance of personal purchasing power by providing services based on need, and in so doing, reduced the dependence of workers on the sale of their labor power to survive, its objections were fuelled even further by the enactment of unemployment insurance (1940), family allowances (1944), and collective bargaining legislation (1944).

State health insurance was neglected during the 1950's due to what Swartz hypothesizes were preoccupations with the cold war and the postwar economic boom, sufficient in themselves to contain the threat of progressive forces. There were exceptions including a federal grant to the provinces to boost hospital construction in 1948, and initiatives in British Columbia and Saskatchewan where the Cooperative Commonwealth Federation (CCF) governed. However, the CCF had initially advocated for socialized medicine, defined as salaried physicians employed in publicly owned and, to some extent, publicly controlled clinics and hospitals. Notwithstanding, the CCF

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[53]The federal government agreed that it would share costs based on actual rather than estimated costs and subject to a limit of $12.96 per capita. Over the years, this pre-set limit would have significantly reduced the amount of funding contributed by the federal government if one takes into account that, in 1971, per capita health expenditures had reached $306 per capita.

settled for universal hospital insurance in 1947, and medical insurance for pensioners in 1950. In both forms of state insurance, clinics and hospitals remained under private ownership, not to mention that the insurance fund itself was administered by a professional commission. Seymour Martin Lipset has since demonstrated that the government was, in effect, denied any control over the provision and price of health services.

In 1955, at a Federal-Provincial Conference, Leslie Frost, the Ontario Premier, was forced to acknowledge that the public was in favor of hospital insurance despite the fact that he personally opposed it on the grounds that it would increase taxes and reduce the country's competitiveness in the eyes of international business, in addition to depressing the domestic commodities market. Swartz speculates that Frost was pressured into his declaration as part of a political strategy underlying the merger of the Trades and Labor Congress and the Canadian Congress of Labor into the Canadian Labour Congress. In 1957, the federal cabinet, under the Right Honorable Louis S. St-Laurent, voted in the *Hospital Insurance and Diagnostic Services Act* (HIDS). Swartz argues that it was introduced reluctantly as a result of the appeal made by Frost in Ontario, support in British Columbia and in Saskatchewan. Moreover, many hospitals, newly built thanks to the federal grant, incurred deficits from serving patients with no private insurance. Such patients represented 50 per cent of the Canadian population. The Act brought about federal/provincial cost-sharing for acute hospital care and diagnostic services.

Nonetheless, Swartz recalls that it was not until 1965 that the Liberal Party firmly supported medical insurance. Support came subsequent to the defeat of the Liberals to John Diefenbaker in 1958, to the favorable presentation made by Tom Kent at the 1960 Kingston Conference (organized to reevaluate policy of the Liberal Party), and to the rallying of Quebec's "Three Wise Men", Jean Marchand, Gérard Pelletier and Pierre Elliot Trudeau with Lester B. Pearson's supporters (Swartz 227). In 1961, the Saskatchewan government deployed the funding provided under the federal/provincial hospital insurance plan to set up a universal medical insurance program. In the hopes of discrediting this initiative, the CMA formed the Royal Commission on Health Services chaired by Emmett M. Hall. Ironically, the Commission's final report vindicated Saskatchewan's universal medical insurance plan. Armed with this report, the Pearson government was able to withstand opposition from business and medical professionals and enact the *Medicare Act* in July 1966.[54] The Act provided for federal/provincial cost-sharing for physicians' services subject to the following criteria: universality, comprehensiveness, accessibility, portability, and public administration. However, the power of the federal government to influence the delivery of health care services was restricted to administrative arrangements under the funding mechanisms. This power was further weakened with the *Federal-Provincial Fiscal Arrangements and Established Programs Financing Act* (EPF), enacted in 1977. By substituting the old funding formula with a combination of tax point transfers and block grants indexed according to

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[54]In order to counter resistance from Quebec and Ontario, the federal government created a social development tax of 2 per cent in the 1968 budget that forced all provinces to contribute to medicare whether they chose to adopt the plan or not.

population growth and gross national product (GNP), the provinces acquired greater flexibility in funding distribution, as well as fiscal responsibility for all above-inflation increases in spending for health services. The federal government attempted to regain some degree of control by replacing the HIDS and Medicare acts with the *Canada Health Act* in 1984. Concerned with the perceived erosion of the Canadian universal health insurance plan, the federal government reaffirmed its five principles and established financial penalties for provinces who refused to comply with these principles by permitting direct user charges for insured services.

Prior to state health insurance of any form, medical practitioners in Canada were, as characterized by Swartz, "petit-bourgeois independent commodity producers, selling their services on a fee-per-service basis at a prevailing price" (228). In order to subdue the competitiveness of the market, and increase their profits, the medical profession sought to regulate membership. In 1865, physicians in Upper Canada were granted a licensing monopoly through the *Parker Act*, legislation that was replicated in all provinces after Confederation. This monopoly was not only economical in nature, it also asserted professional control over the production of health care services. That is, physicians effectively determined what constituted disease and how to go about treating it. Significantly, they further obtained control over hospitals, initially founded as nonprofit organizations for the sick poor. Once hospitals were reorganized to highlight the scientific practice of medicine, as noted in Chapter One ("The Medical Institution: From the Home to the Hospital"), some of them were purchased by partnerships among

socially prominent physicians. Provincial hospital acts granted to the medical profession the authority to nominate who would practice medicine within hospital walls. State hospital insurance did enable some government control over the overall size and cost of the hospital sector by setting contribution amounts according to the number of hospital beds. However, the government cannot regiment how these beds are used.

State medical insurance obliged professional associations to "deal" reimbursement rates. Provincial fee schedules were designed to guarantee physicians payment for services rendered regardless of the patient's ability to pay. As such, reimbursement rates are intended as "floor" prices representing a percentage of the profession's fee schedule (on average, around 90 per cent). With the inception of state health insurance, medical practitioners strongly advocated for their right to charge the entire fee to patients while simultaneously participating in the government plan. The debate over user charges fuelled a physicians' strike in Saskatchewan the outcome of which was to allow physicians to opt out of state medical insurance and hand them control over funding management. Hence, the state's role was relegated to investigating fraudulent business practices within the medical profession. Swartz concludes the following:

> In short, state hospital and medical insurance effected no change in the nature of the health care system. Its control remained firmly in private hands, held by physicians and the drug and medical supply corporations. What public health insurance amounted to under these conditions was a virtually unlimited subsidy to these fractions of the bourgeoisie in the form of a guarantee by the state of

payment for any services and goods physicians mandated. (231)

Likewise, Sharmila Mhatre and Raisa Deber identify two major problems with the current system of Canadian state health insurance: first, health public policy is plagued by federal/provincial jurisdictional issues; second, insured services were initially restricted to those rendered by licensed medical practitioners and hospitals. While these limitations were formally removed in 1977, the power of professional and hospital structures was already deeply-rooted in the Canadian health care system. While Mhatre and Deber acknowledge several studies revealing that Canadians are generally satisfied with the current health care system[55] (648-650), they point to six emerging issues that pertain to the allocation of health care resources. Each issue is profiled in Table 11. In what follows, I will discuss the process by which resources are allocated in health care, taking into account the main principles that guide this allocation. I will also bring forth an alternative model proposed by Susan Goold according to which the current challenges to this process, identified by Mhatre and Deber (Table 11), may be resolved.

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[55]Notably, Karen Donelan, Robert J. Blendon, John Benson, Robert Leitman and Humphrey Taylor have demonstrated that measuring the satisfaction of Canadians relative to the health care system seemingly captures a different set of values and concerns than if it is measured relative to their personal health care experiences (or that of their family members). Ratings of the public health care system brings forth broader concerns about fairness, costs, access, bureaucratic processes etc. Conversely, ratings of personal health care services address the qualitative nature of care received and the ease (or lack of) with which it was obtained. Following their assessment comparing the satisfaction of the Canadian, American and German populations, Donelan et al found that Canadians are least satisfied with their access to physician services. They also discovered that views of persons who are sick tend to be more negative and that views of minorities are lost in the average population response.

1.1 The Allocation of Health Care Resources: The Principles of Distribution

An obvious determining factor in resource allocation is the fact that these resources are publicly funded and, more specifically, funded by a liberal welfare state. Nancy Fraser categorizes the liberal welfare state as an affirmative remedy for injustice, that is, a remedy "aimed at correcting inequitable outcomes of social arrangements without disturbing the underlying framework that generates them" (23). Affirmative remedies are differentiated by Fraser from transformative remedies that correct injustice "precisely by restructuring the underlying generative framework" (23). Affirmative remedies developed by the liberal welfare state are further described by Fraser as follows:

> They seek to redress end-state maldistribution, while leaving intact much of the underlying political-economic structure. Thus, they would increase the consumption share of economically disadvantaged groups, without otherwise restructuring the system of production. Transformative remedies in contrast have been historically associated with socialism. (24-25)

Fraser suggests that affirmative remedies reinforce class division by singling out the underprivileged class as one with constant demands and inherently deficient. She, therefore, concludes: "an approach aimed at redressing injustices of distribution can end up creating injustices of recognition" (25). Fraser contrasts the "official recognition commitment" that presumes to affirm the equal moral worth of individuals, and this stigmatizing "practical recognition-effect" of affirmative redistribution (25).

Likewise, Raymond Williams writes in Towards 2000:

> There was never any way in which the genuinely new ideas and provisions for a caring society could persist as an *exceptional* sector, contradicted by systematic inequality and competition everywhere else. In fact, the models of "relief" and "insurance", from the old order, provided a base from which, in a period of rising incomes, the idea of common social provision was steadily weakened and interpreted as selective "entitlement" and burdensome "cost". It is not by bureaucratic regulation, however complex, but only by *direct communal administration* that an idea of common welfare can become actual. [emphasis added] (100)

Alternatively, R. Williams advances the concept of a "sharing society", characterized by stable and reduced resources and availabilities at the receiving end and efforts and responsibility at the giving end (100-101). For her part, Fraser argues that the crisis of the welfare state is inextricably tied to the collapse of the family-wage ideal caused by less stable employment and the proliferation of diverse family structures. Historically, the family-wage ideal was supported by, what Fraser believes were most industrial welfare states through a three-tiered system: social insurance programs (protections against the risks of the labor market), direct support to the homemaker, and other public assistance programs designed to assist those excluded from the family-wage ideal. According to Fraser, the postindustrial welfare state must, in comparison, be premised on gender equity. It could replace the family-wage ideal with the Universal Breadwinner model (support for women's employment, such as day care) or the Caregiver Parity model

(caregiver allowances). Fraser goes so far as to list a set of seven normative criteria against which could be evaluated alternative visions of a postindustrial welfare state.[56]

Fraser ascertains that each welfare state determines how resources will be allocated "according to a specific mix of distributive principles, which defines its basic moral quality" (49). Fraser posits that there are three such basic distributive principles, or principles of entitlement: those of need, desert and citizenship. Need-based entitlement, while highly redistributive, stigmatizes lower social classes. It has given way to most poor relief and other public assistance programs. Desert-based entitlement distributes benefits with respect to each person's contribution to taxes, the labor market or other services (such as military). While an honor-based system, Fraser points out that it is antiegalitarian and exclusionary. Lastly, citizenship-based entitlement is honorable, universalist and egalitarian, since it guarantees that each member of the society is entitled to receive services. However, Fraser warns that while favorable, this model is expensive and difficult to sustain at high levels of service. Of course, citizenship-based entitlement is consistent with the principle of distribution adopted by Canadian state health insurance.

Having determined that all members of the Canadian population are entitled to receive health care services does not resolve all questions as to how health care resources

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[56]Seven normative principles are indicated by Fraser: the antipoverty principle, the antiexploitation principle, the income-equality principle, the leisure-time-equality principle, the equality-of-respect principle, the antimarginalization principle and the antiandrocentrism principle.

are allocated to the Canadian population. Bronzino, Smith and Wade have identified some critical questions at the macroallocational level that remain unanswered by the distributive principle of citizenship: (1) how many health care resources should be produced in proportion to all publicly controlled resources?; (2) what type of health care resources should be produced? Bronzino, Smith and Wade demonstrate how the second question is especially pertinent to the allocation of medical services and technology. Currently, what they refer to as "rescue medicine" favors the implementation and use of "halfway technologies". Halfway technologies, such as renal dialysis, involve complex and sophisticated technological manipulations that may modify symptoms but do not cure diseases. They are used in cases where the roots and paths of the disease are not fully understood. They are generally more expensive than definitive technologies – those applied to patients once the disease is understood and intended for a quick resolution by attacking its source – and preventive technologies – those that seek to modify individual behavior or the natural and social environment to avoid the development of the disease altogether.[57] Hence, Bronzino, Smith and Wade proclaim that the benefits of rescue medicine are expensive to produce and are experienced by comparatively fewer people

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[57]It has also been argued that developing and using halfway technologies, such as the iron lung, diverts funding away from fundamental medical research that would develop simple and inexpensive definitive and preventive technologies. Others disagree stating that many technologies, including the iron lung, represent primitive versions of more modern, inexpensive and effective equipment. To prove this point, Maxwell (1986) cites the cases of insulin, diuretics, antihypertensives, antidepressants and anti-inflammatory drugs, other narcotics and some surgical procedures, that have been proven to be cost-effective and to improve the patient's quality of life. Maxwell critiques negative views of halfway technologies on the grounds that these are tied to a unidirectional concept of the science and technology relationship, whereby, technological development is perceived as solely the outcome of scientific research.

(mostly elderly and sick beneficiaries) than would be the case for preventive medicine (mostly young and healthy beneficiaries). Notwithstanding, it is important to recognize that, while preventive medicine may save a greater number of statistical lives, rescue medicine represents an attempt to save more identifiable lives. In other words, rescue medicine has a more immediate and dramatic psychological and emotional impact on the Canadian population. The authors conclude that the decision to favor one type of medicine over another involves a decision to favor one group of potential beneficiaries over another. Therefore, the macroallocational question of "what type of health care resources to produce" answers the microallocational question of "who should have access to the health care resources that are produced" with both rules of exclusion and selection.

In fact, what Bronzino, Smith and Wade have recognized is that the distributive principle of citizenship does not ensure the equity of Canadian health care. That is, whether all members of a society are entitled to resources, whether they have equal rights to such resources, does not necessary entail that these resources will be distributed equitably. Stephen Birch and Julia Aberson have extensively deciphered this problematic in Canadian health care. They begin by distinguishing equity from equality, defining the former as "fair, impartial, or relating to some principle of justice" (629). While this principle of justice may require equal treatment of individuals in distribution regardless of certain characteristics (such as race and gender), it may also demand that some individuals be treated unequally with respect to another set of characteristics (such as productivity and class membership). If equity is understood, in the context of Canadian

health care, as the use of, or opportunity to use, health care resources that are allocated equally across populations categorized in terms of their ability to pay, then Birch and Abelson find that this principle of equity is not clearly stated in the *Canada Health Act*. Under the "accessibility" criterion, the Act declares that reasonable access must not be impeded by the uniformly applied terms and conditions of service provision. While "reasonable" and "access" are not defined, Birch and Abelson acknowledge that the consistent interpretation of reasonable access in current federal and provincial health policy documents is "access in accordance with need for services, where need is defined as an *ex ante* expectation of protecting, promoting, or restoring (health-related) well-being" (633). This interpretation, nonetheless, begs the question of whether access is understood as use of, or the opportunity to use, needed services. The de facto definition of equity in Canadian health care then consists of "equal access for equal need", and this definition depends on whether access means use or opportunity of use.

In studying the principle of equity and its various interpretations in federal/provincial health care policies, Birch and Abelson also come to the following observations: because the concept of access is not clear, empirical evidence on the efficacy and equity of the Canadian health care system, if at all available, is inevitably incomplete; the implications of pursuing the principle of equity are unappreciated, even though they may be in conflict with other principles affirmed by the CHA; and finally, the accessibility criterion of the CHA calls for the "reasonable payment of providers", the implications of which have not been considered, especially in terms of whether it may

hinder equal access or equal need (633-634). In 1991, Robin Badgley published a review of five to six dozen articles on the distribution of benefits within the Canadian health care system. Badgley evaluated the results of these studies with respect to regional disparities, access to insured medical care, out-of-pocket expenses, and health status, longevity and disability-free years of life. Badgley's main findings are summarized in Table 12. Essentially, Badgley determined that around 40 per cent of these studies proved that health care resources were allocated inequitably. Birch and Abelson, in considering Badgley's findings, caution that most studies do not focus on the role of health care needs in accounting for variation in use of services. The accessibility principle of the CHA stresses equal access for equal need, not equal access across income groups. Ergo, Birch and Abelson assume that "if we choose to pursue equal access to services for equal need for services, this might require *unequal* access to services among income groups, that is, discrimination in favor of poorer groups because of a greater incidence of treatable conditions" (636). However, this does not appear to be reflected in the current Canadian health care system. In fact, Badgley clearly confirms: "In light of the extensive documentation for Canada that the poor experience more ill-health than those with higher incomes, the results, if accepted, suggest that their health care needs may be less well provided for" (663). In short, the many discrepancies in the research designs and findings of the studies reviewed by Badgley strongly support Birch and Abelson's observation that none resolve the issue of whether reasonable access has been reached in Canadian health care.

In examining the equity principle, Birch and Abelson notice that its fulfilment will significantly challenge the parameters of the current health care system, and, in particular, the concept of reasonable access. They point out that the burden of using needed services, the "opportunity costs of use", may differ among individuals even though the use of the services or the health outcome ultimately does not. Moreover, an individual who places greater value on his/her health status would be more likely to incur opportunity costs of use even if the burden of these costs are equal among individuals. As Birch and Abelson speculate, in order to equate this burden, or to provide for "equal opportunity for equal need" (the equity principle), the following would be required: to redefine the objectives of the system in favor of equity versus equality (equal use for equal need); to resolve many practical problems in monitoring system performance; and, to resolve problems in distribution that extend well beyond health care (how to equate the distance travelled by the individual to reach the needed service, the loss of income, the availability of transport etc.).[58] Furthermore, Birch and Abelson provide a list of potential requirements of the accessibility principle that conflict with the equity principle; to provide reasonable access to services based on equal need, the following may be required: unequal resources for equal communities, unequal expenditures for equal needs, unequal access for equal prevalence of conditions, unequal payment for equal service provision

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[58]Swartz similarly argues that the differences in use of needed services among individuals and populations are tied to "fundamental inequalities inherent in capitalist societies" (236). For instance, the distribution of hospitals and specialist services is determined by the affluence of certain communities. More affluent and educated individuals are more aware of disease symptoms and the organization of health care resources (e.g. distinctions among specialists).

("reasonable compensation").

With regards to the latter, there are three main forms of "reasonable compensation" among health care providers with each respecting its own equity principle.[59] However, Birch and Abelson remark that there are no means of ensuring equity amongst types of providers, that is, equal compensation for equal service that takes into account cost variations in service provision such as differences in transportation costs between communities or differences in the amount of input required to provide the same service. More importantly, no current form of reasonable compensation is consistent with the principle of reasonable access to services. "In order for compensation to be compatible with reasonable access," Birch and Abelson insist, "provider payments would need to be related to *ex ante* expectation of benefit on the part of the patient receiving the service, that is, an equity principle of *equal payment for equal (expected) outcome*" (649). In other words, payment would be directly tied to the need of the individual or population. Swartz has taken an even more critical position relative to the methods of physician compensation, as readily apparent below:

> The evidence that health insurance has had a rather limited effect on increasing access to health care, combined with the enormous increase in costs of that care, suggests that a lot of benefits from these expenditures were appropriated as increases in income by those working within the health system itself. (236)

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[59]These are hospital compensation (equal payment for equal expenditures), physician compensation (equal payment for equal "throughput"), and compensation for non-physician human resources (equal payment for equal input).

Swartz brings forth empirical data in support of his claim.[60] From a review of expenditures on physicians' services from 1957 to 1971 conducted by Robert G. Evans, where he found that the growth of these expenditures was linked to a reorganization of physicians' practices in order to generate more income from a given number of initial patient contacts – such as by expanding hospital-based services, extending diagnostic and curative services, upgrading professional status (from general practitioner to specialist) etc. – it is possible to conclude the following: that the current methods of reimbursement have permitted physicians to further impede reasonable access to services; and, that new medical technology, by being deployed by physicians to increase their income, has also impeded reasonable access.

While the principles of allocation of Canadian health care resources are complex, difficult to realize, and at times, paradoxical, in the US, there is no consensus on distributive principles. It is for this reason that Susan D. Goold has chosen to reframe the question of how to allocate health care resources in terms of "[w]ho shall decide how to limit health services, and how can this be done to promote and respect pluralism" (71). In using the word "limit", Goold is explicitly referring to the rationing, and not only allocation, of health care resources. Hence, her analysis is especially pertinent when taking into account the unavoidable fact that the Canadian health care system, grounded in its current distributive principles, is not sustainable. It has been plagued with dramatic increases in expenditures that have prompted many initiatives in health care reform, the

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[60] Between 1962 and 1972, physicians' income increased by 136 per cent.

last decade of which is addressed later. Goold evaluates three competing processes of rationing decision-making in health care with respect to the criterion of consent, defined as "an attempt to respect a person's own will" (74)[61]. While her analysis is directed to the current US health care system, its profile of cost-utility analysis, informed democratic decision-making and the "veil of ignorance", summarized in Table 13, should be kept in mind when a review of recent health care reform in Canada is later conducted. Moreover, Goold proposes a two-level, ideal approach to rationing decision-making: Level One involves the existing structure of government responsible for broad decisions (e.g. proportion of health care relative to overall resources) and guidelines (e.g. distributive principles); Level Two involves a community-level benefit review board or organization. A quasi-public body overseen by existing political institutions (popularly elected), the board would be composed of representatives from various health-related interests (versus geographic or demographic representation).[62] An advisory group of experts would be assigned a consultative role relative to the board. All decisions by the board would require group consensus.

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[61]Goold establishes three conditions to satisfy the criterion of consent: (1) openness or honesty to ensure informed choices; (2) accountability to ensure individual control over the decision-making process; (3) fair conditions of cooperation and equal treatment of participants.

[62]The board corresponds to a form of selected representation, as described in Table 13. It, therefore, has the potential to satisfy the following features of Joshua Cohen's ideal, deliberative democracy: (1) ongoing independent associations, (2) participants bound only to the results of their deliberations; (3) pluralism; (4) reasoned deliberation, whereby, the participants are required through stipulated procedures to state the reasons for their decisions; (5) formal and substantively equal participation; and (6) decision-making through consensus (Goold 85).

1.2 Models of Accountability: The Debate over Community

Goold's concept of a community-level benefit review board comprises of a new "political" model of accountability, according to the categorization of Ezekiel and Linda Emanuel, specifically designed to handle cost-control in the current US health care system. It is a model that is also based on the community paradigm of health care governance, presented by Donald W. Light. In this next section, I will introduce Emanuel and Emanuel's models of accountability and Light's four ideal types of governance in health care systems, focussing on the community paradigm. I will bring forth other descriptions of this paradigm and review how it has been implemented in the US and Canadian health care systems. Subsequently, in the second part of this chapter, I will study how the community paradigm is implemented in current health care reform "regionalization" initiatives for the main purpose of controlling costs.

In their quest to determine the most appropriate model of accountability for managed care systems in the US, Emanuel and Emanuel discern the main characteristics of the ideal professional, economic and political models of accountability (Table 14). They begin by defining accountability as "the process and procedures by which one party is required to justify its actions and policies to another party" (149). They identify three critical components of accountability: its parties, domains and procedures. Six domains of accountability are known to the authors: professional competence, legal and ethical conduct, financial performance, equity of access, public health promotion and community benefit. While the models advanced by Emanuel and Emanuel are appropriate to the

situation of managed care organizations, they are too vague when applied to Canadian health care. This is mainly due to the fact that Emanuel and Emanuel include under the umbrella of the political model both government accountability (at the macro-level) and the accountability of community health organizations (at the micro-level). Comparatively, Light presents a more comprehensive, analytical framework that differentiates between these two parties, assigning to each a specific model of accountability as described below.

"The theory of countervailing powers," according to Light, "holds that health care is an arena in which contending parties vie for resources, territory, and control to carry out their goals and vision of how health care should be" (107). Extrinsic forces, such as the development of new technology, can influence the balance of power and perhaps even, challenge the leading party. Because the model is ideological instead of hegemonic, Light stresses that legitimation requires the leading party to incorporate the interests and concerns of other groups. The expertise and knowledge claims of the leading group is useful in securing legitimation. As well, the actions/values of the community, including its culture and empathies, act as an important resource upon which legitimation can draw. There are evident parallels between Light's theory of countervailing powers and actor-network theory. Here, the process through which the leading party acquires legitimation recalls the stabilization process of a technological artifact, whereby relevant social groups negotiate to determine a technological frame. This process is known in ANT as technological micropolitics. Of course, Light's subject

matter is not technology but the health care system.

In order to generalize his theory and avoid the pitfalls of dealing with actual cases – the most important being the inherent incomparability of health care systems – Light refers to Weber's concept of the "ideal type". The ideal type consists of an analytical tool useful in comparing health care systems and scripting the actions of various countervailing powers. Simply put, the actual health care system is equal to the interaction of the ideal type with a specific socio-historical context. The ideal type is value-driven, and therefore, it is not intended as an average type or a "typical clustering of characteristics", but rather, as "the conscious highlighting of essential features and motives from the real world" (Light 110). Light identifies four ideal types of health care systems: state or sponsor based, profession based, provider corporation, or community based. Each is detailed in Table 15.

Light discovers many tensions among different ideal types. For instance, he suggests that the efforts toward cost-containment beginning in the 1970's have seriously threatened the professional paradigm. Outcomes research conducted by the state or sponsor has revealed variations in medical practices, the fragmentation of patient care, the impersonal treatment of patients by providers, and the rising incomes of specialists. According to Light, outcomes research "is transforming the goals of medicine, and therefore the shape and balance of specialist services," by the fact that it is broadening the scope of evidence gathered and including in such evidence personal evaluations from

consumers (118).[63] Hence, Light concludes that "the rigorous testing of *medical* interventions is bringing the patient back to a limited degree and shifting the medical care system toward a true health care system" (118). Moreover, the professional paradigm has been pressured by, what Light calls, the "buyer's revolt". The term "buyer" does not refer to consumers but to the state or sponsor. The sponsor is found by Light to have complained for the last fifteen years over costs and other pathologies of professional dominance. This revolt has generated a shift from the professional to the sponsor paradigm which, in turn, has rendered the following: a general distrust of medical practitioners; external monitoring and accountability mechanisms (e.g. outcomes research); and, a cultural shift from subspecialization to prevention, self-care and primary care (Light 119). Due to the fact that the professional paradigm is legitimated by its expertise and knowledge claims, its autonomy relies on the inability of other countervailing powers to judge its actions. However, as Light points out, the advent of medical informatics and outcomes research has seriously weakened professional independence.

In addition, the community paradigm has been reappropriated and instituted in the midst of the sponsor's revolt. The community paradigm also challenges the dominance of the professional paradigm in the following ways: by treating communities versus individual patients; by undermining the fee-for-service reimbursement system; by

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[63]Greater detail will be provided on outcomes research later in this chapter, especially concerning its role in health care reform.

integrating public health considerations in clinical care; by valuing the contribution of other types of providers besides medical providers in health care delivery; and, by asserting the governing power of consumers. The community paradigm incurs a shift from countervailing to participatory powers, and, therefore, "[b]ecause power is diffuse and participatory, it is difficult to appropriate by the state or other countervailing powers" (Light 125). In reviewing the history of community health care in the US, Light draws the conclusion that community health organizations were structurally marginalized and deliberately implemented in market areas that were presumed to be uninteresting and unprofitable by medical providers.

Richard C. Box offers a more extensive understanding of the community paradigm that is not limited to health care. He begins by identifying three values tied to community governance throughout its history: local control of public governance, small and responsive government, and the role of the public service practitioner as adviser and helper to citizens. He then pinpoints the main principles of community governance: scale (to ensure flexibility and closer ties to the public), democracy (to ensure public access to information and free and open deliberation), accountability (to ensure community ownership and the supportive role of representatives and practitioners), and rationality. Below, Box cautions that the rationality principle should not be misunderstood and seeks to clarify the term:

> Rationality in public policy-making is not about thinking or acting in a precise, neatly ordered, unemotional, or predetermined way. It is about recognizing that

> public decision making is an important enterprise, one that deserves time, careful thought, opportunities for people to express themselves and to be listened to, and respect for the views of others. (21)

In reviewing the institutional legacy of community governance in the US[64], Box detects two crucial issues that are of special importance to current American society. The first concerns the scope of local government, that is, the services that should be entrusted to it. The second relates to how to organize local government. The debate over its structural practices concentrates on the opposing views of "public responsiveness (fragmented systems, open citizen access to the public policy-making process, organizational guidance by elected officials), and administrative rationality (centralized scientific-purpose systems, the citizen as outsider and consumer of services, professionalized decision-making)" (Box 38). Finally, upon reviewing much of the literature on community leadership, Box ascertains a four-part typology of community orientations to policy development: (1) accessible and open or excluding and closed governance system; (2) the community as marketplace or the community as living space; (3) a desire for a large or restricted role for government; (4) acceptance of, or resistance to, public professionalism (64-65).

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[64]Box categorizes the history of American community governance in four stages: the era of elite control (seventeenth and eighteenth centuries), the era of democracy (nineteenth century), the era of professionalism (twentieth century) and the era of citizen governance (speculative).

Hindy Lauer Schachter has deciphered two models of reform of community citizenship (in the US) that correspond to the two approaches to structuring the practices of today's community governance identified by Box (public responsiveness and administrative rationality). In support of the structural practice of administrative rationality, the first model of "reinventing government" is defined as "a way of creating change through managerial technique" (Box 72-73). Here, citizens assume no responsibility in community governance since they are regarded as consumers and, as Schachter keenly observes, consumers have no obligations to the entreprise from which they purchase products or services. Reform is placed in the hands of the government itself to reorganize its bureaucratic procedures and managerial style, mostly in favor of evidence-based decision-making (that is, scientific, rational thinking). As addressed in Chapter Two, critical theory has presented several hypotheses as to how administrative rationality establishes structures of domination. Weber and Habermas have both argued that instrumental rationality lays the foundation for the creation of the bureaucracy, whose guiding epistemology is science. The state uses science to legitimate its decisions on the presumption that, if it is made known that the state is acting in accordance with scientific principles, its political actions are perceived as being neutral. Ergo, administrative rationality reinforces the power of the governing body – assisted by elite experts and technicians – as a structure of domination. Conversely, reflecting an inclination toward public responsiveness, the second model of "active citizenship" is depicted as persons deliberating in the name of public interest to influence government decision-making.

In addition to the persistent tension between the contrasting values of administrative rationality and public responsiveness, Box pinpoints several barriers to citizen/community governance: resistance on the part of elite and powerful groups, the "loop" structure of representative democracy (the role of elected officials as biassed mediators between citizens and public service practitioners), a limited scope of responsibility, the need for special expertise, the dominance of special interest groups, agenda-setting, the lack of sufficient time, and information asymmetry among participants. Community representation is commonly used as an alternative to direct democracy in community governance. Box distinguishes three basic forms of community representation: the delegate governing body that seeks to fulfill the majority public will; the advocate body that is driven toward the achievement of particular goals; and third, the trustee body that strives to act in the name of the broader public interest. In order to reduce what can be experienced as an overwhelming burden of representation, Box suggests that community governance be organized in such a way as to differentiate between routine and community interest policy, that is, day-to-day decision-making that can easily be handled by representatives, and review and final approval of the governing body's decisions that require full citizen participation (taking place on appeal, or as a regular part of the governing process).

The final step in Box's analysis consists of bringing together all the elements of community governance reviewed and drafting a Citizen Governance Model. This model is offered as a means to realize a commitment on the part of a community governing body

to move from a centralized decision-making structure to a citizen-based one. Thus, it acts in concert with the four principles of community governance (scale, democracy, accountability, rationality). Table 16 specifies the Citizen Governance Model's three main elements, its five-step planning process and five-step implementation process. The model should be kept in mind when this dissertation addresses approaches to citizen involvement in telehealth in Chapter Five.

While Box discusses the general role of community governance in society, Schlesinger undertakes a history of the community paradigm in American health care within which he discerns four distinct periods: community responsibility and control (1650-1830), fragmentation of community (1830-1900), community as object (1900-1960) and combined community control with community participation (1960-1995). These periods are delineated in Table 17. While Schlesinger studies the American health care system, its history is closely related to the Canadian experience. For the purposes of contextualizing the current role of the community paradigm in Canadian health care public policy, I will now address, in greater depth, the latest period of community governance.

The first community health centre (CHC), named Mount Carmel, was established in 1926 in Winnipeg. Saskatchewan founded CHCs during the physicians' strike of the 1960's, as previously seen, a reaction to the introduction of state medical insurance. While these centres have remained operational, they were barely sustained due to budget

cuts and waning public and political support. After the introduction of state medical insurance, the federal government commissioned a report on alternative delivery mechanisms from the Hastings Commission in anticipation of rising health expenditures. Released in 1972, the Hastings report provided a description of CHCs that is, to this day, referred to by the Canadian Alliance of CHC Associations. According to the Hastings report, CHCs should incorporate the following characteristics: a not-for-profit organization; community governance; community ownership; citizen participation (through boards of directors, committees, and other feedback mechanisms); involvement of members and users in strategic direction; servicing of an identified local community; a geographically or population based definition of community; a multi/intra disciplinary team of health care providers; alternative funding methods (salary, program-based or capitation); a role as the first entry point for health services; a range of primary health care, social, recreation and non-institutional services; an emphasis on health promotion, disease prevention, and community development; partnerships with other organizations and social sectors; a focus on community and population health; a model applicable to all populations; a flexible, responsive and innovative agency. Longstanding CHCs were set up in Quebec, Ontario, Nova Scotia and the Western provinces. Only Quebec has enforced a strict mandate for its CHCs limiting its sphere of responsibility. In fact, many authors, including Dennise Albrecht, perceive Quebec's approach to community-based health care as "the most co-ordinated and comprehensive" of all Canadian provinces and North America, even as of today (vii).

Health care reforms that occurred during the 1970's in the province of Quebec were a direct result of the recommendations of the Castonguay-Nepveu Commission, initially established in 1966. In 1970, the Commission proposed that strong participatory mechanisms be integrated in the system's strategic direction, as well as in daily management. These recommendations were formulated during a politically volatile period in Quebec. The debates relating to the planning and implementation of these recommendations prompted the unionization and first strike of physicians in Quebec. In the end, the extensive participatory mechanisms envisioned by the Commission were not included in the reformist legislation enacted between 1970 and 1972. Instead, citizen participation was restricted to boards of directors of the five new types of health care and social services agencies.

Quebec was first divided into ten health regions, each led by a Regional Council of Health and Social Services (CRSSS). Originally, the regional councils were intended as advisory bodies and as facilitators. Their responsibilities grew to include the following: long-term and program planning; program coordination and evaluation; and, the creation, promotion, organization and access to partnerships and other shared programs. Regional councils were assisted by 32 Community Health Departments (DSC), located in acute-care hospitals. The departments analyzed community health data and elaborated programs for disease prevention and health promotion, as well as conducted program coordination and evaluation. As well, Quebec's Board of Professions (OPQ) and Health Insurance Board (RAMQ) were instituted. Moreover, a network of

Local Community Health Centres (CLSC) was finally completed in 1989 after a tumultuous battle with professional groups.[65] Instead of 210, 160 centres were created through a community-driven process.[66] While initially social services and public health services were appropriated by other agencies (CCS and DSC), they were eventually incorporated into the CLSC's scope of activity. When first mandated, the CLSC boards were composed of twelve members, seven of which were citizens (five elected delegates and two representatives of certain socioeconomic groups nominated by the government). From 1982 onward, citizens occupied seven out of fourteen voting seats (four elected delegates, two government-appointed representatives of socioeconomic groups, one representative of a prominent, local, voluntary organization nominated by the regional council). In 1971, the number of board seats allotted to general members of the population in non-CLSC agencies were distributed as follows: four out of fourteen in hospitals, four out of thirteen in nursing homes, four out of seventeen in social work agencies, four out of fourteen in rehabilitation centres.[67] These seats were further divided into two seats reserved for elected delegates and two seats dedicated to government-appointed representatives of certain socioeconomic groups.

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[65]Physicians reacted by quickly forming their own network of private group practice clinics. Social workers won their own set of Social Service Centres (CSS).

[66]A group of citizens was required to express its interest to the provincial ministry. Assisted by a public service practitioner, it had to conduct a local needs assessment and propose an implementation plan. Godbout, in studying several cases, observed that groups ranging from 50 to 150 people (for average catchment areas of 20,000) would gather to elect the provisional board and approve community proposals.

[67]The number of representatives sitting on these boards, however, was reduced subsequent to legislative changes in 1978 and 1982.

While initial public involvement in the planning of CLSCs was significant, Godbout notices that, once the structure of CLSCs was formalized, the nature of participation was transformed and the power of citizens was greatly diminished. According to Godbout, the general director and staff of CLSCs were in a position to gather support for their views and gradually asserted their control over the organization. Independent citizens who sat on the board were faced with constant struggles to influence professional and managerial practices. Godbout recalls a common conflict between citizen board members who typically favored the extension of curative services, and progressive practitioners[68] who joined the CLSCs in order to advance preventive practices. In spite of such conflicts and other obstacles to citizen involvement, Godbout contends that citizens held legitimate positions of power on CLSC boards. For instance, citizen board members succeeded in expanding the scope of practice of CLSCs to include certain services, such as abortions, that were opposed by health care providers. In the case of citizen participation in non-CLSC agencies, similar issues arose that hindered its contribution to influencing policy, with some exceptions. Lise Brassard has gone so far as to conclude that, overall, citizen participation has failed in Quebec health care. She proclaims that the only influence exerted by citizens on health care agencies has come from the outside, that is, from health-related interest groups, commercial consumer

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[68]In a study published in 1991, 616 family physicians, 333 practising in private practice and 283 in CLSCs, were compared with respect to their personal characteristics and approaches to medicine (Pineault et al). The study found that those physicians practising in CLSCs were younger, more often women and graduates of innovative primary care training programs. Moreover, they tended to focus on the biopsychosocial nature of illness and on the benefits of patient empowerment.

support of alternative medicine etc.

At the macrosocial level, some researchers have denounced the creation of CLSCs as a government ploy to curtail the development of People's Health Clinics in urban sectors of the province. Beginning in the late 1960's, these clinics represented a new type of grassroots organization, called "groupes populaires", started by unions and community leaders in the midst of a socialist, political radicalization that culminated in urban Quebec during the 1970's. Citizens exerted total control over these clinics. Professional authority was minimized and remuneration was equalized amongst all types of practitioners. Donald McGraw argues that the "groupes populaires" were not directly products of citizen uprising. Rather they materialized the progressive visions of, in using Antonio Gramsci's term, "organic intellectuals", that is, politically sensitive individuals from high-income communities. In fact, Frédéric Lesemann and Marc Renaud have gone so far as to suggest that all social reforms of the 1970's were motivated by the endeavour of a new elite of francophone technocrats to overpower prominent anglophone economic elites and francophone elites (from religious and liberal professions) in order to modernize and rationalize Quebec society. Hence, they conclude that "the idea of a 'community'-based health system was not at all meant to empower communities, but was used by these new power-seekers as a symbolic ideological tool to get control over the health and social services system" (O'Neill 298).

In Ontario, the concept of District Health Councils (DHC) was the product of two developments in the early 1970's: the public's growing interest in direct involvement and the government's concern that continuous health system expansion would hinder centralized management. The first DHC was erected in Ottawa-Carleton in 1974. Within fifteen years, 33 DHCs were launched throughout the province. In addition to being responsible for identifying local needs and developing regional health plans, the DHC's role, while fairly broad, remains consultative to the Ministry of Health. The provincial government retains control of resource allocation and, therefore, of health spending. DHC boards are composed of fifteen members, of which six are citizens. Also during the mid-1970's, a pilot project instituted ten CHCs in urban sectors. Currently, there are 56 CHCs across the province. These were set up through a bottom-up approach similar to the one adopted in Quebec, that is by funding proposals submitted from community groups following the completion of a local needs assessment and implementation plan.

Lastly, Health Service Organizations (HSO) represent another innovative means, implemented by the Ontario government, of changing service delivery patterns in favor of health promotion and disease prevention. Like CHCs, HSOs rely on alternative funding arrangements, but unlike CHCs, they are funded mainly through capitation (rather than salary-based).[69] HSOs are directed at ensuring flexibility in service delivery, improved coordination of services, improved accessibility, efficiency and cost-effectiveness, a focus

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[69]An HSO receives a set amount every month from the state for each patient on its roster whether the patient visits the organization or not, so long as he/she does not go outside the HSO.

on population health and health maintenance, and an emphasis on ambulatory care, self care and home care. Currently, there are 71 physician-sponsored HSOs and 6 non-profit HSOs.[70] Due to the fact that the HSO model was initially ill-defined, many of them were incapable of handling the high demand for services in their area and, consequently, could not transfer toward capitation. These organizations chose to call themselves CHCs, foremost advocating health promotion. In 1983, the government formally recognized their contribution to the communities they served and granted them permanent CHC status and funding. Among those HSOs that succeeded under capitation, Albrecht argues that, while some physicians sincerely attempted to innovatively improve service delivery, others realized that more money could be made from capitation without service delivery patterns having to be modified. Ergo, the HSO program has been kept on hold since the late 1980's.

In reviewing the history of community-based health care in the US, Schlesinger has pinpointed five mediating factors that stand out as persistent and broadly applicable, even to contemporary circumstances. I also find these factors to be evident in Canadian experiences. They are: expectations that community-based health care can modify attitudes and behaviors of users; tension between approaches to community as a means of maintaining traditional values and as a means of empowering disenfranchised groups; tension between social commitments and individual rights; conflict between community

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[70]More than 300 physicians are involved in HSOs serving approximately 440,000 enrolled patients.

control and professional authority; and, the ambiguous impact of market pressures and competition (Schlesinger 955-957). Even though Quebec CLSCs are considered by some as the most comprehensive and participatory forms of community-based health care to have been implemented in Canada (and even North America), the experience has revealed the discrepancy between community participation and community empowerment. From his extensive empirical observations, Godbout inexorably holds that citizen involvement in Quebec health care most often consolidates professional and bureaucratic authority in detriment of community empowerment. He, along with Nicole Leduc, distinguish four crucial factors repeatedly present in circumstances where citizen board members have successfully influenced agencies' activities: the provision of adequate information, a strong mandate from the community, a strong personality, and mechanisms in place for citizen board members to easily access their constituencies (O'Neill 297-298).[71] Similarly, Spitz suggests ten conditions for success of community health organizations (CHO): a plan or vision; local leadership and advocacy; a willingness to share control; time commitments; patience; access to epidemiological data for decision-making; technical solutions to economic, legal, organizational and health-related barriers; the ability/cooperation of nonhealth professionals to develop health-related expertise; the

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[71]The importance of mechanisms that directly link CLSC delegates and representatives to their constituencies was acknowledged by the media. In the television program "Commission Mongrain," in a 1996 special on Quebec health care reform, Jean-Luc Mongrain attempted to demonstrate the lack of information and consumer awareness regarding the CLSC's purpose, operation, services, and even, opening hours. The point made by Mongrain was that, while a select group of citizens may be involved in the administration and planning process, they have not been effective in informing their own communities about the CLSC's organization.

prioritization of the CHO plan/deliberations over individual actions; the availability of funds (1044-1045). Spitz believes that the key to an effective representation of community interest is to place the community in appropriate contexts, foremost characterized by appropriate expectations and support. In other words, specificity and moderation are essential features of CHO design.

Section 2: Canadian Health Care Reform

I will now address how the models of accountability, especially the community paradigm, have changed as a result of Canadian health care reform initiatives of the last decade.[72] First, I will review some of the main events of health care reform having occurred at the federal, provincial and territorial levels. Then, I will address the impact of health care reform on community-based health care, including regionalization initiatives, CHC development and the concept of consumer empowerment. Next, I will study the focus of health care reform on evidence-based decision-making (EBDM). Finally, I will look at the role of technology in a reformed, Canadian health care system.

No major structural change to the Canadian health care system has occurred since the implementation of universal state health insurance. Current health care reform public policy is the result of an emerging consensus on the importance of cost-containment. According to a report of the Organisation for Economic Co-operation and Development

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[72]While the principles of distribution of Canadian health care have been challenged by some of these initiatives, they currently remain in force.

(OECD) published in 1994, this consensus was prompted by the convergence of several socio-economic factors: the reduction of federal transfers compounded by the increase of provincial budgets dedicated to health care; the economic recession detrimental to already inflated federal and provincial deficits; the sobering realizations that rising amounts of health expenditure do not result in improving the health status of the population and that Canada ranks amongst the highest in international health expenditure comparisons. Faced with federal funding instability, Health Canada observed that: "A consensus among the provinces has emerged that suggests that prevailing levels of health care are sufficient, and that initiatives are required to limit growth and manage the system more efficiently" (Canada's Health System 5). The cost-control imperative was also driven by an awareness of the changes in future population needs, and by forces external to the health care system per se, such as government debt, the global economy, technological innovation, research and development, labor markets etc.

It is, in fact, the case that, from 1977 to 1995, the federal share of provincial health expenditures decreased from 41 per cent to 32 per cent, including both the cash transfer, reduced from 25 per cent to 16 per cent, and tax points. Federal cutbacks continued with a reduction of $7 billion in the Canadian Health and Social Transfer (CHST)[73] between 1996 and 1998. In 1996, in a paper entitled Maintaining a National Health Care System: A Question of Principle(s) ... and Money, the National Forum on

[73]In 1996-1997, the federal government eliminated the Established Programs Funding (EPF) and the Canada Assistance Plan (CAP). In their place, the government instituted the CHST.

Health (NFH)[74] described the tax transfer as "confusing and unhelpful", allowing the federal government to shield further cutbacks in the cash contribution level while claiming that the CHST remains stable or is marginally increasing (Maintaining). In addition, the NFH argued that the transition from federal/provincial cost-sharing arrangements to block funding obscures the connection between federal action and the concept of a "national" health care system. In short, the NFH expressed strong concern that the structure of federal/provincial financing arrangements, coupled with federal cutbacks, has reduced federal authority to enforce national health programs and principles to an alarming degree, allowing increased instances of de-insured provincial services, user fees, and privatization in health care. After having explored other alternatives to cash as a federal leverage to prevent such occurrences[75], "... the Forum concludes that the federal government must make a firm commitment to a real and stable cash contribution level to symbolize the restoration of the partnership, and its willingness to provide leadership in service of a national health system" (NFH, Maintaining).

Since the publication of the NFH's report, however, the first federal budget surplus in 28 years ($3.5 billion) was successfully achieved in 1997-1998. Subsequently, in 1998, the federal government announced an increase in the CHST (from $11 to $12.5

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[74]The NFH was launched in October 1994 as an advisory body to inform national health policies in four key areas: values, resource allocation, health determinants and evidence-based decision-making.

[75]These included direct regulation, a social charter as part of the Constitution, inter-provincial agreements, and federal, political leadership and moral suasion.

billion). The CHST will be further increase by $8 billion between 1999-2000 and 2003-2004. In effect, in 2001-2002, the CHST's health component will have reached the same level it was prior to the cutbacks of 1996.[76] Furthermore, in order to eliminate provincial disparities in the CHST's health component, all provinces will benefit from a contribution of $960 per person by 2001-2002. As well, an extended Equalization Program will continue to eliminate disparities at the provincial level. Finally, the federal and provincial governments appear to have renewed their commitments to state-wide health insurance and to the five principles of the CHA. Notwithstanding, in November 1999, Alberta's Prime Minister, Ralph Klein, announced a new bill to be introduced the following spring allowing RHAs to pay private providers to render surgical services.

In response to financial pressures experienced throughout the late 1980's and 1990's, federal, provincial and territorial governments undertook several strategies in order to reform the health care system. Many authors have attempted to consolidate the main policy orientations of these efforts. For instance, the NFH suggests that governments responded in three ways: by adopting a health determinants framework; by shifting the emphasis from an institutional delivery model of care to a community-based model involving health promotion and prevention; and, by developing a team approach

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[76]In addition, an immediate one-time supplement of the CHST of $3.5 billion will be distributed from funds available in 1998-1999. The federal government will also invest $1.4 billion over the next three years in health information systems, health research and innovation, First Nation and Inuit health care, and public health programs.

and coordinated management of health sector professionals.[77] The NFH, however, specifies that the actual methods, and not just shifts in emphasis, of service delivery have not yet been reformed, but only the structures of governance and administration. For its part, the OECD report identifies four shifting patterns, or patterns of change, reflected in reformist actions: from expansion to consolidation; from access to contraction for cost-containment; from treatment-oriented care to disease prevention and health promotion; from centralized, authoritative and public governance to a more open, consultative approach that encourages community and stakeholder participation. From my own observations, I have found a new acknowledgement, on the part of federal/provincial/territorial governments, of the interconnection of the health sector with other social, economic and political sectors of government responsibility. For instance, a discussion paper of the Northwest Territories' Department of Health and Social Services, released in the late summer of 1997, reveals that health care reform is expected to contribute to the NWT Government's overall vision for the Canadian territory. It predicts that:

> . . . the NWT will become more established as a politically and economically viable unit of Canada, with a secure financial future and that healthier, better

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[77]Albrecht details the same shifts in service delivery: from resource consumption to health outcome (i.e. a health determinants framework); from illness and injury treatment to include health promotion; from the abundance of data to information that supports decision-making; from solo practitioners to multi-disciplinary teams; a more open and transparent accountability; from a provider-driven system to one based on consumer and community participation; from fragmentation to co-ordination and systems planning; from dependency on the system to self-reliance; from expert-driven goals to community-driven priorities; from a focus on individuals and their illness to a population health approach (viii-ix).

> educated and more self-reliant citizens will enjoy a good quality of life and have access to more of the jobs they want and need . . . (Finding a Better Way)

Here, an improved health system is associated with a stronger political sovereignty and economic prosperity.

Of course, health care reform strategies are not only outlined by national public policy documents, as illustrated by the NWT example. In fact, the majority of such strategies are developed at the provincial and territorial levels. Appendix A highlights the main provincial and territorial health care reform initiatives, emphasizing regionalization initiatives, that have been undertaken during the 1990's.[78] Mhatre and Deber conducted a review of the recommendations of provincial health care policy commissions, published between 1987 and 1991.[79] These commissions were established for the purpose of examining their respective health care systems. While undertaking their review, Mhatre and Deber discovered the following list of recurring themes: a broader definition of health and intersectoral planning; health promotion and disease prevention; from institution to community-based care; increased citizen participation; regionalization; improved human resource planning and alternative reimbursement mechanisms; enhanced efficiency in management through coordinating councils and other bodies; and, health services research (outcomes data, utilization data, technology assessment, program evaluation)

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[78]For more information, I recommend that you consult Health Reform Update, published each year since 1993-1994 by the Canadian College of Health Service Executives.

[79]Commissions reviewed were from six provinces (AL, SK, QC, NB, NS, ON).

(655). Moreover, Mhatre and Deber detected several obstacles to implementing reforms in these areas, including: the difficulty in mobilizing elements implicated in a broader definition of health (such as environmental health); the discrepancy between devolved (including fiscal responsibility/accountability) and decentralized, decision-making bodies; a reluctance to cede authority to regional authorities; the difficulty in assessing the value of community participation (concentrated interests of professionals versus diffuse interests of citizens) (660-664).

2.1 The Impact on Community-Based Health Care

As demonstrated above, both at the federal and provincial/territorial levels, the community paradigm is recognized as a key feature of, or shifting pattern promoted by, Canadian health care reform (by NFH, community-based model; by OECD, more open, consultative approach that involves community participation; by Albrecht, system based on community participation; by Mhatre and Deber, community-based care and increased citizen participation). However, while active participation of citizens through community-based care at all levels of the system (resource allocation, planning, governance etc.) is widely supported in health care reform public policy, this policy is also pushing for cutbacks and downsizing that forces groups such as hospitals to compete against community groups. This precarious position of community-based care is no less evident than in the trend toward regionalization prompted by health care reform. Regionalization is defined by John Church and Paul Barker as "an organizational arrangement involving the creation of an intermediary administrative and governance

structure to carry out functions or exercise authority variously assigned to either central or local structures" (468).

Joseph Mapa and Gerald P. Turner present a more general understanding of regional planning as "a multiorganizational (two or more service organizations) collaborative initiative in priority-setting and rationalization" (51). Mapa and Turner differentiate between horizontal planning and vertical planning in regionalization. In horizontal planning, hospital consortia or other joint groups proceed with service rationalization within their own boundaries. In vertical planning, regional health authorities or agencies are responsible for priority-setting, resource allocation and health policy for the district or community's entire health and social program. Church and Barker's definition of regionalization corresponds to vertical, regional planning.

While regionalization initiatives vary amongst provinces (see Appendix A), they mainly serve to reinforce the cost-control imperative by allowing provincial administrations to retain the power to set benefits, determine eligibility and control coverage through a single-payer system. At the same time, it is assumed that they provide an opportunity for the system to respond more adequately to regional and local needs. As well, it is assumed that they involve a decentralization, if not a devolution, of provincial authority, and citizen participation in decision-making. According to the NFH, the efficacy and efficiency of regionalization initiatives depend on the successful implementation of three key components: service integration, single-point access to a

variety of services, and a multidisciplinary team approach to the delivery of care. The NFH suggests two ways to achieve service integration: integrating funding streams through population-based funding (such as capitation) allocated to regions for multi-faceted service delivery; or, allocating population-based funding (determined geographically or following voluntary enrolment) to independent and publicly accountable organizations. Released in 1997, the NFH's Striking a Balance Working Group Synthesis Report recommended that the federal government provide further incentives to direct heath care reform efforts toward service integration, foremost being a transition fund to support evidence-based projects[80]. A $150 million transition fund was later established by the federal government as a response to this recommendation. Its scope will further be detailed in Chapter Four.

Church and Barker describe the most common components of regionalization as follows: the creation of regional governance and management bodies composed of appointed and/or elected officials; global budgeting (geared toward regional needs and the equitable distribution of resources); a community-based setting for service delivery; outcomes assessment; downsizing and restructuring of provincial ministries of health (from its role in service delivery to one of administrative support and quality management) (471-472). In addition, the authors caution that there are many challenges to implementing regionalization initiatives, including the integration and coordination of

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[80]The significance of evidence-based decision-making for health care reform, as presented by the NFH, will be described later.

administration and service delivery, the consolidation of funding, the meeting of information requirements (how to develop quality indicators for outcomes evaluation), and the achievement of effective citizen participation (472-473). There is, in truth, little evidence to demonstrate that regionalization leads to economies of scale and, therefore, to cost-containment.[81] The same is true of community health organizations. Despite the fact that, for instance, the Association of Ontario Health Centres claims that CHCs have realized the health care reform vision for decades – to promote a more balanced approach in service delivery – and that they seek to contribute substantially to the reform process, Lawrence D. Brown and Catherine McLaughlin have come to the conclusion, following their study of the Community Programs for Affordable Health Care (CPAHC)[82], that the use of community-based care for cost-containment is premised on an "implausible theory" (15). This theory presumes, according to Brown and McLaughlin, "that community leaders will successfully organize themselves into stable negotiating structures that would exert within the health sector economic discipline of sufficient rigor to slow the rate of growth of local health care costs and do so only by socially acceptable and responsible means" (15). In other words, community health organizations are

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[81]To the contrary, a study of the impact of regionalization on local government services in Ontario found that areas of soft services (such as policing and social services) that are more labor intensive are less likely than hard services (such as water and sewage treatment) to render economies of scale (Krushelnicki and Belvedere). While relating to horizontal, regional planning, analyses of the system-wide integration of hospital services in the US have failed to demonstrate that this integration realizes economies of scale, efficiency in service delivery or improved health outcomes (Shortell; Shortell et al; Dowling; Gelmon).

[82]A four-year initiative begun in 1984 and funded by the Robert Wood Johnson Foundation ($15.2 million), implemented across the US.

required to deliver services at lesser cost (technical efficiency), to achieve an appropriate balance of services (allocational efficiency), all the while fulfilling universality and access objectives (Segal 32). In reality, the authors note several obstacles to this ideal process, foremost being a lack of collective will to control costs, enduring professional sovereignty at the local level, the stalemate caused by perpetual cost shifting, and the community's inability to control cost decisions at the outset (fee scheduling, input amounts etc.).

Former Alberta Minister of Health Jane Fulton outlines an extensive, generic list of objectives of regionalization initiatives of which three are directly related to the decentralization of provincial authority and community participation.[83] Notwithstanding, she affirms: "Institutions, agencies, and communities often believe that, with regionalization, there will be decentralization of provincial powers. This seldom happens. Regionalization is much more likely to lead to increased centralization" (15).

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[83]Develop policies and programs which reflect the character and priorities of the region; Reduce intraregional disparities (in terms of access, cost, availability, quality); *Provide greater opportunity for and degree of consumer and community influence and control*; Reduce the parochialism found in individual programs and facilities; Attain financial savings through economies of scale, avoiding duplication and reducing undesirable competition; Facilitate the movement and referral of patients; Increase standardization; Improve information flow; Integrate and coordinate related services; Distribute personnel and facilities more efficiently; Improve quality control techniques; Improve training of staff; Attain the "critical mass" of cases or services necessary if quality and efficiency are to be satisfactory (ensures competency of staff, updated equipment, research); *Reduce the power of some central agencies by creating a smaller jurisdiction and delegating to that jurisdiction*; Develop a regional approach to priority setting, planning, delivery and administration; Rationalize services; Provide greater career opportunities for staff; Create one agency to service a specific population; *Improve interaction for consumers with administrators and planners* (Fulton 15-16).

Likewise, in his study of past regionalization in Quebec, Renaud maintains that it actually served to streamline the administrative process and facilitate a centralized and hierarchical governing structure. "[F]or the government the concept of decentralization," he interprets, "has meant the grouping together of previously separate units within the regional consultative bodies in order to facilitate the handing down of commandments from on high" (381). Renaud believes that citizen participation in the Quebec health care system has been ill-fated from the start, crippled by low electoral participation, elitism amongst representatives and cooption by providers. As noted earlier in this chapter, he contends that health care reform is guided by the rise of a national petite bourgeoisie (the technocrats and bureaucrats) with "vested interests" in the preserved legitimacy and expansion of the state (385). As such, he argues that it is primarily driven by tensions between the bureaucrats, who denounce the abuses of monopolistic providers, and the providers, who oppose the intrusion of the bureaucracy in issues of quality of care and the doctor-patient relationship.

Morton Warner goes further in his critique by claiming that regionalization arises from the need of governments to maintain control. By officially delegating some limited authority to citizens, according to Warner, governments deploy their participation to control conflicts between the bureaucracy and providers. Hence, Warner resolves that citizens involved as decision-makers in the health care system act as "buffers" in the balance of power between the state interveners and providers. However, he recognizes that the more citizens have access to information and knowledge regarding health care,

the more they pose a threat to the prestige and power of the medical profession. In an article commissioned by the NFH's Evidence-based Decision-Making Working Group, Carol Kushner and Michael Rachlis describe the benefits of the limited participation of consumers for governments:

> Consumers can facilitate government reform processes and may, in fact, be essential to overcoming the predictable resistance to change that will come from those who work in the system. Consumers have unique information, which improves decision-making by ensuring that services are better tailored to consumer expectations and preferences. They also bring balance and fresh perspectives to the traditional debates that occur between funders and service providers. This *balancing function* can moderate or bolster resource demands or influence reallocation decisions. Finally, consumer involvement can contribute to a society's "civic sense" by strengthening the public's sense of ownership over public institutions and processes. [emphasis added] (70-71)

Kushner and Rachlis also list several challenges to the efficacy of consumer participation: the lack of financial support and the fear of cooption, the lack of a structured process providing for accountability, limits to patient expertise due to personal health conditions, the lack of opportunities for public debate and networking, and the need to present a united front. In response to these challenges, the authors recommend that the federal government fund consumer interest groups, support and mandate consumer participation in decision-making, develop and fund a national consumer health forum and support a national consumers' health conference. In their synthesis report, the NFH's Determinants

of Health Working Group reiterates the need for state support of citizen participation. The Group recommends that the state support local leadership and create a national foundation to fund health-enhancing, community-based initiatives. Thus, it would appear that the state will continue to fuel arguments denouncing the state's cooption of community/citizen participation in the health care system.

Elsewhere, Renaud describes the state's deployment of citizen participation as part of a more comprehensive strategy intended to control the involvement of the private sector in health care, rather than solely as a means to control provider authority and influence. Renaud suggests that:

> It seems as though the state sought to subordinate or even absorb the private sector from above as well as from below: from above, by increasing bureaucracy and civil servants, from below by co-opting consumer movements, social activists and feminists, whose objective was to stop the absorption of civil society by the state. (qtd. in Crichton, Hsu and Tsang 247-248)

Essentially, Renaud argues that health care reform initiatives, including regionalization, consistently fail due to two contradictory and intrinsic functions of the state apparatus: maintaining the capitalist system and legitimizing the social consequences of the accumulation of capital. Simply put, according to Renaud, the state defines health as a privileged value in society because it is a precondition for the principle of equality of opportunity, and, therefore, a precondition for the proper functioning of capitalism. Moreover, health – as it is defined according to the dominant, medical model – depends

on the production and consumption of commodities and services. Consequently, if the state chooses to intervene in the health care system, Renaud deduces that it cannot move away from the capitalist model, whereby, health problems are defined in terms of problems of individual consumption in a sector-specific market. While the state may enact legislation and direct public policy in favor of collective principles such as universality and accessibility, Renaud assumes that it does so in order to legitimize the social counter-culture of capitalism. When the system is in crisis, he explains, the state designates problems in terms of consumption patterns, whether those of providers (supply-induced demand) or of consumers (abuse). Therefore, Renaud concludes:

> When the state intervenes, it can only produce changes which reinforce, or at least maintain the allocation of resources towards the market of therapeutic techniques, personnel, and health organizations, and towards the technologically sophisticated means of prevention. It is not in a position to produce the social conditions which would systematically improve the public's state of health. (389)

Likewise, Robin F. Badgley and Samuel Wolfe postulate that social policy emphasizes cost containment and equality of opportunity – the latter defined in terms of access to benefits – instead of focussing on changing the skewed structures of the system that perpetuate "ingrained inequality" (194).

Whether characterized as a buffer or as passive consumerism, there appears to be a general consensus among analysts that citizen participation in regionalized health care

organizations is not empowering.[84] Empowerment is most commonly defined as the ability of citizens to understand and control the personal, social, economic and political forces that will enable them to make effective decisions in order to improve their lives. In the context of health care, empowerment requires relevant information about health and health services, but it also requires personal confidence and competence to act on this information, as well as a capacity to influence service provision (Segal 37). Hence, Leonie Segal maintains that the empowerment of citizens "requires an understanding of their own health, of the available service options and acceptance of responsibility for decisions about their own health care" (37). Segal also points out that community empowerment is increasingly tied to notions of health and well-being. This is due to the assumption that active participation in a community of interest generates a sense of belonging that directly contributes to health and well-being.

As well, Segal notes that community empowerment is a central component of the World Health Organization's (WHO) definition of health promotion.[85] In the WHO definition, as well as in public policy documents – such as Achieving Health for All: A

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[84]Consistent with these observations, a summary report of the NFH's Evidence-based Decision Making Working Group records the following impressions of consumers, expressed during a Consumer Dialogue held on June 24-25, 1995, formed with regards to their involvement in the health system: feelings of disempowerment, an uneven distribution of information between providers and consumers, a trend toward consumerism instead of advocacy, a reluctance to be involved in decision-making, and a fragmentation amongst special interest groups.

[85]The WHO defines health promotion in the *Ottawa Charter for Health Promotion* (Geneva, 1986) as follows: "Health promotion is the process of enabling people to increase control over, and to improve, their health".

Framework for Health Promotion (Government of Canada, 1986) – while inequities in health and issues of accessibility in the health system are recognized, embedded in such documents is the call for individual responsibility for health and well-being, a call for empowerment problematized by Joan Anderson as follows:

> Thus, although empowerment might be seen as a consumer movement, in its adoption by policy makers, it focuses on what people can do to empower themselves, and deflects attention from social issues, for example, labour market segregation, racism, sexism and the structural conditions that perpetuate poverty in the underclass. Thus we are all encouraged to follow the trend towards the prevention of illness (presumably to decrease health care expenditures) through healthy lifestyles even though those who live on the margins might neither have the money nor time to engage in fitness activities or to eat healthy diets. The gaze of the health professional becomes fixed upon the behaviour of the individual as structural constraints fade into the background. (702)

This depiction of health promotion reflects the observation of Renaud, earlier brought forth, that reform strategies perpetuate the capitalist notion of health care as a form of individual consumption. Alternatively, Anderson suggests that reform must be accompanied by more egalitarian structures, more equitable distribution of power and a change in the relations of power between providers and patients. As well, she stresses the need for flexibility in patients' relationships with health care providers as their needs and

wishes change throughout their lives.[86]

Segal has observed several common problems from the supply and demand sides of the health care market that severely hinder the ability of citizens to assert their control over service provision. From the supply side, Segal identifies as significant impediments: the preferential status conferred on certain types of health care services by funding arrangements (such as the medical/physician bias asserted through fee-for-service); program-based service provision that limits the flexibility of the system (i.e. its ability to respond to citizens' needs); shared responsibility for health that causes poor coordination and cost shifting; and, the types of care relating to public health whose benefits are not recuperated directly by citizens (34-35). From the demand side, Segal finds the following limitations to citizen involvement: restricted access to information by citizens (evidence-based and personal health information); the role of the provider as agent of the patient who, in fee-for-service arrangements, has a financial incentive to generate more services but none when it comes to making decisions on the basis of the patient's perspective; the limited ability of providers to access all relevant and current health information; and, the lack of comprehensive control over health care financing (35-36).

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[86]According to a study by Michael Bury, younger patients want a more "instrumental" style of intervention and more information on tests and treatments while older patients want to communicate with their physicians about their personal and family situation and the wider impact of their condition.

In addition to all the structural obstacles listed above, Segal warns of the negative impact of a general lack of support amongst health care providers (including administrators) for community/citizen empowerment.[87] According to Segal, this lack of support stems from their belief that such empowerment is inappropriate and unfeasible and that citizens are generally disinterested in being involved in decision-making. Notwithstanding, Segal hypothesizes that "[t]his presumption may be consistent with current observations as a reflection of health systems which are disempowering" (38). She, in fact, brings forth several instances in which a sense of individual empowerment has been proven to exert positive influences on health and well-being, such as in the case of heart disease, stroke, disability, diabetes, arthritis, chronic pain management and cancer (38-40). She does not, however, nor would she intend to, bring forth any evidence that empowerment leads to economic efficiency. Finally, Segal suggests several strategies to promote empowerment, the first and foremost being to set empowerment as

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[87]In his study of public attitudes towards the role of community in social policy, Schlesinger drew his conclusions from two surveys, fielded in 1995, among the US public and among congressional staffers who oversaw health issues for members of the Senate and the House of Representatives. Schlesinger found that 40-50 per cent of the public and less than 20 per cent of staffers thought that community-oriented health care reform would be a favorable approach, while two thirds of the public and half of staffers thought it would have a positive influence on low-income households. However, if community-oriented health care reform is presented as the only, preferred strategy, then support wanes to 31 per cent of the public and 11 per cent of staffers. While 58 per cent of staffers did think community-based groups could reduce the misuse of public benefits, Schlesinger reports that the public appeared to favor community-oriented reforms mainly because of their presumed potential for empowerment rather than for their ability to control costs, misuse of benefits or their conservatism. Briefly, support for community-based policy amongst the general public and staffers is much less when applied to mainstream medical care than if applied to other policy domains, including health-related services such as long-term care and substance abuse treatment.

an explicit objective of the health system or organization. Other strategies considered by Segal to be pertinent are: to ensure a flow of information to citizens about their health status, service options and opportunities for involvement; to support patient education and promote greater individual responsibility for health and health care; to train providers and agencies to adopt more open, consultative approaches to service delivery that encourage citizen involvement; to facilitate good communication between providers; to structure the role of care coordinator in such a way that it supports empowerment and addresses potential conflicts of interest; and lastly, to devolve responsibility for health care budgets to citizens and communities (41).

2.2. The Focus on Evidence-Based Decision-Making (EBDM)

Citizen access to evidence-based health care information, while not in itself guaranteeing empowerment, is regarded by Segal and others as an important stepping stone. Evidence-based health care information is a product of outcomes assessment. According to David O. Weber, there are two parts to outcomes assessment, or what he calls the "outcomes movement": outcomes research and outcomes management. Outcomes research, Weber states, involves the study of the impact of medical care on patients.[88] This research is typically published in traditional medical journals and serves as a foundation for formulating clinical practice guidelines (CPGs). Comparatively,

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[88]A more detailed definition is offered by Edward Guadagnoli and Barbara J. McNeil: "outcomes research involves comparing the type of care received by a variety of patients with a particular condition to positive and negative outcomes in order to identify what works best with which patients" (14).

outcomes management is directed toward improving health care accountability. Data on outcomes obtained from continuously monitoring patients is fed into the system to influence routine practices. In order to grasp the significance of the "outcomes movement" in current health care reform, it is also important to understand the difference between evidence on efficacy and on effectiveness. Evaluations of efficacy are conducted through randomized clinical trials that test medical interventions under strict conditions for the purposes of reducing the impact of extraneous variables. Evaluations of effectiveness seek to test interventions as they occur in their ordinary contexts to study the role of extraneous results in determining outcomes. Hence, if outcomes assessment is conducted in the everyday practice of medicine, than it corresponds to effectiveness research, as well as technology assessment (Guadagnoli and McNeil 15).

According to Field, the demand for evidence on effectiveness was heightened during the 1970's and 1980's due to rising health care costs and costs of new medical technology, as well as due to the publication of numerous studies acknowledging wide variations in clinical practice and questioning the appropriateness of many practices. Kathleen N. Lohr suggests that the emphasis of outcomes assessment for the past twenty years has been on process-of-care evaluations and the technical quality of care. However, she believes that the current trend is to stress patient outcomes, that is focussing on outcomes (as opposed to the structure or process of care) that are directly tied to patient well-being. She further posits that this trend was the product, from an intellectual standpoint, of the "health accounting" concepts advanced in the 1970's. It came about,

from a practical standpoint, as a result of the growing preoccupation over rising health care costs. Outcomes assessment aimed at evaluating effectiveness is generally viewed as a cost-control measure that influences resource allocation decisions, and as a means to improve quality of care/service. In short, as observed by Karen Sandrich, while only a decade ago outcomes assessment was strictly considered to be a research activity, it is now a common measure of cost containment and a daily part of the management of health care organizations. Today, different stakeholders in the health care system can make use of outcomes information in various ways, some quite innovative, as documented in Table 18.

Several new initiatives in outcomes assessment are identified by Field: less expensive and more realistic methods of testing the effectiveness of alternative clinical practices; better measures of health outcomes, delivery system characteristics, and other variables that may affect outcomes; statistical and other tools that provide more meaningful and credible analysis and presentation of data; computer-based patient records and other electronic information systems (including the Internet) for fast and easy access to large databases; decision support tools and learning systems that assist clinicians and patients in evaluating information, preferences, and options; strategies for providing information to patients, clinicians, and others in ways that promote informed decisions and stimulate desired changes in behaviors and outcomes; and lastly, evaluation of the impact of information and decision-support strategies on behaviors and outcomes (23). Important for our purposes in Field's list is the acknowledgement of the value of

consumers' assessments of the quality of care. There has been much skepticism to using such assessments on the grounds that they vary according to consumers' characteristics, that they assess the quantity more so than the quality of care, that they disagree with physicians' judgements regarding quality, and that they are solely based on the interpersonal aspects of care (Davies and Ware 7). Notwithstanding, Allyson Ross Davies and John E. Ware, Jr. point to several favorable arguments to using consumers' assessments, accentuating their ability to predict consumer behavior in the system, the proven accuracy of consumers' reports, their low cost and the unique information that they contribute (12).

With respect to the last advantage listed by Davies and Ware, Madeleine Boscoe has also noted that consumers tend to have a more conservative approach to treatment options than providers. As well, she claims that consumers' perspectives and priorities are very different from those of providers. Having reviewed all available evidence on the quality and validity of consumers' assessments, Davies and Ware conclude the following: the bias from personal characteristics is negligible; consumers' ratings do reflect, to some extent, the quantity of care; consumers are able to distinguish between physicians' ratings of the technical quality of care; consumers' ratings of interpersonal features of care do not affect their ratings of technical quality; consumers' ratings of quality, however "quality" is understood, do affect their health care choices; consumers' reports are valuable for quality assessment and assurance; costs of obtaining consumer data are not higher, and probably lower, than traditional data sources; consumers' ratings are the most valuable

source for assessing the interpersonal aspects of care (18).

The role played by outcomes assessment in Canadian health care reform is defined in large part by the NFH. In its Synthesis Report published in 1997, the NFH's EBDM Working Group recommends that the "federal Minister of Health champion the creation of an evidence-based health system, built on the foundation of a national health information system . . . [in] collaboration with both provincial and territorial health ministers and other federal departments"("Creating" 26). According to this working group, the objective of an evidence-based health system is to collect "relevant and timely information on population health strategies and both medical and non-medical determinants" in order to render more accountable and transparent the process of decision-making for all health and health care decisions (NFH, "Creating" 7). The group also proposes three key ingredients to achieve the vision of an evidence-based health system. The first ingredient is timely evidence available to all stakeholders: patients, administrators, providers and policy-makers. The group affirms that patients should have access to information regarding their health status, treatment choices and the risks and benefits of these choices, as well as other support tools. It claims that "informed" patients will become more involved in decision-making at other levels of the health care system (NFH, "Creating" 7). It cites instances when the public has exerted influence on policy and practice issues[89] and argues that such instances will multiply once patients

[89]Examples brought forth are: the development of acupuncture programs in some provinces, the development of culturally sensitive addiction programs for First Nation and Inuit communities, and advocacy for breast cancer research.

have access to increased amounts of reliable health care information. It also contends that the main drivers of public access to medical and health information are citizens who have expressed their desire to become more involved in health policy and program development. As the group relates: "They [citizens] express an increasing reluctance to leaving system-wide decisions in the hands of experts and governments" (NFH, "Creating" 10). The group thus recommends that government strongly promote the role of the public in creating a culture of EBDM in health.

Longitudinal and comparative data on socioeconomic factors, medical and non-medical determinants of health, utilization costs, health care capacity and performance indicators, should also be made available to administrators, as recommended by the NFH's EBDM Working Group, to improve their understanding of relative contributions of inputs (practices, operations, services) to outputs (population health status, health outcomes) and to enhance their flexibility in providing focussed responses to well-defined policy questions. The group also recommends that providers have access to: high-quality evidence regarding the effectiveness of patient care that takes into account gender and cultural specificities, information on CPGs, cost evaluations and health and medical records at the point of care. Lastly, the group stresses that policy-makers benefit from information on patient care and cost-benefit analyses, longitudinal studies and projections, and information on the interests and opinions of their constituents to facilitate patient involvement. According to this vision of an evidence-based health system described by the working group, various forms of evidence are integrated into the health

system to guide the actions of all stakeholders. The group argues that the need for such evidence is driven by advances in research and technology that have produced new types of information and knowledge, by the public's request for access to more information, and by health care reform, its funding constraints, its focus of population health and health determinants, and its regionalization of service delivery.

Concerning the role of evidence-based health care information in regionalized reform, the group maintains:

> Regionalization and decentralization of our health care system require effective monitoring of performance standards and accurate information on how health care resources are being utilized, providing a method to compare with other regions. (...) [They] will place more demands on administrators for accountability about decisions and their health outcomes. (NFH, "Creating" 9-10)

This last statement corresponds to the second key ingredient in the achievement of an evidence-based health care system, pinpointed by the group: the accountability of decision-makers and performance feedback. The Federal/Provincial/Territorial Advisory Committee on Health Services recently established a Working Group on Regionalization Performance Indicators. Assisted by Health Canada's Research Synthesis Program, the Canadian College of Health Service Executives (CCHSE) reports that "the group has requested research proposals on the issues, challenges, approaches, and experiences associated with developing accountability frameworks that monitor, assess, and report on health system performance" (Health Reform Update 1998-99 77).

The third key ingredient is "the uptake of information with appropriate incentives, methods and tools to ensure use" (NFH, "Creating" 25). EBDM calls for the transformation of collected information into knowledge. This process then requires the evaluation of information in terms of its relevance and relationship to outcomes, the standardization of information, the linking of technological systems for collection and analysis (i.e. the transformation of information into data), and security systems to ensure the reliability and credibility of information (e.g. encryption and public key infrastructures). There exist several evidence-based research initiatives in the area of health in Canada that have the capacity to analyze health information and transform it into valuable knowledge for long-term improvement of the health system. Such initiatives include activities of Statistics Canada, the Canadian Cochrane Collaboration, the Canadian Association for Quality in Health Care, the Manitoba Centre for Health Policy and Evaluation, the Institute of Clinical and Evaluative Sciences of Ontario, Med-Echo of Quebec, the Saskatchewan Health Services Utilization Review Commission, the Centre for Health Economics and Policy Analysis of McMaster University, the University of British Columbia Centre for Health Policy, the Université de Montréal Groupe de recherche interdisciplinaire en santé, the Queen University's Health Policy Unit, the Canadian Institute for Health Information etc.

Despite the state's great push for integrating EBDM in the Canadian health care system[90], outcomes assessment should not be accepted uncritically. In fact, it has important consequences for the present and future role of citizen involvement/the community paradigm in health care that is admitted by the NFH. As we have seen, the initial resurgence of outcomes research in health care during the 1970's revealed wide discrepancies in the patterns of medical practice. These revelations led Lynn Payer to study the variations in medical worldview and treatment practices in the US, Britain, West Germany and France. In conducting this study, she observed that, while such variations unquestionably exist, life expectancies are virtually identical in all four countries. In the foreword of Payer's book, Dr. Kerr White acknowledges that only about 15 per cent of all current clinical interventions are supported by objective, scientific evidence that proves that they are more beneficial than harmful (Peters 43). Moreover, 40 to 60 per cent of all therapeutic benefits, according to White, are rooted in a combination of placebo and Hawthorne effects, that is, of caring and concern (Peters 43). Observations of the cultural determinants of medical practice lead to questions about the scientific validity of medicine. They complicate the concept of evidence-based information used for clinical decision-making. In truth, they beg the question, appropriately phrased by Boscoe, of "who's evidence?", "Based on whose research questions and methodology?", is the state and others promoting to orient health care

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[90]Following the NFH's recommendations, the federal government has increased funding for health research and innovation by $550 million in the 1999 budget alone. As well, it has introduced a new organization, the Canadian Institutes of Health Research, that will be responsible for coordinating and integrating health research across the country.

reform (7).

In an attempt to clarify the source and nature of evidence-based, clinical information, and at the same time provide an alternative source and nature of such information, the Canadian Women's Health Network (CWHN) was officially launched in 1993 by women representing over 70 organizations across Canada. Funded by the federal government, it is aimed at offering community-based access to research and resources on women's health. Hence, the case of the CWHN illustrates the reflexivity of outcomes assessment and how, in recognizing this reflexivity, alternative forms of EBDM can come about that seek to empower communities and citizens as opposed to controlling costs. That is not to say that the vision of an evidence-based health system advanced by the NFH automatically contradicts the CWHN philosophy. The NFH consistently promotes EBDM as a form of improving health care accountability and public access to outcomes information. What will ultimately determine whether the NFH's vision is empowering to communities and citizens is the type of information provided, its research framework, sources, and the ways in which it is put to use. How the NFH's vision is being implemented in Canada through health information networks, demonstrated in Chapter Four, will clarify whether its impact will be empowering to communities/citizens.

Another critical viewpoint of outcomes assessment that should be kept in mind concerns the impact of public access to evidence-based information on medical practice. The CCHSE reports, in its Health Care Reform Update 1998-99, that physicians have

been the primary consumer of evidence-based information to support their own decision-making. However, the CCHSE predicts that other stakeholders, including patients, will continue to increase their demand for such information. If such a situation does take place, it will threaten professional dominance, as argued by Light and previously brought forth. Instances of the negative impact of EBDM on provider authority are becoming quite prevalent in the US. For example, the MediQual's Atlas Physician Report Card produces an analysis of patient care provided by physicians, comparing it to care provided by their peers. Trends in their practices can be deciphered for up to one year. The Report Card, while intended for personal reference by physicians, is used by hospitals and other forms of health care administration. A second example taking place in Arizona, PCS Health Systems has introduced a Performance Health Program to monitor physicians' prescriptions with the ultimate objective of modifying inappropriate behavior. Lastly, an insurer in Massachusetts creatively linked physicians' malpractice insurance rates and liability to compliance with CPGs through a software program entitled Chartchecker. Adherence to CPGs rose to 95 per cent among emergency physicians who applied the program.

2.3 The Role of Technology

In addressing this last issue, I will conclude this chapter and, thus, bring together some of its main points. The main role of technology in Canadian health care reform is to cultivate EBDM, as illustrated in the three examples cited above. Recalling theory introduced in Chapter Two, technology, in the context of EBDM, is resorted to by the

state to control the flow of ever-proliferating amounts of information to assist the work of the bureaucracy, which is another control mechanism of information flow instituted by the Technopoly. Curiously, even though (medical) technology was a main factor in producing a predisposed market for information, technology is seen as the solution to an oversatiation of this Technopolist market. In other words, there is an ironic twist to the role of technology in Canadian health care that revolves around this idea of using technology as a solution to two main problems created in large part by technology: the overflow of information and increasing costs.

Medical technology has greatly contributed to rising health care costs. Some may argue that this is due to the increasing costs, with inflation and sophistication, of medical technology itself. Others may argue that it stems from the impact of technology on medicine and health care. Now again, opinions will differ as to the nature of this impact. For instance, it is possible that costs have increased because medical technology has improved diagnoses and, thereby, more conditions that require treatment are identified. Or, medical technology has lengthened life expectancies, but, at the same time, generated more demand for more expensive, chronic and long term care. Or, as has been suggested by Swartz, medical technology has reinforced the monopoly of physicians and specialists. Concurrently, the dominance of these professional and hospital structures has been further strengthened by state health care insurance through the fee-for-service mechanism. In part by extending technology-intensive diagnostic and curative services, physicians and specialists have been the most important benefactors of state medical insurance, all the

while impeding equal access to services. Ergo, technology is an intricate player in securing the financial prominence of medical practitioners reached through state health care insurance.

The irony becomes obvious when we look at current health care reform initiatives undertaken by the state. In order to control frenzied increases in health care costs, the state seeks to reform the health care system partly through the implementation of new technology. In other words, technology is positioned so that it can create a new evidence-based health care system. Health care reform, when viewed from this angle, involves the substitution of one technologically-based system for another technologically-based system. Knowing this, the question remains as to what will be the roles of communities and citizens in this new health care system and whether these will be empowering. As we have seen, in the past, the community paradigm in Canadian health care has failed to empower citizens, primarily due to professional monopoly, a lack of information and a lack of power. Referring to Box's analysis, these barriers appear to be common to community/citizen governance across all social sectors. It has been argued that EBDM can threaten professional monopoly and provide citizens' access to information. Therefore, the new evidence-based health system has the potential to resolve two of the three main barriers to community/citizen empowerment in health. What about the lack of power?

When implemented in the seventies, community-based initiatives in Quebec were born out of elitism. Godbout claims that they served as a means of consolidating professional and bureaucratic authority. According to Fulton, Renaud and others, this deployment of community-based initiatives was extended in regionalization where communities act as buffers between professionals and the state. Meanwhile, the position of citizens as passive consumers of iatrogenic medicine is retained in order to reinforce capitalist imperatives. Regionalization, thereby, consists of a centralization of power in the hands of the state. Past and present initiatives in community-based health care are heavily criticized, in large part, because they have adopted administrative rationality (versus public responsiveness) as their preferred approach to community governance, described by Schaechter. Having determined that EBDM is a component of regionalization, it would logically be assumed to be disempowering for communities and citizens when integrated in a disempowering, political and organizational framework. However, this last assumption has not yet been put to the test. In the next chapter, I will address, in greater detail, the role of information and communications technology in health care, known as telehealth, and, more specifically, the role of health information networks in EBDM. In Chapter Five, I will consider whether this technology in health care has the potential to subvert the disempowering effect of past community-based and regionalized health organizations.

CHAPTER FOUR: TELEHEALTH

As previously defined, telehealth is "the use of communications and information technology to deliver health and health care services and information over large and small distances" (Picot, Telehealth Industry 1). Because of the central role played in telehealth development by, what is most commonly referred to as, *information and communications technology (ICT)*, this chapter will first concentrate on improving understanding of ICT by reviewing the main theoretical approaches to the study of ICT[91], by reviewing the last decade of Canadian public policy documents in the domain of ICT, and by examining the most recent extent of community involvement in ICT development.[92] While I have not found a clear definition of ICT in the literature, information technology generally comprises of computer software and hardware, that is, of an electronic, and most often digital, medium that receives, processes, stores or sends data in high speed through programming. Communications technology encompasses *broadcast communications* and *telecommunications*, the former intended for public, and the latter for private,

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[91]This review consists only of a quick survey of the literature in order to mainly contextualize the analytical approach adopted in the dissertation, that is, cultural studies.

[92]In case of any confusion, in the first and second chapters, I addressed histories and critiques of technology that did not distinguish between different types of technics. These were appropriate since they could be applied to the subject of medical technology. The latter, in fact, encompasses several different types of technics, such as medical devices, medical drugs, record-keeping technics, financial/accounting technics, and ICT. Attached to these technics are various sets of practices and knowledges. In this chapter, I will undertake a review of theories that focus on the specific technics, practices, knowledges and implications of information and/or communications technology. Now, some ideas, authors, theoretical arguments and concepts will overlap between the first/second and fourth chapters.

communications. Broadcast media include newspapers, radio and television. At present, telecommunications media available in Canada are copper wire, fibre optic cable, co-axial cable, satellite and microwave (Picot, Telehealth Industry 67). While Picot's definition of telehealth, as well as those of others[93], employs the comprehensive term of "communications technology", most of what are categorized as today's "telehealth applications" solely involve information technology and telecommunications (IT&T)[94], excluding health-related content broadcast on radio or television. For instance, a report on hospital closures televised nationally on the late news would not typically be considered as a telehealth application. However, in the first section of this chapter, theoretical analyses of ICT will be brought forth that relate to the role and impact of broadcast media in order to demonstrate the evolution of these analyses, especially in light of the development and implementation of new technology. The second section of the chapter will describe telehealth in greater detail, providing the scope of its applications, the range of its projects, and the ideology of its public policy. The continuity of approaches to the critique of ICT and of telehealth, as well as of ICT and

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[93]Field defines telemedicine as "the use of electronic information and communications technologies to provide and support health care when distance separates the participants" (1).

[94]In their influential report entitled Towards a Canadian Health Iway, CANARIE Inc. envision economic benefits of technology-enabled health care reform, reaching beyond the health system itself, originating from "the development of the Canadian Information Technology and Telecommunications (IT&T) sector, as part of an emerging 'telehealth' or 'health-IT&T' industry' " (4). As well, NASA defines telemedicine as "the integration of telecommunications technologies, information technologies, human-machine interface technologies, and medical care technologies for the purpose of enhancing healthcare delivery" (qtd. in Rusovick et al 157).

telehealth public policy frameworks, will be demonstrated. As well, the continuity of forms of community/citizen involvement in ICT and in telehealth will be exposed in Chapter Five.

Section 1: A Look at ICT

1.1 Critiques of ICT

Hanno Hardt has found that pragmatism represents the chosen philosophical foundation of American critical communication studies primarily due to the fact that it supports liberalism's drive toward progress and scientific/technological rationality. Hardt elaborates: "In this [philosophical] context, communication research has operated with a functional definition of the individual that emerged from the requirements of a technologically driven society in which cultural attitudes, that is, the potential of literary or historical explanations of social existence, gave way to the demands of industrial growth and technological superiority" (5). According to Hardt, prominent American pragmatists, such as William James, Charles Sanders Peirce, John Dewey and George Herbert Mead, adopted a social-scientific perspective that sought to reconcile morals and science, to promote scientific practice determined through expert deliberations, to clarify the role of ethics in social development, and to ground the practicality of individual thought in a behavioral interpretation of the mind (34). Pragmatist philosophy, in addressing the issue of communication, emphasizes the role of individuals and communities in society, and advocates the establishment of democracy with the support of social science. In other words, pragmatism describes democracy as a communicative

process between communities of experts and the public. The public is believed to lack the knowledge and competence to participate in informed, political decision-making. Pragmatist philosophy further questions the moral implications of individual and community participation in the process of communication, that is, in knowledge acquisition and the use of symbolic power (Hardt 35).

Authors such as Lester Ward, Thorstein Veblen and John Dewey, Hardt recalls, in their attempt to devise an ethical trajectory toward desirable progress, suggested a strong role for the liberal state, mainly to protect civil liberties in the face of increased industrialization. Influenced by these authors, Albion Small, Edward Ross, Robert Park and other founding members of the Chicago School of Sociology, later advocated for radical reform informed by social thought. Park, for instance, envisioned the cultivation of a democratic public through improved communication. Inspired by pragmatism and the Chicago School, during the late nineteenth and early twentieth centuries, communication and media research examined related means to social control and public opinion, an orientation characteristic, according to James Carey, of the transportation view of communication. In considering the works of Ross, William Graham Sumner and Charles H. Cooley, Hardt concludes:

> In the minds of social critics, the Great Community, or the ideal democracy, was populated by individuals whose interests, capabilities and understandings coincided with the essence of the community, while communication [consistently an abstract concept] became the vital, integrating and socializing force in the

> process of democratization and, as such, remained a major concept in social theory and research. (64-65)

In addition, Hardt points out that while critics, such as Walter Lippmann, recognized the political implications of control over communication media, they did not ascertain the historical, cultural and economic character of the communication process.

In the 1940's, while European social theory dealt with the issue of totalitarianism, American social sciences were preoccupied with the effects of modernization and a "mass society" on social organizations and collective behavior. In communication studies, Harold Lasswell introduced the concept of *mass communication* when tackling political implications of media and propaganda. Hardt insists that while communication and media research continued to be influenced by pragmatism and the Chicago School, a shift did take place that substituted concerns with the creation of a democratic community and "enlightened" society with those relating to particular political and economic interests. Talcott Parsons evoked a movement toward structural functionalism that directed the study of the social environment, and its impact on social structures, to serve specific needs or ends. Hardt speculates that "the notion of functional analysis . . . meant that the study of communication, including 'mass' communication, became identified with the search for dependencies or consequences that would challenge or maintain the stability of the social system" (83). Functional analysis consists of a social-scientific, and therefore, quantitative analysis. With regards to communication studies, it prompted the formulation of analytical instruments such as surveys, content analysis, and audience

measurements. Early, important proponents of mass communication research that greatly contributed to its establishment as an independent and recognized field of study are Carl Hovland, Bernard Berelson, Moris Janowitz, Frank Stanton, Paul Lazarsfeld, Lasswell, Wilbur Schramm etc.[95] Of course, the social-scientific perspective of mass communication research has been highly criticized for aligning itself with dominant economic and political systems, for ignoring the historical context of the communication process, for defining communication-related phenomena in technological terms, for legitimating its status by showcasing its empirical, methodological expertise, and for producing essentially *administrative* versus *critical* research (Hardt 112). In other words, mass communication research excelled by reproducing scientific/technological rationality. Robert Merton has gone so far as to suggest that its main intellectual conditions were shaped by "market and military demands" (qtd. in Hardt 114).

During the 1960's, Hardt recognizes that some efforts were made among American social theorists to develop a critical research perspective of communications technology. By revitalizing democratic principles of pragmatism, the cultural critiques of Hugh Dalziel Duncan, C. Wright Mills, Daniel Riesman and Kenneth Burke among others, moved away from a mechanistic view of communication, and instead, concentrated on its socio-symbolic significance. The historical and dramaturgical analyses of Duncan, Burke and Erving Goffman were illustrative of this new and unique

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[95]For a more detailed review, you may consult Theories of Mass Communication by Melvin L. deFleur and Sandra Ball-Rokeach (fifth edition published in 1989).

approach. As well, Mills, Riesman, Herbert Schiller and Dallas Smythe studied the negative, political impact of media on public participation and opinion, effected through its presumed manipulation of information and cultural domination. Faced with the continued threat of totalitarianism, the Frankfurt School and other European theorists argued that a critical approach to the social and economic impact of late industrial capitalism would serve to redefine the democratic society, to support opportunities for achieving freedom, and to propel a movement toward true humanism (Hardt 136). It sought to shift the emphasis of traditional philosophy on science and nature to that of history and culture, and demonstrate the relationship between epistemology and politics. In Chapter Two, I described some arguments on technology advanced by Adorno and Horkheimer, Marcuse and Habermas. Richard Coyne summarizes the main arguments of critical theory that pertain to the analysis of information technology: it marginalizes the ethical; it decontextualizes human experience; it amplifies and promotes domination; it reveals the irrationality of technological rationality.

Although not a member of the Frankfurt School but certainly a critical theorist and neo-Marxist, Ellul argues that ICT clearly demonstrate the extent to which the "technique" acts as an environment, whose main features are its autonomy, unity, universality, totality, automatic growth, causal progression and absence of finality. The "technological bluff" described by Ellul as the "force of circumstances" according to which techniques proliferate, is diffused by the media and communications (The Technological Bluff 18). This force encircles "points of resistance" until they "dissolve"

(Ellul, The Technological Bluff 18). Hence, the force, which consists of a new rationality/scientific ideology and the suppression of moral judgement, is instrumental in social integration. Furthermore, Ellul stresses the ambivalence of technique, that is, technique has an impact on society quite independent from the manner in which it is put to use. He concludes that, because of its ambivalence, technique never brings about any definitive progress; rather, technical development fosters a double play of progress and regress. It reaches a "threshold of reversal" (Ellul, The Technological Bluff 108). For instance, "[t]he computer which might lead to local initiatives," Ellul hypothesizes, "cannot avoid interconnections that inevitably mean centralization" (The Technological Bluff 163). As well, Ellul cautions that new technique is more fragile than in the past due to the increased centralization that it facilitates. The Y2K phenomenon is a case in point. Finally, he concludes that technical ambivalence has caused technique to change from a function of rationality to one of irrationality, from utility to generalized inutility.

Despite American contributions to the critical approach, complemented by influences of the neo-Marxist approach of the Frankfurt School, the socio-scientific perspective continued to dominate North American studies of communications technology until the 1980's. That is, it was not until a second, alternative perspective emerged from British cultural studies that a rising amount of critical communications research was disseminated throughout North America, including journals, published articles and books, and curriculum development. In its beginnings, authors such as Richard Hoggart, Raymond Williams and E. P. Thompson sought to personalize history

and culture, emphasizing their "lived" and subjective dimensions. British cultural studies benefited from the influences of postwar Marxism and the works of other Europeans such as Georg Lukács, Antonio Gramsci, Walter Benjamin and of structuralists, such as Claude Lévi-Strauss and Louis Althusser. Hardt distinguishes two main research interests of British cultural studies that have been pursued in the US: the study of culture as a site appropriate to the analysis of communication and media; the sociopolitical critique of society that primarily questions ideology, power and domination in the context of social communication (195).

The cultural studies approach considers communication as part of culture because, R. Williams indicates, it is "concerned with practice and with the relations between practices" (qtd. in Hardt 181). In stressing the interdependency of the organization of mass culture and that of capitalism, R. Williams called for the theoretical consideration of the means of communication as means of production. In so doing, he established the foundation for a theory of liberation that took into account the complexity of culture and the critical role of universal access to, and participation in, the means of production in the advent of a democratic society. Thereby, he advocated public ownership, decentralization and self-management of media to provide for pluralistic expression. Stuart Hall and John Fiske both revised earlier versions of "mass" audiences as passive, and instead envisioned active audiences, empowered and, therefore, capable of resistance, meaning generation/articulation, and social, political and economic participation. While American communications research of the 1970's also viewed audiences as active, it restricted their

roles to those regarded as functional, that is, as consuming and needs-fulfilling, such as the uses and gratifications theory advanced by Elihu Katz, Jay Blumler and Michael Gurevitch.

According to Hardt, American cultural studies have been influenced by four main sources: pragmatism and progressive historians of the 1970's and 1980's; history and technology studies of Harold Innis and Marshall McLuhan; the anthropological study of culture as a symbolic system conducted by Clifford Geertz; the neo-pragmatism of Richard Rorty. Despite noteworthy efforts by authors such as Lawrence Grossberg, Hardt criticizes American cultural studies for its retention of dominant systems of meanings and values formulated under the auspices of pragmatism and the socio-scientific perspective. Hardt insists that American cultural studies should ground its scholarship on a new radical critique that "overcomes the ideological conditions of the prevailing theory of democracy" (203). For instance, Grossberg examines the ways in which individuals are empowered or de-powered by their access to knowledge of reality offered by the media or other cultural systems. In other words, Grossberg questions how ideas or beliefs of individuals are conditioned by structures of domination established by social institutions such as the media. Hardt distinguishes Grossberg's assessment because of its "real sense of engagement between political practice and theoretical consideration within the public sphere," that reveals, " a qualitatively decisive difference from a system in which the nature and extent of social research depend upon the relationship between academic organizations, economic interests and the political system" (194).

Hardt qualifies Carey as the most prominent representative of American cultural studies. Carey depicts communication ritualistically as a form of conversation among structures, itself being a structure of human action. He sees communication as the process through which a shared culture is created, evolves and is maintained. In conducting a review of approaches adopted by contemporary philosophy and social theory regarding communications technology, Carey finds that these approaches are organized according to their emphasis of three moments in the history of communications: talk, text, and template (20). Carey elaborates: "The construction, reconstruction, or deconstruction of philosophical questions around the image of a conversation, text, or program is one way of looking at hermeneutics, deconstructionism, and structuralism" (20). Carey further suggests that the central debate in communications studies on administrative versus critical research should be substituted by one that contrasts *expressivist* and *objectivist* conceptions of reality. The expressivist tradition, to which he contributes, contemplates cultural history and anthropology in order to account for cultural difference. Carey summarizes the tradition with the following five propositions: (1) language actualizes human consciousness and is not simply an instrument of communication/transmission; (2) technical extensions of language – writing, printing, programming – are means of realization of human consciousness, of self-constitution rather than tools or skills; (3) the mind is an instrument of production of the world, that it renders symbolically, at times, through the material form of technology; (4) the mind not only contributes to the symbolic transformation of nature into culture, but also to the penetration of culture into the natural order; (5) reality is a site of constant struggle

among groups with different sets of purposes and interests (23-24). Carey traces these five propositions to his interpretation of the work of many authors, such as that of Pierre Bourdieu. Bourdieu understands communication/symbolic action/cultural activity, and studies of communications, as the intermingling of structure, action and power, that is, communication and its technology are instruments to think with, instruments to form social relations and construct reality, and instruments to obtain and reinforce power.

Carey also identifies three subtraditions in historical writings on communications technology: the *anthropological*, focussing on the evolution of structures of the mind (e.g. Eric Havelock, Lévi-Strauss, Jack Goody); the *historical*, comparing movements toward various technologies (e.g. McLuhan, Elizabeth Eisenstein); and, the *commonsensical*, concentrating on the exercise of power through communications (e.g. Innis). On a related note, Arthur Kroker wrote of the works of George Grant, McLuhan and Innis that "their competing perspectives on technology represent at once the limits and possibilities of the Canadian mind" (15). It is his contention that Grant's critical perspective of *technological dependency*, Innis's more balanced view of *technological realism* and McLuhan's more optimistic belief in *technological humanism*, "structure the Canadian discourse on technology" (Kroker 17). Briefly, Grant denounces the radical colonization of the modern self occurring at the psychological level. He trusts that transcendence of the technological imperative would entail an awareness of the "intimations of deprival", a rejection of the modern project at the ontological level and the reformation of human identity. Comparatively, Innis pinpoints the bias in communication in its over-emphasis

of either the configuration of time or space at the detriment of the other, an over-emphasis that organizes the centralization of power. On the other hand, McLuhan attempts to decipher the inner structural code of the communicative experience. He depicts the technostructure as an environment that simulates and amplifies the bodily senses and, consequently, colonizes the self at the biological level. The communications researcher, in McLuhan's view, should strive to find a new way of seeing and humanizing technology through "in-depth" participation. He outlines, what Kroker describes as, a medical account of technological evolution, listing symptoms, classifications of pathology, therapeutics etc. While Grant, Innis and McLuhan have often been presented as technological determinists, Kroker prefers the characterization of technological "monists", that is, like Ellul, they position technology as the central paradigm in social history (80).

The cultural studies approach to ICT differs from that of critical theory in several respects. In Designing Information Technology in the Postmodern Age, Coyne claims that the critical position retains the Enlightenment tradition and, in so doing, conceals power relations within its own position and adopts some forms of technological thinking. Coyne, thus, proposes an alternative theory of information technology that corresponds to postmodern theory, formulated within the cultural studies approach. A postmodern theory of information technology, as delineated by Coyne, involves the following shifts: from the concept of domination to that of power, in essence, disassociating power from oppression; from a dialectic to a hermeneutical notion of distanciation using metaphors of

dialogue and play; from causality to community, recognizing the role of norms and expectations of the community in the interpretive situation, abolishing the "objective" position of the researcher and the "neutral" character of technology; and, from consumers as victims to participants as users. In Chapter Two, I quickly reviewed Lyotard's postmodern analysis and its application to the computer.

Also included under the umbrella of the cultural studies approach to ICT are alternative models of society – such as the postindustrial society, the information society, the third wave, the electronic or nuclear age etc. – conceived in order to contextualize changes in the social order that have taken place during the last few decades. In an attempt to define the information society, Charles Steinfeld and Jerry L. Salvaggio undertake a literature review of relevant research perspectives. They categorize five of these perspectives as follows: those focussing on changes in economic structure, the consumption of information, technological infrastructure, and those qualified as critical approaches (e.g. Dallas Smythe) and multidimensional approaches (Daniel Bell, Yoneji Masuda and B. J. Bates). Bell's description of a postindustrial society is summarized in Table 19. Poster cautions that, in displacing critical theory, such alternative models have but substituted one totalizing position for another. Bell, for instance, differentiates the model of a postindustrial society from all previous social formations and, in so doing, integrates all of social history in his comparative scheme. Poster further criticizes Bell's model for its technological determinism – the postindustrial society is the result of the technical innovation of ICT – and its depiction of communication and information in

purely quantitative and economic terms, a conceptual framework borrowed from cybernetic theory.

In considering the wide range of perspectives on ICT[96], Poster concludes the following: "These perspectives all recognize and account for one sort of modification introduced by electronic communications: the exchange of symbols between human beings is now far less subject to constraints of space and time" (Mode of Information 2). However, Poster pays greater tribute to analyses, like Carolyn Marvin's, that acknowledge the main impact of ICT as lying beyond increased technical efficiency. Marvin regards as most important to the evolution of ICT the negotiation of issues relating to social organization or reorganization. She points out that familiar social routines are reorganized by ICT to the extent that they are transformed into "new events" (qtd. in Poster, Mode of Information 5). Concurrently, Poster proposes the concept of the mode of information, described in Chapter Two, to designate the linguistic dimension, or the configuration of language, of the new forms of social interaction brought about by electronic communications. Choosing to ground the mode of information in poststructuralist theory, as opposed to critical theory or alternative models, his preoccupation is less with sites of resistance to domination/power than with the

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[96]Poster relates the essence of the following perspectives on ICT: Marxist (different access according to class), neo-Marxist (support culture industry and hegemonic force of ideology), economist (access determined by laws of the market), Weberian (support power of the bureaucracy), liberal (struggle for power among pluralist factions), technological determinists (favorable progress) (Mode of Information 2).

constitution of the self in cultural experience through structures of communication.[97]

Having briefly reviewed the main theoretical approaches to ICT formulated since the beginning of the century, I would now like to address in greater detail a new conceptual framework of ICT advanced by cultural studies. Virtuality is introduced as a new form of social interaction brought forth by the development and implementation of ICT in which concepts such as reality, identity, experience, community, politics and technology take on meanings and have implications that are currently highly debated in communications research. For the sake of brevity, I will introduce only those concepts tied to virtuality that are pertinent to the study of citizen involvement in telehealth, that is, virtual technology, virtual community, virtual corporeality, and cyberdemocracy.

1.1.1 Virtual Technology

David Holmes insists that virtual technology must first be understood as a context that brings about new corporealities and politics rather than an instrument that supports bodies, communities and organizations in social reality. Poster uses an interesting analogy to communicate this point:

> . . . the Internet is more like a social space than a thing so that its effects are more like those of Germany than those of hammers. The effects of Germany on the people within it is to make them Germans (at least for the most part); the effects

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[97]Poster argues that current ICT have heightened the "representational power of language", its self-referentiality (Mode of Information 12). By being farther removed from the referent, cultural meanings are fragile and problematic. The destabilization of language transpires in the destabilization of the subject as an interpretive being.

> of hammers is not to make people hammers . . . but to force metal spikes into wood. ("Cyberdemocracy" 216)

In other words, the Internet is an environment and not a tool according to Holmes and Poster. Holmes claims that the immersive environments created within cyberspace, or virtual reality, are equivalent to new forms of social integration. These new forms displace or "lift out" the "real" configurations of time and space experienced in day-to-day life, substituting them for "successive levels of 'new nature' for the contemporary individual" (Holmes, "Virtual Politics" 6). Holmes goes even further by stating that virtual technology seriously challenges socio-scientific conceptions of communication and conventional understandings of human behavior, and renders obsolete structuralist/poststructuralist critiques of individuality by actualizing these critiques in practice. Virtual technology has shifted the theoretical debate, according to Holmes, from questions relating to social equality to those concerning the new ontologies of space, time, community and corporeality.

1.1.2 Virtual Community

Holmes identifies three main views of virtual or abstract communities. The first view affirms an interest-based definition of community, that is, individuals – or what Holmes calls a "functional substitute such as a computer identity" – assemble to discuss or pursue common interests ("Virtual Identity" 28). In accordance with this view, ICT acts as an instrument of assembly, rather than a context that gives meaning to the encounter. The second view defines community in geographic terms. Subsequently, virtual technology is perceived as disrupting to communities because it reduces the

number of spontaneous, physical encounters among members of such communities. Holmes criticizes this view for assuming "that identity exists only in the physical world and that individuals are able to use technologies which simulate presence and overcome absence as ways of facilitating the culture of the physical world" ("Virtual Identity" 28). Lastly, the alternative view is the one presented by Holmes and described above, that is, the one that considers virtual technology as a self-contained, self-referential context for social interaction. Here, virtual or abstract communities arise from the need of individuals for "communion, commonality and fraternity" (Holmes, "Virtual Identity" 29).

Holmes differentiates between the influence of broadcast communications and that of interactive communications on communities, as described in Table 20. The main distinction between interactive communications, like the Internet, and broadcast communications, like television, Holmes suggests, is that the Internet propagates the "seductive illusion" that the public or mass audience can participate in the production of media form and content. However, Holmes disagrees with the common assessment of interactive communications as a substitute, or second media age. Instead, he positions interactive communications as a second media layer that is overlaid on broadcast communications. He argues that broadcast communications integrate social organization by facilitating social and cultural solidarity through image identification. At the same time, they are driven to sell products to consumers and commodify consumer consciousness and audience attention spans for advertisers. Paradoxically, Holmes

recognizes that, in fulfilling these functions, broadcast communications transcend geographical borders, while simultaneously, consolidating the nuclear family unit. The lasting impact of broadcast, he intimates, is to reindividuate citizenship and individuality ("Virtual Identity" 34). Holmes's theory is one of technological dependence, that is, individuals are presented the promises of a global landscape while they remain dependent on television to possess the cultural materials with which to acquire a "lifestyle of personal object-meanings" (Holmes, "Virtual Identity" 34). In other words, television has cultivated a postmodern identity, a concept advanced by Gerry Gill, whereby the individual is pressured to participate in globalized consumption and, at the same time, to retreat to his/her private world. Dependence on broadcast communications comes about as a result of the displacement of forms of interactivity experienced in the material world which previously facilitated social and cultural solidarity. Hence, the Internet offers a new commodification of consumer consciousness premised on the reappropriation of displaced levels of community, and concurrently, a re-experiencing of the qualitative aspect of interactivity. Holmes reiterates:

> If broadcast integration provides the socio-spatial as well as the ideological preconditions of virtual communities, the promotion of any such community can only be successful to the extent that the Internet provides what broadcast lacks: connectivity and reciprocity. ("Virtual Identity" 35)

Notwithstanding, the reciprocity that the Internet provides is problematic, Holmes cautions, because it involves very low levels of recognition. That is, an Internet

communication is detached from all meanings except for the one it acquires from its technological reproduction. The meaning of a communication is recognized solely through a fetishism of the technology that reproduces it in a decontextualized form. What Holmes is describing parallels the Mode of Information presented by Poster, rooted in the self-referentiality of language. Holmes akins the fetishistic process to the "sending and receiving of a message in a bottle across the oceans" ("Virtual Identity" 37). Therefore, he contends that the popularity of the Internet is due, in contrast, to the anonymity of authoring and sending a message without a specific destination. He dispels the notion that the Internet primarily serves to reconstitute community, replacing it with the thought that the popularity of the Internet is "the outcome of commodity fetishism" ("Virtual Identity" 38).

Challenging Holmes's counter-argument, Michele Willson observes that the lack of accountability facilitated by anonymity on the Internet has caused some centres of activity on the network to require stable user identification and to establish normative guidelines for participation. Subsequently, she speculates that the main, promoted advantage of virtual technology is the accentuation of choice (152). Nonetheless, she does recognize that only a small percentage of Internet users have been found to actively participate in form and content production while the majority occupy a "voyeuristic or 'viewer' position" (153). One final point, Willson criticizes current analyses of virtual community for neglecting to study virtual relationships among individuals and to ethically consider the Other in virtual reality, instead choosing to focus on the individual

and the impact on/for the individual. Mainstream analyses, she states, objectify the Other as an instrument in the constitution of the self, and fail to acknowledge the importance of the relationship between the self and the Other in the functioning of the community.

1.1.3 Virtual Corporeality

Holmes suggests that cyberspace can be understood in two ways: as an entertainment space of consumption and as an electronic meeting place ("Virtual Politics" 9). However, Cathryn Vasseleu is more interested in a third, more general understanding of cyberspace as a "*medium* of participatory orientation between bodies and objects in different spaces – cyber means to steer" (46). It is this conception of cyberspace that is motivating medicine, the military, the game industry and others, to explore the potential of virtual realities, constructed within cyberspace through devices such as the virtual environment helmet, glove and suit. Vasseleu studies the virtual subjectivity of dis/embodiment that is "fabricated" by these devices. She argues that human consciousness in virtual reality is absorbed by the illusion of a self-contained, rational universe within which it produces its own experience through proprioception.[98] The illusion depends on conformity of the objective world to the subject's evaluation and on the disavowal of the body/consciousness division (i.e. dis/embodiment). The virtual environment suit stretches the limits of corporeal experience to an even greater extent. As Derrick de Kerckhove points out, it reverses human consciousness from being contained inside the body to acting as a skin orienting the body in cyberspace. In

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[98]Proprioception is defined by Vasseleu as " the body's so-called 'internal sense' of its own position, both spatially and in the relation of parts to each other" (51).

addition, dis/embodiment provides an outlet for experience and fantasy without responsibility, accountability or vulnerability, or as simply put by Vasseleu, for a "reality without risk" (56).

Nonetheless, Nicola Green reminds us that virtual realities are embedded in social practices – including inequalities and relations of difference – established in the material world. In fact, in their study of psychological therapy using virtual reality technology, Max M. North, Sarah M. North and Joseph R. Coble position previous life experiences as one of a three-axis taxonomy in the formation of a sense of virtual presence. They state that previous life experience of the participant "represents the existential world (or personal reality) which the participant brings to the virtual environment, in the sense that a person's perception is not merely a reaction to the present sensory environment, but also an interpretation of that environment in light of all the individual's previous experiences" (166). Green is, therefore, correct in rejecting the view of virtual bodies as lying "outside" and, therefore, freed of socio-cultural markings. This view, she confirms, relies on a neutralization of technology, that is, on an understanding of technology as an a-social/cultural/historical component of social organization. It has, of course, been strongly denounced by critical, cultural and feminist theorists.

The feminist critique has, in fact, labelled the promise of virtuality to liberate the body from its physical limitations as a masculinist ideal, one corresponding to a corporeality designed by scientific/technological rationality around the assumption of a

masculine embodiment. As well, Greene has found that " 'generic' digital representations of bodies situated in a field of signs, referents and meanings . . . are formulated in contexts of phallogocentric and Eurocentric representations," and thereby concluded: "Such representations code dominant understandings of bodies" (67).[99] Moreover, Green proposes that the virtual experience provides an ideal forum to explicitly negotiate embodiment since it brings to the surface the construction and simulation of bodies. According to Green, virtual politics consist of tracing back the creation of virtual systems in certain locations, and then, revealing the relations of power and knowledge embedded in such systems.

Similarly, Simon Cooper has raised the issue of whether the virtual subject is empowered. He comes to the conclusion that "VR will only be able to empower the subject if its 'insights' are read reflexively back into the world outside its parameters" (94). Even so, he admits that the utopian fantasies surrounding virtuality are more tied to a wish to escape the fragmentation of the material world through its self-referential environment than to a wish to alter it. And, he never clarifies the "insights" that he alleges virtual reality contributes, but Patricia Wise does. Wise returns to the original definition of the virtual as "not quite there", "not quite real" and "that is so in essence or effect, although not recognized formally, actually, or by strict definition as such; almost

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[99]This function of virtual representation of the body – technical systems act as interpretive vehicles in social experience – corresponds to the second, hermeneutical level of phenomenological human/technology relations identified by Zoë Sofia. Other levels are embodiment relations (technical extensions of organs/senses), alterity relations (technical systems as object-in-themselves with quasi-human properties) and background relations.

absolute" (180). She concludes that, according to this original definition, women have *always been virtual* in modern and postmodern epistemologies and power structures. Significantly, she contends that virtual reality simplifies and amplifies the attainment of domination and mastery by the abolishment of physical restrictions and material consequences. As a result, she urges women to deploy their knowledge and capacity as virtual beings, including their ability to assume multiple identities, literacies and voices, to undertake strategies to express their subjectivities (e.g. Haraway's cyborg manifesto), and to found political, academic or creative affinity groups.

1.1.4 Cyberdemocracy

In looking at the Internet as a potential vehicle of cyberdemocracy, Poster pinpoints two theoretical limitations: the lack of an adequate postmodern theory of politics and the issue of democracy as a modern, political category associated with the project of the Enlightenment ("Cyberdemocracy" 213). The modern theory of politics – that delimits the latter in terms of the left/right spectrum – is thought to be inadequate by Philippe Lacoue-Labarthe and Jean-Luc Nancy because it imposes linear and totalizing historical development, disregarding any discontinuities, contingencies etc., any phenomena that can be discerned only from a non-linear approach. As well, the emancipatory project of the Enlightenment requires, at its base, a pre-historical/pre-social individual identity that is later assumed to be corrupted by externally imposed forms of domination. Hence, the Internet, if used only to distribute political propaganda, such as government websites, or to conduct electronic forums/referendums initiated by the state, will extend exclusionary modern, political systems. Conversely, a postmodern theory of

politics would minimally provide for the constitution of individual identity within the social, and within language. Ernesto Laclau depicts postmodern democracy so that it involves new positions of speech, the empowerment of previously marginalized groups, and the incorporation of new aspects of social life in the political process. According to Poster, the true political significance of the Internet is rooted in its decentralization and dematerialization of communication that enable new forms of dialogue, collective voices and interactivities and new human/technology assemblages to act as potential building blocks for the creation of political groups/associations ("Cyberdemocracy" 220). As well, the decentralization and dematerialization produce a "democratization" of subject constitution and, in so doing, deflate hierarchies of race, gender, class, age and status.[100] While other political inequalities remain[101], Poster affirms that the Internet has brought about cyborg politics centred on the "communicative practice of self-constitution" ("Cyberdemocracy" 224). There are several parallels between Poster's and feminist conceptions of virtual politics. While many authors agree that the Internet enables the construction of new forms of identity, as Feenberg cautions, it remains unclear how these new identities relate back to the material world, and its intrinsic scientific/technological rationality.

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[100]Conversely, as noted in Chapter Two, Poster denounces the constitution of multiple identities of the individual in databases as a new form of biopower.

[101]For instance, Michael R. Ogden argues that the use of the Internet to apply pressure to politicians may cause rushed responses and the "tyranny of the majority". Furthermore, Ogden warns that increased dependence on cyberspace for the proliferation of political discourse will reinforce the domination of information-rich individuals and groups.

1.2 ICT Government Policy Frameworks and Initiatives

Next, I will concentrate on how existing Canadian political institutions are framing the development of ICT. Later in this chapter, I will demonstrate that ICT and health care reform public policy frameworks overlap and, in so doing, have given way to national, provincial and territorial public policies on telehealth development. There are two domains of public policy relevant to ICT: telecommunications and information. Telecommunications policy deals with regulatory issues, standards and international trade issues directing the Canadian and global telecommunications industry. Information policy pertains to the state's interest and the public's rights to information (such as privacy and security), access, intellectual property etc.

In his study of telecommunications public policy in Canada, Robert Babe identifies five myths relating to telecommunications development that he dispels through a critical analysis of the political economy of the telecommunications industry. These myths are technological nationalism, technological dependence, technology and industrial structuring, efficacy of regulation and creative destruction. Babe's critical assessment of each is summarized in Table 21. Briefly, his analysis reveals the importance of government action in shaping the telecommunications industry, its products, services and publics. As Babe clearly resolves:

> This brings us to the heart of the matter: the role of government in structuring and restructuring industries, in propping up and dismantling monopolies, in allowing activities to converge or encouraging them to diverge. In all these roles

> government is not, nor can it be, neutral. . . .Indeed government is in the business of awarding and withdrawing rights and freedoms, of imposing and relaxing duties and obligations. One might say this is its principal duty – setting the framework within which citizens and economic players interact . . . (244-245)

Robin Mansell has also looked at Canadian telecommunications development, outlining two models of development: the ideal and the strategic. The main assumptions underlying each model are listed in Table 22. Succinctly, the ideal or utopian model pertains to the classical economic model whose market premises reiterate the myths identified by Babe. Conversely, the strategic or reality-based model critiques the classical model and recognizes the market realities demonstrated by Babe. For instance, the ideal model is guilty of technological dependence by assuming that technology is the cure for society's ills. That is, it presupposes that new technologies will provide for the natural integration of information and communication services within a permeable, seamless network. In opposition, the strategic model admits that network integration is unlikely and that competition, facilitated by public policy-making, will give way to new inequities in access. Ultimately, the following review of ICT government policy frameworks and initiatives will show that the Canadian state is promoting a mixed model of industrial development.

In accordance with its mandate to regulate ICT – derived from the *Broadcasting Act* of 1991 and the *Telecommunications Act* of 1993[102] – the Canadian Radio-Television and Telecommunications Commission (CRTC) favors competition in the distribution and programming of the information highway as the best means of achieving innovation, efficiency, and economic growth. However, the CRTC does acknowledge, although superficially, the socio-cultural dimensions of the ICT sector. In its May 1995 report entitled Competition and Culture on Canada's Information Highway: Managing the Realities of Transition, the CRTC concludes the following from the opinions, issues and recommendations expressed during a public hearing held from March 6 to 31, 1995:

> The information highway is more than cable and copper wire; it is a metaphor for the promise and uncertainty surrounding the emergence of a world-wide communications network driven by innovation, competition and technology. The highway links past achievements in communications to future aspirations, binds economy and culture in ways that harness the creative energies of Canadians, and opens gateways to global trade in information products and services. (5)

The CRTC has instituted some strategic initiatives in order to benefit access and privacy – the two main conditions to achieve success in the implementation of the information highway identified by the Information Highway Advisory Council (IHAC) –

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[102]Specifically, section 5.(2) of the *Broadcasting Act* states that the Canadian broadcasting system should be regulated in a flexible manner to ensure that it is "readily adaptable to scientific and technological change; [and] does not inhibit the development of information technologies and their application or the delivery of resultant services to Canadians . . ." In section 7.(a) and (f), the *Telecommunications Act* provides for a policy framework "that serves to safeguard, enrich and strengthen the social and economic fabric of Canada and its regions [and] to foster increased reliance on market forces . . ."

complementary to its efforts to offer a competitive model for ICT sector development. Such strategic initiatives include: a September 1994 decision to remove any barriers to the involvement of telephone companies in the content of information services[103], to split the rate bases of the major telephone companies, to monitor their investment in broadband facilities and to control the impact of this investment on basic local rates and on contribution charges[104]; a recommendation for access points to the information highway in each community, supported and subsidized by the federal government; an approval of preferential telecommunications service tariffs for non-profit educational and

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[103]In so doing, it ascertains that it is in the public interest for basic telecommunications and innovative information services to be offered competitively so long as these services be made accessible to all sectors of the public and that the facilities used for these purposes be open to various, potential providers on reasonable terms and conditions. While telephone companies are granted the possibility of service integration and of providing content-based information services, safeguards were initially suggested, such as equivalent access tariffs to prevent unjust discrimination of customers. Previous to this decision, the CRTC had rejected a proposal submitted by NB Tel to offer a Healthnet service consisting of a data communications network designed for the transfer of health information between 49 hospitals across the province. The CRTC rejected the proposal because it involved the introduction of a Special Assembly Tariff while the CRTC's review concluded that Healthnet was a frame relay service and, therefore, a basic service. A preferential tariff for Healthnet customers would, consequently, confer an undue preference to these customers. In the May 1995 report, the CRTC reiterated its belief that structural separation of carriage and content services was not necessary for non-programming services such as health information networks. Furthermore, it recommended an amendment to the *Broadcasting Act* that would redefine broadcasting so as not to include content-based information services for the purposes of not subjecting these services to licensing requirements.

[104]Succinctly, the rate base is split to ensure that rates for local services (the Utility segment) do not carry costs related to investment in competitive services. This regulatory framework clearly establishes that the cost of this investment is the responsibility of shareholders and not of customers. Price regulation was also instituted with price caps that came into effect in January 1998.

health entities (including content-based, telemedicine services), judged as not anti-competitive[105]. Notwithstanding, on May 17, 1999, the CRTC announced its decision not to regulate new media services on the Internet. The CRTC arrived at this decision after concluding that the current state of the Internet, characterized as "vibrant, highly competitive and successful without regulation," is consistent with objectives of the *Broadcasting Act* (Internet 1). More specifically, it looked at the extent to which content on the Internet considered to be broadcasting maintains the cultural integrity of Canadian media.[106]

Consistent with the objectives of CRTC policy, the Information Highway Advisory Council (IHAC)[107] supports the role of the federal government in establishing a

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[105]These preferential tariffs were granted in September 1996 to non-profit educational and health service entities, applying only to competitively provided provincial services. These tariffs must also cover the cost of providing the service.

[106]Briefly, broadcast content on the Internet consists of all content that is not alphanumeric text or "customizable" material (that can be modified by any individual user). The CRTC found that broadcast content on the Internet complemented rather than substituted traditional broadcasting, included significant Canadian content – in part supported by current, national and provincial state initiatives – and offered further incentives for future production and distribution of Canadian content. As well, the CRTC found legislative, regulatory and technical measures presently in place sufficient to deal with offensive and illegal content.

[107]A federal strategy for developing and implementing a Canadian Information Highway was first announced in the January 1994 Speech from the Throne. In the following spring, the Minister of Industry Canada, John Manley, introduced a strategic framework that included the creation of the IHAC. The framework would be guided by five operating principles: an interconnected and interoperable network of networks, collaborative public and private sector development, privacy protection and network security, competition and lifelong learning. It would be directed toward the achievement

clear regulatory framework geared toward fair and sustainable competition. However, it warns that this framework must be constructed strategically in order to safeguard Canada's economic, social and cultural objectives.[108] Furthermore, the Council promotes the effectiveness of ICT in the process of "re-engineering" of the state. It advises that the government act as "a persuasive model user" of ICT (Connection xi). In the Final Report of Phase I published in September 1995, it calls for a national access strategy based on the following four principles: universal affordable and equitable access, consumer choice and diversity of information, competency and citizen participation, and open and interactive networks. As well, it makes several recommendations regarding privacy listed in Table 23.

In response to these recommendations, Industry Canada released in 1998 a discussion paper entitled The Protection of Personal Information: Building Canada's Information Economy and Society. The Coalition for Public Information (CPI)[109], among others, responded quite favorably to the paper. During February and March 1998, the

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of three objectives: creating jobs through innovation and investment, reinforcing Canadian sovereignty and cultural identity, and ensuring universal access at reasonable cost (IHAC, Building the Information Society 4).

[108]In its Final Report of Phase II, released September 9, 1997, the IHAC announces that it no longer deals with the economic, social and cultural dimensions of the information society separately, but instead recognizes their "seamless interdependence" (Preparing for a Digital World 7).

[109]Established in 1993, the Coalition ensures public representation in policy- and decision-making processes relating to the development of the Canadian information highway. The Coalition is represented on the boards of the IHAC, CANARIE Inc., and the National Community Advisory Board of Industry Canada.

Coalition participated in an Online Privacy Forum, along with the Media Awareness Network, the Public Interest Advocacy Centre, the Consumers' Association of Canada, Telecommunities Canada and others. The forum provided an opportunity for citizens to express their opinions regarding the discussion paper.[110] Recommendations emanating from the forum addressed the definition of informed consent, special protection for health information, genetic information and children's personal information, the expressed purpose of the collection of information, the value of privacy as a human right, the registration of information policies of organizations with a government body, the feasibility and effectiveness of the complaints procedures, the privacy impact assessment of new technologies, and the prioritization of public education on privacy (CPI 6-9). Both the participants of the online forum and the Coalition (as communicated in a separate response to the discussion paper) support retention of the "fair information principles" of the Canadian Standards Association or CSA's Model Code for the Protection of Personal Information as the foundation for any new privacy legislation.[111]

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[110]The Coalition reported that 266 people responded to the online survey and more than 60 posts were made on the online discussion group. 52 per cent of participants indicated that they had visited the Media Awareness Network Privacy Pages and, of these participants, 50 per cent believed they had increased their understanding and formulated a different opinion of the issue at hand.

[111]The Code distinguishes ten main principles to be adopted by an organization: (1) accountability; (2) identifying purposes for which personal information is collected; (3) consent of the individual required for the collection, use or disclosure of personal information; (4) limiting the collection of personal information to the purposes outlined; (5) limiting the use, disclosure and retention of personal information; (6) accuracy of personal information; (7) security safeguards; (8) openness, making information on the organization's policies and practices available; (9) individual access to his/her own personal information; (10) challenging compliance.

On October 18, 1998, the federal government passed Bill C-54 establishing a right to privacy for personal information – including medical information – collected, used and disclosed by private organizations for the purpose of commercial activity.[112] The bill's backbone is the CSA's Model Privacy Code. Most crucially, the bill requires that an individual's consent be obtained prior to any collection, use or disclosure of his/her personal information.

In addition to the privacy legislation, a number of strategic actions were undertaken by the federal government following the IHAC's recommendations, including a national access strategy and a framework for action that supports the use of ICT applications and information services in the areas of learning and health. An additional $30 million was allocated to the Community Access Program (CAP) expanding the target number of remote and rural communities from 1500 to 5000 by March 2001. Initially established in 1995, the CAP subsidizes public and informed access to the Internet for remote and rural communities through the founding of community teleservice centres

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[112]That is, the bill does not apply to hospitals, public health clinics or physicians delivering health care services when they are engaged in non-commercial activity. However, the bill does apply to unlicensed workers in community care, such as volunteers, family members, homemaker and meals service providers, emergency workers etc., which can, according to Dr Gordon Atherley, seriously comprise access to, and the quality of, such care. If important information is withheld from community health workers, or, if access to personal information is granted and misused by workers who are not subject to professional standards, consequences harmful to the patient can result.

(CTSCs).[113] The program is currently considered part of the federal government's "connectedness agenda" that has six pillars: Canada Online, Smart Communities, Canadian Content Online, Electronic Commerce, Canadian Governments Online, and Connected Canada to the World. Industry Canada, leader of the agenda, set performance goals tied to each pillar in 1998-1999, outlined in Table 24. Complementary to the CAP, the Smart Communities initiative[114] is a more comprehensive, program-driven version of the CAP in that it seeks to improve access to, but also the quality of, information and services through ICT. By the year 2000, a Smart Communities Demonstration Project involving up to 20 communities across Canada will be implemented upon completion of a phased competitive process. In accordance with recommendations of the Panel on Smart Communities, the initiative will also encompass a Resource Exchange, Facilitation Tool Kit and Skill Development Program (including needs assessment software, business planning software, implementation guidebooks, outreach plans, workshops and

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[113]CTSCs are defined as "multi-purpose centers that provide telecommunications and computer facilities and support in small villages in rural and remote areas around the globe . . .as information gateways into communities; and out to the world . . .as a 'virtual community' . . . initially conceived as a means of maintaining the economic and societal cohesiveness of rural communities in the face of changing economic conditions" (Nunavut Implementation Commission, Nunavut Telecommunication Needs 5).

[114]A "Smart Community" is defined by the Panel on Smart Communities as "a community ranging from a neighbourhood to a nation-wide community of common or shared interest, whose members, organizations and governing institutions are working in partnership to use information and communication technologies to transform their circumstances in significant ways". These transformative powers, the Panel proposes, include the use of ICT "to contribute to the interactivity between information providers and information seekers, creating a human process with the potential to empower all citizens to become decision influencers [vs. decision makers]".

inventories of Smart applications, services, technologies, and vendors), and a Benchmarking and Recognition Program. Finally, telehealth initiatives will no doubt have a significant presence in the Smart Communities program.

The CAP has been denounced by advocates of community networking as "a unilateral, internal and top-down initiative" (Graham and Regan Shade 7). Certainly, this criticism can further be applied to the phased competitive process of the Smart Communities initiative. Moreover, the fact that government organizations insist on referring to "consumers" of information is a source of frustration for community networking activists because it reflects the predominance of the economic dimension in information policy. Correspondingly, Heather Menzies argues that Canadian public policy in the domain of ICT adheres to the transmission model of communication, whereby communication is a means of transportation of static goods (information as commodity) across geographical boundaries. In contrast to the community model, the transmission model, Menzies contends, translates to a bias in communication that institutes favorable conditions for centralized decision-making, global versus local organizations, and homogenized content and participation.

As demonstrated in CRTC and IHAC policy documents, as well as in provincial and territorial public policy frameworks summarized in Appendix B, the general tendency of Canadian public policy in the domain of ICT is to promote competition, while identifying some critical or "privileged" areas where government intervention is deemed

necessary. That is, it favors the adoption of a mixed model of technological development that reflects ideal and strategic market premises and assumptions. Its strategic aspect is rooted in its recognition of the "seamless interdependence" between the economic and sociocultural dimensions of the information highway. It is understood that this sociocultural dimension involves more than content, but also access and privacy. Andrew Avis suggests that recognition by the state of the social implications of ICT represents the advent of a necessary third stage in the understanding of the concept of *public interest* in the history of Canadian communications regulation. While in the first and second stages the public interest was defined in terms of protection of large industry players and in terms of preservation of cultural integrity respectively, "the third stage," according to Avis, "sees laissez-faire governance as the best way to ensure the health of communication systems and that social needs are met" (Ch. 3). In addition, the third stage is characterized by a view of the information highway as "not only a valuable communication service and source of entertainment but . . . also a vital economic utility, a tool for education, and an important conduit for access to government"[115], which requires a more broadened interpretation of the public interest (Avis Ch. 3). In expanding the scope of the information highway, and relatedly, its potential for non-commercial uses and social benefits, public policy organizations are promoting a more comprehensive

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[115]According to Avis, recognition of the sociocultural implications of the information highway is due in large part to the contribution of advocacy groups at the CRTC hearings conducted in March of 1995.

notion of *basic service* as it is applied to service universality.[116] To conclude, a report of the Manitoba Highway Advisory Council concisely depicts the third stage of Canadian communications regulation:

> The Manitoba Government should adopt the position that with respect to the development of the Manitoba Information Highway and the expansion of network infrastructure and services, the best regulation is the least regulation. Regulation should continue only to encourage the interoperability and accessibility of the network of networks, to prevent abuses of market dominance, to encourage new entrants, and to ensure the use of the network for applications serving the public good, such as education and health. (Recommendation No. 18)

1.3 Community Involvement in ICT Development

The main form of community involvement in ICT development is through the establishment of community networks.[117] As seen above, while public policy organizations address the issue of access in terms of communications connection, applications and services, Garth Graham and Leslie Regan Shade point out that

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[116]The CRTC's resolution that content-based information services provided by telephone companies are to be considered basic services is a precursor to this trend.

[117]These networks are following in the footsteps of former community media (radio and television). Anne Beamish identifies four different types: Free-Nets, bulletin boards, government-sponsored networks, and wired cities. Another notable form of involvement are CTSCs. Potentially funded through national/regional/local economic development programs such as the CAP, CTSCs provide access to computer and multimedia services and training at a single location within each community. They can include child care facilities, meeting rooms for videoconferencing, classrooms for training, or a resource library.

community networks provide for a second level of access: "access to the means of participation in the virtualization of social networks" (1). That is, community networks offer access to the Internet understood, like Holmes and Poster, as a new "zone of socialization" (Graham and Shade 1). Graham and Shade determine the critical components of the new zone: a community defined by its geographical location, a community "space" that acts as an "electronic commons", and the citizen as member of the electronic community/public space (1). Hence, Graham and Shade distinguish community networks by the fact that they are not content providers, and rather serve to ensure "universal participation, and access to, electronic public space as a commons,"[118] whereby, ". . . [t]he community itself is the network [and] . . . supplies the content as a byproduct of its communications behaviours in [this] space" (2). Interestingly, a pioneer in community networking, the first of its kind, the Cleveland Freenet was originally an in-hospital help network. While continuing to be active in providing health/medical services, it was then sponsored by Case Western Reserve University, the city of Cleveland, the state of Ohio and IBM until it was discontinued on October 1, 1999.

Graham and Regan Shade identify five shifts in social networks that result from the implementation of ICT: from professional to experiential expertise; from structured to

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[118]Douglas Schuler brings forth three important points to be kept in mind when providing such access: that information and services offered through the network are interesting and useful; that the system is usable by everyone (regardless of literacy and computer literacy, physical impairments, computer aversion, time constraints etc.); that access is made available at low-cost, at several public and private locations and at minimal inconvenience (such as "busy signals").

situational problem-solving strategies; from decentralization of power to disintermediation (the substitution of material and human resources for knowledge); from information as a resource to information as context; from cooperation and competition to interdependence (4-5). Elsewhere, Graham – at the time Director of Research for Telecommunities Canada – is adamant that the "central role of community networks is to sustain participatory social systems" (8). Community networks, he also affirms, offer a means to controlling the impact of ICT on the communities themselves and to proactively manage the transition from an industrial to a knowledge-based society.[119] Community networks act, according to Graham, as a strategy of "engagement" to revitalize communities (3). Similarly, Beamish pinpoints three common goals or expectations of community networks: to strengthen community; to improve democracy; and, to ensure inclusion in the national information infrastructure. She brings forth the work of Jeffrey B. Abramson, F. Christopher Arterton and Gart R. Orren who contend that computer networks can improve three types of democracy: plebiscitary (direct citizen participation through referenda), communitarian (public debates), and pluralistic (access to competing interest groups). However, views of community networks expressed by Beamish and Abramson et al are more instrumental than those of Canadian advocates, as indicated by their suggestion that community networks are simply useful in extending the reach of

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[119]Maureen Cubberley and Stan Skazeswski define a knowledge society in terms of the following characteristics/components: personal empowerment, imagination, interpersonal discussion, informed, active and healthy communities, decreased number of "have-nots", decision-making from a global perspective, local action (25). The authors state: "The basic goal of a knowledge society is to increase the knowledge levels and capabilities of individuals and communities through universal, inclusive communications [;] access to information [; and,] participation" (25).

current, political and social organizations. For instance, Beamish stresses the potential of community networks to reinforce face-to-face encounters among community members. Beamish and Abramson et al also retain modern, political categories. In conclusion, while Graham and Regan Shade offer an alternative view of the Internet as a new form of socialization and promote the role of community networks in sustaining participatory social structures, they do not go as far as Poster in alluding to the political, "cyberdemocratic", contribution of community networks rooted in identity constitution.

Section 2: At last... Telehealth

In this next section, I will finally focus on the main topic of the project: telehealth development in Canada. While Chapter One contextualized telehealth within the history of medical technology, Chapter Two brought forth some critiques of medical technology that included telehealth artifacts (such as computers and the EMR), and Chapter Three contextualized telehealth within the Canadian health care system and its reform, Chapter Four has, as of yet, critiqued the main component of telehealth technics, that is, ICT and its public policy, as well as demonstrated important roles of communities in ICT development. As I demonstrated the continuity between the history of medical technology and telehealth development in Chapter One (the increased distanciation of the physician from his/her patient, the objectification of bodily processes), demonstrated the continuity between critiques of technology, medical technology and telehealth technology in Chapter Two (illustrated with the EMR), I will now demonstrate the continuity between health care reform government initiatives presented in Chapter Three and ICT

government initiatives presented in Chapter Four, and telehealth government initiatives.[120] First, I will begin by reviewing national, provincial and territorial government policy frameworks and initiatives in the area of telehealth. Second, I will review the current state of telehealth development in Canada by succinctly describing the main categories of telehealth applications and bringing forth concrete examples of projects included in each category.

2.1 Telehealth Government Policy Frameworks and Initiatives

It is possible to conclude from reviewing national, provincial and territorial public policy frameworks in the domains of health care reform and ICT that they favor a mixed model of development, ideal and strategic, of the health system and of ICT. In both domains, the policy frameworks endorse fair and sustainable competition in product and service delivery so long as appropriate safeguards are in place to ensure universal access, quality of service, cultural integrity and the respect of individual rights (including privacy). Several common objectives in health care reform and ICT public policy frameworks can also be identified: government re-engineering, universal access, information delivery, service integration, public/private partnerships, community involvement, research and development, cost-effectiveness, and strengthening Canadian

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[120]In Chapter Five, theoretical concepts and frameworks brought forth to critique the Canadian health care system/reform and to critique ICT will be applied to critique the various roles of citizens in telehealth initiatives. Hence, a final continuity will be revealed.

culture and identity[121]. I contend that the overlapping of public sector interests relating to health care reform and ICT is due, in large part, to three phenomena: the "privileged" status allotted to the health sector that calls for, and naturalizes, government intervention; instances that indicate a commonality of expertise within the public sector[122]; and, the common agenda within multiple levels of government to work toward debt reduction and economic growth. As well, I maintain that telehealth public policy frameworks originated in the domains of health care reform and ICT, and reflect their common objectives and models of development.

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[121]A CANARIE report mentions a 1996 poll where Canadians ranked the health system as the top symbol of Canadian nationalism, above the flag, the Parliament and hockey (Telehealth 5). The NFH's Values Working Group reports that, in public consultations, ". . . [Canadians] agreed that the universality of the system helped distinguish Canada from the United States in a way that showed us to be a more generous and compassionate society. Others said that they derived a sense of pride with the quality of the system" (Summary Report). As well, CIHI confirms: "Our universal health insurance system is the centre-piece of the social safety net in Canada, and for many Canadians, is a defining characteristic of the country and a symbol of the nation's values" (1). In the case of ICT policy – reflecting the myth of technological nationalism – telecommunications technologies have historically been used as a means of asserting Canadian sovereignty. It is often argued that the development of telegraph systems across the East and West, North and South Canadian coasts was as much a source of Canadian nationalism as the railway and canals of the nineteenth century. Current public policy documents repeatedly describe the information highway as exemplary of the bridging force of Canadian technology.

[122]Some experts have made significant contributions to background public policy research in both areas of health care reform and the ICT sector, primarily motivated by their interest in telehealth. For example, Dr. Mamoru Watanabe, Professor Emeritus of Medicine, is the former Dean of the Faculty of Medicine at the University of Calgary. He served as a former member of the NFH and the IHAC. He is currently Chair of the CANARIE Board of Directors, member of the Advisory Council on Health Info-Structure, and a member of several other health-related and telehealth-related organizations.

The first step in formulating telehealth public policy was to recognize and promote the role of technology in the health care system, as exemplified in the following excerpt of the Government of Canada's Science and Technology Strategy: "Science and technology (S&T) play a critical role in the health and well-being of Canadians . . ." (1). Published in 1996, the federal S&T strategy proposes a National Health Information Network (NHIN)[123] to respond to the following objectives: improve health service delivery and access to medical expertise in remote communities; assist the flow of research results and information; more effectively manage hospital in-patient services, community and home-based programs; expand public health surveillance capacity and disseminate information on health promotion and disease prevention. The strategy also suggests that a Health Intelligence Network be created to improve national surveillance and disease monitoring. Subsequently, Health Canada's S&T Action Plan, also released in 1996, sets out five strategic objectives: to address critical knowledge gaps focussing on the decision-making process with regards to health promotion, prevention, maintenance and care; to commit to excellence, continuous renewal and cost-effectiveness; to improve competitive health S&T capacity; to build partnerships; and, to mobilize S&T information and IT&T[124]. The plan grants the mandate to Health Canada to provide

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[123]As early as 1991, the National Task Force on Health Information had outlined a broad framework for the development of a national health information infrastructure.

[124]The Action Plan offers a list of projects/information networks in which Health Canada was already involved: the workers' compensation payments/management information system (WHMIS), a national network on adverse drug reaction linking reporting centers to the Health Protection Branch, interactive videodiscs for patient education and decision support funded by the National Health Research and Development Program, the Heart Health Initiative, Health Promotion On-Line, a future National Health Research

practical guidance and to develop applications to improve the dissemination and utilization of "health knowledge". That same year, the Government of Canada's Information Highway Action Plan – outlined in the IHAC Final Report of Phase I – announced the development of a national strategy for an integrated NHIN, to be undertaken by the Minister of Health in cooperation with provincial and territorial governments, other federal departments, the private sector and professional bodies. In addition, the plan projected the introduction by the ministers of Industry and Justice of a proposed legislative framework specifically governing the protection of personal information in the private sector.

In 1995, CANARIE established a Health Information Infrastructure Advisory Committee to elaborate strategies relating to the advancement of a Canadian health information highway. In September 1996, in a report entitled Towards a Canadian Health Iway: Vision, Opportunities and Future Steps, CANARIE acknowledges that "Canada's health system has become a strategic priority for every government in the country and virtually all of the studies of health care reform in Canada have emphasized the critical link between health care reform and the effective use of information technology" (3). While praising the important efforts on the part of provincial governments to integrate

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Information Network, various Bulletin Board Services, the Laboratory Centre for Disease Control's (LCDC) use of Geographic Information Systems and advanced communications technologies, videoconferencing, fax-link and Internet conferencing to disseminate research results and training, involvement in the Pan American Health Information Network and the European Public Health Information Network, an LCDC network linking the health regions, provinces, US Centre for Disease Control and the Pan American Health Organization.

ICT into their health systems, CANARIE advocates a national strategy and framework to create a Canadian Health Iway that would incorporate provincial initiatives and, at the same time, "would also transcend traditional organizational, program and geographic boundaries" (Iway 5). "The Canadian Health Iway," CANARIE proposes, "will be a virtual 'information centre' that is created and used by communities and individuals across Canada. . . .The Network will be an agent of change for the health system and contribute to improving the health of Canadians" (Iway 5). However, CANARIE lists several challenges to the implementation of the Health Iway: the lack of national leadership that has caused a fragmentation of initiatives; the need for a common framework that includes standards and policy/regulation; the need for seamless, user-friendly and open architecture; the need for reliable, up-to-date, health-related information adapted to new technologies; the need for community education and training; and, the need for strategic partnerships occurring at three levels (federal/provincial, public/private, Industry Canada/Health Canada). Pursuing its goal of formulating a national strategy for telehealth development, CANARIE organized a set of workshops, that began in 1997, inviting various stakeholders to discuss the issues of privacy and confidentiality (October 1997), marketing telehealth (February 1998), regionalization (May 1998), interoperability (May 1998), distance learning (November 1998) etc.

As seen in Chapter Three, the NFH's EBDM Working Group supported the launch of a national health information system that would benefit patients, administrators, providers and policy-makers. As well, the group made several recommendations, listed

in Table 25, specifically regarding the proposed legislative framework for the protection of personal information in the private sector. In the federal budget announced in February 1997, the Government of Canada dedicated $300 million over the next three years to respond specifically to the recommendations made by the NFH. The amount of funding included a transition fund of $150 million allocated to the provinces on a per capita basis to initiate pilot projects evaluating health care reform initiatives (including regionalization and the rationalization of services) and exploring new models of care in four focus areas: primary care (including citizen participation), home care, pharma care and integrated services delivery (including telehealth). Decisions on how to allocate the transition fund are made cooperatively by the national and provincial ministers of health. Also as part of the $300 million fund, "[t]he federal government announced a $50 million investment to promote and stimulate the development of a health info-structure in Canada that will support the emergence of an evidence-based decision-making culture" (The Arlington Consulting Group 20). Elsewhere, the Canadian Health Info-structure (CHI) is defined as "an integrated network of networks that will enhance the sharing of health and health-related knowledge, information, and expertise across Canada to help maintain and improve the health of Canadians" (Fortier). The term "health info-structure" encompasses the technological framework, the available information, the governance, management and use of information, as well as the people and organizations involved in creating the information (The Arlington Consulting Group 4-5).

Responsible for the design and implementation of the national infrastructure for the CHI, the Office of Health and the Information Highway (OHIH) of Health Canada, founded in August 1997, envisions three main components to the CHI: the National Health Surveillance Infostructure (NHSI), the Canadian Health Network (CHN) and the First Nations Health Information System (FNHIS). The NHSI involves a series of pilot projects that contribute to the development of Internet-based tools and capacity to support national surveillance for health protection and health promotion.[125] In September 1998, the Federal/Provincial/Territorial Surveillance Integration Design Team published its Discussion Paper on an Integrated National Health Surveillance Network for Canada, bringing together some of the lessons learned from the various pilot projects. At the most recent Conference of the Deputy Ministers of Health, held in June 1999, the proposal for a national surveillance network was endorsed. The second component of the CHI, the CHN, provides public access to health information – information for health promotion, disease prevention, risk management, treatment options and health system performance – through the Internet, a toll-free telephone line, interactive voice response and fax-back capability. Lastly, the FNHIS is described by Health Canada as a "holistic and culturally-relevant First Nations case management tool at the community level, and a surveillance tool at all levels" (Fortier). The main objective of the FNHIS is to standardize data collection in 500 to 600 First Nation communities across Canada. In addition to

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[125]The projects are the Canadian Integrated Public Health System, the Global Public Health Intelligence Network, the Local Public Health Infrastructure Development (LoPHID), the Spatial Public Health INformation eXchange (SPHINX), the Product Related Risk Data Network (ProdNet), the Public Health Intelligence Database and Electronic Standards for the Transmission of Regulatory Information.

developing the three components of the CHI, in March 1998, Health Canada set up a Health Infostructure Support Program to fund pilot projects on a shared-cost contribution basis in the areas of public health, health surveillance, pharmacare, First Nation health, home care and telehealth. Thirty-six projects have so far been undertaken by 33 non-profit NGOs. Descriptions of each project are available on the website of the OHIH (http://www.hc-sc.gc.ca/ohih-bsi/hihsp/comp_award/sucapp_e.html).

According to Health Canada, the concept of the CHI is the result of stakeholder consultations conducted across the country in March 1996. The background paper prepared for the National Conference on Health Info-Structure[126], which was held in Edmonton in February 1998, provides a detailed conceptual overview of the CHI. It lists the following principles to guide the development of the CHI: a health determinants focus, EBDM, a consumer focus (to increase individual responsibility and to facilitate informed choices), professional support, effective service delivery, a private and secure network, national partnerships, coordinated development, leading edge Canadian technology, open architecture and distributed management (accountability). Moreover, the paper determines six critical areas that have the greatest potential for CHI applications development: clinical decision-making; consumer and provider education; policy, management and administration; research and development; wellness/public health/population health; and economic development. Finally, the overview refers to a

[126]The National Conference on Health Info-structure was organized by Health Canada and Alberta Health. It was the second of three national conferences funded by Health Canada. The others focussed on PharmaCare and Home Care.

CHI framework elaborated by the Canadian Institute for Health Information. The framework details the health information needs of each stakeholder of the health system, reproduced in Table 26. It mentions two additional stakeholders that were not considered independently by the NFH's EBDM Working Group: researchers and educators. As well, the framework uses the connotation "client" instead of "patient", "governor" instead of "policy-maker" and "manager" instead of "administrator".

According to the Final Report of the National Conference on Health Info-structure, the majority of delegates were primarily concerned with privacy and confidentiality issues. Other issues relating to the implementation of the CHI were discussed: the role of the private sector (that poses a threat to the public character of health care), the need for quality health information (including the potential for alternative models of health), the development of knowledge and measures (the need to define a set of benchmarks and institutional "report cards"), challenges in implementing telehealth[127] (jurisdictional issues, professional reimbursement, liability, accountability,

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[127]The Council defines the health infostructure as the application of ICT in the health sector in order to allow stakeholders to communicate with each other and to make informed decisions about their own health care and about the health system. Comparatively, the Council defines telehealth as the use of ICT to deliver health information, services and expertise over short and long distances. The difference between the concept of health infostructure and telehealth initially appears to be rooted in the focus of each, the former stressing decision-making and the latter emphasizing service delivery. However, service delivery involves decision-making. Furthermore, both the health infostructure and telehealth play a role in the delivery of health information. In truth, the difference lies in the idea of distance/connection. The health infostructure can account for applications that would not be considered as telehealth, such as the delivery of health information through a computer terminal that is not linked to other terminals (e.g. self-contained databases). For instance, the Institute of Clinical and Evaluative

accreditation, education and funding), and the need to consider information and other requirements of various stakeholders (such as training and economic considerations) (Lee 5-6). Recommendations formulated by delegates were organized according to different themes: issues relating to policy, information management, stakeholders and technology. Recommendations revolving around stakeholder issues, reproduced in Table 26, are noteworthy since they take into account contingencies that were never before acknowledged in a national public policy forum tied to the domain of telehealth, such as the special needs of Aboriginal populations, health inequities in the Canadian health care system, and the importance of public involvement in decision-making and system design.

In August 1997, the federal Health Minister appointed a 24-member Advisory Council on Health Info-structure with the mandate to "consider how information technologies and systems could best support and promote better and more informed decision making by individual Canadians, health professionals, administrators, researchers, planners and policy-makers", and with a focus on a "client-centred health infostructure" (ACHI, Connecting v). Madeline Boscoe, Executive Director of the Canadian Women's Health Network, is the only representative from a consumer interest group appointed to the Council. The Council released its Interim Report in September 1998 requesting public responses to its recommendations. It reaffirmed the key features of the CHI previously delineated and, furthermore, described four values of the CHI

Services, situated in Ontario, has produced a Second Practice Atlas that stores patterns in the activities of patients and professionals on an interactive computer disk.

(respect of the principles of the *Canada Health Act*, privacy, inclusiveness, collective and personal responsibility). It proposed a three-part strategic framework for the CHI that would later be reworked into four strategic goals of the *Canada Health Infoway* presented in the Council's Final Report submitted to the federal Minister of Health on February 3, 1999. The significance of the Final Report should not be underestimated. Following its release, the federal government announced a funding allocation worth $328 million, part of the 1999 Canadian Budget, dedicated to the building of the CHI, in addition to $75 million awarded to the National Health Surveillance Network and the Canada Health Network. In justifying this investment to Canadians in a Health Canada news release dated February 23, 1999, Minister Allan Rock reiterated three of the four strategic objectives of the CHI elaborated by the Council and indicated that the investment is specifically intended to respond to the Council's recommendations.

The four strategic goals identified by the Council for the Canada Health Infoway are: "empowering the public; strengthening and integrating health care services; creating the information resources for accountability and continuous feedback on factors affecting the health of Canadians; and, improving privacy protection within the health sector" (Canada Health Infoway 6). The vision is normative and also, the Council insists, "people-focussed" (Canada Health Infoway 6). By "public", the Council refers to individual Canadians (as patients, informal caregivers, citizens and consumers), health care providers, health researchers, managers and policy-makers. By "community", the Council includes local communities, Aboriginal communities, organizations, and

geographically dispersed communities with a distinct interest. In other words, the Council's vision is inclusive and hopeful that every human entity in reach of the Canadian state will be empowered by the CHI despite other existing socio-economic inequities.

While difficult to believe that such a health-optimizing, virtual utopia could be realized, the Council lays out a convincing strategy that warrants careful examination. Its report should not be dismissed as political rhetoric disguised as myths of technological development. While, at times, some such myths are clearly evident, the report also highlights some critical arguments presented throughout the dissertation. For the sake of brevity, I will concentrate on the Council's recommendations relating to public empowerment through the CHI, reproduced in full in Table 27. For public empowerment to be accomplished, the Council pinpoints three conditions: to provide the public with credible information that will enable informed decision-making; to ensure equitable and affordable access to the infostructure and the distributed information; to provide opportunities for community involvement to increase health system accountability and to contribute to health policy development. Key to public empowerment, the Council suggests, is the issue of privacy.[128] It explains: ". . . empowering the public needs to revolve around protecting the privacy – including the identities – of individuals requesting health information or visiting a website for that purpose" (Canada Health

[128]In addition, the Council asserts the rights of individuals to own their medical records. It recommends that this right, while legally instituted, should be more frequently actualized in practice.

Infoway 2.1). Hence, it appears that the Council recognizes, as does Holmes, that an attractive feature of online communication is its potential for anonymity.

The Council lists many different types of health information to which it agrees the public should have access: health promotion and maintenance information; empirical evaluations of treatment options, drugs, methods of illness management; public health information (air and water quality); report cards on health programs, services and providers; health-related public policies; local directories of health services; assessments of the outcomes of health policies and health determinants (Canada Health Infoway 2.2 - 2.3). The Council goes further than simply citing various forms of health information – the majority of which are related to EBDM. It acknowledges the frustrations expressed amongst the public with the "expertness" of health care, and the need to develop alternative sources of information. It promotes interactive media that offer new forms of socialization, such as chat and news groups, bulletin boards, community networks etc. It tentatively argues that interactive resources like e-mail may improve the physician-patient relationship with the former acting more as "a coach, a consultant or a facilitator than a final authority" (Canada Health Infoway 2.3). It believes in the complementarity of educational initiatives that cultivate skills in the appraisal of health information. These skills, along with access to accurate information, the Council trusts, can assist citizens in their duties as board members of regional or community health agencies, hospitals or other health-related organizations. Hence, the Council is suggesting that the CHI act as a means of strengthening the citizen/community paradigm in the health care system. As

noted in Chapter Three, the main barriers to citizen/community involvement are: professional dominance, the lack of information and the lack of power. The CHI, if it is implemented according to the Council's specifications, can reduce professional dominance by increasing access to health information and cultivating expertise amongst citizen representatives. While the CHI will not directly grant communities or citizens any additional governing power in health care institutions and authorities, it can render communities and citizens more informed, and therefore, more active and effective in the current decision-making process and in their lobby for greater power in the future.

The Council does not presume to homogenize the "public", but instead recognizes that health information needs differ according to condition, background and personal situation.[129] For instance, while an individual may wish to join an online support group, another may be anxious to participate in a health advocacy forum. The Council also makes note of the testimony of many Internet users who complain that health information currently made available is miscellaneous, and therefore, not very useful or applicable to their personal situation. As well, the Council admits that expert opinions differ as to the proper approach to health and health care, comparing, for instance, alternative versus

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[129]In October 1998, the Council's Working Group on Health Information for the General Public organized a workshop with key informants. The Council, along with CIHI and Statistics Canada, participated in identifying health information needs by consulting approximately 500 stakeholders. These interviews produced a Health Information Roadmap released by CIHI in December 1998. Part of the Roadmap's action plan are: stakeholder consultations; standards development; collection of data on health services, outcomes, and health determinants; the Canadian Population Health Initiative; and, public reporting and special studies. On February 16, 1999, the federal government agreed to fund three to four years of the Roadmap program.

conventional medicine. While it responds to the issue of divergent perspectives by recommending the development of standards and rating criteria to generally assess the quality of health information, it does imply that this quality is reflected in "objective, empirically based health information" (Canada Health Infoway 7). To be fair, the Council does underline the need to respect individual preferences for personal testimonials versus controlled clinical trials.

The Council adopts a comprehensive view of access policies that take into account technological infrastructure and social circumstances, such as language, literacy, comfort, age, gender etc. It values the contribution of community networks in offering " 'electronic public spaces' for citizen participation and community development" (Canada Health Infoway 2.9). Similarly, it envisions a Canada Health Space, publicly funded so as to prevent the costs of distributing government information from being shifted to the citizen or health intermediaries (libraries, community centres/associations etc.). Finally, in seeking to fulfill the objective of public input and accountability, it positions the CHI as a strategy of citizen engagement, recalling Graham's view of community networking. Sensitive to the fragmentation and struggles of consumer organizations faced with limited resources and overworked volunteers, it seeks the establishment of an independent office for citizen advocacy. Moreover, it supports the use of evidence-based information obtained from individuals in light of the "fresh perspectives [they contribute] to the traditional policy debates between funders and health care providers" (Canada Health Infoway 2.12). While Renaud, Warner and others would

no doubt insist that the Council, a government-sponsored entity, is intending for consumers to act as buffers between the state and providers, the Council does caution that "it will be crucial that Health Canada proceed sensitively to ensure that the consumer health community can take ownership of the organization [citizen health advocacy office] and feel that it responds to consumer health needs" (Canada Health Infoway 2.13). While I was pleasantly surprised in reading the Council's vision for the CHI, I remain sceptical as to whether it can be implemented as it is, particularly taking into account that it will be subject to the constraints imposed by government bureaucracy. My own experience, while limited, in community-focussed government initiatives has revealed that these initiatives are impeded by process requirements, complex organizational structures, time and funding constraints, that distract from their original design.

Provinces and territories differ in the extent to which they promote telehealth, as illustrated by the review of their policy frameworks and initiatives in Appendix C. The majority are investing in core infrastructure development. With regards to telehealth projects, they are, on average, motivated by the prospect of improving access to health services and continuing professional education in rural and remote communities.[130] However, provincial/territorial development is plagued by the difficulty of producing an

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[130]There are nearly ten times the number of physicians in urban centres compared with rural communities, and thirty times more specialists. In 1993, there was one physician per 476 patients in most of Canada's regions, while at the 65 degree north latitude and above, the ratio climbed to 3,974 patients per one physician. According to figures dated 1994, there are no dermatologists, rehabilitation specialists, anaesthesiologists, pathologists, urologists, or cardiovascular and thoracic specialists in the Yukon or Northwest Territories.

adequate business case for telehealth, in part due to a lack of assessment of its effectiveness and efficiency, and in part due to its many contingencies (technical infrastructure, human resources, medico-legal issues etc.). Even the national Advisory Council on Health Infostructure is forced to admit that "[f]unding for the Canada Health Infoway is not an investment where short-term payoffs provide a sufficient rationale. . . .Investments in health infostructure – and in its essential building blocks at the provincial and territorial levels – must take the long-term view" (Canada Health Infoway 14). As a result, pilot projects abound across Canada but largely remain unsustainable and unevaluated. Successful projects often rely on partnerships with the private sector. The lack of standard evaluation criteria and methodology to assess pilot projects is an important obstacle to further development mentioned by the Council.

Notwithstanding, the CIHI estimates that $2 billion has so far been spent on province-wide health information networks. In March 1998, I conducted a preliminary overview of these networks across Canada, summarized in Table 28.[131] The Arlington Consulting Group ascertains that governments are adopting two major approaches to the development of these networks. In the first approach, the state builds a core, province-wide infrastructure within which various service- and client-based applications are integrated (such as in Alberta, Manitoba, Saskatchewan, New Brunswick, Prince Edward Island, Newfoundland). Provinces/territories adopting the second approach fund regional

[131]Information was obtained from a search of Canadian provincial and territorial government websites and the Canadian Initiatives on Networking Clearing House (part of Industry Canada's Strategis website located at http://strategis.ic.gc.ca).

and local consortia of providers and private sector partners who, in turn, set up local initiatives (such as the Ontario Network Infrastructure Program that supports HealthLink and Health Information Partnerships, and Quebec's Inforoute santé). My own overview demonstrated that most of the provincial/territorial networks incorporate applications that facilitate EBDM for clinical, management and/or research purposes. It revealed that the health care provider is the type of stakeholder most targeted by EBDM applications. I also found that the majority of provinces and territories did not directly involve communities nor citizens in the planning process of health information networks, unless they are represented on the boards of regional or community health authorities and these authorities are invited to participate in the planning process. However, there are noteworthy exceptions: the president of the Alberta Cancer Board is a member of Alberta *Well*net's Senior Reference Committee and planning of HealthLink is guided by Community Advisory Committees.

2.2 Today's Telehealth in Canada

As demonstrated in the review of telehealth government policy frameworks, the government, in investing in pilot projects, small and medium-sized businesses and public/private partnerships, and in promoting the socio-economic benefits of telehealth applications, has greatly stimulated telehealth development in Canada. Aside from government investment[132], Picot points to other factors implicated in its current

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[132]"When government funding is withdrawn, withheld, or directed toward other programs," Picot observes, "the telehealth industry flounders, as it did immediately after the end of the satellite experiments in the early 1980s" ("Telemedicine" 203).

momentum: *at the technical level*, expanding ICT capacity, the convergence of ICT, advancements in wireless technologies and in communications infrastructure and the popularity of the Internet; *at the organizational level*, the proliferation of health and medical information, the reform of health care delivery patterns, rising health care needs of an aging population and the availability of funds for telehealth development ("Telemedicine" 203). Other drivers of telehealth growth are recognized by Picot: the difficulty of providing universal access to high-quality health care services; the scarcity and isolation of health care professionals working in remote communities; and, the hardship of travel, in part due to a harsh climate ("Telemedicine" 200). Her observations are confirmed by the review of provincial and territorial telehealth initiatives that revealed a common incentive was to improve access to health care resources in rural areas. Notably, Picot has innovatively demonstrated how telehealth applications can facilitate health care procedures and respond to health care reform measures in two tables, reproduced in this project as Tables 29 and 30.

While the recent proliferation of telehealth projects are clearly visible to those who work in the field, Picot attempted to show the extent of rising activity over just a two-year period when researching a Sector Competitiveness Framework (SCF) on the Canadian telehealth industry, later published by Industry Canada.[133] She found that, while 17 Canadian projects were discovered in a first search conducted in 1995, in April 1997,

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[133]SCFs consist of studies on growth industries that assist Canadian businesses in seizing market opportunities and understanding policy issues.

a broader search was undertaken and 65 Canadian projects were recognized.[134] The second search also revealed that 20 per cent of the 65 projects were involved in research and that over half of the projects benefited from participation of the private sector. That same year, a survey of Canadian initiatives making use of health information technologies was prepared by the Centre of Health Economics and Policy Analysis for the OHIH. Comparatively, the survey identified only 40 initiatives. It emphasized provincial/territorial initiatives and, therefore, resembles the review conducted in the context of this dissertation. At the moment, 61 projects are listed under the category of "telehealth" in the Canadian Initiatives Networking Clearing House (CINCH). Notwithstanding, many Canadian-born projects of which I am aware are not acknowledged in CINCH. In looking at companies rather than projects, Picot reports the following: in 1996, 6 of 295 suppliers listed in the Buyer's Guide and Directory, published by Telemedicine Today, were Canadian; in June 1997, 300 companies were reported in the SCF to be active in telehealth[135]; in 1998, 254 companies were listed under the keywords "telemedicine" and "telehealth" in the Canadian Company Capabilities (CCC) database on Industry Canada's Strategis website. In September 1999, however, only 196 companies were listed on the CCC database under those keywords.

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[134]During the first search, Internet sites, popular media, literature and interviews with government officials were the main sources of information. The second search expanded the literature review, undertook a greater number of interviews and included information obtained from attendance at various conferences.

[135]An estimated 20 per cent of these were new ventures, having been founded that year.

Despite the recent surge in telehealth activity, many barriers to its further development still remain. *From a technical standpoint*, reliable, turn-key telehealth solutions that comply with common standards and are interoperable with the equipment of other manufacturers, are rare. Technical solutions are lacking in certain applications such as in tele-homecare. As well, many current users of telehealth equipment argue that it should be subject to certification by medical device regulations to ensure quality. *From an industry standpoint*, there is a need for greater marketing of telehealth. The building of a convincing business case is difficult for many reasons, including a lack of knowledge of the telehealth market (domestic and foreign), fragmentation of the industry, and the lack of standard performance measurement mechanisms.[136] *From an organizational standpoint*, the main impediments are the lack of stable funding, the need for partnership models, the lack of common standards (of technics and of information), the need to protect security and privacy, and the need to better respond to human factors.

Field suggests that ". . . telemedicine's successful transition from the demonstration phase into one of wide-spread use depends on better approaches to the human factors in telemedicine" (75). Field distinguishes between human factors of a practical and socio-economic nature. The former category encompasses: problems

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[136]Field points to several obstacles in the evaluation of telehealth applications: rapid advances of ICT (issues of obsolescence), complexity and variability of technical infrastructure (lack of ubiquity and user-friendliness); the adoption of sophisticated and state-of-the-art systems versus practical and sustainable systems; the need for cooperation among various institutions (potential restrictions to the volume of cases and extensive comparisons needed for a credible analysis); and the lack of support for clinical research under cost-containment imperatives (4).

relating to equipment (convenience, reliability, quality, integrity, time invested in training, equipment purchase decisions constrained by grant and other requirements, lack of flexibility with proprietary systems etc.); the difficulty of integrating telemedicine into current practices; and, the inadequate assessment of needs (wish lists versus realistic assessment of priorities and lack of information about complexity of implementation and use). In terms of socio-economic, human factors, Field names professional culture and image (such as current referral procedures), the lack of documented benefits, the issue of remuneration, problems caused by health care reform, and I would add, the need for professional certification in the use of telehealth equipment, liability, licensing and other jurisdictional issues.

It has been frequently argued that an important step in resolving this amalgamation of economic, sociocultural, organizational and political barriers to telehealth development is to produce and distribute a set of best practices recognized throughout the field. This list of best practices would serve to guide new market entrants and innovators and encourage further integration, standardization and interoperability in the field. The benefit of best practices is tied to the idea that they are relevant to all telehealth applications. Picot and Field have both elaborated categories of telehealth applications. Picot's analysis is more comprehensive; she details each type of application and identifies the users of each. Conversely, Field's categories take into account the focus of the applications. Moreover, she only outlines a few examples of each application. While I have reproduced the tables of telehealth applications provided by

both Picot and Field in Tables 31 and 32, I will, from now on, refer only to Picot's categories. In Table 33, I have attempted to describe the state of development of each category of applications in Canada by bringing forth examples of projects in each of these categories, as well as indicating implementation issues specific to each category. Please note, however, that issues relating to roles of citizens in these applications will be discussed in Chapter Five.

This chapter began with a review of the four principal approaches to the critique of ICT: pragmatism, socio-scientific, critical theory and cultural studies. Hardt has shown that throughout the evolution of ICT critique, the socio-scientific perspective has remained dominant in North America. In the introduction to this dissertation, I stated that the dominant form of telehealth research is also socio-scientific. Evaluations of telehealth pilot projects, overviews of the telehealth industry, assessments of the clinical and financial impact of telehealth infrastructures and applications etc., produce administrative versus critical research. While Robert Merton suggested that mass communication research was shaped by "market and military demands", I would similarly argue that telehealth research is currently driven by market and medical demands (qtd. in Hardt 114). For instance, the importance of formulating a compelling business case for telehealth development is repeatedly affirmed in research and in policy. This emphasis on the business case is detrimental to the development of applications that might potentially contribute to community and citizen empowerment. While telehealth offers immediate benefits to the individual that are easily observed (such as improved access to

services), and reduces costs incurred by the individual in attaining services (such as the costs of travel, missed working days, meals etc.), it does increase costs to governments and health care organizations in the short-term. It is for this reason that the Advisory Council on Health Infostructure stresses the need for a long-term vision of investment in telehealth.

The continuity between the dominance of the socio-scientific perspective in critiques on ICT and in telehealth research is not the only point of convergence between the two domains. As previously stated, telehealth public policy frameworks and initiatives are a direct product of the marriage between ICT and health care reform public policy frameworks and initiatives. Telehealth public policy addresses the common objectives of ICT development and health care reform, that is, government re-engineering (the government as a model user), universal access (improved access to rural areas), information delivery and service integration (health information networks), public/private partnerships, community involvement (community access to online health promotion/prevention information and support), research and development (EBDM), cost-effectiveness (rationalizing of administrative services), and cultural integrity (telehealth as a bridge amongst various provincial/territorial health care systems, as a sector for global competitiveness). It also supports a mixed model of development that, while cultivating the competitive advantage of the Canadian telehealth industry for the sake of sustainability, will also ensure the protection of key stakeholders in the health care system (by examining such issues as privacy, liability, training, certification etc.).

My intent in this project has been to diverge from dominant trends in telehealth research and adopt a cultural studies approach. While generally absent in telehealth public policy frameworks, the recent publications of the Advisory Council on Health Infostructure offer some support to this approach. I would venture that the Council's views reflect pragmatist philosophy to the extent that it advocates the involvement of citizens and communities, and the enhancement of the democratic process. It presumes that the "public" presently lacks the knowledge and competence required to undertake informed decision-making in the political, and health, sectors. Notwithstanding, unlike pragmatism, the Council believes that the health infostructure can cultivate public knowledge and competence and reduce the need for "expertness" in health care and policy. Flirting with ideas expressed by R. Williams, Hall and Fiske, the Council claims to support decentralization and self-management of some components of the health infostructure in order to provide for pluralistic expression, and thereby, fulfilment of health information needs. As well, it rejects the concept of passive consumers and instead favors active, empowered audiences capable of social, political and economic participation. And so, it is possible to conclude that the Council adheres to the approach of American cultural studies, as described by Hardt, an approach that retains dominant systems of meanings and values under the auspices of pragmatism and the socio-scientific perspective. The Council envisions that information exchange, undertaken through technical means, will achieve public empowerment. Hence, it is guilty of technological dependence since empowerment appears to rely mainly on access to the infostructure. Moreover, the Council also stresses the need for objective, empirically-based information,

such as report cards and benchmarks for assessing quality, and the skills necessary to properly appreciate this information. In so doing, it promotes the cultivation of scientific and technological rationality among citizens. It does not discern, like Grossberg, that ideas/beliefs of individuals are inevitably affected by structures of domination established by social institutions, such as, in this case, medical and administrative structures established by the state. Furthermore, the Council does not question how the health infostructure will influence the self-constitution of the individual, how he/she will experience new forms of social integration and interaction. The Council is solely concerned by social equality versus new ontologies of space, time, community and corporeality. According to Poster, the potential of the latter is where true democracy in cyberspace lies.

Having demonstrated the continuity between critiques of, and public policy frameworks relating to, ICT and those of telehealth, I have also indicated that forms of community involvement existing in the context of ICT development, that is, in community networking, are extended to the field of telehealth. This extension, as I have pointed out, is supported by the Council. However, citizens occupy several roles in telehealth initiatives, roles that I will seek to decipher in the next chapter. I have already established that citizens are rarely involved in the development of telehealth initiatives and projects, except in some national stakeholder consultations. After having identified these roles, an analysis of their implications will ascertain whether or not they can be considered as empowering.

CHAPTER FIVE: THE ROLES OF CITIZENS IN TELEHEALTH

Preamble: Why "citizen"

Raisa Deber elucidates how the nomenclature used to describe people who receive health care reflects the capitalist nature of the health system. According to Deber, "The terminology of client, customer, consumer implies that medical services are commodities which should be managed in a market" (NFH, Summary Report). In Table 34, she clearly explains the root of these designations, demonstrating the passive, powerless characterization of the individual that they imply. She does the same for the term "patient" which she reminds us comes from the Latin word "to suffer".

The goal of this chapter is to determine what roles individuals – who have no professional stake in the health system unlike health care providers, researchers, administrators, educators, technicians – play with regards to telehealth, and whether these roles have the potential of empowering these individuals.[137] Hence, it is important to not designate these individuals with terms that, Deber argues, are disempowering from the start. Terms that connote passivity and powerlessness in the health system, if used by this author, would inevitably signal a bias in the analysis. Conversely, the argument could be convincingly made that the use of terms other than those raised by Deber would not be true to the actual situation of the lay persons in the health system, prior to their involvement in telehealth. Any discussion of such involvement should work within the

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[137]I will later clarify my understanding of the concept of empowerment.

confines of the current health system. While I agree with the need to reflect the social reality of lay persons in the analysis, the problem remains of what to do if a telehealth application is found to be potentially empowering. Do I then switch from the term "consumer" to the term "citizen". I feel that I could not talk about "consumer empowerment" since it is an oxymoron, although it is commonly referred to by consumer groups, such as the Cochrane Collaboration's Consumer Network. These groups claim that they have broadened the meaning of the term to describe those who use, and are affected by, or who are entitled or compelled to use services (Bastian 10).

Having obviously struggled with this issue, I have chosen to employ the term "citizen" throughout this chapter simply because of its political connotation, a term that, generically speaking, also implies a passive position of the individual, this time, in the context of the state.[138] Of course, the term "citizen" is unfortunately exclusive to the extent that it does not designate all residents in a country. While I acknowledge this discrepancy, I have, nevertheless, chosen to employ the term. If "consumer", "client" and "customer" are indicative of an economic reality, and "patient" recalls a medical relationship, then "citizen" entails a political context. Chapter Five, after all, is an analysis of the political implications of telehealth technology. Politics in this chapter is used in the sense of the process of asserting power in leadership, the means of obtaining control in governance, the ways of possessing a voice and a capacity in participation,

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[138]In Webster's Encyclopedic Unabridged Dictionary, the term "citizen" is defined as "a native or naturalized member of a state or nation who owes allegiance to its government and is entitled to its protection . . ." (270).

rather than in the sense of the procedures of national or provincial/territorial governments. The political stakes can range from control/power/participation in the *medical* (in the physician-patient relationship, in health care institutions, in personal health management), in the *institutional* (in health care public policy-making, in community-based health care governance, management and delivery) and in the *technical* (in design, use and implementation of the technology).

I will decipher the political implications of telehealth by first identifying the roles in which citizens are positioned by telehealth technology. My observations will be supported by reported experiences in current applications and projects. I will categorize these roles according to the impact of telehealth technology on social reality. It is my contention that the impact of telehealth varies when it is used as an instrument of extension that facilitates or re-engineers current processes/practices of existing institutions, from when it is used as a means to innovation that creates new processes/practices and changes the underlying values, roles and actions of existing institutions. As previously brought forth, Poster suggests that the effects of the Internet are more like those of a social space (such as Germany) than those of a thing (like a hammer). Similarly, I argue that telehealth is both used as a *thing* so that its effects are perhaps reform, re-engineering, efficiency, cost-effectiveness, timely access to care etc.[139], and as a *new environment*, its effects perhaps being social change, participation and

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[139]Here, telehealth is deployed as an instrument, a view consistent with that of technological rationality according to how it is defined by Marcuse (discussed in Chapter Two).

empowerment. Hence, I contend that telehealth applications and projects differ in the roles in which they position citizens in accordance with their use of telehealth either as a thing or as a new environment.

I attribute two roles of citizens to telehealth applications and projects that make use of telehealth as a thing: *the citizen as a recipient of telemedical services* and *the citizen as an object of research*. In the first role, the citizen receives health care services at a distance through ICT. Here, telehealth extends current health care delivery mechanisms of clinics, hospitals, nursing stations etc. In the second role, the citizen's use of health care services and his/her health status is monitored through networked computerized databases. Subject to privacy regulations, the personal health information is then exchanged, compiled and analyzed through ICT systems in order to improve the decision-making processes of existing health care institutions with regards to resource allocation, financing and the effectiveness of care. The ultimate goal of this form of administrative and clinical research is to build an evidence-based health system in Canada. Comparatively, two roles can be attributed to telehealth applications and projects that consider telehealth as a new environment for health care: *the citizen as information-seeker* and *the citizen as interactor*. In the first role, the citizen accesses health care information through the Internet or other forms of ICT. He/She may seek to improve his/her ability to make informed decisions about his/her personal, family and community health. In the second role, the citizen interacts with other citizens, one-on-one or in groups, through ICT. He/She may be doing so in order to obtain or provide

support, voice his/her opinions regarding health-related matters, or participate in health care planning or policy-making. These last two roles correspond to the vision of public empowerment promoted by the Advisory Council on Health Info-structure.

While the first part of this chapter will involve a discussion of the political implications of each of these roles, the second part will consider how to achieve citizen empowerment though telehealth, whether this is presently accomplished in telehealth applications and projects or not. Alternative theoretical frameworks will be concisely described that can contribute to developing new technology in such a way that it can prompt social change and citizen empowerment. They will include *alternative technological models*, *alternative health/medical models* and *alternative citizen/community participation and governance models*. These frameworks are put forward as theoretical starting points to evaluating the political implications of telehealth applications and projects in Canada and, if it were found that none such applications and projects currently contribute to citizen empowerment, then they can serve as a guide to attaining this in the future.

Section 1: Roles of Citizens in Telehealth

Joshua Meyrowitz posits that social roles are partly determined by social situations and that the latter are generally related to a physical location. In addition, he contends that the logic of behaviors exhibited by social actors in a particular situation are, to a certain extent, the result of patterns of information flow. It follows that electronic

media, in influencing these patterns and weakening the relationship between social situations and physical places, have strongly impacted social roles. Of course, as Meyrowitz concludes, the greatest impact has been on social groups, previously isolated, whose roles are tied to specific locations, such as a hospital or clinic. As well, social hierarchies established by inequitable patterns of information flow, formed in a print society, have been significantly affected according to Meyrowitz. While Meyrowitz himself admits that his thinking is somewhat deterministic, he characterizes electronic media as an "instrument of demystification"[140] (309), offering new opportunities for horizontal information exchange and the moderate reversal of some disciplinary practices, a counter-process he remarks was not considered by Foucault. Meyrowitz goes so far as to suggest that electronic media have incited a trend toward social integration of all previously segregated and homogenized groups, and foster "the potential of the closest thing the earth has ever witnessed to participatory democracy on an enormous scale" (323). Postman, having also stressed the impact of new technology on information flow in his theory of the Technopoly, similarly discusses power struggles prompted by technological development:

> Surrounding every technology are institutions whose organization – not to mention their reason for being – reflects the worldview promoted by the technology. Therefore, when an old technology is assaulted by a new one, institutions are threatened. (18)

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[140] "Many formal reciprocal roles," Meyrowitz explains, "rely on lack of intimate knowledge of the 'other.' If the mystery and mystification disappear, so do the formal behaviors" (309).

Following arguments advanced by Meyrowitz and Postman, telehealth, in changing patterns of information flow, could be accused of threatening the dominance of Western medical expertise, or even bureaucratic public health insurance programs and policies.

Tom Ferguson has done just that in presenting a new Information Age of health care. Essentially, my interpretation of T. Ferguson's main hypothesis is as follows: computers will empower consumers to actively practice self-care and, while he recalls that the self-care movement originated in the 1970's, self-care will now become the central, organizing paradigm of health care in the Information Age. Computers will accomplish this amazing feat by developing the field of consumer health informatics. T. Ferguson reminds us that, in the Industrial Age of medicine, "[t]he whole realm of lay medicine was literally left off the map. Healthcare providers have habitually overlooked (and often actively discouraged the use of) the biggest health resource of all: people's ability as informed layfolk and experienced self-helpers to prevent and manage their own health problems" (T. Ferguson, "Consumer" 30). From being seen as problems to being regarded as resources, consumer health informatics, T. Ferguson projects, will supply consumers with the knowledge and skills necessary to take on the role of primary care provider, a change equivalent to "the toppling of the 'Berlin Wall' " in medicine ("Consumer" 30).

Ronald J. Christie and C. Barry Hoffmaster review how this "Berlin Wall" has presented itself in various forms of the physician-patient relationship. The aftermath of

the Wall's downfall has given way to alternative models of this relationship. They bring forth three models of the physician-patient relationship formulated by Szasz and Hollender: the *activity-passivity model* applicable when the patient is inanimate; the *guidance-cooperation model* applicable in acute care when the patient seeks help from, and therefore accepts the authority of, the physician; the *mutual participation model* applicable when both parties are equal. This equality, Szasz and Hollender claim, is more appropriate when the physician and the patient benefit from similar intellectual and life experiences. They also hint that the guidance-cooperation model is, for good reason, the most commonly applied in medicine. Christie and Hoffmaster criticize Szasz and Hollender's taxonomy because they attempt to disguise its normative foundation, paradoxically tying the appriopriateness of each model to vague situational contingencies, while, at the same time, favoring the mutual participation model only in cases where the patient is judged to possess equal knowledge and experience, and even suggesting that patients' preference for this model may be rooted in an attempt to overcompensate for their fear of passivity and powerlessness.

In contrast, Robert Veatch's models of the physician-patient relationship, as pointed out by Christie and Hoffmaster, are clearly based on the normative issue of with whom the decision-making power *ought* to lie. These models are: the *engineering model* where the physician is hired to act on value-free decisions made by the patient; the *priestly model* where the physician is authorized to make moral decisions on behalf of patients; the *collegial model* where the physician and patient esteem each other as

colleagues working toward the common goal of preserving the health of the patient; the *contractual model* where both parties agree, in an informal covenant, to certain obligations and benefits in the spirit of mutual trust. The latter model, which Veatch favors over all others and praises for its universal applicability, is the only model in which both parties share decision-making, ethical authority and responsibility. While Veatch specifies that the covenant will solely be founded on the patient's moral values, Christie and Hoffmaster still accuse Veatch's model of generalizing professional expertise, whereby technical knowledge spills over into moral advice. Veatch himself had denounced the fallacy of this generalization in the case of the priestly model.

Notwithstanding, T. Ferguson proposes a model similar to Veatch's contractual model as the one cultivated in the Information Age of health care. In T. Ferguson's view, self-care, legitimated as the central organizing paradigm of health care, implies that consumers go in search of resources as they need them, including the services of physicians. Physicians are retained in the various roles of facilitators, partners or authorities depending on how consumers assess their present need. In all cases, the physician is a consultant to the consumer, his/her responsibilities and level of authority being directed by the consumer. Physician and consumer are involved in a "joint process of *clinical negotiation*," according to T. Ferguson ("Patient" 11). The Advisory Council on Health Infostructure proposes that the CHI would serve to implement exactly this new model of the physician-patient relationship, whereby, the physician acts more as "a coach, a consultant or a facilitator than a final authority" (Canada Health Infoway 2.3). T.

Ferguson outlines an Information Age map of health care to be contrasted from the Industrial Age's three facets of health care (tertiary, secondary and primary). The Information Age map is comprised of 6 resources: individual self-care, friends and family (for advice, information and support), self-help groups and networks, health professionals as facilitators (for consultations), as partners (for regular contacts during chronic or acute problems), and as authorities (in emergency situations).

If we follow T. Ferguson's model, it is impossible not to conclude that telehealth, by enabling consumers to access "expert" information flows, weakens past authority structures in medicine and engenders a complete reversal of former medical disciplinary practices, as predicted by Meyrowitz. However, Joan Anderson does not accept this line of reasoning uncritically. In looking at academic and policy discussions addressing the movement toward health promotion, instigated by health care reform, she notes two divergent viewpoints described below:

> on the one hand the structural barriers to equality are recognized, and empowerment is the outcome of more egalitarian structures that permit disenfranchised voices to be listened to; on the other, though structural barriers are recognized, the focus is on enabling the individual to take greater control of his or her life by mobilizing resources, and the notion of empowerment becomes seamlessly interwoven into the discourse on personal responsibility and self-care, minimizing, it would seem, the demands of illness that might impinge on people's ability to solve their own problems and meet their own needs (699).

I agree with Anderson that, the second orientation, the one clearly sustained by T. Ferguson, corresponds to the notion of empowerment advocated by health care reform. I would also distinguish, for the sake of clarity, the first understanding as *collective empowerment*, and the second as *selective, in the sense of prejudiced, empowerment.* Wrought with individualistic assumptions, selective empowerment puts aside the reality of sociostructural inequities, created by institutional practices, and the physical and psychological barriers imposed by the personal experience of illness (perhaps to be dealt with later in an undetermined time frame). Hence, Anderson reasons that the self-care movement, in support of selective empowerment, privileges the already privileged, not only the literate, information- and technologically-rich – those inequities could be resolved to some extent by state support for universal access (the solution proposed by the Advisory Council on Health Infostructure) – but also the cultural and linguistic majority, those with flexible time, work and family commitments, and the higher socioeconomic classes. Anderson does agree with T. Ferguson that there is a need for fluidity in the physician-patient relationship to allow for accommodation of the patient's needs in a particular situation, at a particular age. However, unlike T. Ferguson, she maintains that "the interactions between health care providers and patients cannot be isolated from the bureaucratic organizations within which they take place, and the institutional constraints that are a reality of life; time schedules must be adhered to, and dwindling resources must be kept in mind . . ." (703). Anderson, therefore, comes to the conclusion that restructuring of health care services in favor of self-care and greater consumer involvement in decision-making should not be perceived as (collective)

empowerment, but rather as resource allocation and cost-containment measures. "The real concern," Anderson elaborates, "is that the politicizing of 'empowerment' could provide the rationale for 'off loading' of responsibilities to people who have been made vulnerable through illness, who have few resources, and who are least able to assume the responsibilities that the empowerment movement suggests" (703).

So, what are the implications of Anderson's analysis for the study of citizen involvement in telehealth? Simply put, telehealth cannot be seen to be collectively empowering if it does not address the sociostructural inequities and psychological and physical barriers related to the personal experience of illness. The individual transfer of "expert" skills and knowledge to citizens satisfies only selective empowerment. Earlier in this project, I suggested that perhaps the generalization of professional, medical expertise might help citizens to be more effective as decision-makers within the context of current institutional power structures, and as lobbyers to gain more direct power over the allocation, distribution and use of health care resources in the future. However, as appropriately pointed out by Anderson, "[a]lthough governments have been encouraging greater consumer participation in health care decision-making, those who participate, like those who are in positions of authority in the health care system, are usually privileged men and women" (703). In other words, the "expertization" of citizens in health-related matters will be restricted to those already privileged by sociostructural inequities, and, while it might enable them to obtain more power, they will continue to be "empowered" at the detriment of others.

Taking all these observations made by Meyrowitz, Postman, Christie and Hoffmaster, T. Ferguson and Anderson into account, I will now analyze the roles of citizens in telehealth with respect to the notions of selective and collective empowerment. Correspondingly, in an extensive study assessing the impact of health telematics in Europe, largely prepared by The Tavistock Institute, health telematics were evaluated in terms of their contribution to a devolved model of health care[141], implying a shift to managed self-care. The Tavistock Institute hypothesizes on how health telematics could actualize self-care:

> The notion of 'managed self-care' . . . envisages greater public access to medical information; more opportunities for managed self-care and home-based service provision; reducing the effect of the "inverse care law" – unequal access to health resources – by improving service provision in "deprived" areas such as inner cities and rural areas; closer and more accurate monitoring of community health through "point of care" information systems supplying national epidemiological and other data. (2.2.iii)

The European study never clearly pronounces whether or not the devolved model is achieved through health telematics. Nevertheless, it lists the main consequences of the implementation of health telematics, only one of which could vaguely provide for some devolution of power: the "engineering of new institutional arrangements promoting

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[141]This model is described in the study as community-led health care structures characterized by a shift from a medical emphasis to one on health and telehealth, a movement toward preventive care, long-term care, outpatient and self-managed care, and the erosion of traditional authority (The Tavistock Institute 2.2.iii).

structural changes in healthcare provision" (The Tavistock Institute 4.3.1).[142]

1.1 Citizen as Recipient of Telemedical Services[143]

Bronzino, Smith and Wade postulate that today's health care systems are plagued by a crisis that is independent of costs, a *crisis of dehumanization*. Dehumanization in modern medicine is experienced in three main ways by patients, according to Bronzino, Smith and Wade: patients are treated as things and machines; patients are reduced to the disease element; patients sense an indifference on the part of providers, a lack of empathy, warmth and compassion. For this reason, they warn that "[t]his widespread sense of dehumanization constitutes a crisis because it poses a threat to the health of many individuals. Precisely because they find modern medical care dehumanizing, many individuals are avoiding entry into the health care system until their illnesses are acute . . . or they are ignoring the advice of their physicians, or . . . they are turning to the unproved, and sometimes proved harmful, methods offered by so-called holistic medicine" (534). This dehumanization, Bronzino, Smith and Wade add, is worsened by technology. In fact, they identify the integration of technology by medical specialities and the

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[142]Other main impacts are: stimulated diffusion and adoption of information technology in traditionally resistant domains; new forms of financial arrangements; strategic service integration; a national communications infrastructure intended to decentralize health care (through decision support systems, regionalized health care records, hospital information systems, and community health and patient monitoring systems) and to standardize technologies, protocols and patient classification systems (The Tavistock Institute 4.3.1).

[143]Here, telemedical services refer to services rendered by all forms of medicine-at-a-distance (the first category identified by Picot), in addition to services delivered by telecare, telemonitoring, remote home care etc. (Picot's second category).

technological imperative – that defines high-quality medicine in terms of technologically-intensive medicine – as two of five sources of dehumanization in modern medicine, the others being scientific rationality, medical specialization, and the mechanistic conception of the body. The solution proposed by Bronzino, Smith and Wade, is to "reintroduce warmth, and human contact" into the provider-patient relationship (546). As a first step, they suggest that medicine learn from the humanities and social sciences to fully grasp the social, psychological and spiritual dimensions of care.

Similarly, Christie and Hoffmaster affirm the therapeutic dimension of the physician-patient relationship, that is, its ability to improve the quality of care. They argue that the physician-patient relationship is key to effective diagnosis and treatment, suggesting like Reiser, that physicians should foster its improvement, for example, by practising nursing technics. Moreover, they contend that a more personalized relationship can be cultivated in private practice than is possible in the hospital. Notably, teleconsultations, relying on access to specialist services, reinforce the position of hospitals and tertiary care centres, increasing the amount of contact that a patient will have with these institutions across his/her lifetime.

In Chapter One, I quoted Reiser who states that technics influence the physician-patient relationship, the physician's image of himself/herself as a decision-maker, the association of physicians amongst themselves, and the organization of medical institutions. Reiser further suspects that new technology will not permit physicians to

spend more time with their patients, but instead will move attention away from human factors related to illness and will estrange the physician from his/her patient and his/her personal judgement. Reiser advises, as a counter-measure, the decentralization of medical practice. Generally, it can be assumed that the dehumanization of medicine will be perpetuated by the delivery of telemedical services. The delivery of these services extends the reach of iatrogenic medicine: it further distances the physician from the patient through technological mediation, reduces the amount of face-to-face contact between the physician and the patient, and depends even more on objective, medical images and data since physical contact is impossible. Hence, on this basis and in this role, it can be concluded that citizens will not be selectively nor collectively empowered by telehealth.

Notwithstanding, citizens' access to home-based medical services is improved through telecare/remote home care. As well, access to medical services in "deprived areas", such as rural and remote areas, is increased. The Tavistock Institute and other contributors to the European study argue that access is, in and of itself, empowering. This assumption is debatable. It is founded on the idea that access to medical services increases an individual's *normal opportunity range*. Norman Daniels defines the latter as "the array of life plans reasonable persons in [a given society] are likely to construct for themselves" (qtd. in Bronzino, Smith and Wade 555). Individuals who are ill, and therefore impaired, cannot access the normal range of opportunity allotted to other

unimpaired citizens.[144] However, some researchers, such as Illich, believe that modern medicine inflicts harm on patients with the intent of curing them, a phenomenon which Illich calls clinical iatrogenesis. Illich attributes the reduction in morbidity to improvements in public health (sanitation, agriculture etc.) and not to medical discovery. He also uncovers that socio-economic conditions generate an environment that is detrimental to health regardless of available medical services. And even Daniels admits that the normal opportunity range is strongly impeded by the underdevelopment or misdevelopment of knowledge and skills due to sociostructural inequities, leading Bronzino, Smith and Wade to conclude that: "[w]hatever equitable access to medical technologies may mean, it does not mean absolute protection against illness, impairment, and premature death" (557).

Moreover, projects that are directed toward improving access to telemedical services are most often faced with bureaucratic and professional constraints. As a result, they are forced to extend the procedures and structures of existing health care institutions. As already mentioned, the authority of tertiary care centres is further centralized and reinforced through telemedicine. These centres are now in a position to broker their specialist services to whomever they wish, beyond jurisdictional borders. They must increase their strategic leverage in the field to effectively compete against other centres in

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[144]The concept of normal opportunity range is reflected in the accessibility criterion of the *Canada Health Act*, whether access is defined as the use of, or opportunity to use, needed health care services, and taking into account that equity of access is understood as "equal access for equal need," as noted in Chapter Three.

the same province. Still, the possibility to develop alternative models for health care delivery remains. For instance, First Nation communities across Canada are interested in the prospects of telehealth since many are located in rural and remote areas. They are also keen on looking into alternative health care practices, especially in the areas of mental health and community health promotion. While they are currently spread out over long distances, making collective organization a difficult task, telehealth could assist them in setting up, for instance, First Nation mental health and health promotion centres whose services could be dispensed at a distance to communities throughout Canada and beyond.[145] Indeed, I would consider such an application to be collectively empowering.

1.2 Citizen as an Object of Research

In Chapter Three, I made the point that whether the NFH's vision of an evidence-based health care system – whose main objectives are to improve health care accountability and public access to outcomes – would be collectively empowering to Canadians would depend on the type of information provided, the research framework adopted, the sources of information and the ways in which the information is put to use.

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[145]For example, the National Native American AIDS Prevention Centre, located in California, operates the Native Care: HIV/AIDS Integrated Services Network, a collaboration between several Native American organizations. The network establishes contractual relationship with local service providers to ensure access to services by Native Americans infected with HIV. The network also offers Native-specific resources, emphasizing spirituality, traditional healing, and cultural awareness. Network sites coordinate cultural awareness training to service providers. All participants in the network implement the Ahalaya Case Management model to create culturally responsive HIV-case management services and HIV education directed at local communities. While the Centre does not yet offer its services electronically, it represents a case where telemedical service delivery could collectively empower the Native American population.

The dominant research framework, adopted by health care systems including HINs, is a quantitative, scientific and empirical design. Reflecting a bias toward scientific/technological rationality, this type of data gathering and analysis generally disregards more subjective evaluations of patients' and providers' experiences. It is worth noting, as done by Field and Davies and Ware, that the rising popularity of effectiveness research has introduced a new source of information and prompted consideration of the value of citizens' assessment of the quality of care. In addition, efforts such as the Consumer Network of the Cochrane Collaboration are attempting to introduce citizen involvement in research design and the evaluation of research results.[146] This network is against the quantification of the values of individuals, in QALYs and other forms. In her proposal to form the network, Hilda Bastian states: "Values cannot be measured with a ruler, and the pain of peoples' struggles with ill-health should not be homogenised till it is no longer recognisable" (5). Bastian calls for the production of research information that is important to consumers, that meets their individual and collective needs. An important struggle for the network's members has been to participate in systematic reviews as advisors while, at the same time, question the

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[146]A priority of the network is to prepare materials addressed to consumers and community groups explaining the Collaboration, RCTs, and the process of systematic reviews. The basic goals of the network are to foster an environment with the Collaboration which allows for consumer input and to promote the participation of consumer groups in the Collaboration's systematic reviews of the impact of health care (Bastian 17). Its main activities are to bring together interested individuals, produce and distribute consumer-directed information; liaise between consumer representatives and the Collaboration; develop the skills of critical appraisal amongst consumers; conduct, coordinate and encourage reviews and research related to consumers' interactions with health care systems and their participation in research (Bastian 17).

appropriateness of quantitative and scientific methodology. Bastian claims that consumers in their roles as advisors should not be expected to justify this methodology and conform to the Collaboration's preferred approach to medical evidence. The network, of course, strongly supports research conducted by consumer groups themselves, a trend that is rapidly growing with network support. While the backbone of the network is ICT, members of the network cannot simply rely on electronic communication since this would exclude too many consumer groups around the world who do not have access to the technology. I would definitely label the Consumer Network a collectively empowering telehealth initiative in evidence-based medical research since its ultimate goal is to protect the interests of consumers in medical research and advance the development and use of alternative research frameworks, all the while remaining sensitive to sociostructural inequities (technological access, but also, language, literacy etc.).

As previously mentioned in Chapter Three, Weber identifies two main categories that orient the ways in which evidence-based information is used in the health system: outcomes research whose goal is to assess the impact of health care on patients for the development of clinical practice guidelines (CPGs), and outcomes management geared toward improving health care accountability. Outcomes research would generally not be thought of as collectively empowering since it preserves and reinforces the dominant, iatrogenic medical model, except, of course, for initiatives related to citizen involvement like the Consumer Network that can potentially alter this model. However, there are

other exceptions such as Chartchecker, initially presented in Chapter Three, whereby physicians' malpractice insurance rates are set by compliance with CPGs. Outcomes management can be deemed collectively empowering when it involves performance measurement and monitoring of providers using health information systems or databases which connect patient and/or clinical records, especially if these measurements are made available to citizens. MediQual's Atlas Physician Report Card, PCS's Performance Health program, PCS's Quantum Alert drug utilization review program and Chartchecker are such examples profiled in Chapter Three. Notwithstanding, the monitoring of providers' performance can only be characterized as empowering if it also encourages the development of alternative models of care, rather than substituting providers with unsatisfactory performances with others indoctrinated in the same dominant medical practice.

In addition, the production and use of the Electronic Medical Record (EMR) – the core of many HINs – is problematic. As seen in Chapter Two, Berg and Bowker assert that the EMR is constitutive of three main dimensions of medical organization: institutional, work practice and the processes of professionalization. Most significantly, the EMR is a legal document that establishes the physician as the core decision-maker. Moreover, it provides for the rationalization of the patient's history and the deductive processes of diagnosis and therapy. It reproduces the body politic of the medical clinic in several ways (its temporal structure, division of labor, geography and hierarchical design). In requiring the standardization of data, it reinforces the scientific operation of medicine.

In other words, it controls the flow of patient information through abstract models that delimit the experiences of patients. Berg and Bowker go so far as to conclude that the EMR reconfigures the material body itself, not just its representation. In fact, the EMR produces a cyborg body through a process of communication engineering (i.e. by structuring a network of medical practices), resulting from the interplay between the material body and its representation.

Also troubling, outcomes management can serve to monitor the performance of patients in the health system. More specifically, Prognosys's MakeTrax is a tool that synchronically produces clinical profiles and assessments of patients' progress toward certain goals. Data on patients' medications, diagnostic tests, therapies etc. can enable health care providers and institutions "to know what milestones the patient is expected to achieve so we can help them work toward these milestones and traverse the continuum more quickly," according to Del Joiner, director of the program (Sandrick, "Waiting" 33). Initiatives such as MakeTrax enforce the patient's compliance to an imposed medical regimen by constantly monitoring him or her, a clear example of the Superpanopticon. In addition, it also strives to reduce the amount of services utilized by a patient – by pressuring the patient to comply with medical regimens and by monitoring him/her, more than by improving his/her health – an obvious cost-cutting measure.

While citizens are inevitably objectified in outcomes research and outcomes management simply by the fact that their personal information and experiences are

operationalized in aggregated data (such as in the EMR), research networks like POPULIS, nevertheless, offer a hidden opportunity for collective empowerment. Through a measure known as the Socio-Economic Risk Index (SERI) developed by the Manitoba Centre for Health Policy and Evaluation, POPULIS can determine where health care resources should be allocated, that is, where they are most needed. This is done by tying the socio-economic situation of individuals to their health status and revealing important social discrepancies. In so doing, POPULIS provides continuously mounting support for the notion that sociostructural inequities are responsible for ill-health. R. J. Currie, speaking on behalf of the Centre, views POPULIS as the ultimate means to direct health care providers to concentrate on the societal causes of poor health, rather than further perfecting current medical practices.

Returning to the NFH's vision for an evidence-based health system, I will examine whether the provincial/territorial HINs currently implemented in Canada fulfill this vision in a way that is collectively empowering to citizens. As indicated in Chapter Four, with the intent to facilitate cost-cutting and rationalization processes of health care reform, the majority of these networks produce evidence-based information for clinical, management or research purposes. These networks most often target the health care provider in EBDM applications.[147] Finally, the majority of provinces and territories did not directly involve citizens and community groups in the planning process of HINs,

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[147]This observation is supported by the CCHSE, as demonstrated in the following: "Thus far, it is primarily physicians wanting up-to-date information to support better decisions [that] have used evidence-based decision-making" (Health Reform Update 1998-99 9).

aside from their possible representation through regionalized health authorities. In Chapter Three, I also determined that regionalization facilitates the centralization of power by the state primarily because it involves little, if any, devolution of power in funding allocation to communities and citizens. Taking into account all these factors, I conclude that, unless new initiatives are integrated, the majority of provincial/territorial health information networks do not constitute a form of collective empowerment of citizens.

1.3 Citizen as Information-Seeker

In the area of consumer health information, the *lifestyle approach* consists of "educating" patients to comply with a certain regimented set of behaviors (Bang et al 104). Prescription tools can be used to further this approach, such as Info Script, an experimental project started in 1996 by the Father Sean O'Sullivan Research Centre, located in Ontario. Through Info Script, physicians can direct patients to access information at a Community Health Information/Family Resource Centre.[148] It is easy to see how such tools could be extended to health information on the Internet. Karen Sandrick argues that the key to ensuring proper use of health information displayed on the Internet is physician involvement. She promotes the use of electronic patient education tools, such as Pediatric Advisor, a computer patient education program accessible in the

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[148]A study of the project conducted by Bang et al demonstrated that the majority of participants indicated the health care provider as their main source of health information. In addition, 59 per cent visited the Centre because of Info Script and 53 per cent thought they would not have come without it.

waiting and exam rooms on a PC that can be customized to fit the physician's personal style (versus the patient's). The software identifies benchmarks of normal child development and prints out instructional sheets for patients, known to the patients as "homework sheets" (Sandrick, "Teach" 17). Dr Michael A. Gilchrist, an avid user of the program, shows how easy compliance can be: "Many [parents] put them on the refrigerator door and check off items as the child accomplishes them" (Sandrick, "Teach" 17). Another example intended for a more general audience is the PatientEd clinical software tool. The tool offers customized documents to the patient that detail the reason for his/her visit, his/her entire care plan chosen by the physician (medications, home treatments, safety measures etc.)[149], and a list of external, "appropriate" sources of information. A last example, provided by Sandrick, is a CD-ROM named the A.D.A.M. Interactive Anatomy used by massage therapists to demonstrate to their patients where the ailment lies and how they can participate in the healing process. Arthur Madore, a massage therapist working in Massachusetts, characterizes it as "an instant credibility creator" for the profession (Sandrick, "Teach" 17).

The health information tools depicted above, while used by citizens, are designed strictly with the health care provider in mind. They are customized to the providers' ways of functioning, in order to increase patients' compliance to his/her prescriptions and to rationalize his/her business practices. The provider directs the citizen to use health

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[149]The physician chooses amongst hundreds of disease-specific guidelines called EduCare Templates.

information resources, which is obviously not a form of selective nor collective empowerment. Conversely, Deborah R. Dakins has recently reported in Telehealth Magazine that "[w]ith an estimated 60 million patients annually turning to the Internet instead of a family doctor for healthcare information, physicians increasingly are going online themselves – whether they want to or not". Moreover, an Internet Survey of Medicine, conducted since 1996, revealed that 90 per cent of physicians who responded to the survey admitted that patient enthusiasm for the Internet is affecting the way they practice (Dakins). Dr. Edward Fotsch, vice president of member organizations for Healtheon, the California-based company who released the survey, confronted with these results concludes: "In this context, 'impact' is not a positive thing. It means that physicians are being challenged, both in the way they practice and in the way healthcare information is being given to their patients" (Dakins). As a counter-measure, 50 per cent of physicians responded that they have set up their own website or are planning to do so in 1999. Physicians' instincts may be right; another survey conducted in 1997 by a research and consulting firm in New York, found that 77 per cent of patients would prefer to access online health information supplied by their own physicians, such as through e-mail, than other generic sources (Dakins).

These surveys reflect a movement in *consumer health informatics*[150] from the lifestyle approach to shared decision-making and self-management of care. As previously

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[150]Consumer health informatics are defined by T. Ferguson as "the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers" (qtd. in US Congress 24).

described, the central organizing paradigm of the Information Age of health care, as it is presented by T. Ferguson, is the self-management of care, or simply put, *self-care*. Important components of the Information Age of health care identified by T. Ferguson include the self-care computer, health care hypermedia and the patient-centered hospital. Health care hypermedia will enable individuals to "extract exactly the information they want" (T. Ferguson, "Patient" 13). Bill Gates, who is involved in the health care technology market, has a similar vision. He forecasts that digital convergence will reduce all information presently used by citizens to their lowest common denominator (1's and 0's), allowing it to be stored and accessed on demand by citizens on small personal devices that they conveniently carry with them. For the moment, shared decision support systems take the shape of, for instance, an interactive videodisk developed by the Dartmouth Medical School to assist patients with benign prostatic hyperplasia and the early stage of prostrate cancer to participate in decisions made regarding their course of treatment. In addition to these systems, consumer health informatics can incorporate tools in demand management, that is, tools that help patients understand the options offered to them and risks and benefits implied in each of those options. The Office of Technology Assessment of the US Congress, based on opinions expressed by Donald M. Vickery, suggests that ". . . these comprehensive [demand management] services will allow consumers to understand, choose, and evaluate health services in new ways, and could have a positive impact on health care costs and quality" (24). While perhaps true, the problem remains that knowledge communicated by these tools is restricted to health services currently made available by existing institutions who espouse the dominant

medical model of care. To clearly illustrate, interactive websites are set up in the US to enable members of health care plans to "log in" and review their benefits, claims, treatment options etc., or even physicians credentials.

The dilemma of whether or not self-care can be considered empowering, even if only selectively empowering, has been debated in social theory by Anthony Giddens and Foucault, among others. In his theory of self-identity in modernity, Giddens hypothesizes that the relationship of individuals to expert systems, such as medicine, is based on trust. He recognizes that, because of the specialization and fragmentation of knowledge and the extension of expert systems to every facet of life (such as family, community, education and health), individuals must increasingly depend on these systems to accomplish their daily functions. However, he notes that expert systems as modern institutions, while ubiquitous in society, are also reflexive which means that they are subject to constant revision and conflicting interpretations. Subsequently, Giddens characterizes modernity as a period of radical doubt; he proclaims that it signals the end of the certainty of knowledge.

According to a study conducted by the New England Journal of Medicine and quoted by Martin Hewitt, the total number of visits to alternative providers (425 million) exceeded the number of visits to all US primary care physicians (388 million) in 1990. The increased popularity of alternative therapies – which has come about in tandem with health care reform efforts promoting health promotion – can be interpreted in various

ways. For his part, Giddens posits that the movement toward self-therapy is indicative, not only of the reflexivity of expert systems such as medicine, but also of each individual's own reflexivity. Giddens depicts self-therapy as a "dialogue with time", a "corrective intervention into the past" (72). In other words, for him, self-therapy involves a reappropriation by the individual of existential notions, such as time, and a revaluation of such notions in a positive way.[151] Consequently, it is a way to restore unity of the self, previously fragmented by the exclusion of such notions from social life. According to Giddens, self-therapy extends to the body and not only to the mind. It does so by positioning the body as a mode of praxis fundamental to the development of self-identity. Giddens further illustrates how guides to self-therapy consider the monitoring of the body's general state of health as an important part of life-planning. In books such as Vernon Coleman's Bodysense, an individual is taught how to "read" and "listen" to his/her body in order to develop the proper means to health care. In doing so, self-therapy will reach its ultimate goal of "body power", defined by Giddens as "the increased capability to avoid serious illness and the capacity to deal with minor symptoms without drugs" (102). Giddens claims that self-therapy – and the vehicles which help to promote it (publications, alternative providers, seminars, natural food stores etc.) – can lead to different reactions to expert systems: empowerment (when expert information is available to the lay person), fatalism (when a decision is abandoned if there is no expert knowledge

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[151]Giddens asserts that existential notions, such as those of time and space, that followed a natural progression for the individual in traditional societies, have become standardized, universalized, separated from an individual's natural rhythms and from his/her personal experiences.

to support it), tradition (signalling the reflexive project's return of the repressed), and pragmatism (when expert knowledge is reappropriated in more useful ways for the lay person).

To conclude, Giddens advances the concept of *life politics* as a consequence of late modernity's reflexive order and the self's absorption in its own reflexivity. He proposes that life politics bring about emancipation from the rigidity of tradition and the oppressive conditions of modern hierarchies and other forms of domination. Freedom in life politics takes the shape of choices in lifestyle and generative power (an individual's transformative capacity). Giddens explains:

> Life politics concerns political issues which flow from processes of self-actualisation in post-traditional contexts, where globalising influences intrude deeply into the reflexive project of the self, and conversely where processes of self-realisation influence global strategies. (214)

Briefly, Giddens views ways of self-actualization, such as self-therapy, as a technic of emancipation from pre-modern structures and acknowledges the possibility of empowerment through citizen access to information developed by expert systems. Correspondingly, Rick M. Rusovick, David J. Warner and David C. Balch do not underestimate the power of citizen access to medical information. They contend that "patients' knowledge is moving so far out of the realm of conventional medicine that the medical community cannot avoid having to come to terms with a transcultural multiplicity of viewpoints on what constitutes health in the first place, let alone the

methods for dealing with its aberrations" (157). Moreover, they declare that the use of multimedia communications "will fundamentally change medicine and its socially grounded culture of disease recognition and healing" (158). In the spirit of revolution, they propose the Distributed Medical Intelligence model understood as a theory for the integration of medical communication systems aimed at supplying expert medical knowledges, and their ancillary supports, to multiple points of need in real time (158). Its main components are a point of need care portal, a point of expertise docking station and an optimizing interconnector or bridge. The bridge, Rusovik et al speculate, could, after having assimilated cumulative expert knowledges, become a meta-expert or intelligent synthesis engine.

In contrast, Foucault views self-therapy as a product of bio-politics, enforced by social policy, institutionalized, professionalized, and specialized knowledge, the sequestration of experience (such as illness), and the construction of appropriate public spaces (such as hospitals). Social policy, for instance, is perceived by Foucault as a technic of intervention that prescribes a series of rights to each individual to normalise his/her needs, wishes and "spaces" for action, such as the right to life, to the body, to health services etc. Foucault identifies two main mechanisms used to constitute bio-power: disciplines (like self-therapy) and regulatory controls. Similarly, Georgia Guldan strongly criticizes the notion of empowerment presented in health promotion documents:

> The model used is still that of the health education approach devoted to training people in the 'appropriate' ways of thinking and doing but with little emphasis on

> enhancing the opportunities for collective action born of conflict and tensions between subcultures. The medical establishment's health promotion priorities are professionally medically defined with "community participation" being used to describe what often amounted more to community manipulation. (694)

Even if one agrees with the vision of self-therapy presented by T. Ferguson and Giddens, or supports Rusovick et al's efforts to create a culture of "medical cybernauts" (160), or even the consumer-focussed vision of the CHI, the form of empowerment generated by these initiatives is confined to selective empowerment. It is significant to realize that discrepancies exist in the use of publicly accessible expert knowledge, delivered electronically or not, by different social classes, cultural groups, age groups etc. A study on the effectiveness of TELMED – a nationally distributed health information system in the US begun in 1972 – uncovered that 59 per cent of individuals earning $15,000 or more, and 20 per cent of those earning less than $5,000 or with some high school education, were informed about TELMED, compared to 73 per cent of those with graduate school education (Bang et al 106). A study conducted by the US Cancer Information Service reported that callers to the service tended to be older, white and better educated than the average population (Bang et al 106). Callers to an arthritis telecare service were most often found to be older, white, female and high school graduates (Bang et al 106). In their review of literature on health information-seeking behaviors, M. Deering and J. Harris have concluded that income and education highly

influence how health information is consumed by individuals.[152] Thus, consumer health informatics and telematics, in addition to telecare services, will need to address these sociostructural inequities before they can be valued as collectively empowering.

1.4 Citizen as Interactor

In their roles as interactors, citizens encounter many of the same issues as they do in their roles as information-seekers. They are positioned by electronic networks in such a way as to extend and reinforce current systems of health care delivery. For instance, a research team at George Mason University created HealthWorld, portrayed by Linda M. Harris and Catherine M. Crawford as follows:

> an experimental program [that] uses simulation technologies – some originally developed for defence purposes – to create a shared synthetic space in which people can learn health promotion practices alone or in teams. Individuals experience virtual counselling sessions, engage in vicarious experiments with alternative lifestyle decisions, and gain healthcare knowledge during virtual tours of the human body. (31)

HealthWorld consists of a, perhaps frightening, virtual environment to promote patient compliance to prescribed forms of self-care. Meanwhile, Edward J. Madara, Director of

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[152]Deering and Harris estimate that the "Health Poor" have greater health risks, are twice as likely to avoid treatment, are five times more likely to use home treatments and two or three times more likely to be suspicious of medical professionals (Bang et al 111). Furthermore, they are less likely to look for health information, half as likely to read it, and experience twice as many problems initially finding the health information (Bang et al 111).

the American Self-Help Clearinghouse, defends the effectiveness of online support groups as a cost-cutting measure. In presenting his case, Madara identifies four ways through which cost savings can be realized: by reducing stress (which can favorably impact health); by preventing health problems from reaching the point where they require professional treatment; by supplementing or shortening treatment; by providing follow-ups and ensuring support after hospitalization. Likewise, an evaluation of the Comprehensive Health Enhancement Support System (CHESS)[153] revealed that participants infected with HIV/AIDS reduced their medical bills by 30 per cent and shortened their hospital stays (Cowley).

Another issue common to the roles of citizens as information-seekers and interactors is the impact of sociostructural inequities on the use of electronic health care and health information delivery systems. T. Ferguson clearly indicates this when he raises the question "Who are the best candidates for such online [support] groups?", and answers as follows: "People who are computer-savvy, people who are already connected to the Internet or one of the commercial services, and people who are information workers," however he also adds, "[o]nline groups also appeal to people who have trouble

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[153]Operated by the universities of Wisconsin and Indiana, CHESS offers the following services: anonymous consultation with peers, expert referral, peer support/sharing of experiences, research and information, risk assessment and decision support tools. It has six main topics: breast cancer, AIDS/HIV infection, sexual assault, substance abuse, stress, and my favorite, academic crisis. Information made available on each of these topics is produced only after extensive needs assessments are conducted (through surveys, focus groups, interviews). The CHESS has nine components: Q&As, Instant Library, Getting Help/Support, Personal Stories, Expert Mail (anonymous), Discussion Group (anonymous), Decision Aid, Action Plan, Assessments.

attending face-to-face meetings because they have a rare disease, or have physical limitations or time constraints that make it difficult to travel to local self-help groups" ("Consumer" 30). Without a doubt, the anonymity offered by network services, such as CHESS, makes possible the assembly of individuals, such as victims of sexual assault, that would not necessarily come together in face-to-face meetings. However, some participants in online support groups have admitted that the experience cannot compensate for face-to-face contact when feasible.[154] They insist that such groups should be regarded as an enrichment rather than a replacement, further suggesting that these groups extend current health care delivery patterns rather than significantly alter them. In other words, while some people believe that virtual communities fulfill the need of individuals for "communion, commonality and fraternity," Holmes has cautioned that they, in truth, isolate individuals in their homes, and more specifically, in front of their workstations ("Virtual Identity" 29). While I certainly agree that access to information and peer support can be very helpful, and perhaps even empowering to these individuals or groups, the exclusion of other individuals, such as those with restricted access to the technology, limited reading ability, language barriers etc., impedes its potential for collective empowerment unless programs are especially in place to help marginalized groups to overcome these barriers.

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[154]Participants attempt to compensate for the lack of physical contact by introjecting in the text symbolic nods, grins or hugs through punctuation marks. A virtual hug, for example, is accomplished by typing a person's name and framing it with parentheses.

Certainly well aware of sociostructural inequities, and of the need to move away from existing health care delivery patterns in order to resolve them, Boscoe of the Canadian Women's Health Network debates the appropriate vision for the network: "Are we trying to increase patient compliance with medical directives or are we creating a tool that will enhance critical thinking, competency and empowerment" (7). Evidently, Boscoe is contrasting the view of electronic communications as a new zone of socialization versus the instrumental view. The key to achieving the former and avoiding the latter, Boscoe claims, is *interaction*, that is, "to create opportunities to come together to learn from each other; to gain new information but then to debate and discuss these ideas if this new information is to be integrated and acted upon" (7). Boscoe also specifies that interaction should involve multiple stakeholders in an atmosphere of mutual respect. Howard Rheingold suggests that health problems often act as catalysts to draw people together in communities through the deployment of community networks. Madara recalls the benefits of general, that is not necessarily technological, networking for health care:

> Networking has often been the first activity leading to an early identification of new or growing health/social problems, the organization of actual mutual aid self-help groups, and the development of more formal health and social service organization. The seeds of many longstanding health foundations, societies, and agencies dealing with various health and social problems have generally first taken the form of mutual aid and self-help groups or networks. (qtd. in Schuler 161-162)

The American Self-Help Clearinghouse, in which Madara is involved, organized several online conferences for people suffering from Ehlers Danios Syndrome (EDS). The conference resulted in the establishment of a national EDS organization whose efforts to rally awareness and support have led to the incidence of EDS now being quoted as one per 5,000, compared to the previous quote of one per 750,000. At times, networking can, not only provide the foundation to develop health and social organizations, but also challenge those already in place. For instance, Liz Moore, a 75-year-old resident of Denver, Colorado, set up her own website listing "Ten Commandments for HMOs" (referring to health management organizations), and questions to be asked by citizens to HMOs prior to enrolling in their managed care plans. Her efforts, and the tremendous popularity of her website, rallied support for improved access to information on managed care plans to the extent that the state legislature passed a bill mandating HMOs to fully disclose benefits information in a standard format so that citizens may readily compare Colorado's managed care providers.

Extending the argument that the networking of health-related groups or health-interested individuals changes, or creates new, health and social organizations, John Hatch and Eugenia Eng go so far as to propose that "[i]f one seeks change in health status, through community participation and control, then one will certainly alter the existing economic and political systems" (qtd. in Schuler 174). All the same, while not directly related to health, the effectiveness of community participation in political issues through community networking has been highly debated and remains uncertain. In his

case study on the National Capital Freenet (NCF), located in Ottawa, Avis reported that the NCF – even taking into account its propensity toward politics due to the proximity of elected officials and government institutions and to the large user base of civil servants and well-educated individuals (such as the vast student populations) – encountered resistance on the part of political candidates to participate in online discussions and debates because users represented such a small proportion of voters and because they were concerned with liability. In fact, users of the NCF are primarily of a high income bracket which means that any effective political participation achieved by citizens through the network would comprise of a form of selective empowerment. To conclude, while citizens involved in electronic interaction for health-related purposes – whether to obtain professional or peer support and information, to participate in personal or collective decision-making, or to influence health services delivery – may derive significant benefits and a sense of personal empowerment, sociostructural barriers, unless especially recognized and resolved, prevent them from being collectively empowered. Among these barriers are not only personal impediments to access and use, but also the lack of decision-making power of citizens and communities in the health system itself. Despite the fact that interactive telehealth programs and projects – like the citizen health advocacy office proposed by the Advisory Council on Health Infostructure or the Smart Community program – appear to offer the greatest potential for collective empowerment, if they are implemented in current sociopolitical contexts, such as health care reform, they will inevitably serve to extend and reinforce the structures and practices established within these contexts. Simply put, online support groups will most likely continue to be

seen as a cost-cutting measure. Even so, innovative initiatives like the Canadian Women's Health Network may succeed in collectively empowering previously marginalized groups in Western medicine, that is, if women answer Boscoe's call for mobilizing their capacity in, and knowledge of, virtuality and to propagate various forms of pluralistic expression. It is crucial to recall that Poster tied the potential of the Internet for collective empowerment to the decentralization, dematerialization, and thus, democratization of subject constitution.[155]

Section 2: Exploring Alternatives

The next section will focus on how to foster telehealth development so that it can provide a means for the collective empowerment of citizens. While I will not personally propose a magical solution, nor have I found anyone else who has succeeded in doing so, I will bring forth some theoretical frameworks that offer a starting point for thinking about alternative models of telehealth development. Since there are no such frameworks directly addressing telehealth, I have decided to explore alternative technological models, alternative health/medical models and alternative citizen/community participation or governance models. Alternative models of telehealth development could then be

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[155]While here it might appear that empowerment occurs at the individual level, and therefore, would correspond to selective empowerment, Poster would reject the notion of an "individual" as a pre-social and pre-historical entity, along with his rejection of modern, political categories such as democracy. Hence, the realization that "individuality" is socially constructed, and that the self can be constituted and reconstituted by electronic media at multiple levels (race, gender, etc.), is, in and of itself, collectively empowering. It frees people from static and rigid concepts of individuality and other modern, disciplinary concepts.

formulated from merging alternatives discussed in each of the three categories. Theoretical frameworks will be briefly introduced. While they originate from various academic disciplines and approaches, I will not deal with the divergence of their perspectives, but rather choose to emphasize the convergence of their ideas.

2.1 Alternative Technological Models

The common thread amongst the theoretical models relating to technology presented below is citizen involvement in technical design. As Franklin recalls, it has historically been assumed in modern societies that citizens surrendered a part of their autonomy to the state in order for the state to protect the "common good". However, as Franklin points out, public infrastructures supported by the state are currently put into place to serve technological development and generate divisible benefits, leaving indivisible benefits unprotected (as evident in global environmental decay). Technological planning, excluding citizen involvement, furthers the overlapping interests of the state and industry, and follows a *production model*.[156] The production model of technological development leads to the dominance of *prescriptive technologies* that are "designs for compliance" (Franklin 23).[157] It is for this reason that Franklin claims: "The

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[156]Franklin compares the production model to the growth model, whereby the former is closed, predictable and oblivious to its impact on the external context, and the latter is open, unpredictable and keen to recognizing (rather than imposing) the best conditions for development.

[157]Lyotard has nominated the computer as a prescriptive technology since it prescribes which statements are to be regarded as "knowledge" statements (as seen in Chapter Two).

degree of effectiveness of participation by the plannees[158] in long-term planning operations seems to me a true measure of democracy in the real world of technology" (81).

The displacement of social logic – such as the logics of compassion, ecology, justice – by the logic of production and of technology, has resulted in a crisis of technology, that Franklin resolves, is actually a crisis in governance. According to Franklin, this crisis of governance has come about with a loss of the institution of government in terms of its responsibility and accountability to its citizens. Franklin believes that the solution to this crisis will originate in grassroots movements. She suggests several components that should be incorporated into this solution: a reintroduction of reciprocity, human contact and value judgements; questioning technological planning on the basis of broad principles such as justice, equality and fairness; citizen involvement in technological planning and decision-making; the development of *redemptive and bottom-up technologies*[159]; and a *new social contract*

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[158]Franklin uses the term "plannees" to designate those who normally conform to the plan, to be distinguished from those who plan, that is, from planners (81).

[159]Franklin proposes that redemptive technologies would develop in three ways: from a reappraisal of current technologies in terms of their scale and appropriateness; from the identification of effective practices and technologies; and, from the needs and experiences identified by users. As examples of these "technologies from the bottom up", she mentions "personal monitoring of health – and environment-related parameters, easy ways to access relevant information, and low-cost protection of individual privacy against assault by noise and persuasion" (129). Franklin's new models of technical design recall those of "appropriate technology" and "technology blending" that initially surfaced in the 1970's and had important implications for international development. They were interpreted as the linking of scientific and indigenous expertise through dynamic

based on a "demonstrated stewardship for nature and people by those who govern" (130). Finally, she provides a checklist for the evaluation of public projects, including questions relating to whether the project: "(1) promotes justice; (2) restores reciprocity; (3) confers divisible or indivisible benefits; (4) favors people over machines; (5) maximizes gain or minimizes disaster; (6) favors conservation over waste; (7) favors the reversible over the irreversible" (126). The checklist, she specifies, should be enforced by those who are currently disenfranchised, whose experiences are currently dismissed as marginal and irrelevant. Essentially, what Franklin is recommending is a reversal of the rational consensus that secures technological domination according to Honneth, by inserting new norms and moral viewpoints.

Menzies has also noted that public discussions on technological planning recalls "the sound of one hand clapping" (59). Moreover, she describes economic restructuring, such as in health care reform, as "*not* simply a technical management matter [but] . . . a rewriting of a social contract which redefines people's relationship to one another in society, and reshapes, ultimately, their national and personal identity" (40). "As such," she concludes, "it needs to be openly negotiated by *all* those concerned not 'managed' by a select group of experts . . ." (40). Menzies believes that this open renegotiation needs to

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processes of experimentation occurring in traditional settings and by building local capacity to adapt second-hand or upgrade traditional technology. The goals of these models were to encourage "learning-by-doing", to reduce dependence, urban/rural disparities, inequality of access to science and technology, and to, subsequently, strengthen technological autonomy (see Pradip K. Ghosh). They remain controversial however, since they continue to impose the diffusion of Western practices and values, tied to technology, in other sociocultural settings.

take place by leveraging new institutions and alliances, including communities, special interest groups (like women and unions), and local governments. She also shares the notion of a post-industrial social contract, whose main components are: a recovery of the personal power of naming, a recovery of the marginalized voices, a personal and collective counter-consciousness, a democratic middle ground of shared values, and autonomy and association. In accordance with the post-industrial social contract, technological planning would expand its terms of reference to fulfill a broadened, two-part definition of efficiency comprised of a technical meaning (how technology serves to accomplish certain goals), and a social meaning (how well it achieves these goals) (Menzies 252-253). For instance, the contract would dictate that it would be more efficient to disseminate technological control, decision-making and initiative among all citizens. Lastly, Menzies encourages the use of appropriate social technologies such as "telecommunications systems for linking community and community-economics groups with union locals, women's groups, and environmental and peace groups in grassroots coalitions" (245). Similarly, R. Williams advocates the benefits of new interactive technology for voluntary association, alleviating previous impediments such as travel and funding.

Feenberg summarizes the three main points of his book Critical Theory of Technology as follows: technical design is socially relative; social injustices arise from the unequal distribution of social influence over technical design; some cases are known where citizen involvement in technical design has prompted changes in the design. In his

next book, Feenberg undertakes a more in-depth study of the possibility of the democratization of technical change, defined in terms of "granting actors who lack financial, cultural or political capital access to the design process" (7). Democratic interventions in technical design generally take the form of local resistance by, what Feenberg refers to as, active minorities, and of reappropriations of technics through innovative applications.[160] Feenberg identifies three main objections to these interventions: efficient industrial production relies on centralized, administrative authority; views of protesters are not necessarily representative; the politicization of technical design threatens the professional freedom of technical experts. In order to explain the root of the last objection, Feenberg refers to Habermas's theory of communicative rationality. In formulating this theory, Habermas traces the foundation of modernity to the differentiation between the cognitive, normative and expressive spheres of society. This institutionalized differentiation is threatened, Feenberg explains, by citizen involvement in technical design since political opinions and situated knowledges of citizens are less rigidly structured than specialized scientific and technical knowledge. Hence, it is on this basis that the democratization of technical design appears as a regressive movement.

Notwithstanding, referring to the mutual interdependency between the public sphere and formal democracy in modern society, Feenberg insists that "[t]he extension of

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[160]Feenberg contends that any public intervention in technical design should be sanctioned as democratic so long as it respects civil rights.

this dual system to technology promises an enrichment of public life, an advance in what Habermas calls the 'communicative rationality' of society", and further underlines that, "[o]nce again, it is the undetermination of technical decisions that leaves a space of public intervention" (10). However, while Habermas stresses the importance of consensus in the legitimation process of public knowledge[161], Feenberg denounces this emphasis as an imposition of technocratic authority. In contrast, Feenberg entertains dissensus as a core element in the politicization of technology. Finally, he posits that citizen involvement will be reconciled with the autonomy of the technical professions since the latter "has less to do with their separation from politics than with their capacity to translate politics into rational technical terms" (11-12). That is, technical experts will assimilate social initiatives in their technical design. Echoing sentiments expressed by Franklin and Menzies, the main product of citizen involvement, Feenberg concludes, will be a broadened range of values taken into consideration in technical decisions, including aesthetic and ethical norms[162], and national identities. Thus, technology will no longer reflect pure rationality, but instead, will be embedded in a value-governed action system (Feenberg 14).

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[161]As stated in Chapter Two, included in Habermas's conditions for the ideal speech situation are agreement, common ideologies and rational consensus.

[162]Reiser identifies the main ethical values/issues implicated in current technological assessment: the provider-patient trust; the scientific basis of medicine; the difficulty of determining how to justify the right time to introduce new technology; and the use of technological assessment in the allocation of health care resources (according to principles such as distributive justice and cost-benefit).

In the field of telehealth, G. Vassicopoulos et al outline a model for the participatory development of Hospital Information Systems (HISs). The rationale behind this model is to incorporate user participation in the design and implementation of HISs for the stated purpose of better responding to the needs of users, that is, ensuring that the systems are useful, usable and suitable. Central to the participatory approach proposed by the authors is effective communication. As well, they list the approach's main stages.[163] However, Berg opposes this attempt to democratize technologies through user participation. He raises two important discrepancies: the idea of "users' needs" is in itself ambiguous; and, one technology is assumed to consolidate all divergent views expressed by participants. Proponents of user participation hide their own politics, Berg uncovers, under "a white flag of 'neutral democracy' " ("Politics of Technology" 480). That is, they presume that outcomes of democratizing technical design will always be favorable, and do not consider the possibility that new inequities will result from the participatory process. Hence, Berg is of the opinion that the notion of participatory development substitutes one form of neutralization of technology (technology as the product of a rational, efficient process) for another (technology as the product of democracy). I would also add that the participatory approach suggested by Vassicopoulos et al is aimed at improving existing institutional structures rather than changing them.

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[163]These stages are: to define the stages of the project lifecycle; to specify the extent and content of user participation for each stage; to define the functional subsystems supported by the HIS; to identify the roles of users in each subsystem and select representatives of each role to participate in the development of the HIS; to train these representatives; to undertake the project's stages through user participation; to monitor progress and take control action if necessary (Vassicopoulos et al 160).

Alternatively, Berg suggests that criteria and procedures determining technological development should not be rooted in the democratic/undemocratic dichotomy. Rather, technical design should be approached in a piecemeal way. Berg observes that the integration of social theory in technical design has given way to approaches of participatory design and Computer-Supported Cooperative Work (CSCW), whose various understandings of "technology" and "work practice" bring about different politics of technology. Some common critiques of rationalistic design advanced by advocates of CSCW are reformulated by Berg: technology functions poorly if users are ignored; technology encompasses managerial perspectives; work practice must be studied in its habitual environment. Berg also cites Mike Robinson's criteria for creating successful CSCW applications: equality, mutual influence, the development of new competence, and the communication of a double-level language (cultural and formal). He differentiates negative studies adopting the CSCW approach from positive ones. The former separate the categories of technology and work practice in order to emphasize their irreducibility, while the latter focus on the connections between the two. Positive analyses explore how technology can support articulation work and serve as resources for situated action as opposed to pre-determined, automated tools. The technology, therefore, remains flexible and adaptable, Berg explains, and the ontologies of each category are maintained. Consolidating the ideas of many positive analyses, Berg finds:

> Here, the balance of domination is tipped in favor of the human workers: the instrumental rationality of technological artifacts can only work positively if it remains controlled by those that work with the artifacts. Only modest

> technologies, whose functioning is transparent to the user, whose work flows are not too explicated and detailed, and whose structure is redesignable by the users themselves. ("Politics of Technology" 474)

Berg admits that the CSCW approach is guilty of a humanist determinism, that is, the impact of technology is regarded as secondary to, and in fact the product of, human work. The CSCW approach differs from actor-network theory and Haraway's description of the object as actor since it does not grant agency to technology. Instead, central to the approach, Berg pinpoints, "is the idea that the mingling of diverse actants results in new worlds in which both technologies and human actors acquire specific characteristics" ("Politics of Technology 476). CSCW recalls Illich's depiction of technology as a *tool of conviviality*. Conviviality is interpreted by Illich as "autonomous and creative intercourse among persons, and the intercourse of persons with their environment" (Tools 11). Accordingly, in CSCW, the politics of technology are complicated by the fact that the authoritarian/democratic axis to describe human-technology relations is no longer applicable. If technology is perceived as a creative force and emergent phenomena, then it cannot be assumed to act as "propellers of ideologies" (Berg, "Politics of Technology" 478). The CSCW approach tells us that ideologies, such as democracy, will inevitably be altered by, and within, technological development. For instance, the Internet may greatly influence our understandings of indirect democracy, by linking it to notions of access, subject constitution, and participation in policy- and decision-making. As well, the approach holds that there is no neutral, objective or independent standpoint from which to

judge technology, making it impossible to distinguish "democratic" technologies from "prescriptive" ones.

A precondition to the advent of a *convivial society*, Illich projects, is the institution of socialist justice. He depicts the convivial society as "the result of social arrangements that guarantee for each member the most ample and free access to the tools of the community and limit this freedom only in favor of another member's equal freedom" (Tools 12). Ergo, free access to convivial tools must conform to three values: survival, justice and self-defined work. Following this criteria, the telephone can be designated as a convivial tool, as done by Illich, while consumer health informatics cannot. In the case of the telephone, the content of the interactive communication is not externally controlled, while, as seen earlier, this is not the case with consumer health informatics, along with telemedical services, health information networks and most other telehealth applications. In order to achieve conviviality, technological micropolitics must be directed toward "the development of design criteria for tools rather than as now with the development of production goals [such as efficiency]" (Illich, Tools 43). Convivial design will come out of a process of recovery whose main stages are pinpointed by Illich: the demythologization of science, the rediscovery of language and the recovery of legal procedure.

2.2 Alternative Health/Medical Models

In her study of the symbolism in American health care, Marta Clark discovers five

dominant categories of popular metaphors used in medicine to depict the human body and perspectives on illness and treatment: war/combat, sports, gender stereotypes, capitalism and the machine. Examples of each category brought forth by Clark and George J. Annas are listed in Table 35. Clark acknowledges that some of these metaphors are presently being challenged. For instance, sports metaphors are tending to highlight more positive aspects such as cooperation and teamwork. "Feminine" strategies are more commonly integrated in medical practice, such as prevention, home care, and supportive education. Finally, some evidence-based research has validated mind-body connections, along with the role of social factors in determining health status. Correspondingly, Margaret Lock and Nancy Scheper-Hughes have found three types of symbolism of the body in medicine: the individual body (mind, body, soul etc.), the social body (nature, group, cultural identity), and the body politic (public policy, regulations, surveillance). Lock and Scheper-Hughes demonstrate several parallels made between the body and society in medicine. Relatedly, Laurence Kirmayer hypothesizes that symbolism of the body reflects a desire for community, that is, for bodily connection and participation. Hence, it can be deduced that, at the symbolic level, medicine implicitly recognizes the ties between the healthy body and the healthy community/society. Annas hopes to propagate an alternative metaphor of ecology in medicine that would further reiterate the body/community connection. The ecology metaphor involves several priority shifts, indicated by Annas: conservation versus waste of resources, sustainable versus runaway technology, acceptance versus denial of death, and community versus individualism (33).

Patrick Pietroni takes the application of ecology to medicine beyond the level of symbolism, as the title of his book, The Greening of Medicine, clearly illustrates. He compares the ecocentric from the technocentric orientation of medicine (see Table 36), based on an earlier distinction made in the context of modern environmentalism by Tom O'Riordan. The ecocentric orientation is partly founded on the Gaia hypothesis, formulated by Dr James Lovelock, according to which the earth is a living organism.[164] Lovelock declares the need for a planetary medicine and General Practitioners, as opposed to specialists, to administer to its overarching needs. In addition to the Gaia hypothesis, Pietroni contends that General Systems Theory contributes to the greening of medicine, the stipulation that all parts of the biopsychosocial medical system, a concept borrowed from George Engel, are interdependent. In so doing, the theory affirms that the boundaries between health and disease are constantly blurred by cultural, social and psychological influences. Expanding on Engel's work, Pietroni compiles an exhaustive list of all the "languages" that the systems-oriented physician needs to take into account in his/her practice of *holistic medicine*.[165] Pietroni asserts that the value of holistic medicine lies, not only in its regard for the whole person, but in its consideration of

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[164]Eco-feminism also views the earth as an active subject, as opposed to an exploitable resource.

[165]These are: "the medical, molecular, material language of classical science; the psychological, psychodynamic and psychosomatic language of Sigmund Freud, Michael Balint and Grodeck; the cultural, social and political language of Socrates Helman, Talcott Parsons and Sir Douglas Black; the archetypal, metaphorical and symbolic language of C. G. Jung, Zeidler, Mircea Eliade and James Hillman; the preventive, educational and anticipatory language of several official and governmental reports; and, finally, the spiritual, temporal and energetic language found in Eastern medical texts and closely associated with much of alternative medicine" (Pietroni 23-24).

divergent perspectives on what constitutes the person and how to treat him/her. Briefly, Pietroni describes the greening of medicine as the exploration and development of the reciprocal connections between individual existence and the environment/nature (ecology), other people and other species (incorporating feminism, consumerism, animal rights), and "inner selves" and "outer gods" (working on spirituality, consciousness raising) (26).[166]

While Pietroni acclaims Illich's observations relating to iatrogenic medicine, brought forth in Chapter Two, he, nonetheless, criticizes Illich for not determining that cultural iatrogenesis is the product of the physician-patient relationship, that is, of their mutual expectations and dependencies. To demonstrate the importance of this relationship, Pietroni reveals some potentially hidden functions of drug prescriptions, a common transaction among the physician and patient. He speculates that the drug may signify the physician's power to heal, the power of medical technology, a validation of the patient's experience of illness, a fulfilment of the physician's contract, the physician's control, a medium of communication between the physician and the patient, the clinical

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[166]A parallel can be drawn between applying the general systems theory to medicine and the synergy paradigm to the allocation of health care resources. Presently, within the scarcity paradigm, health care resources are regarded as scarce, and therefore, are valued due to this scarcity. As well, because of this presumed scarcity, resources are distributed inequitably amongst the population and communities must compete with each other to obtain them. Comparatively, the synergy paradigm, envisioned by Richard Katz and Niti Seth, distributes renewable and expandable resources equitably amongst the "synergistic community" (111). A paradigm applied in traditional and non-Western populations, synergy can produce bountiful amounts of resources from disparate units, simply by recognizing the interrelationship among these units and collecting them in a somewhat illogical manner.

legitimation of the situation, the patient's control etc. These functions are totally independent of the drug's actual effectiveness. In fact, non-drugs are often prescribed to patients to study the placebo effect. Pietroni reports that this effect has been known to heal patients in 30 to 40 per cent of all cases in which it is administered, regardless of the severity of the disease (39).[167] Lynn Payer, in reviewing the cultural roots of Western medicine in Britain, West Germany, France and the US, discovered that only about 15 per cent of all contemporary clinical interventions are proved to be beneficial by objective, scientific evidence. In addition, Payer attributes to a combination of the placebo and Hawthorne effects 40 to 60 per cent of all therapeutic benefits derived by patients. In noting Payer's findings, Clark endorses the reevaluation of medical practice in terms of the patient's experience of illness. This, Clark intimates, could be achieved in three parts: by demythologizing the scientism of medicine; by rejuvenating the language of medicine to stress the human realities of its practice; and by reaffirming through teaching and practice the reality of human experiences of disease and death.

Second only to environmental activism, Pietroni attaches much significance to the influence of the consumer movement on medicine. In fact, he considers it a prime feature of the greening of medicine. The movement is manifested in the pervasiveness of self-

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[167]Studies on the efficacy of the placebo effect are, at times, so detailed that the color of the pill has been found to influence results. Green pills are supposedly the best option to treat anxiety, yellow pills for depression and red pills for pain (Braithwaite and Cooper).

care and alternative medicine.[168] To clarify the broad range of activities included under the umbrella term of "alternative medicine", Pietroni provides a model comprised of four groups: complete systems of healing, diagnostic methods, therapeutic modalities and self-help measures. These groups are profiled in Table 37. Common factors of many alternative therapies, Pietroni proposes, may disclose the reasons behind their increasing popularity. Four such factors were identified by a Scientific Committee of the British Medical Association: time, compassion, touch, authority and charisma of the provider. I would also add that these therapies may give the patient a renewed sense of control and self-esteem. Notwithstanding, sociostructural inequities in the use of alternative medicines were encountered in many studies. M. Kelner, B. Wellman and B. Wigdor report that these studies have repeatedly demonstrated that the most educated and highest income-earners of the population are the most common users of alternative medicines.

Illich identifies as key to a general improvement in health care, "the level of willingness and competence to engage in self-care" (Limits 271). He also accentuates the deployment of political countermeasures in the process of recovery: the recognition of medical nemesis, the recovery of a sense of personal responsibility and of autonomous action (such as the self-sufficient production of remedies and services), support for

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[168]The following statistics clearly indicate some moderate interest in alternative medicine within the Canadian population: 12 per cent of Canadians consulted both a physician and an alternative medical provider in 1994; only 2 per cent solely depended on alternative medicine; alternative medicine is more frequently used among women (16 per cent) than men (13 per cent) (Millar and Beaudet); 42 out of 240 respondents living in Toronto were found to have consulted an alternative medical provider (Kelner et al).

alternative views and models of care, a renewed focus on population and environmental health, the limitation of professional monopolies and the legislation of the public's right to have a voice in the allocation of resources (including human resources). Some authors have tried to imagine what a reformed, citizen-led health care system might look like, aside from T. Ferguson and others previously mentioned. For instance, Erie Chapman considers as central to the "liberation of our patients"[169] the deinstitutionalization of health care to a large extent. He compares today's hospitals to prisons, remarking many resemblances among them: a uniform imposed on the patient, the separation of the patient from his/her valuables, the assignment to the patient of a number and a cell, restricted food options, the patient's vulnerability to "physical punishment" from the guards/doctors/nurses, bleak surroundings, the patient's inability to voluntarily leave the facility, the patient's restricted ability to control his/her activities (17). Although not acknowledged by Chapman, these resemblances, as uncovered by Foucault, are due to the fact that both institutions are Panoptic structures of domination. Alternatively, Chapman presents the efforts of pioneering organizations who aim to move away from the traditional model of health care delivery and deinstitutionalize the experience of the patient in the following ways: by providing optional hospital gowns and flexible visiting hours, by respecting the patient's sense of personal space, by offering a wide range of food options and optional use of a kitchen facility, by focussing on patient education and other interactive activities (reducing the emphasis on physical intervention), by creating

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[169]While Chapman calls for liberation, he paradoxically uses the possessive pronoun "our" to designate patients, which is hardly liberating.

warm and subtle settings (muted lighting, music, colors, carpeting, plants) (18). Chapman uncovers two main premises underlying the new model adopted by these organizations: active participation of the patient in his/her care and the involvement of family (the latter being loosely defined) (18).

Another example of a citizen-centred model of health care is imagined by Emily Friedman who chooses to grapple with the physician-patient relationship. She isolates five phases that are subject to renegotiation: the "Me hospital, you patient" Tarzan-Jane relationship, a product of the Age of Paternalism and colorfully described by Chapman; the patient versus provider struggle over authority, emerging during the civil rights movement and prompted by the advent of feminism; the period of *détente* characterized by a collaborative form of decision-making between patients and providers[170]; the "blame the patient" scapegoat where health outcomes are mainly tied to patient compliance to health promotion/prevention directives and treatments; and, lastly, the "running past each other" phase during which neither patients nor providers trust the sincerity of the health care system (9-10). I would suggest that our current phase of mistrust is clearly the result of health care reform cost-cutting measures, anchored in the fear of yet another free-fall. Finding all these contracts inadequate, Friedman formulates some general principles to guide the renegotiation of the physician-patient relationship, that could, of course, be

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[170]Here, patients more openly express their preferences. During this period, various initiatives granting greater control to the patient became more pervasive (such as living wills, birthing centres, midwifery, home care, complementary treatments for chronic illness, lumpectomies etc.).

applied to the contractual model projected by T. Ferguson.[171]

2.3 Alternative Citizen/Community Participation or Governance Models

Peter Beresford and Suzy Croft distinguish two approaches to citizen involvement, consumerist and democratic, that lend support to my comparison of selective and collective empowerment. The *consumerist approach*, Beresford and Croft argue, came about in tandem with the expansion of commercial services in health care. Issues pertaining to the roles of users in the health care system were, subsequently, reconfigured in terms of market preferences, product development, consumer choice, competition, the commodification of needs etc. While the US situation is certainly more market-driven, the influence of the commercialization of health care delivery is also felt by Canadian providers and citizens, for instance, when confronted by pharmaceutical marketing. Conversely, key to the *democratic approach* is empowerment, whose objectives are civil rights and equality of opportunity.[172] Simply put, Beresford and Croft differentiate the service-led, consumerist approach, from the citizen-led, democratic approach (9). Schuler, similarly, acknowledges a current trend pointing to democracy "as

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[171]These principles are: mutual respect, honesty, the discussion of incentives, reasonable expectations, the patient's right to know, support of the rights of both parties and mutual understanding (Friedman 11-12).

[172]Beresford and Croft contend that democratic citizen involvement requires equal access and opportunity in three overlapping spheres: mainstream life, support services and arrangements for involvement (75). They also underline that a democratic equal opportunity policy should take into account four elements: equal access, equal shares (a quantitative measure of the proportion of people using services for their particular needs), equal treatment (a qualitative measure of appropriate treatment without discrimination), and equal outcomes.

the public problem-solving approach it was originally intended to be" (11). He also contrasts participation (understood in terms of the consumerist approach) from citizen-led action as follows:

> Whereas participation suggests a general acceptance of existing processes, the idea of citizen-led action transcends the status quo. While participation is basic to functioning and vital community, citizen action is in some ways more important, for action implies leadership . . .Moreover, when community members establish their own projects, they set the agenda. When they participate in others' projects, the agenda is often set by someone else. (19)

While consumerist forms of citizen involvement are typically restricted to information-gathering and consultation (such as needs assessments, profiling, surveys, focus groups etc.), democratic forms of citizen involvement strive for access to, and support from, material and personal resources in order to secure a direct say in decision-making (at the personal and collective levels). Beresford and Croft explicitly recognize the political implications of citizen involvement, as illustrated in the following: "Involving is not just a matter of neutral techniques, but a *political* activity. . . .Nor is involving people just a set of procedures. It is a *process* of both personal and political change" (60). While the authors admit that there is a need for more information on citizen involvement, including evaluations of current initiatives[173], they articulate a set of

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[173]Beresford and Croft offer a set of initial guidelines on how to develop an evaluation framework for the assessment of citizen involvement: to undertake participatory research from the start; to follow an action-research model continually incorporating informed

guidelines for empowerment to be adhered to by structures of citizen involvement: to monitor gains and costs, to recognize tensions between formal and informal arrangements, to admit problems, to identify best practices, to start locally, to identify key allies and supporters, to develop regular exchanges between different groups to learn lessons and share experiences, and to gain realistic expectations of obstacles to empowerment (155). Nonetheless, the authors concede that while organizations may succeed in empowering citizens, the wider context may be fundamentally disempowering and, therefore, seriously limit overall benefits.

Fraser attributes to liberalism the assumption that it is possible to institute a democracy founded on socioeconomic and sociosexual structures that generate systemic inequalities (79). This assumption is reiterated, Fraser points out, in the bourgeois public sphere outlined by Habermas. In formulating a postbourgeois conception of the public sphere, Fraser attempts to renounce four presumptions central to its predecessor: that social equality is not a precondition for political democracy; that a single, comprehensive public sphere is preferable and more democratic than a nexus of multiple and competing publics; that discourse should be restricted to deliberations about the "common good" versus private interests and issues; that in order to function, civil society must be segregated from the state (76-77). Alternatively, Fraser suggests that "subaltern

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changes (such as the Participation Action Research Network launched by Cornell University); to be based on clear criteria (such as an equal opportunity policy, conditions of involvement, rights and outcomes) (73-74). Furthermore, the authors construct a sample evaluation instrument, condensed in Table 38.

counterpublics" will best contribute to the ideal of *participatory parity* and of "an egalitarian, multicultural society," that is, a multiplicity of publics will require a plurality of fora that will not filter their voices (81, 84).[174] As well, Fraser insists that rough socioeconomic equality is necessary to achieve participatory parity. Finally, Fraser claims that the liberal public sphere encourages the formation of *weak publics*, "publics whose deliberative practice consists exclusively in opinion formation and does not also encompass decision making" (90). It is feared by advocates of the liberal public sphere that granting decision-making power to weak publics will threaten its autonomy and render it vulnerable to corruption by the state. However, Fraser remarks that parliamentary sovereignty has since constituted a public sphere within the state itself. Ergo, Fraser names sovereign parliaments *strong publics* since they are empowered to implement opinions in authoritative decisions. She envisions the possible extension of strong publics in the form of self-managing institutions.[175] However, Fraser cautions that the issue of accountability of strong publics to other external, weaker publics who may also have interests in collective decisions, remains so far unresolved by the conception of the postbourgeois public sphere.

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[174]She, in fact, criticizes the Internet, depicted as "a culturally specific rhetorical lense," for not allowing unaltered plural expression (83).

[175]Fraser describes these institutions as "constituting sites of direct or quasi-direct democracy wherein all those engaged in a collective undertaking would participate in deliberations to determine its design and operation" (91).

Also pertaining to an alternative model for telehealth development, Fraser explores the redistribution-recognition dilemma that lies at the heart of the postsocialist condition.[176] Redistribution is a paradigm focussed on socioeconomic injustice, while recognition opposes cultural domination. Fraser yields that the two paradigms are intertwined in practice to the extent that redistribution takes into account recognition at some level. For instance, socioeconomic redistribution is often based on principles of recognition such as the "equal moral worth of persons" (Fraser 15). Each paradigm endorses affirmative and transformative remedies to injustice[177], profiled in Table 39. The majority of strategic initiatives currently promoted in telehealth government policies and initiatives could be categorized as redistributive-affirmative remedies since they are directed toward improving access to services provided by the liberal welfare state, as well as to citizen/community participation within existing social structures (weak publics). However, initiatives targeting First Nation communities, like the National First Nations Telehealth Research Project, could be considered as a recognition-affirmative remedy.

The self-managing institutions put forth by Fraser as a form of strong publics would constitute a redistributive-transformative remedy since they are designated by R.

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[176]The postsocialist condition has three constitutive features highlighted by Fraser: the lack of a progressive, alternative vision to the present society (i.e. the absence of emancipatory grand narratives noted by Lyotard), a shift from demands for social equality to those for recognition of group difference, a resurgence of economic liberalism.

[177]These remedies were first defined in Chapter Three. Affirmative remedies are "aimed at correcting inequitable outcomes of social arrangements without disturbing the underlying framework that generates them". Transformative remedies correct injustice "precisely by restructuring the underlying generative framework" (Fraser 23).

Williams's as the only realistic avenue for socialist democracy in our present society. Compared to bourgeois democracy where economic contingencies prevent political representation and participation, socialist democracy, R. Williams hypothesizes, could be actualized by "communal, cooperative and collective institutions" that would practice, under legal provisions, "free speech, free assembly, free candidature for elections" and "open decision-making" (123). These institutions, R. Williams projects, "would introduce the distinctive principle of *maximum self-management*, paired only with considerations of economic viability and reasonable equity between communities, and decisively breaking with the now dominant criterion of administrative convenience to the centralised state" (125). Hence, self-managing institutions would not obtain power from state "decentralization" or "devolution", that is, through a downward assignment of constrained responsibility, but would instead possess power at the base, at the grassroots.

Pauline Vaillancourt Rosenau directly addresses the issue of community health organizing by undertaking a postmodern deconstruction of concepts central to it: representation and participation; community and identity; causality, accountability and responsibility; and, authority and the privileged voice. Her analysis of these political concepts is summarized in Table 40. In comparing postmodern and modern social movements, she finds that the former warrants "grassroots activity, voluntary associations, openness to other worldviews, and divergent political orientations," echoing and somewhat consolidating, views expressed by Fraser and R. Williams (317). Postmodern social movements are delineated by particular issues and are characterized by

Rosenau as spontaneous, transient and constantly in flux. They espouse "life politics" –a concept previously described by Giddens – versus emancipation, that is, decentred, local, disorganized, and fragmented identity politics vaguely targeted toward self-actualization, globalization, fleeting solidarity etc. Rosenau contemplates three models for community health organizing from a postmodernist standpoint. Her de-scription and deconstruction of the models of social planning, community development and social action is brought forth in Table 41. Post-deconstruction, Rosenau attempts to re-construct community health organizing by suggesting the following "unmodern" guidelines: (1) take people seriously, listen, wait, and be patient; (2) show respect for individual preferences, even when they are contradictory, ill-informed, self-destructive, and lacking coherence; (3) accept that you cannot do for people what they must do for themselves, when and if they are ready; (4) be realistic; (5) emphasize choices rather than use a take-it-or-leave-it approach; (6) don't discount the irrational, emotional, and intuitive; (7) do not expect consistency (325-326). These guidelines reflect Pietroni's ecocentric perspective.

Conclusion: Merging Alternatives

A quick summary of the main conclusions derived from this chapter is in order. Prior to directly addressing the roles of citizens involved in telehealth initiatives, the work of Meyrowitz, T. Ferguson and others was brought forth to explore whether or not electronic media could be found to empower citizens by reducing the power of expert systems and disciplinary practices. From this discussion, I found the need to distinguish selective empowerment from collective empowerment. As well, I concluded that

telehealth could only be regarded as collectively empowering if it dealt with sociostructural inequities and the physical and psychological barriers to empowerment related to the experience of illness.

Having determined this, I turned to the role of citizens as recipients of telemedical services. I established that telemedical services – corresponding to redistributive-affirmative remedies to injustice (using Fraser's typology) – further the dehumanization of health care and, in most cases, reinforce sociostructural inequities (for instance, by increasing the centralization of power in tertiary care centres). In addition, I did not presume that access to such services is, in and of itself, empowering since medical services are not necessarily beneficial to citizens or communities. Nevertheless, I did accept the possibility that alternative models of health and health care, such as that of First Nation traditional holistic health and mental health, could be dispensed through telemedical applications that would then constitute recognition-transformative remedies to injustice.

Medical research and health information networks, within which citizens are objects of study, generally operate under the imperatives of scientific/technological rationality. The majority, as I demonstrated, seek to strengthen iatrogenic medicine, increase patient compliance, reduce citizens' use of health care services and facilitate health care reform initiatives. However, I also admitted that networks that are used to monitor the performance of health care providers have the potential to open doors to

alternative models of health and health care and, therefore, may be collectively empowering to citizens. Furthermore, I distinguished initiatives such as the Consumer Network of the Cochrane Collaboration and POPULIS because these can be characterized as redistributive-transformative remedies to injustice. I suspect that they may, in the future, become recognition-transformative remedies if they succeed in validating alternative models of health/health care.

In their role as information-seekers, I revealed that citizens are often targetted by tele-education applications in order to increase their compliance to prescribed health treatments and regimens. In bringing forth the debate between divergent perspectives on self-care (including those of Giddens, Rusovick et al, Anderson, Foucault and Guldan), I sought to determine whether or not consumer health informatics could, in emancipating citizens from expert systems, collectively empower them. I decided that such empowerment, if it did take place, would be restricted to select groups of citizens and communities since sociostructural inequities affect the use and, therefore, the impact of health information on citizens. Finally, in their role as interactors, citizens face similar obstacles to collective empowerment. That is, interactive telehealth applications extend current health care delivery practices and institutions. Moreover, sociostructural inequities affect the use of these services by citizens and, thus, their effectiveness and value. While the potential for selective empowerment exists in redistributive-affirmative applications that allow the involvement and interaction of citizens with special, physical and psychological needs, there is a need for recognition-transformative applications to

enable the assertion of power by citizen and community groups with respect to their involvement in health care policy- and decision-making. Notably, the Canadian Women's Health Network, I would argue, is a recognition-transformative remedy to injustice that promotes the mobilization of women's knowledge of, and skills in, virtuality, along with pluralistic expression.

The second part of the chapter briefly profiled various alternative models focussed on technology, health and medicine, and citizen/community participation and governance. These models were chosen for their possible contribution to the elaboration of an alternative model of telehealth development. While I will not reiterate the observations made by the authors cited, for the sake of brevity, I will attempt to merge their ideas and apply them to telehealth development. It can be deduced, from these models, that technical design of telehealth applications and initiatives needs to be transformative, rather than affirmative, in order to facilitate the advent of self-managing institutions. A form of subversive technological micropolitics, self-managing institutions obtain their power at the grassroots level and operate in accordance with new social contracts that reflect broadened norms and values. These social contracts are positioned at the forefront of the production of normatively regulated communication and technical entreprise, that is, they dictate how norms and values that legitimate forms of medical/health knowledge will be defined. These norms and values may tend toward an ecocentric perspective on health and medicine, encompassing new ethics, aesthetics (suggested by Marcuse), cultural and social symbols and identities, and perhaps integrating the "successor science

project" proposed by Harding and Generator of Diversity (G.O.D.) perspective envisioned by Haraway.[178] While Menzies stresses the importance of achieving consensus in the new social contract[179], Feenberg, Fraser, Haraway and Rosenau support dissensus and pluralistic expression to prevent the imposition of dominant viewpoints – currently, an inevitable consequence of the realization of the modern conception of empowerment as pointed out by Rosenau. In other words, telehealth applications and initiatives should be designed so as to accommodate and account for pluralistic expression (alternative health services, various definitions of health, social characteristics and needs of citizens such as language, levels of use of technology, literacy etc.). In accordance with postmodern politics, an incompatible difference, the Differend, remains to prevent the centralization of power and the dominance of one language game in social integration.

However, as Berg has insisted, the fact that technical design is approached democratically does not mean that it is collectively empowering, even if it is part of transformative remedies of injustice. Berg has denounced the assumption that empowerment automatically results from the democratization of technology, as another form of neutralization of technological development. He contends that technologies are

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[178]Such broadened values could take into account: the interdependence of all living organisms (including the earth), time, touch/human contact, compassion (that is, social logics), justice, fairness, equality, reciprocity, conviviality (survival, justice and self-defined work), connectedness versus causality etc.

[179]Menzies's position echoes that of social constructivists who recognize technical and moral conflicts among relevant social groups during technological development, but ultimately presume a resolution to these conflicts.

not simply propellers of ideologies, but rather these ideologies are affected by technological development or mediation. This view is held by social anthropologists like Pfaffenberger that, as seen in Chapter Two, submit the reciprocal regulation of the technological artifact within a particular social context through symbolic media. As well, Berg claims that there exists no neutral, objective standpoint from which to judge technology and determine whether or not it is democratic or consumerist, affirmative or transformative etc. Similarly, Ellul strongly asserts:

> all the dissertations on autonomy (individual and institutional), decentralization, personalization, the growth of liberty, the opening up to small groups, and democratization thanks to new technologies – and these dissertations have multiplied infinitely over the past few years – are absolutely futile and inconsistent. For they ignore the feature which is intrinsic to the very being of technique: its *irrepressible ambivalence*. [emphasis added] (Technological Bluff 76)

Ellul outlines four propositions to help elucidate the nature of this ambivalence[180]: all technical progress has its price (e.g. quality of the environment, poverty, ill-health); at each stage, it raises more and greater problems than it solves (e.g. the prolongation of life leads to the population explosion; capitalist expansion increases the gap between the higher and lower social classes and the info-rich and info-poor); its harmful effects are

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[180]Lyotard considers the ambivalence of postmodern technology in a more positive sense. Previously mentioned in Chapter Two, this ambivalence is rooted in postmodern technology's ability to reflect multiple rationalities and adopt both the performativity and paralogy criteria for legitimation. The computer is favorably portrayed by Lyotard as an example of this ambivalence.

inseparable from its beneficial effects (e.g. increased interactivity through the Internet further isolates the individual in front of his/her workstation); it has a great number of unforeseen effects (e.g. the psychological effects of medical treatments). Faced with this ambivalence, Ellul comes to two conclusions: technical development entails a double play of progress and regress; and, ambivalence takes the form of reverses (from rationality to irrationality, from utility to generalized inutility). While Ellul recognizes the value of developing critical awareness, he, nonetheless, identifies three obstacles to this development: the reigning techno-military-statist complex, the massive public/private resources dedicated to this complex, and the dominant economic framework that directs aid and compensation.

Taking into account technology's ambivalence, as well as its influence on ideological frameworks, Berg suggests an alternative conception of technology as a creative force and emergent phenomenon, in other words, as a tool of conviviality. In accordance with convivial design, the meaning and impact of technology is context-specific and determined in concert with human and non-human actants who are themselves influenced by technological development. Convivial design, in other words, rests on the interpretive flexibility of the technological artifact, established by the social constructivist approach. Hence, technology as a tool of conviviality does not guarantee empowerment nor subjugation. It is malleable, flexible, an open system. Notwithstanding, it generates an interplay of negative and positive effects, of progression and regression, that is impossible to forecast. The odds are that, considering its

military/market/medical origins, it will reinforce the power of existing institutions and the marginalization of currently disenfranchised groups. However, I am not as fatalistic as Ellul.[181] In observing initiatives such as the Canadian Women's Health Network and the Cochrane Consumer Network for example, I cannot but acknowledge the potential of telehealth applications and initiatives to achieve collective empowerment, which does not mean that new inequities or negative effects will not result from these initiatives. Definitely, it is important to be aware of the unforeseen impacts of empowering initiatives and, thereby, to study these initiatives. Since so few have as of yet been implemented, I do not believe, like Ellul, that they should be dismissed off-hand without having been first actualized or examined in practice.

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[181] In fact, even Ellul has advanced a new form of ethics to counter the power of "technique", with four primary characteristics: an ethics of non-power, freedom, conflict and transgression.

CONCLUSION

What follows is a quick summary of the main arguments presented. The summary will demonstrate how the conclusions of each chapter successively contribute to meeting the objectives of the dissertation and answering the research question, simply stated as *"Can telehealth empower citizens?"* In defining the terms "technology" and "technics" and in introducing approaches to the social history of technology, it was indicated at the outset that the dissertation would focus on the social dimensions of telehealth development. In other words, telehealth development would be considered in concert with evolving social practices and organizations. Succinctly, the social history of medical technology tied technological development to the elevated scientism of medicine. That is, medicine uses technology as a means to heighten the appearance of its scientific character. In so doing, it objectifies the body of the patient, centralizes the power of the medical profession, and establishes the hospital as the main centre of medical practice. As a result of the more intensive use and eventual dependence of medical practice on technology, the medical practitioner has become more distanced from the patient, creating a sense of dehumanization of health care. It is for this reason that Reiser favors a more decentralized approach to medicine that would foster a greater sense of trust among practitioners of their own judgement and a greater personalization of the process of care. Similarly, Mackenzie suggests that medical technology be rendered obsolete once the practitioner learns to acquire the same knowledge and experience without it.

Having introduced several theoretical concepts derived from critiques of technology, it then became possible to apply these concepts to medical technology so as to analyze more extensively its fundamental parameters. It was then ascertained that medical technology is an instrument of social control and information control. It produces and legitimates medical knowledge in accordance with ethics and politics that favor professional and bureaucratic expert systems. At the heart of medical technology lies a technocratic cultural code that supports the centralization of health care through iatrogenic medicine and state health insurance, both of which reinforce capitalist production and consumerism. By contributing to this centralization, medical technology causes health care costs to increase and health-related information to proliferate continuously. Paradoxically, it is put forth in the health care reform agenda as the solution to these consequences. To illustrate, health information networks are created as backbone information and communications infrastructures to regionalization initiatives, the latest incarnation of the community paradigm in the health system. Also geared toward administrative rationality, these initiatives follow the traditional community model of accountability, plagued in the past by professional monopolies, a lack of information and a lack of governing power.

While some cultural theorists and community networking advocates promote the democratizing potential of electronic media, others caution that changes in the wider sociopolitical context are required in order to subversively impact social institutions and practices. In the case of telehealth, its development has been appropriated by and

integrated in dominant medical practice and in health care reform, as noted with health information networks. These social institutions, despite the fact that they are sustained by Canadian health care ideology that stresses equality of access, perpetuate sociostructural inequities.[182] Thus, the majority of telehealth applications were found not to be collectively empowering to citizens. Reflecting the individualist and consumerist nature of current health care delivery, some applications were identified as selectively empowering for citizens already privileged by sociostructural inequities in Canadian society.

Notwithstanding, the potential for collective empowerment through telehealth was recognized, implemented to some degree, for instance, in the Canadian Women's Health Network and the Cochrane Collaboration's Consumer Network. Alternative models were discussed that presented empowering forms of citizen involvement in technological design, empowering mechanisms of citizen/community participation and governance in social institutions, and empowering means of understanding, preserving and delivering health and health care. Their common reflections led to the conception of an alternative model of telehealth development propitious to collective citizen empowerment. Essentially, this model has five components: transformative and convivial technical design, self-managing institutions, power at the grassroots, new social contracts, and pluralistic expression.

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[182] Class disparities in health status and in access to health services were demonstrated by Badgley.

While the model remains general and appears unattainable, it provides some guidelines for the design of evaluation criteria and frameworks applied to telehealth initiatives, and for the interpretation of evaluation outcomes. While the current drive in telehealth evaluation to build an adequate business case does not accentuate citizen empowerment, the recommendations of the Advisory Council on Health Info-structure call for a longer-term vision of the Canadian Health Infoway and for public empowerment through the Infoway, projecting the need for expanded evaluation criteria that takes into account citizen empowerment. This dissertation has established that expanded evaluation frameworks should distinguish between initiatives intended as redistributive and as recognition remedies to injustice, and between affirmative and transformative initiatives. As well, they should determine whether initiatives are geared toward selective or collective empowerment. These distinctions can influence the interpretation of evaluation results. For instance, the National First Nations Telehealth Research Project is directed toward improving access in remote First Nation communities to health care services currently dispensed to these populations. Hence, the project is a redistributive and affirmative remedy to injustice. While the project does not specifically state collective empowerment of First Nation communities in its objectives, according to the alternative model, it can be deduced that such an objective would be unrealizable since it would require transformative design. Therefore, failure to yield collective empowerment would not be due to any technical problems, human issues, financial burdens or any other conditions specific to the project as might be assumed, but rather due to the project's intrinsic structure.

The purpose of the example cited above is to demonstrate how the alternative model of telehealth development consists of an "object-to-think-with", how it can be deployed in the planning and evaluation of present initiatives. The goal of this dissertation was to adopt an original approach to the study of telehealth development, a cultural studies approach that would contextualize telehealth in social history and theory and that would decipher its political implications. However, it was also crucial that the dissertation not seem disassociated from the reality of implementing telehealth. While many discussions relating to the implementation process tend to focus on technical and social barriers imposed by current infrastructures (technological, medical, legal), the intent of this dissertation was to draw attention to the source of these barriers, their historical and institutional roots, and how to move beyond them.

Further exploration is naturally needed. Comparative analyses of community and/or citizen-directed telehealth initiatives would be ideal although these initiatives are rare. Analyses of the experiences of citizens in traditional health care models compared to their experiences with telehealth would point to evaluation criteria unique to telehealth. The study of telehealth initiatives incorporating alternative health models would enrich understanding of these models and their possible impact on health status, interactivity, personalization, democratization, dehumanization etc. Research on the effects of interactive health-related communications and consumer health informatics on citizens with diverse social, economic and cultural characteristics, as well as of the efficacy of special access provisions, would help design telehealth initiatives that address the issue of

sociostructural inequities. Many more research questions could be raised. Now is the time to raise them.

TABLES 1 - 41

Table 1

Social History of Technology: Shared Principles and Assumptions

Principles	1. Heterogeneity of technology and the study of the content and context of technical change.
	2. Dilemma of deriving more general models from case studies.
Assumptions	1. Technological change is contingent. The "social" and "economic" are also heterogenous and emergent. Social relations are constituted and shaped, in part, by technology and economics.
	2. Technology originates from conflict/difference/resistance.
	3. Difference may not necessarily take the form of overt conflict. Social historians of technology seek to map the strategies deployed by those involved in such disputes.
	4. Technology forms part of, or is involved in, strategies of protagonists. A technology is not stabilized until the social relations in which it is implicated are stabilized.
	5. These strategies and their consequences are treated as emergent phenomena. Social and technological determinism are avoided.

(Bijker and Law, "General Introduction" 7-9)[183]

[183]If the source of the table is indicated in this manner, it means that I have condensed the material presented by the author in order to clearly bring out its main points. However, if the source is written as follows "(reproduced by [author's name and page numbers])" then it means that I have copied "as is" a table found in that particular work.

Table 2

The Clinical Gaze

Codes of Knowledge	
1. The symptoms constitute a primary stratum, indissociably signifier and signified.	In clinical medicine, the symptom constitutes the visible form in which the disease is presented, while the sign is a symptom with special meaning. There are three main categories of signs, each designating symptoms presented during a specific time-period in the progression of the disease: prognostic (future symptom), anamnestic (past) and diagnostic (present). In clinical medicine, there is no essence of the disease beyond the symptom that becomes sign. This standardization of meaning of the symptom establishes the dichotomy health/pathology. The symptom is no longer viewed as a natural phenomenon but rather is a signifier of pathology.
2. It is the sovereignty of consciousness that transforms the symptom into a sign.	The symptom becomes the morphological support of the sign through an operation that acts as follows: • that totalizes by comparing organisms; • that recalls normal functioning; • that registers the frequency of simultaneity or succession; • that scrutinizes the body and discovers post-mortem the visible invisible.
C. The being of the disease can be entirely stated in its truth.	Disease exists only in its visible form. What can be seen can be immediately stated. Therefore, the manifest truth of the disease can be communicated.
Principal Stages	
1. Complexity of combination	The complexity lies not in individual modifications that hinder the definition of essential truths, but rather in the combination of simpler forms of pathology. These forms have become simpler as they have become generalized through an accumulation of cases. Compared with strict classificatory thought where a combination would be perceived as a unique phenomena of divine

	intervention, clinical medicine adopts an approach to the progression of knowledge that mirrors the progression of life, that is, knowledge "becomes" through an empirical process.
2. Analogy	A disease is identified by distinguishing analogical relations among symptoms (combinations, successions, etc.).
3. Perception of frequencies	"Medical certainty is based not on the *completely observed individuality* but on the *completely scanned multiplicity of individual facts*" (101). Compared with the classificatory gaze that effaced individual variations through abstraction in order to arrive at delimited essences, the clinical gaze integrates variations in its nosology. However, these variations are cancelled out by the paradigm of probability.
4. Calculation of the degrees of certainty	Each sign is assigned a degree of probability. While this probabilistic value stems from a *pathology of cases*, its value as a sign originates from a *pathology of phenomena*. That is, the symptom becomes sign because it is associated to a set of phenomena. The probability that the sign is related to a specific disease is calculated on the number of cases in which this has been known to occur.

(Foucault, Clinic 91-103)

Table 3

New Rules of the Anatomo-Clinical Gaze

1. Substitution of the localization of the fixed point for the recording of frequencies	Probabilistic thought of the clinical method is tied to local constancy versus temporal frequency. The chronology of symptoms is tied to that fixed point, according to the aftermath of the lesion and the logic that has been attributed to it.
2. The notion of the "seat" of the disease is not automatically tied to its cause.	Bichat's pathological anatomy differs from Morgagni in this respect. The seat of the disease indicates the fixed point from which the pathology emanates. The seat is not the final cause but the original site of the disease.
3. Death no longer signifies the end of the disease but instead, represents the point of association between the set of symptoms and the set of lesions.	This reconceptualization of death alleviates the fear of death from medicine. Death is no longer viewed as an absolute, irrevocable point, but rather as a series of miniscule, partial deaths gradually overtaking organic life. In death, the essential truths of life and disease are revealed. Death is a life-defining moment of revelation.

(Foucault, Clinic 139-146)

Table 4

History of Telemedicine

Date	Type of Application	Telemedicine Initiative
19th c.	teleconsultation	Telegraph first utilized to transmit voice communications between physicians and to evaluate patients at a distance.
1860	telecardiology	J. B. Upham translated cardiac motion into currents and transmitted them from Boston to Cambridge through the telegraph.
1861-1865	military telemedicine	During the American Civil War, the military used the telegraph to transmit casualty lists and order medical supplies. It is also believed that the telegraph was used for medical consultations.
1877	telecardiology	An attempt at monitoring chest sounds through the telephone at a distance of 800 feet failed due to the weakness of sound quality. Others that followed also failed due to the susceptibility of telephone transmissions to external electrical currents and extraneous sounds. Similarly, early experiments in tele-auscultation using the microphone were impeded by the extraneous sounds produced by contact of the instrument with the body.
20th c.	teleconsultation	The diffusion of the telephone amongst the general population rendered the physician more susceptible to frequent calls from anxious patients. On average, physicians resisted evaluating patients over the phone because it did not allow for the use of diagnostic technology.
1905	telecardiology	Wilhelm Eithoven coined the term telecardiogram (now, tele-ECG) after successfully sending electrocardiograms from Leyden Hospital to his laboratory.
1910	telecardiology	S.G. Brown developed an electric magnifying stethoscope specifically for use in tele-auscultation.
1947	teleradiology	Teleradiology first took place when x-rays were sent through the telephone from West Chester, Pennsylvania, to Philadelphia.

1950's	general	The US Indian Health Service, NASA and the Lockheed Company sponsored the STARPAHC program (Space Technology Applied to Rural Papago Advanced Health Care). Lasting until the late 1970's, the project sought to demonstrate satellite-based provision of distance medical services to astronauts and residents of the remote Papago (now Tohono O'odham) Indian Reservation in Arizona.
1952	telecardiology	Tele-ECG was first performed using telephone transmission.
1956	tele-neurology	Dr. Feindel, a neurosurgeon from Saskatoon, Saskatchewan, transmitted live electrocorticography tracings through a closed-circuit television system.
1959	teleradiology	In Montreal, Dr. Jutras transmitted x-rays by coaxial cable and performed remote control fluoroscopy (the examination of objects by observing their x-ray shadow on a fluorescent screen to study patient physiology, such as pulse and breathing). Also, the Jean-Talon Hospital in Montreal launched a teleradiology program during the 1950's.
1959	tele-education	Neurological examinations and other patient information were transmitted by videoconferencing at the University of Nebraska.
1961	telemonitoring	The journal Anesthesiology published an article on radiotelemetry used to monitor patients at a distance.
1964	general	A telemedicine link was established between Norfolk State Hospital and the University of Nebraska to conduct speech therapy, neurological exams, psychiatric consultations, research and education/training.
1965-1967	general	Ship-to-shore transmission of ECGs and x-rays, and transoceanic transmission.
1967	telemonitoring	A telemedicine link was set up between the University of Miami School of Medicine, the City of Miami Fire Department and the Jackson Memorial through existing voice radio channels for the purpose of transmitting electrocardiographic rhythms.
1968	general	As early as 1963, a nursing station at Boston's Logan Airport was linked to the Massachusetts General Hospital. In 1968, Kenneth Bird established an interactive television microwave link. Nurses located at

		the station could send cardiac and respiratory signals, blood pressure readings, ECGs and x-rays to physicians working in the hospital. The television camera served to transmit non-verbal communications and magnified images of any part of the surface anatomy. The hospital later founded a telepsychiatry program with the Veterans Administration Hospital in Belford that continued to operate until the mid-1980's.
1970	teleradiology	The US Public Health Service and the US Department of Defence launched several teleradiology projects that culminated with the Digital Imaging Network Project in the 1980's. The Project was dedicated to R&D in the field of civilian and military teleradiology.
1972	telepediatrics	The Mount Sinai School of Medicine in New York City experimented with a black-and-white cable television link that was aimed at supporting nurses practising at a pediatric primary care clinic in a Hispanic neighborhood.
1975	general	First Canadian Telemedicine Symposium was held.
1976-1982	general	The Federal Department of Communications supported several projects using the Hermes and Anik B satellites. The Ontario Ministry of Health studied the feasibility of using VHF radio and satellite to monitor vital signs of a patient being evacuated from a remote community. The University of Western Ontario linked London's University Hospital, the Moose Factory General Hospital and the Kashechewan Nursing Station on James Bay to provide medical consultations and some continuing education. Finally, Memorial University directed a televised health education program from St-John's, Newfoundland, to hospitals in Stephenville, St-Anthony, Labrador City and Goose Bay. Since then, Memorial University has participated in over 30 telemedicine projects, many of which are on-going.

Table 5

Historical Development of Technology

Primitive Technology	There were two main types: material and spiritual (magic). Technology had a two-fold function. It was used as a means of protection and defence and as a means of assimilating, and subsequently, manipulating the environment. However, magical technology differed from material technology in two ways. First, it did not evolve according to a progression of discoveries, but rather discoveries emerged independently from one another. Second, evidence of its efficacy was not readily visible.
Greece	It was the first society to cultivate coherent scientific activity, grounded in the belief that science was tied to wisdom and contemplation. Technology was separated from science and rejected in the name of self-mastery. Greek society sought to achieve human mastery of material needs versus technological mastery.
Rome	Roman society, characterized by a more concrete, experimental conception of life, relied heavily on civil and military technology. Roman technology had three main characteristics: it was disciplinary; it represented an equilibrium between technological and human factors; and, it was aimed at achieving an internal coherence of society.
Christianity (10^{th} - 14^{th} centuries)	Technology was generally limited to that based on custom, on imitation. Its development (or lack of) was inescapably tied to Christian moral judgement.
15^{th} century	Notable technology, including printing, gunpowder, the nautical compass, was introduced in the West, although it originated in the East. Technological progress was supported by the great voyages.
16^{th} - 18^{th} centuries	Only mechanical technology significantly advanced. Organizational technology was strikingly lacking. Technological progress was limited by the remnants of humanism that advocated the supremacy of man over means.
Industrial Revolution	Systematization of technology in the rationalized systems of administration, law (Napoleonic codes), science (Descartes principles), the economy (liberalism) and the military (Frederick the Great and Napoleon strategy) came about with the emergence of an autonomous state dedicated to safeguarding its own interests (a product of the French Revolution). This systematization was followed by

	mechanical development evoked by the exploitation of energy. The industrial revolution was a product of the simultaneity of five phenomena: the fruition of a long technical experience; population expansion; the suitability of the economic environment; the disappearance of social/religious taboos and of a natural hierarchy (clergy, nobility, monarchy) in favor of safeguarding the rights and liberties of the individual (raised importance of the state vs. the family, the guilds, the communes etc.); the appearance of "power through efficiency" as a clear technical intention.

(Ellul, Technological Society 23-63)

Table 6

New Characteristics of Modern Technology

Characteristic	Aspect(s)
Automatism of Technical Choice	1. Once the availability and the efficiency of a technology is recognized, its adoption is automatic. The "choice" among technologies is grounded on a mechanical process that determines efficiency, i.e. "the one best way". 2. Technology automatically eliminates non-technological activity.
Self-augmentation	Technology progresses autonomously, as a result of its own accomplishments. It establishes the conditions necessary for its own advancement. The significance of human intervention is muted. Self-augmentation is formulated in two laws: 1. Irreversibility of technological progress; 2. Geometric vs. arithmetic progress of technology, i.e. technologies are interdependent. Technology progresses unevenly and unpredictably. It poses only technological problems to be resolved by technology itself. It does not progress toward a pre-determined objective but advances in a causal way (through combination of its elements).
Monism	The technological phenomenon forms a whole delimited by certain fundamental characteristics (i.e. rationality and artificiality). There is no sense in distinguishing the impact of one technology from another since they are part of the same technological complex.
Universalism	1. Geographic aspect: The spread of the technological phenomenon has depended much on commerce and war. 2. Qualitative aspect (its totalitarianism): The technological phenomenon cultivates a common bond and worldview across humanity. However, the specialization to which it gives rise prevents mutual understanding and promotes isolation/distanciation.
Autonomy	1. Technological determinism: the conditioning of social, economic and political change by technology; 2. Lack of moral and spiritual values in the technological phenomena, however, technology is itself sacred.

(Ellul, Technological Society 79-147)

Table 7

Pragmatics of Scientific Knowledge Vs. Narrative Knowledge

Scientific Knowledge	Narrative Knowledge
1. Privileges denotation.	1. Applies various language games.
2. Set apart from other language games that form the social bond although it remains indirectly a part of this bond by establishing a profession and social institutions.	2. Customary Knowledge.
3. Competence is tied to the position of sender. Exceptionally, in didactics, the student as receiver must be intelligent.	3. Competence is rooted in the sender having previously heard the story. The receiver, therefore, gains the same authority once he/she has heard the story.
4. Scientific statements are not validated from being reported. There is no truth from performativity.	4. Performativity (the act of narration), and not just the content of stories, provides a foundation for the social bond.
5. Scientific knowledge is a cumulative process. It is characterized by a diachronic temporality that is a memory of past projects and knowledge of a future project. That is, the sender must be familiar with previous knowledge and propose new, innovative knowledge.	5. Narrative knowledge follows a certain rhythm. It has an effect on time. Narrative, as a form of competence, substitutes the need to recount social history.

(Lyotard 18 ff.)

Table 8

Principles of Symmetry and General Symmetry

Symmetry (Bloor on science)	Symmetry (Pinch and Bijker on technology)	General Symmetry (Callon on sociotechnology)
Impartial to a statement being true or false.	Impartial to a machine being a success or failure.	Impartial to an actor being human or non-human.
Symmetrical with respect to explaining truth and falsity.	Symmetrical with respect to explaining success and failure.	Symmetrical with respect to explaining the social world and the technical world.
"Nature" is the result, not the cause, of a statement becoming a true fact.	Working is the result, not the cause, of a machine becoming a successful artifact.	The distinction between the technical and the social is the result, not the cause, of the stabilization of sociotechnical ensembles.

(reproduced from Bijker 275)

Table 9

Configuration Model for Mapping Sociotechnical Change

Possible Configurations	Outcome
No dominant technological frame	A radical, alternative sociotechnical ensemble is established and all of its aspects are subject to variation. The process of stabilization depends on the "enrollment" by one group of all other groups in support of the alternative ensemble.
One dominant technological frame	Actors with high and low inclusion within the dominant group should be distinguished. Actors with high inclusion will typically support conventional inventions (improvements, adaptations).
Two or more dominant technological frames	Closure of the ensemble will be erratic. It will be determined by criteria that is external to all the dominant frames, either through rhetorical closure or through an amalgamation of vested interests.

(Bijker 276-279)

Table 10

Reproductive Technology – A Form of Technoscience

Principles of Scientism (Postman)	**Reproductive Technology**
Misapplication of technology.	The misuse of forceps initially provoked much criticism of forceps during the 18th and 19th centuries. However, the power of this instrumentation to reinforce the role of male medical practice in "women's business" caused forceps use to persist, as well as to give way to other forms of medical instrumentation.
Confusion of the material and social realms.	Foetal monitoring attempts to discredit women's experiences in pregnancy. It discounts these experiences by replacing them with evidence-based medical imagery.
Application of the objectives and methodologies of the natural sciences to social phenomena.	Infertility is considered an illness because of the possibility of technological intervention. This strengthens the maternal function of all women.
Attempt to use science to provide an objective answer to the meaning of life.	The scientific paradigm of medicine enables the documentation, intensive measurement and monitoring of the birthing process, the truly embryonic stage of the development of life. Abortion is an attempt to control the death of human life.
Aspects of Medical Practice Reflecting Technoscience (Casper & Berg)	**Reproductive Technology**
Role in the construction of human bodies.	Pre-natal genetic screening, in-vitro fertilization and other reproductive technologies can materially alter the natural development of women's bodies.
Role in the transformation of categories of life, health, death etc.	Childbirth is transformed into a pathological process that requires technological intervention and treatment. Pre-natal genetic screening can change the view of disability in society.

Role in the control of bodies and lives.	Technologies such as the stethoscope and foetal monitoring provide information to the physician that cannot be obtained by the pregnant mother. This allows them to gain control over her body by offering "options" for intervention. In addition, reproductive technology can be used as a means of population control, especially in the Third World (e.g. birth control).
Iatrogenic Medicine (Illich)	**Reproductive Technology**
Clinical iatrogenesis.	The prevalent use of ultrasound technology persists despite the fact that its routine use has never been proven to be effective.
Social iatrogenesis.	Expropriation of women's reproductive experiences in favour of medical management of the process of reproduction; denial of self-care and strict regulation of midwifery.
Cultural iatrogenesis.	The reduction of women to passive, reproductive objects by the male medical profession has engendered negative and alienating emotional experiences of childbirth for women.

(Several critiques of reproductive technology were reviewed in Wajcman 54-80.)

Table 11

Emerging Issues in the Allocation of Health Care Resources

	The Issue	The Debate
Internal to Health Policy	Access to Technology	Some studies have argued that US citizens have greater access to high-technology care than Canadians. However, these studies are strongly criticized for their limited scope and their simplistic analysis. For instance, they do not consider unnecessary diffusion, the quality of care received, the number of technological systems versus the number of procedures etc. Nonetheless, these studies have been used to justify the right of high-income individuals to purchase cross-border services. These well-to-do individuals, it is feared, would encourage "two-tier" medicine and jeopardize the universality of the Canadian health care system. Other studies have found that waiting lists are, on average, caused by organizational bottlenecks (poor referral patterns, lack of appropriate information about service availability) and sudden changes in medical practice (including referral patterns).
	Limits of Medical Care	Since the 1970's, the main objective of the Canadian health care system has shifted from equal access to medical care to equitable access to health. Simultaneously, the definition of health and health care has expanded in scope to include other social and environmental factors. Hence, the health care system is faced with the challenge of defining its boundaries.
External to Health Policy	Economic Trends	The federal government set up a task force chaired by Heagerty once it adopted state medical insurance because it foresaw an important escalation of health care expenditures. While the task force suggested strategies to reform traditional delivery mechanisms (such as community health centres, salaried providers, para-professionals), these strategies were quickly discounted once the government was forced to confront tough objections from the medical profession. The medical profession accepted the implementation of reform only in cases where the provision of services was not considered profitable,

	The Issue	The Debate
		such as in remote, rural, inner city and other underserved areas. After the economic recession of the 1970's, the provinces began to exert some indirect control over hospital and medical expenditures by closing hospitals and refusing demands for fee increases. Physicians responded to the provinces' cost-cutting measures with extra-billing and, antagonistically, the federal government counter-responded with the *Canada Health Act*. Reacting to a rising national deficit, the federal government has progressively reduced the growth of transfer payments to the provinces. The EPF formula has undergone a series of modifications (in 1986, 1989, 1990, 1991) to the point where it is projected that the cash portion of transfer payments will eventually be eliminated. Hence, the federal government will loose all financial leverage to enforce the CHA principles. Health care reform during the 1990's was incited by the fact that the rate of utilization of health care services outgrew population growth and that costs rose to a rate surpassing increases in provincial revenues.
	Demographic Projections	While Canada has the youngest population of all OECD countries, it is projected that the demographic shift to an older population will cause the health care system to become unmanageable once European levels are reached. The shift from infectious diseases to chronic and degenerative disorders will greatly strain the system.
	Federal/ Provincial Disputes	The preservation of national standards has been hampered by cuts to federal transfer payments, as well as threatened by regionalism in the Western provinces and separatism in Quebec. Nonetheless, health care continues to be viewed as an element of Canadian nationalism, as reported by the Citizens' Forum on Canada's Future and the National Forum on Health. In 1991, an unprecedented lobby group, HEAL, composed of seven of the largest health care and consumer groups, was established to defend national standards.

	The Issue	The Debate
	Ideological Beliefs	State health care insurance is continuously eroded by provincial governments who attempt to transfer costs to users to avoid tax increases. They do so by charging annual premiums, by reducing the list of services considered as "medically necessary", by charging users for "unnecessary" emergency room visits etc.

(Mhatre and Deber 650-654)

Table 12

Empirical Evaluations of Canadian state health insurance

Subject Area	Results
Regional Disparities	In 1985-86, the four Western provinces spent a fifth (18.9 per cent) more on health care per capita than the four eastern provinces. There are also differences in the provision of specialty services. In 1986, in terms of rates per 100,000, residents in the four provinces with the highest per capita incomes had 72.3 per cent more CAT scans, 85.5 per cent more diagnostic ultrasound images, 77.8 per cent more hip replacements and 42.8 per cent more individuals benefiting from renal dialysis. In 1975, Saskatchewan urban residents received 17.7 per cent more services (in terms of expenditures) than rural residents. This amount had increased to 23.1 per cent in 1985. While frontline primary care services are more uniformly available across Canada, and infant mortality rates and longevity have stabilized to the same levels across regions, regional disparities in per capita health expenditures and in the availability of some services (especially specialist and technology-intensive) remain.
Access to Medical Care	Among studies dating back to the period immediately following the introduction of state health insurance, one third concluded that class differences were eliminated, one fourth found that the lower class increased their use of services and even surpassed the rate of use of the higher class, and the rest concluded that use remained a function of class position. Among recent studies, their conclusions vary according to research design and analytical method rendering them virtually incomparable to one another. In addition, they rely on administratively available indicators and, therefore, fail to take into account qualitative indicators of care and differences in experiences of more vulnerable groups. Notwithstanding, Badgley concludes that class disparities in the use and type of medical service remain prevalent in Canadian health care.
Out-of-pocket Expenses	From 1964 to 1982, national family expenditure surveys confirmed that higher-income individuals have consistently spent more on health care (in 1964, 4.5 times more; in 1972, after the introduction of state insurance, 3.3 times more; in 1982, 3.9 times more).

Health Status, Longevity, and Disability-Free Years	The persistence of higher levels of occurrences of illness and disability among the lower classes prior to, and following the introduction of state-wide health insurance is demonstrated by national health surveys and research documenting the relationship between class position and health status (such as work-related injuries, emotional well-being of welfare children, and illness and health among the unemployed). The gap between life expectancy of the higher and lower classes approximates six years for men and three years for women. One major study has proven that this gap has widened in recent years.

(Badgley 660-665)

Table 13

Approaches to Decision-Making in the Rationing of Health Care Resources

Cost-Utility Analysis	1. It requires the aggregation of health benefits across a population but is implemented for and affects individuals; 2. It forces the exchange of incommensurable goods, goods with qualities that are valued differently; 3. It ignores the value of health services that may not result from changes in health status; 4. It ignores the distribution of benefits and hides the rationing process. For these reasons, Goold finds that it violates the criterion of consent. She concludes: "As a technological approach to centralized decision making, cost-utility analysis has been criticized for distancing decisions from decision makers, making them less accountable to those whose consent is being sought or presumed" (82).
Informed, Democratic Decision-Making	1. It ensures fair representation; 2. It provides a basis for self-respect; 3. It allows pluralistic conceptions of the good (public and private); 4. It involves public deliberation. Hence, Goold concludes that it satisfies most criteria for consent. She describes ways in which it can be achieved: A. By using existing structures of government where the difficulty lies in fulfilling the information requirement (information on costs, outcomes, epidemiology, population preferences etc.); B. By adopting a grassroots approach where the difficulty lies in achieving satisfactory representation; C. By instituting selected representation (a body whose mandate is restricted to health care).
Veil of Ignorance	This is a hypothetical situation where free and equal citizens deliberate without knowing their present and future, social and economic positions. If applied to health care rationing, this process would require information about social resources and health needs, the effects of health care and its impact on the population. However, participants would remain unaware of their current and future personal health status and needs.

(Goold 77-87)

Table 14

Models of Accountability in Health Care

Characteristics of Accountability	Professional Model	Economic Model	Political Model
Conception of Patient	Participant recipient of professional services	Consumer of health care commodity.	Citizen member deciding over public good.
Conception of Physician	Professional dedicated to patient well-being.	Provider, economic unit.	Citizen member.
Conception of Health Care	Professional service in which the goal of promoting the patient's well-being is specified by shared decision making between patient and physician.	Commodity that has fixed, objectively defined performance characteristics that consumers select to satisfy their subjective preferences.	Public good in which the goal of promoting the patient's well-being is specified by the political community.
Primary Domains	Professional competence and legal and ethical standards.	Financial performance and professional competence.	Any domain(s) selected by the health care community.
Primary Parties/Locus	Interaction between physicians and professional association and patients.	Interaction in the marketplace between provider and consumer with oversight by government regulatory body.	Interaction between physicians and governing representatives and governing representatives and citizen members.
Primary Procedures	Licensure, certification, and malpractice suit.	Exit: switching providers.	Voice: expressing dissatisfaction and ideas for reform.

Characteristics of Accountability	Professional Model	Economic Model	Political Model
Institutional Structures	Accreditation, licensure, and legal proceedings.	Consumer protection policies, standard price and quality information (report card), and frequent enrollment opportunities with an array of alternative providers.	Open forums for members to express their views, member board of directors, and other procedures for control over administrative decision making.

(Reproduced from Emanuel and Emanuel 163)

Table 15

Ideal Types of Health Care Systems

	State/Sponsor	Professional	Corporate	Community
Key Values & Goals	*To strengthen the state or sponsor by a healthy, vigorous population.* To minimize illness and maximize self-care. To minimize the cost of medical services to the state. To provide good, accessible care to all sectors of the population. To instill loyalty, gratitude.	*To provide the best possible clinical care to every sick patient* (who can pay and who lives near a doctor's practice). To develop scientific medicine to its highest level. To protect the autonomy of physicians and services. To increase the power and wealth of the profession. To increase the prestige of the profession.	*To maximize market share and profits of each corporation.* To increase demand through better or more convenient services, creation of new services, and creation of new demands. To minimize, neutralize, or circumvent regulation and restraints by government or payers.	*To develop with others priorities and programs that minimize disease, disability, death, and suffering.* To promote ties and mutual support among members. To minimize the financial impact of illness.
Image of the Individual	A member, and thus, the responsibility of the sponsor.	A private person who chooses how to live and when to use the medical system.	A private consumer, the object of marketing to maximize expenditures for health care services.	An active, self-responsible, informed member of the community.
Power	Either democratic or autocratic or a cross-mixture. Secondary power to medical associations.	Centers on the medical profession and uses state powers to enhance its own.	Centers on corporate headquarters.	Local control. Mutual decision making. State and profession relatively weak.

	State/Sponsor	Professional	Corporate	Community
Key Institutions	The ministry or department of health and its delegated system of authorities.	Professional associations. Autonomous physicians and hospitals.	Health care corporations. Governments, as the source of revenues and protection from unwanted competition.	Community boards. Mutual benefit associations.
Organization	An integrated system, administratively centralized, or decentralized. Organized around the epidemiological patterns of illness. Organized around primary care. Relatively egalitarian services and recruitment patterns. Strong ties with health programs in other social institutions.	Centered on doctor's preferences for specialty, location, and clinical cases. Emphasis on acute, hi-tech interventions. A loose federation of private practices and hospitals. Weak ties with other social institutions peripheral to medicine.	Monopolies or oligopolies in market segments or whole markets. Integrated delivery systems with doctors as employees, contractees, or partners.	A loose federation of member groups. Administratively collegial. Organized around work or communities. Emphasis on low-tech, primary care, and prevention. Strong ties to other community programs (educational, occupational, social services).
Division of Labor	Bureaucratic, physician controlled. More health care teams. More delegation, substitution. Strong primary care base.	Hierarchical, doctor controlled. Specialty oriented.	Whatever maximizes profits and market appeal.	Egalitarian. Participatory. More health care teams. More delegation, substitution. Strong primary care base.

	State/Sponsor	Professional	Corporate	Community
Finance & Costs	Taxes, premiums, or mix. Community-based budget that contracts with doctors and facilities for service. All care free or nearly free at point of service. Costs low compared to the professional model.	Private fees paid by individual to doctor when feasible. Private, voluntary insurance as passive vehicle to pay bills. Highly inflationary.	Private, voluntary insurance as passive vehicle for paying bills. Highly inflationary.	Taxes, premiums, or mix. Community-based budget that contracts with doctors and facilities for service. All care free or nearly free at point of service. Costs low compared to the professional model.

(Reproduced from Light 112-114)

Table 16

Citizen Governance Model

Elements	Planning Process	Implementation Process
1. *Coordinating Council*: delegating issues to citizens' boards and hearing their recommendations, ensuring these fit within overall community goals. 2. *Citizens' boards*: advisory, delegate. 3. *Helper*: public service practitioners as advisers and implementers of daily tasks.	To be undertaken perhaps by a *Committee on Citizen Governance*: 1. Inventory of services governed by community body and identify which services would benefit from citizen governance; 2. Determine scope of responsibility taking into account the limits of individual knowledge; 3. Determine scale of board (composition, representation); 4. Determine sphere of responsibility; 5. Work in concert with an outside citizen involvement program.	1. Formalize the structure (allowing flexibility and incremental implementation); 2. Train the staff; 3. Train the board members; 4. Resolve issues (scheduling, reporting or joint membership agreements); 5. Make mid-course corrections.

(Box 164-167)

Table 17

Historical Periods of Community Involvement in US Health Care Policy

Fostering Community Responsibility and Control (1650-1830)	Communities were held responsible for the destitute, a responsibility formalized in multiple statutes. Communities were viewed as instruments of social control. Statutes set the community's boundaries: the conditions under which familial obligations superseded those of the community, and residency requirements to receive assistance (mixed funding).
Fragmentation of Community (1830-1900)	The community's customs and medical beliefs played a determining role in the development of health care within its boundaries. Access to resources was granted, not so much on the basis of residency, as on the basis of an individual's economic productivity. Local governments established municipal hospitals to offer services to those rejected by private, nonprofit hospitals. As the number of hospitals increased, hospital admission procedures were transferred from elite community members to medical practitioners due to rising market pressures.
Community as Object (1900-1960)	The growing authority of the medical profession, supported to a large extent by the diffusion of scientific knowledge and specialist practice in medicine, dramatically reduced community responsibility and control. The community was viewed as an object of the health care organization's practices, as opposed to an arbiter of its performance. Community members were positioned as consumers within the health care system.
Combining Community Control with Community Participation (1960-1995)	Community responsibility is revitalized in new forms of organization, including district health systems, community health organizations or centres, consumer boards, community/citizens' forums etc. Initiatives are plagued with professional resistance and the emergence of market pressures and cost-containment concerns.

(Schlesinger 943-954)

Table 18

Various Uses of Outcomes Information

Stakeholder	Uses
Public and private payers	• reduce costs • ration care • establish national guidelines for care • make decisions on reimbursement of professionals • make decisions on the purchase of services
Hospitals and other health care organizations	• establish local guidelines for care • market services • improve services • ensure regulatory compliance
Individual providers	• make diagnostic and treatment decisions
Patients	• make treatment decisions • make purchasing decisions

(Guadagnoli and McNeil 16-20)

Table 19

The Postindustrial Society: A Comparative Scheme

Modes	Preindustrial	Industrial	Postindustrial
Mode of production	Extractive	Fabrication	Processing and recycling services
Economic sector	Primary: agriculture, mining, fishing, timber, oil & gas	Secondary: goods, producing, durables, nondurables, heavy construction	Tertiary: transportation, utilities; Quaternary: trade, finance, insurance, real estate; Quinary: health, research, recreation, education, government
Transforming resource	Natural power-wind, water, draft animal-human muscle	Created energy-electricity, oil, gas, coal, nuclear power	Information-computer & data transmission systems
Strategic resource	Raw materials	Financial capital	Knowledge
Technology	Craft	Machine technology	Intellectual technology
Skill base	Artisan, farmer, manual worker	Engineer, semi-skilled worker	Scientist, technical & professional occupations
Methodology	Common sense, trial & error, experience	Empiricism, experimentation	Abstract theory, models, simulations, decision theory, systems analysis
Time perspective	Orientation to the past	Ad hoc adaptiveness experimentation	Future orientation, forecasting & planning
Design	Game against nature	Game against fabricated nature	Game between persons
Axial Principle	Traditionalism	Economic Growth	Codification of theoretical knowledge

(reproduced from Bell 94)

Table 20

Communities of Broadcast versus Communities of Interactivity

Communities of Broadcast	Communities of Interactivity
The many "speak" to the many by way of the agent of message producers ("media workers", the culture industry etc.)	The many speak to the many by way of the computer-mediated simulation of presence
Centred	Decentred
Influences consciousness	Influences individual experience of space and time
High level of recognition/identification between individuals	Low level of recognition/identification between individuals
Very low level of reciprocity	Very high level of reciprocity
Individual experiences strong identity/identification with figures of authority, charisma or cult movements	Individual experiences weak identification with others as figures of authority or charisma
Concentration spans of audiences are sold to advertisers	The need to communicate in highly urbanized settings is sold to individuals
Primary basis of the cellularization of social interaction in information societies	An extension of the cellularization of social interaction via the workstation as well as household

(reproduced from Holmes, "Virtual Identity" 32)

Table 21

Critique of Canadian Telecommunications Public Policy

Myths	Analysis
Technological nationalism	It is intended to cultivate "*nationhood through deployment of industrial devices*" (Babe 5). Especially significant due to Canada's geographical vastness and cultural diversity, communications technologies play a role in creating "*the shared experience of living together in the second largest country in the world*" (Babe 6-7), and in asserting Canadian economic and political sovereignty. However, Babe contends that the importance of American content and control in Canadian telecommunications is downplayed in federal policy in order to secure the illusion of technological nationalism. He further claims that "... *computer networks extend the hegemony of transnational corporations*" (8).
Technological dependence	It encompasses the technological imperative and technological determinism. The imperative dictates that technological change is a necessity in the order of the world, that it is a form of natural evolution. Technological determinism conditions people to believe that technology is the origin of all things and phenomena important in the world, including social change, and that with it necessarily comes new values, new ethics etc. Both myths portray resistance as regression and as a threat to the inevitability of progress. To dispel the myth of technological dependence, Babe points to the amount of resources invested by governments to shape the "information revolution", as well as the historical role of military procurement and government R&D in the growth of high-technology industries and markets.
Technology and Industrial Structuring	It entails three main assumptions: (1) efficient and existing industrial structures are founded on the corresponding technic (the "natural monopoly"); (2) cultural and communication industries were historically kept separate because of their underlying industrial arts; (3) convergence is a result of industrial applications of scientific knowledge (the "technological evolution"). Once, again, in order to dispel this myth, Babe reiterates the importance of the role of government in securing monopolies and forcing convergence through deregulation (or "re-regulation") of the telephone and cable markets.
Efficacy of Regulation	It suggests that regulation protects against unrestrained monopoly power, while Babe demonstrates that regulation has often contributed to such monopolies.
Creative Destruction	It alleges that technological innovation – the result of the capitalist, entrepreneurial spirit – protects against "old monopolies". Innovation

	guarantees competition, whether reactive or proactive. Notwithstanding, Babe recognizes that innovations are most often absorbed by old monopolies.

(Babe 5-20)

Table 22

Models of Telecommunications Development

Idealist (Utopian) Classical, Economic Model	Strategic (Reality-based) Critique of Classical Model
MARKET PREMISES	
• amount of sellers with negligible, individual importance; • perception by buyers of a homogenous product; • assumption that buyers possess sufficient, adequate knowledge to render informed, rational decisions; • absence of barriers to enter or exit the market; • technology as a cure of society's ills.	• institutions are, of a majority, unstable, oligopolistic powers that employ short-term pricing strategies to gain monopolistic control over markets (telephone/cable companies); • all market participants are not served equally (remote and rural communities).
ASSUMPTIONS	
• integration of information and communication services within a permeable, seamless network (no boundaries between private/public); • ubiquitous and universal service diffusion through lower costs of extending services, an increased feasibility of responding to consumer needs (through interactive services), and competition in supply; • transition from a supply-led to a demand-led industry; • subsequent rationalization of supply and introduction of high quality and flexible services at reduced costs; • disappearance of incumbents due to market forces; • resolution of minor market disruptions through minimal forms of regulation; • collaboration in partnerships to respond to consumer demand; • creation of specialized regulative agencies at the national and regional levels to ensure efficiency and fulfillment of public service objectives.	• network integration unlikely; • competition (pricing, propriety standards and policy intervention) is likely to result in new disparities; • subsequent disparities and uneven development reflected in the terms and conditions of network access; • largely supply-led industry with the only significant influence of demand coming from multinational business interests; • technical innovation as a weak stimulus for competition which cannot impede monopolization and network segmentation created from supply/demand balance; • pressures created by new regulatory agencies to incite suppliers to dominate markets.

(Mansell 7-10)

Table 23

IHAC – Recommendations regarding Privacy

Protection should embody all principles of fair information practices of the Canadian Standards Association or CSA's draft "Model Code for the Protection of Personal Information".
The federal government should continue to participate in the development and implementation of effective national, voluntary standards based on this model code.
A federal/provincial/territorial working group should be established.
A flexible legislative framework should be established that applies to the public and private sectors.
In cooperation with the CSA's Working Group on Privacy and other bodies, the federal government should study the development of effective oversight and enforcement mechanisms.
The working group should study the possibility of using privacy-enhancing technologies to provide government services and information.
Governments should update and harmonize appropriate privacy protection policies, legislation and guidelines applicable to government operations, service delivery and information.
Industry Canada should form a working group which would include representation from consumer organizations to create public awareness and understanding of issues and rights through educational materials.
Industry Canada should aid the CSA in promoting its expertise in international fora.
The provinces and territories should adopt their own measures.
A security infrastructure should be established that is consistent with OECD Security Guidelines (1992) including an oversight body to address issues such as a Public Key Infrastructure certification authority.
The federal government should lead the development of a PKI to serve its own needs.
Encryption guidelines should be set.
Any action should take into account the need to preserve legitimate research opportunities, especially in the health domain.

(IHAC, Connection 141-147)

Table 24

Six Pillars of the Connectedness Agenda

Pillar	Performance Goal	Examples of Activities
Canada Online	Provide access to a world-leading Information Highway infrastructure and to the learning network.	• 10,000 CAP sites (5000 rural and remote, and 5000 urban) connected by 2000 and made self-sustaining by 2001-2002 for lifelong learning and e-commerce; • 16,500 schools and 3,400 libraries connected to the Internet in 1998-1999 through SchoolNet; • 450 First Nation schools connected to the Internet (including hardware/software, free satellite channels and subsidized telecommunications access); • Student Connection Program, National Graduate Register and Campus Worklink; • Computers for Schools Program (transfer of surplus computers to schools and libraries); • upgraded Internet infrastructure by CANARIE; • 10,000 voluntary and charitable organizations connected to the Internet by 2000 via VOLNET; • francophone communities connected to each other across Canada through a Francophone Intranet.
Smart Communities	Encourage communities to become leading-edge users of information technologies through a coast-to-coast network of Smart Communities.	• Report of the Panel on Smart Communities citing recommendations regarding the implementation of the initiative; • Results of the first phase of the process of selection of communities for the Demonstration Project to be released in the Fall of 1999.

Pillar	Performance Goal	Examples of Activities
Canadian Content Online	Make Canada a world leading-edge supplier of digital learning materials and multimedia content.	• multimedia collections of Canadian content produced through contract employment of young adults via the SchoolNet Digital Collections Program and the Aboriginal Digital Collections Program; • Spirit of Aboriginal Entreprise Initiative.
Electronic Commerce	Create a legal and regulatory framework that will make Canada a global centre of excellence for electronic commerce.	• policy development; • OECD Ministers meeting held in Ottawa in October 1998 to discuss global e-commerce.
Canadian Governments Online	Connect citizens and government.	• Strategis (Industry Canada's website for business and consumer information); • Internet access to the Canada Business Service Centres; • Aboriginal Business Map; • ExportSource.
Connected Canada to the World	What else could it be but promote a connected Canada to the world.	• Participation in the ITU and World Radiocommunications Conference (WRC 99).

(Industry Canada, Making a Difference 15-21)

Table 25

Recommendations of the NFH's EBDM Working Group on the Protection of Personal Information in the Private Sector

The Group recommends that the model legislation:

(a) recognize that the interest of commercial bodies in data may differ significantly from the public interest in research and:
  (i) distinguish between the administrative use of data and statistical use of data;
  (ii) distinguish between the use of data to advance the public interest and its use in pursuit of a private or commercial interest.

(b) follow the lead of the European Parliament in balancing privacy and access to data for health research in the public interest and exempt health research from the following:
  (i) except with informed consent, not use data collected for any other purpose (or for a purpose other than that intended);
  (ii) destroy information after a specified time period;
  (iii) prevent an agency from disclosing information to a third party unless it has been part of the stated purpose or otherwise authorized by the individual.

(c) provide for the adoption of an information infrastructure which includes an access and confidentiality committee, university-based ethics committees, professional standards and clear instructions on the methods for keeping data confidential.

(d) assure privacy with the computerization of personal information through safeguards such as Personal Information Identifiers (PIN).

(NFH, "Creating" 34-35)

Table 26

Recommendations of the National Conference on Health Info-structure concerning Stakeholder Issues

Stakeholder Group	Priorities and Needs
Policy-makers/ Administrators	The Council should articulate a vision for the CHI. New funding is required. Health Canada should take on a leadership role in the development of the CHI that would include stakeholder consultation, standards development, enforcement of provincial compliance with current reporting data requirements, coordination and strengthening health information resources. Coordination of existing efforts to define information needs and priorities is needed. Accountability to the public through system-wide disclosure of the public/private relationships in the CHI should be strengthened.
Health service providers/ researchers	The CHI should be developed by a national body and include: resource integration, new money for new resources, broad representation and the leadership of Health Canada. Two outputs should be pursued: evidence-based information for service providers and information for accountability to the public. Demonstration projects to evaluate ways of delivering evidence-based information to practitioners should be funded.
Members of the public	Public involvement in an ongoing broad consultation process at the federal and provincial levels on the CHI should be facilitated to discuss public education, public participation in decision-making, and designation of health information as an integral component to the Canadian public health care system. The health infostructure should be funded by new money. An ongoing mechanism for public input into the CHI should be established to address the following priorities: accountability to the public and custody of the CHI to remain in the public health care system. Various means of providing balanced and equal access to health information should be enabled taking into account multicultural needs, affordability, technical access and making use of existing, quality health information in non-electronic media. Comprehensive privacy legislation should be enacted to cover the public and private sector, requiring individual consent for access to personal medical information, providing for individual ownership of that information and the application of strict conflict of interest guidelines. Health information should be knowledge-based, such as tangible

Stakeholder Group	Priorities and Needs
	consumer information on health outcomes beyond medical records.
Aboriginals	The issue of basic health inequities among different Aboriginal populations should be considered. To address the issue of trust, Aboriginal communities should retain governorship and ownership of the health system and information. Health information systems should be flexible in order to accommodate cultural and community sensitivities. Communities should be involved in system design and development. Changes should not prejudice existing treaty rights and fiduciary relationships.

(compiled[184] from Lee, National Conference on Health Info-structure 73-75)

[184]Statements were reproduced with certain revisions.

Table 27

Recommendations of the Advisory Council on Health Infostructure concerning "Empowering the Public"

2.1 Health Canada, in partnership with provincial and territorial ministries of health, should recognize in its funding decisions for a health infostructure that health information is an essential public good which should be readily available and accessible to all Canadians as a component of Canada's publicly funded health system.

2.2 To understand better the health information needs of the public, strengthen people's ability to access and use evidence-based information, and provide mechanisms for public access to reliable information, Health Canada should:

- undertake, in partnership with other levels of government and health stakeholders, an investigation of the health information needs of the general public, using a variety of culturally and linguistically appropriate, interactive and ongoing strategies;
- promote, in partnership with other federal departments and agencies (e.g. the Canada Institute for Scientific and Technical Information) and provincial and territorial departments and agencies, the ability of Canadians to access and use evidence-based, non-identifiable health information to meet their health information needs and concerns by establishing a fund that will support demonstration projects;
- establish a fund to allow consumer and health intermediaries to develop and provide access to consumer health information; and
- support the Canadian Health Network as one mechanism for providing Canadians with access to reliable health information.

2.3 Health Canada, in partnership with provincial and territorial health ministries, should take the lead to:

1. ensure that standards/benchmarks/guidelines are developed and implemented to allow the general public to distinguish objective, empirically based health information from information intended to promote a product; and
2. expand these standards/benchmarks/guidelines eventually to include rating criteria for websites providing health information.

2.4 Health Canada should work with other health stakeholders to:

1. ensure that health concerns such as consumer protection with respect to health products and services are adequately reflected in the present work of federal, provincial and territorial governments to develop legislative and regulatory frameworks for electronic commerce on the Internet; and
2. take appropriate alternative action if health and safety issues are not adequately reflected in this work.

2.5 Health Canada should work with other federal departments and agencies and specialists in the field to encourage development of:

1. an Internet search capability which is specific to health and, at a minimum, fully and equally meets the needs of Canada's English- and French-speaking communities; and

2. Internet content on health in French and English.

2.6 Health Canada, in partnership with representatives of user communities such as the Canadian Association of Public Data Users, should take the lead in approaching Treasury Board and other federal departments and agencies to review the policies and practices with respect to cost recovery and revenue generation governing the availability and redistribution of publicly funded collections, statistical databases and other government information relevant to health.

2.7 Investments in the digital networking of the Canada Health Infoway should be balanced by appropriate investments in the other (i.e. non-electronic) mechanisms for sharing information that can lead to improved health.

2.8 To ensure that health information is accessible on a universal, equitable and affordable basis, it is vital that:

1. the federal government continue to ensure universal, equitable and affordable access to existing and future basic telecommunications infrastructure; and
2. Health Canada, in partnership with provincial and territorial ministries of health, take a leadership role in ensuring that health information and health care applications for the general public are developed in such a way as to be accessible to all citizens, irrespective of their geographic location, income, language, disability, gender, age, cultural background or level of traditional or digital literacy.

2.9 Health Canada, in partnership with other federal departments, provinces and territories, and health stakeholders, should:

A. ensure establishment of a "Canada Health Space" as a universally accessible health information/communications commons;
B. capitalize on and support the nation-wide networking of health intermediaries;
C. ensure adequate funding and technical support to health intermediaries to develop and/or maintain their capacity to provide the general public with timely, credible and "understandable" health information and to assist in overcoming access barriers; and
D. accept, as a normal budgeted cost of doing business electronically, the need to sustain health intermediaries and support them for providing affordable electronic health information services to disseminate health promotion, health protection and other kinds of health information to wider publics, just as such costs have been accepted in the paper-based world in the past.

2.10 Health Canada, in partnership with provincial and territorial ministries of health, should work closely with Industry Canada to ensure that all public and not-for-profit health care institutions in Canada are aware of:

A. the CAP; and
B. how they can apply for resources to locate public electronic access facilities on or near their premises to help ensure that their clients can use on-line health information.

2.11 As a means of ensuring more equitable access to health information and health care services, Health Canada, in partnership with provincial and territorial ministries, should work closely with CANARIE and Industry Canada to investigate the further integration of new technologies, including satellite

technologies, into health networks at all levels.

2.12 Health Canada should establish a non-governmental office of citizen health advocacy to coordinate and facilitate input and participation by the general public into health policy deliberations, including policies relating to the Canada Health Infoway. This office would:

A. coordinate and facilitate the linking of community-based voluntary health organizations and health consumer organizations to enable or enhance their capacity to participate effectively in health and public policy development; and

B. constitute an ongoing, stable mechanism for obtaining reliable and representative input and feedback from the health consumer sector.

2.13 The office of citizen health advocacy should ensure production of assessments and evaluations of health sector activities relating to the general public. These would include setting agenda and critiques for report cards on the performance of health care programs and services, outcomes of interventions and treatments, and the actual health impact of health policies.

(reproduced from ACHIS, Canada Health Infoway 2.3-2.13)

Table 28

Provincial and Territorial Health Information Networks

Province/ Territory	Health Information Networks (HINs)
Alberta	**Alberta *Wellnet***: province-wide HIN for EBDM (health determinants, performance monitoring and assessment), administration and research. Standardized information will be collected at the individual person level and aggregated to support research, planning and decision-making in the area of population health. Applications are focussed on human resources and finances, and includes a Pharmacy Network. Alberta Health is the main health agency of the network. **Community Health Immunization Information System (CHIIS)**: Calgary Health Services, 16 community based offices and Alberta Health have access to 9 CHIIS databases distributed through a wide area network.
British Columbia	**HealthNet/BC**: open data network and information sharing facility with restricted access. Projects include the Connections Project (links between acute care hospitals, government offices, RHBs and CHCs for access to communications services, such as an e-mail directory and a product and services catalogue, and PharmaNet access for hospitals), a Client Registry (demographic information), PharmaNet (drug use and interaction, on-line claims adjudication), Teleplan (electronic submission of physicians' claims). The BC Ministry of Health is the main health agency of the network. **Information Resource Management Plan (IRMP)** of BC Ministry of Health composed of an integrated record of health services received by an individual over time; a common information repository for health planning, evaluation and research; common data and processes to ensure consistency of demographic, enrollment and eligibility information; common computer communications network (extending the model of the Continuing Care Data Warehouse Network or CCData currently operating).
Manitoba	**MHIN**: province-wide HIN that includes the Drug Programs Information Network (DPIN) to manage prescription records, process claims, provide drug histories/warning notifications, and provide real-time adjudication of Pharmacare reimbursement to patients and pharmacies (also provides medication

	dispensing information in emergency rooms); a Decision Support System; a Diagnostic Services Information Network to link laboratories; Community Health component (not yet specified); a Physician/Primary Care Provider component (not yet specified). The Network is being developed by the Health Information Services of Manitoba Steering Committee, a corporation whose sole shareholder is the Minister of Finance of Manitoba. The Department of Health acts as the main health agency. **Continuing Care Management Information System (CCMIS)**: a decision support tool for workers. The Screening Assessment Care Planning Automated Tool (SACPAT) is used by health care workers to conduct interviews through a Local Area Network and the use of laptops. **POPULIS**: Population-based Health Information System for the statistical analysis of population data for health system monitoring, research and policy analyses. Its five major databases are Hospital Discharge Claims, Physician Claims, Manitoba Centre for Health Policy and Evaluation Research Registry, Vital Statistics, and Personal Care Home Claims. Other databases concern home care, drug use and finances. The system is led by the University of Manitoba, the St. Boniface General Hospital and the Manitoba Health Services Commission. **Integrated Information Systems**: The Community Data Group, formed by community health service providers in Winnipeg, seeks to improve the automated acquisition of population health data, clinic or agency management data, and practitioner data for daily service delivery.
NB	**Wellness Network**: an e-commerce infrastructure (profile management, navigation, security, directory Internet access) accessible to 51 hospital facilities, the Red Cross, the Worker's Compensation Board, physicians (currently 15 per cent) and allied health care workers. Applications are not pre-determined by a lead health agency or partner committee, but rather by the system's users on an incremental basis. The Network includes systems such as the Regional Addictions Services System (RASS), the Extra-Mural Program Patient Unit Information System (UIS), the Medicare Administration and Technical Services System (MATS), the Prescription Drug Program and telemedicine. However, the system can potentially be used for a wide array of services. It is led by a forum of Chief Information Officers from a health corporation that is chaired by the Department of Health.
Newfoundland	**Newfoundland and Labrador Centre for Health Information (NLCHI)**: a comprehensive system for

	health and social services that will distribute health records to individual health institutions and to authenticated providers. In addition, a central database system will register demographic information with reference to the individual's EMR. The database will further incorporate data related to the Department of Human Resources and Employment to take into account non-medical determinants of health in outcomes measurement (income, employment, housing etc.). The Centre will be responsible for the coordination, monitoring and analysis of health data province-wide. The lead health agencies of the project are the Department of Health and Social Services, the Health Care Corporation of St. John's and Memorial University's Centre for Health Research.
NWT	**Network 99**: a health and social services computer network, including WellCom (a record-keeping and electronic data transfer system for CHC management), the Child Welfare Information System (record-keeping) and a telehealth system.
Nova Scotia	**NS Telehealth Network**: a province-wide computer-based telemedicine network connecting all hospitals, spanning 43 sites by the end of 1998. Funded by the Department of Health and managed by TecKnowledge, it will involve the exchange of administrative/financial information but the priority remains clinical and emergency ward applications. **NS Home Care Information System**: the use of SACPAT (mobile computing) by health care coordinators for case and program management.
Nunavut	N/A
Ontario	**Health Information Partnerships** between DHCs, Public Health Units and academic science centres in regions: to support community needs assessment, program design and evaluation, skills transfer and to provide population health data and health intelligence (the use of data in planning, education and research). One such partnership is the Central West Health Planning Information Network that is managed by a Steering Committee made up of representatives from public health units and DHCs in Central West Ontario and the Faculty of Health Sciences of McMaster University. **HealthLink**: a clinical data network that connects seven Toronto hospitals, six CCACs and three private sector partners. The network includes a health records transfer capability for perinatology and oncology, e-mail, Ontario Health Card validation, telemedicine and remote home care, and medical research databases. The network will also be used for CME. The Network is governed by an

	independent corporation and funding is received partly from an Ontario government infrastructure program, partly from shareholders and users. The network involves consumers through Community Advisory Committees. **Smart System**: to share models and infrastructure and integrate computers and information databases via a telecommunications network. This is being accomplished by adopting standards, developing policy/regulations, optimizing technical infrastructure and conducting research through 'breakthrough' projects (such as the assignment of a unique health identifier regardless of OHIP eligibility creating a Master Patient Index), hospital on-line registration for newborns, a drug health network, and a laboratory results transfer capability. Other applications of the network are telemedicine and health system management information (to support province-wide planning and client services). **CCAC Information System**: patient information database integrated province-wide via telecommunications. **CHC Information System**: for management purposes, to support the integrated team approach, for education and research purposes, to streamline administrative processes, to support fund-raising.
PEI	**Island Health Information System (IHIS)**: to support service delivery by linking care providers, to provide patient information, to provide planning and evaluation information and to provide research information. Currently, the IHIS runs the following applications: the provision of a personal health number, financial/enterprise automation, payroll/human resources, an ADT system, the interconnection of institutional pharmacies, medical records management, the pharmacy informatics program, integrated physician billing, a social services medical information system, a senior assessment database, and a health needs index. *Future directions*: case management, patient care system, laboratory information system, radiology information system and a clinical information system.
Quebec	**Integrated action plan (Inforoute Santé)** for a provincial health and social services information network, consumer health (EHRs) and telehealth (telemedicine, telediagnosis, teleservice). *Objectives*: collected and analyzed population-based information; increased patient autonomy and improved patient decision-making; information networking for improved access to, and management of, services; security mechanisms (smart cards); remote access to medical services. The lead agency is

	the Health and Social Services Ministry.
Saskatchewan	**Saskatchewan HIN (SHIN)**: province-wide information management system, including: a service event management system liked to a personal registry system; development of EMRs; links among health district providers and district health facilities (hospitals, DHBs, CHCs, long-term care facilities) for ordering, recording and monitoring health services; telehealth pilot projects in the areas of teleconsultation, EMRs, telemedicine, public and professional education. **Provincial Immunization Record System**: connecting 30 districts and First Nation health delivery agencies to a secure immunization database (monitoring of immunization status by public health nurses) through the Internet. **Newborn Registration System**
Yukon	N/A

Table 29

Telehealth Applications that Can Facilitate Health Care Procedures

Health care Procedure	Possible Telehealth Application
Telephone-based or face-to-face consultation between specialists and general practitioners	Videoconferencing, interactive television, e-mail
Physical transfer of medical images for specialist consultation	Electronic transfer of images to specialists via several types of networks; comparison of images against banks of stored electronic slides and images
Hand-written, paper-based patient files and charts	Palm-top, pen-based computer tablets, desktop workstations, EMRs
Hand-written, paper-based prescriptions	Electronic ordering of the prescription through an HIN or PharmaNet
Consulting Compendium of Pharmaceuticals and Specialties for information on drug being prescribed	Drug interaction software, online drug information database
Home visits	Laptop with modem to communicate with physician or health care institution (mobile computing), telemonitoring, assisted devices
Visits to the emergency room of the local hospital	Telecare, tele-assisted triage, video visits
Referrals from general practitioner	Appointments by e-mail or by electronic scheduling from the general practitioner's office
Patient travelling from remote location if requiring specialist consultations, diagnostic tests or treatments	Teleconsultation
Literature search in health library	Electronic search through MEDLINE or other medical information databases
Travel to another location for grand rounds, CME, conferences, meetings	Attendance from home or office via audio, video or computer conferencing, or interactive television
Clinical trials	Clinical trial management systems, expert advice online

(Truncated version reproduced from Picot, Telehealth Industry 13)

Table 30

Telehealth Applications that Can Respond to Health Care Reform Measures

Health Reform Measure	Telehealth Applications
Cost-containment	Some applications demonstrate cost and time savings.
Hospital closures, reduced beds, increase of ambulatory care	Home telecare and telemonitoring systems, telephone triage
Hospital mergers	Multi-functional networks to link facilities and allow the exchange of an EMR
Regionalization	HINs geared toward EBDM of various stakeholders
Rural medicine	Remote telemedicine and telelearning
Private funding of health services	Remote access to international specialist services, consumer HINs for health promotion, prevention and self-care
Focus on EBDM	HINs, information management systems, multimedia content (research data) and performance measurement tools
Reduced health care human resources	Telelearning, multimedia training software for retraining in the areas of home care, telenursing etc.
Integration of community resources	HINs, PharmaNets, home care information system, registration systems etc.
Alternatives to emergency rooms and hospitals	Telecare, tele-triage, telenursing etc.
Increased media and public involvement	Online or stand-alone, computerized patient education materials and tele-education
Shift from acute care and illness-based model of care to health promotion/prevention and wellness model	Patient and public health tele-education, self care and personal monitoring devices, online health information
Redistribution of specialist services	Teleconsultation networks, portable clinical workstations, electronic diagnostic tools and decision support systems

Health Reform Measure	Telehealth Applications
Revenue generation	Products/services to increase global distribution and sale of health-related expertise, educational and training services
Transfer of authority/ management of health services to Aboriginal communities	Remote telemedicine and tele-education networks, health information and research networks, online or stand-alone computerized patient education materials

(Truncated version reproduced from Picot, Telehealth Industry 70-72)

Table 31

Telehealth Categories and Users

Category	Users
All forms of medicine-at-a-distance: teleconsultations, telepathology, teleradiology, telepsychiatry, teledermatology, telecardiology etc.	Physicians Health care professionals Health care institutions
Interinstitutional, patient and clinical records and information systems, electronic health and clinical records and databases accessible by network	Health care institutions Health care professionals Health care workers Physician's offices Researchers
Public Health and Community Health Information Networks (CHINs)[185] and multiple-use health information networks	Government (including policy makers) Epidemiologists Public health professionals Physician's offices Pharmacies Clinics
Tele-education and multimedia applications for health professionals and patients, and networked research databases; Internet services	Universities and colleges Associations Researchers Physicians Health care professionals Patients

[185]CHINs are defined by Tim K. Zinn as "an integrated collection of computer and telecommunications capabilities that facilitates communication of patient, clinical and financial information among multiple providers, payers, employers, pharmacies and related healthcare entities within a targeted geographic area" (28). Similarly, Chuck Appleby defines CHINs as "regional electronic networks that link all health care players in the area . . .A CHIN provides the data, voice and image network – in other words, the information highway – that supports a region's delivery system, including the entire continuum of care" (43).

Category	Users
Telemonitoring, telecare networks, telephone triage, remote home care[186], and emergency networks	Consumers Elderly Chronically ill Disaster victims Accident victims Nurses Call centre users or operators

(Reproduced from Picot, Telehealth Industry 10)

[186]The terms tele-homecare, remote home care, and telecare are often used interchangeably. They generally refer to "the use of electronic communication networks for two-way transfer of information and data required for medical diagnosis, treatment, consultation, and/or, health maintenance between a patient's residence and a health care facility" (Health Canada, Tele-homecare 2-3).

Table 32

Categories and Examples of Telehealth Applications

Categories	Examples
Patient care	Radiology consultations, postsurgical monitoring, triage of emergency patients
Professional education	CME programs, online information and educational resources, individual mentoring and instruction
Patient education	Online help services for patients with chronic health problems
Research	Aggregation of data from multiple sites, conducting and coordinating research at multiple sites
Public health	Access to care for disadvantaged groups, poison control centres, disease reporting
Health care administration	Videoconferences for managers of integrated health systems, utilization and quality monitoring

(reproduced from Field 29)

Table 33

Examples of Telehealth Applications Categorized According to Picot

Category	Implementation Issues and Examples
All forms of medicine-at-a-distance: teleconsultations, telepathology, teleradiology, telepsychiatry, teledermatology, telecardiology etc.	*Relevant implementation issues*: remuneration, professional and technical certification, liability, jurisdictional issues, privacy, security, technical quality of images/voice, professional resistance (referral patterns etc.). *Examples of Canadian projects:* the National First Nations Telehealth Research Project, the Atlantic Health Sciences Corporation Imaging Network (NB), the Maritime Children's Telehealth Network (NS), the Baffin Health Network (Nunavut), the NS Telehealth Network, Westnet (NWT), Quebec Inter-regional Telemedicine Network, East Quebec Network, Provincial Mother-Child Network (QC), Quebec Pediatric Telemedicine Service, Whitehorse Hospital Network (YK), Hospital for Sick Children Telehealth Program (ON), Telemedicine Research and Development Pilot Project (MA).
Interinstitutional, patient and clinical records and information systems, electronic health and clinical records and databases accessible by network	*Relevant implementation issues:* standardization of data and technology, security, data ownership, privacy, data access, outcomes measurement methodology/standards/benchmarks. These networks can include decision/diagnostic support systems that make use of electronic patient and clinical records. Expert systems integrate a knowledge base and an inference engine. They typically adopt either a rule-based approach, pattern matching or pathophysiologic reasoning (where causes of disease are unknown, such as in psychiatric disorders). They can support diagnosis, operational planning, forecasting, and resource optimization. Bronzino et al find the following advantages to these systems: no memory loss or fatigue, exhaustive searches, access to specialized knowledge available anywhere, precise and calculated measurements (such as body weight), transparency in decision-making, monitoring of a wide range of factors (such as drug interactions). Disadvantages are: resistance on the part of professionals; lack of assessment of costs and benefits; restricted to narrow fields of application. These systems can be integrated to other categories of applications (such as remote home care and HINs). *Examples of Canadian projects*: First Nation Health Information System, Community Health Immunization Information System (AL), Continuing Care Data Warehouse Network (BC),

Category	Implementation Issues and Examples
	NLCHI (NF), Health Information Partnerships (ON), CCAC Information System (ON), CHC Information System (ON), Newborn Registration System (SK), Provincial Immunization Record System (SK).
Public Health and Community Health Information Networks (CHINs) and multiple-use HINs	*Relevant implementation issues*: fee structure, liability, standardization of data and technology, data ownership/privacy, data access, security, jurisdictional issues, technical quality of images/voice for clinical applications, professional and technical certification. According to Appleby, the key to success in developing CHINs is a previous history of community collaboration in health care. However, Appleby contends that most CHINs are moving in the direction of closed systems set up to gain a competitive rather than a community advantage. Initially designed to combine the idealism of community-based health care with the promise of computer automation, Appleby suggests, CHINs are now driven by business needs. *Examples of Canadian projects*: National Health Surveillance Network, Alberta *Wel*net, HealthLink, HealthNet/BC, Manitoba HIN, NB Wellness Network, Network 99 (NWT), Smart System (ON), Island Health Information System (PEI), Inforoute Santé (QC), Saskatchewan HIN.
Tele-education and multimedia applications for health professionals and patients, and networked research databases; Internet services	*Relevant implementation issues*: standardization of data and technology, privacy, data ownership, security, data access, credibility and quality of information, credentialing/curriculum development. In their analysis of evaluations conducted on computer-based instruction (CBI), Peter A. Cohen and Lakshmi S. Dacanay found a moderate contribution to the effectiveness of teaching in heath professions education. They detected a greater positive impact, however, in the case of computer-enriched versions involving simulations through interactive video/videodiscs and expert systems. Thereby, the authors concluded that CBI is most effective when used as an enrichment rather than a replacement. In an attempt to assist consumers in assessing the quality of health-related information obtained from the Internet, the Health Information Technological Institute has established a set of evaluation criteria for websites that act as gateways to such information. The criteria are: credibility (source, context, currency, relevance), content (accuracy, hierarchy of evidence, original source stated, disclaimer, omissions noted), disclosure (purpose of the site, profiling), links (selection, architecture, content, back linkages), design

Category	Implementation Issues and Examples
(continued) Tele-education and multimedia applications for health professionals and patients, and networked research databases; Internet services	(accessibility, logical organization, internal search engine), interactivity (mechanism for user feedback, chat rooms, tailoring of information to user), caveats (such as "miracle cures"). *Examples of Canadian projects:* the Canada Health Network, the Health Knowledge Network (AL), POPULIS (MA), HEALNet, CMA Online and "Doctors on the Net" training program (Canadian Medical Association), CCHSE/INSIGHT Interactive Distance Initiative, the Canadian Public Health Association's National AIDS Clearinghouse, Clinical Practice Guideline Infobase, McGill University Molson Informatics Project (QC), TETRA (Memorial University - NF), GlobalMedic's Self Care Solutions and Health Care Manager (QC). The Canadian Wellness Network, sponsored by the CAP, provides links to non-profit health organizations on its website, including ParentNet (a pilot project which hosts online discussion groups amongst parents and provides parenting information). MEDLINE offers free access (since June 1997) on the Internet to indexes and abstracts of articles published in 3800 biomedical journals. While not a Canadian project, it is heavily deployed in Canadian medicine. It is operated by the National Centre for Biotechnology Information of the US National Library of Medicine (NLM). Rita Vine cautions that the information processed in MEDLINE is not consumer-focussed. While consumer awareness and interest in MEDLINE was heightened once free access became a reality, there are problems relating to its lack of an adequate interface, which Vine insists can negatively impact the quality of search results, as well as the lack of consumer-directed content[187]. According to a study conducted by the NLM in 1988, MEDLINE is very useful to professionals for decision support (over half of respondents reported that it contributed to their medical decision-making), research, education and medical administration. Similarly, Synapse Publishing Inc. produces a Disease Guiding System available to professionals on the Internet. In contrast, Bell Canada's HealthyWay website enables consumer access to more than 6000 health and wellness sites and to 3000 newsgroups. Bell Canada has reported a monthly increase of 20 per cent in the number of subscribers who access the site since its launch in April 1996.

[187]MEDLINE does not index alternative therapeutic approaches, lay descriptions of diseases etc. (Vine 3).

Category	Implementation Issues and Examples
Telemonitoring, telecare networks, telephone triage, remote home care, and emergency networks	*Relevant implementation issues*: professional resistance (fear of job loss among nurses), training, standardization of data and technology, liability, privacy, security, privatization of services, professional and technical certification. E. Andrew Balas et al have conducted an extensive review of evaluations of provider-initiated computerized communication, interactive telephone systems, telephone access, screening, counselling and reminders directed to patients. The authors found that 63 per cent of the 80 eligible clinical trials reported positive outcomes. The main benefit of telecare, the authors concluded, is to improve the continuity of care. *Examples of Canadian projects*: Continuing Care Management Information System (MA), Home Care Information System (NS), Telecare (NB), VITAL (NB), Infosanté (QC). MediNovum, formerly Telemedysis, sells a proprietary palm-size ECG device that allows patients to take his/her own ECG and send the data through telephone lines. The patient pays a monthly amount for the service. The company estimates that the service eliminates 82 per cent of unnecessary emergency room visits for the purpose of cardiac care. The company also claims that emergency medical response time is reduced from three and a half hours to 20 minutes.[188] It will coordinate ambulance services in case of an emergency and transfer the patient's medical record and ECG to the appropriate hospital. Similarly, the Althin Biopharm Inc. software development project facilitates the remote monitoring of a patient's hemodialysis from anywhere in the world via the Internet.

[188]According to the Heart and Stroke Foundation, one quarter of victims of acute myocardial infractions die prior to being admitted to the hospital.

Table 34

Nomenclature Designating Individuals Who Receive Care

Patient	comes from the Latin word "to suffer". It is defined as having or showing patience, as a person receiving or scheduled to receive medical treatment, and it carries the connotation that the physician knows best.
Client	comes from the Latin root meaning "dependent" and is defined as someone under the protection of another or using the services of another as, for example, a lawyer.
Customer	is defined as a person who buys goods or services from a shop or business. It is obsolete for "tax collector", obsolete for "prostitute" and for "a fox that affords good sport in a hunt".
Consumer	comes from the Latin word "consumere" which means to take completely. It is defined as to destroy or to do away with completely, to spend wastefully, to squander, use-up, or to utilize an economic good in the satisfaction of wants.

(NFH, Summary Report)

Table 35

Symbolism in Health Care

Categories of Metaphors	Examples
War/Combat	Immune system is compared to a nation-state with fixed, closed boundaries under attack from foreign invaders. War is waged against the clock, disease, loss of control and death. Medicine is portrayed as dysfunctional. More sophisticated technology is proposed as the solution. Focus is on short-term, single-minded goals. Hierarchical and patriarchal organization is enforced. Focus is on the physical, on control and on the expenditure of massive resources.
Sports	Illness is depicted as "whole new ball game". Physician's authority is expressed as the "ball being in his/her court". To "Play hardball", to "level the playing field", to have a "game plan" etc., consist of pervasive medical action strategies.
Gender Stereotypes	"Hard" science, aggressive intervention, conquest of disease are idealized idioms of masculinity.
Capitalism	Cost-benefit analyses, resource savings and commodities, a focus on the bottom line, on "covered lives", on the management of resources, on consumer satisfaction, on profit maximization, on efficiency and competition, propagate capitalist ideology in medicine.
Machine	References to engines, fuel sources, repairs, spare parts, mechanical failures reflect a human/machine convergence. Brain death has substituted heart failure as the medico-legal definition of death. Metaphor of the mind as a computer has contributed to this notion of the brain as the prime location of the self (reflected in cryogenics) and as the processor and storage of information, further evident in metaphors of mental illness as "faulty processing" and of therapy as "reprogramming".

(Clark, "Metaphorically Speaking" 22-23; Annas 32)

Table 36

Ideology and Structure of Modern Environmentalism

Eco-centrism		Techno-centrism	
Gaianism	*Communalism*[189]	*Accommodation*	*Optimism*
belief in the rights of nature and of the essential co-evolution of humans and natural phenomena	belief in the co-operation capabilities of societies to be collectively self-reliant using "appropriate" science and technology	faith in the adaptability of institutions and mechanisms of assessment and decision-making to accommodate environmental demands	faith in the application of science, market forces and managerial ingenuity
redistribution of power towards a decentralized, federal political economy based on the interlinkage of environmental and social justice →		← maintenance of the status quo in existing structures of government power	

(reproduced from Pietroni 9 whose original source is O'Riordan)

[189]Similar to the communitarianism movement pioneered by Amitai Etzioni, Robert Bellah, Harry Boyte, John Kretzmann, John McKnight, Benjamin Barber et al etc., that reconceptualizes community development in terms of a focus on community assets and developing community capacity (skills and knowledge, local institutions and resources).

Table 37

Activities of Alternative Medicine

Groups	Activities
Complete systems of healing	This group is distinguished by its theoretical base to the causation of disease. As well, there are some similarities between the practices of this group and those of Western medicine (such as their own educational and regulatory framework, and ethical guidelines). Its main activities are: acupuncture (or traditional Chinese medicine), herbal medicine, osteopathy, chiropractic, homoeopathy, naturopathy (or Ayurvedic medicine).
Diagnostic methods	Its main activities are: kinesiology, iridology, hair analysis and aura diagnosis.
Therapeutic modalities	This group specializes in marketing complementary or supplementary treatments such as massage, reflexology, aromatherapy, spiritual healing or hydrotherapy.
Self-help measures	Its main activities are: breathing and relaxation technics, meditation, visualisation, yoga and other exercise routines, fasting or dieting.

(Pietroni 180-181)

Table 38

Framework for Evaluating Citizen Involvement in Agencies and Services

Dimensions	Criteria
Objective	• involve citizens in mainstream life and services; • provide mainstream services; • offer an empowering service that increases citizen control.
Access to agency or service	• open access; • any restrictions on use of service; • sensitivities to varying needs according to age, gender, class etc. • policy, provisions and monitoring for equal access and opportunities; • the relation of the *actual* to the *potential* use of the agency or service.
Extent of involvement	• the range and proportion of potential participants involved; • the involvement of citizens without organizational affiliations; • the duration of citizens' involvement; • the relation of participants to the eligible population (according to age, race, gender etc.); • the attitudes and expectations of potential participants towards involvement.
Access to, and support for, involvement	Support for group self-advocacy: • to develop their own accounts; • to set up and run their own independent groups and organizations; • to learn to work together; • to form their own judgements; • to negotiate decisions and develop demands; • to take action to achieve change and secure their rights; • to involve members of marginalized communities; • to exchange information and experience with other groups. Material support: translation and interpretation, respite support, child care, appropriate and adequate information, travelling, funding, training, consultancy, meeting places, other resources (paid workers and operational costs). Opportunities for involvement include: • participation in administrative and political systems; • representation in management structures and fora; • access for individual and collective involvement; • formal and informal opportunities for involvement; • opportunities for continuous and periodical involvement; • opportunities for observation.

Nature of involvement	• control of the agency/service; • different approaches to involvement; • levels of involvement; • areas of involvement; • conditions of involvement.
Agency/ service practice	• citizen involvement in practice (needs assessment, planning, recording, action, review, code of practice, choice of service and provider, publication of materials, employment); • protection of individual rights (complaints procedures, data protection, access to records).
Agency policy for involvement	• agency resources for involvement; • components for effective policy for involvement (clear agency goals and values, key people dedicated to the initiative, widespread support within the agency); • emphasis on citizen involvement in recruitment, training, promotion; • funding conditional upon involvement; • earmarked budgets to increase involvement; • emphasis on involvement in planning; • participatory management systems; • continuous monitoring and evaluation of effective involvement.
Effectiveness of involvement	• participatory process of involvement (source of initiative, stages of participation, interests involved in developing initiative, implementation process); • citizens' experience of involvement (attitudes toward agency/service, awareness and understanding of opportunities for involvement, views of outcomes); • outcomes of involvement (relationship between involvement and change; agency/service outcomes such as improvements in accessibility, acceptability, flexibility, reliability etc., outcomes for agency/service users).

(Beresford and Croft 205-218)

Table 39

Remedies to Societal Injustices

	Affirmation	**Transformation**
Redistribution	*Liberal welfare state* surface reallocations of existing goods to existing groups; supports group differentiation; can generate misrecognition.	*Socialism* deep restructuring of relations of production; blurs group differentiation; can help remedy some forms of misrecognition.
Recognition	*Mainstream multiculturalism* surface reallocations of respect to existing identities of existing groups; supports group differentiations.	*Deconstruction* deep restructuring of relations of recognition; destabilizes group differentiation.

(reproduced from Fraser 27)

Table 40

Deconstruction of Concepts Central to Community Health Organizing

Concepts	Postmodern Analysis
Representation and Participation	Only an object or individual can re-present itself or him/herself. Some AIDS activists have affirmed their "right to self-representation" in medical decision-making. Authentic representation and participation is presumed to require the empowerment of communities. The modern notion of empowerment – the transfer of information, skills or resources to improve the decision-making power of individuals – assumes that some skills are superior to others and that the information is credible and valuable. As well, postmodernists reject other modern understandings of empowerment as the adoption of a certain worldview, or as a means of asserting control over others. Postmodernists support the concept of empowerment if it is linked to self-esteem, individual competence, self-confidence, self-awareness, self-development etc., or if it corresponds to the ability to choose or to increase an individual's own problem-solving and decision-making abilities. The postmodernist reconceptualization of empowerment is free of the criterion of truth or of a privileged voice.
Community and Identity	Postmodern identity opposes the oppressive character of the modern community – focussed, unchanging, systematic – that demands self-sacrifice, the sharing of resources, mutual service in the name of a public, grounded or geographic interest. Conforming to the postmodern view, a "community without unity" would be preferable for allowing greater individual freedom. Practically, such a community would operate through temporary solidarity.
Causality, Accountability & Responsibility	A modern preoccupation with causality is substituted by consideration of intertextuality, of "an infinitely complex set of interwoven interrelationships". Absolute intertextuality assumes that everything is related to everything else, hence, direct causal connections, notions of accountability and responsibility are suspended.
Authority and The Privileged Voice	Postmodernists reject the logocentric position of experts established on the basis of truth claims. Paulo Freire has criticized experts by arguing that they view people as things that passively receive information and knowledge; in other words, people act as depositories of expert information systems. The postmodern view is relativist.

Rosenau (309-315)

Table 41

Postmodern Critique of Models of Community Health Organizing

Models	Postmodern Critique
Social Planning	This model is modern in character. It privileges notions of rationality, efficiency, causality, objectivity, special expertise etc. In this model, the role of high technology is emphatically positive. Conversely, postmodern planning is inclusive and participatory, while remaining aware and respectful of the heterogeneity of the social collectivity. It favors interactive adaptation, diversification of means and actions, needs-based development, the microsocial versus the macrosocial etc. Postmodern medicine does not pretend to be neutral, but rather recognizes that values are implicated at every level of clinical decision-making.
Community Development	This model is built on the process of decision-making, rather than its outcome. In so doing, education, participation, the development of local leadership are more important steps to this model than the final step of goal attainment. The process is aimed at long-term sustainability and investment, and community ownership of the particular project. While postmodernists support this process orientation, they do not believe in the special value of consensus and compromise promoted by this model. Both the community development and postmodernist views hold that the local and personal are superior to the universal and general.
Social Action	This model is directed toward the politics of redistribution of resources from the privileged to the underprivileged through direct social, economic and political actions. Collective responsibility is highlighted at the expense of individual rights. Similar to the community development model, the social action model also seeks to incite community participation and leadership. However, rather than emphasizing process, it is geared toward changes in the status quo. Postmodernists consider this model as too rigid, logocentric, dogmatic, and premised on artificial notions of causality, responsibility and class consciousness.

(Rosenau 320-324)

Appendix A: The Last Decade of Provincial and Territorial Health Care Reform Initiatives

Provincial and territorial health care reform policy-makers have already begun to reach some degree of consensus. In January 1997, the Conference of provincial and territorial ministers of health discussed the development of a "national" health care reform public policy. The intention of this new "national" policy would be to clarify federal/provincial/territorial roles and responsibilities, and create a Future National Health System with 3 main components: personal health services (primary care, acute care, continuing care, health promotion and prevention), population-based health protection and health promotion, and a rebalanced emphasis on health and wellness (achieved through policy, standards, individual and community responsibility, and the allocation of human and financial resources). The ministers also recommended that a new administrative mechanism be established to oversee federal/provincial/territorial arrangements and partnerships. The mechanism would consist of an expert advisory panel jointly appointed whose primary functions would be: to operate in accordance with the principles of the *Canada Health Act* and relevant provincial/territorial legislation; to act as a reference body, making recommendations relating to disputes or issues brought forth by the federal or provincial/territorial ministers; and, to act as a conciliatory or arbitration body.

Alberta

Alberta's 17 Regional Health Authorities (RHAs) are responsible for community health needs assessment. Based on the principle of evidence-based decision-making (EBDM), this process involves: collecting a solid base of information about health needs, environmental and behavioral influences on health, and community resources in the region; involving communities through planned input sessions; designing action plans and setting priorities to address needs; integrating regular monitoring and evaluation; building the resulting information into business cycle plans. In November 1998, the foundation for an accountability framework for the Alberta health system was released. It is aimed at improving accountability, access of Albertans to outcomes information and general improvement of the health system. That same month, a governance assessment instrument for RHAs was published, as well as a document on governance expectations. As well, RHAs are assisted by the Provincial Health Authorities of Alberta (PHAA), formerly called the Alberta Healthcare Association. PHAA provide research services, human resource planning, bargaining services, insurance, secretariat support and other business services. RHAs are required to oversee a minimum of one Community Health Council per region. In 1996/97, RHA expenditures for community and home-based services increased by 301 per cent from 1990/91. As well, the Provincial Mental Health Advisory Board and Alberta Cancer Board spent 15.4 per cent more on community and home-based services in 1996/97 than the previous year.

British Columbia (BC)

In the early 1990's, BC's Health and Ministry for Seniors initiated plans to regionalize the delivery of health services. However, on July 5, 1996, Health Minister Joy MacPhail announced a temporary hold on the existing plans for devolution justified by the need for greater assessment of the cost-effectiveness of this particular regionalization framework. Consultations were held from August 12 to September 5, 1996. Essentially, the report of the regionalization assessment team called for greater flexibility in hospital amalgamation and in regional governance structure. The team recommended: provisions allowing for "voluntary amalgamation", labor mobility, direct responsibility of Aboriginal communities, distinct strategies for rural and urban communities, and opportunities for fund-raising activities of institutions. These provisions were the result of a desire expressed by BC communities to preserve the "uniqueness" and individualized character of each community and organization. The report stated: "Many individuals regard their community as 'unique and distinct' and believe that planning for health services should recognize the distinct nature of BC's communities and regions".

In a news release dated November 29, 1996, the Health Minister announced the government's new approach to regionalization entitled "Our Better Teamwork, Better Care Approach". The approach involved spending cuts of $750 million over the next 18 months; $28 million was directed at the management and administration of the Ministry of Health headquarters. According to this new approach, the number of Regional Health

Boards (RHBs) and Community Health Councils (CHCs) were to be significantly reduced from 102 to 45. Only a single layer of regional governance was to exist in any part of the province, that is, only an RHB or a CHC. Furthermore, the boards and councils were to be smaller in size and their members were to be appointed. Finally, specific performance guidelines were to be developed by the Ministry for annual auditing and monitoring. In April 1997, authority over governance, management and delivery of most health services was transferred to regional authorities. Currently, 34 CHCs administer small hospitals and long-term care facilities within the geographic boundaries of Community Health Services Societies (CHSSs). CHSSs coordinate service delivery structure for specific community health programs in parts of the province that are not governed by RHBs. Eleven RHBs assumed responsibility for services in 1996.

On November 1, 1994, the Health Minister introduced the Health Information Management Project (HIMP) with the objective of reforming information management in the health system. Three advisory bodies were established to guide its development: an Information Standards Council, a Health Information Management Coordinating Council and an Information Management Group. On July 15, 1997, the HIMP advisory bodies released the BC Health Information Management Policy. This policy was intended to determine how RHBs, CHCs and newly introduced Community Health Services Societies (CHSSs) should plan, manage, operate and evaluate health information management activities. The policy created Information Management Steering Committees to monitor RHB, CHC and CHSS activities. As well, it mandated RHBs to appoint a Chief

Information Officer (CIO), and in the case of CHSS/CHCs, a common Information Management Coordinator to undertake such activities. Lastly, it established a Health Information Management Coordinating Council to identify and prioritize province-wide activities, composed of the CIOs of each RHB and one member of each CHSS/CHC information management steering committee. According to the policy, each RHB and CHSS/CHC was required to develop a three-year Information Resource Management Plan (IRMP) which would include the following items: a business perspective, a current inventory of information, data, systems and technology, a report on local information, systems and technology needs, a three-year directional plan (targets, integration, compliance) and a one-year plan (deliverables, development, funding, staffing requirements). The regional health authority and the Ministry are directly accountable for plan expenditure.

On July 1, 1997, the Health Ministry itself released an IRMP for 1997-2002. The Plan responds to health care reform public policy objectives of improved service integration and evidence-based decision-making. According to the IRMP, in the past five years, reform measures that succeeded in enhancing the cost-effectiveness of the health system were labour agreements, caps on physicians' fees, reference-based pricing for Pharmacare and reduced expenditures in acute care facilities. The Ministry is now placing its trust in the next step to health care reform public policy: information management. Initial key components of the plan comprised of: an integrated record of health services received by an individual over time regardless of the source of the service;

a common information repository for health planning, evaluation and research; common data and processes to ensure consistency of demographic, enrollment and eligibility information; a common computer communications network for the exchange of information taking into account required privacy and security concerns. The Ministry promised to allocate 110 million or 1.5 per cent of the total budget annually to the IRMP. For the first five years, however, annual contributions were to total $140 million (1.9 per cent). The Continuing Care Data Warehouse Network (CCData) is currently operating as a mediator between the Ministry and provincial health units to coordinate data sharing for the purposes of EBDM.

Manitoba

In 1994-95, Manitoba Health created the Community and Mental Health Services Division, consolidating the Policy and Programs sectors in order to integrate the development of public policy and program direction of institutional and community health services. The division adopted a "multi-disciplinary, multi-faceted and participatory" policy framework (Manitoba Health, Annual Report 95-96). In November 1995, the Urban Health Planning Committee was formed through Manitoba Health to lead the process of reorganization of hospital-based patient care and support services. Recommendations of the Committee were presented in January 1996. Overall, the model of delivery proposed would comprise of five acute care hospitals, three long-term facilities and an ambulatory care facility in Winnipeg. Each distinct category of resources/services, such as hospital beds, operating rooms and long term care beds, would

be managed as a single resource within each category regardless of the source/location of delivery. The model would further integrate information systems across facilities for planning and effective management. Importantly, the committee specifically recommended that the implementation of alternative community-based care services precede amalgamation and the closing of hospital beds. In April 1998, the Brandon Health Authority and the Winnipeg Hospital Authority assumed their governance. As well, the Winnipeg Community and Long Term Care Authority was introduced.

In 1996, ten RHAs were established, followed by DHCs and CHCs in eight health regions. Three additional RHAs have since been founded. Other alternative service delivery programs were instituted, including Nurse Resource Centres (NRCs) and salaried physician programs. The first NRC was erected at the Youville Centre in St. Vital. It offers primary care while emphasizing health promotion, prevention and patient education. Salaried physician programs were introduced at the request of several rural communities. The Northern/Rural Regionalization Task Force was put in place in order to guide the reform of health services in remote communities. In 1997, ten new rural/northern RHAs were founded. Another community-based program was created, the Healthy Communities Development Initiative, intended to achieve "a better balance between prevention and community oriented and institutional services". The program is responsible for the redirection of financial savings derived from the consolidation of hospital programs, to alternative community-based programs such as home care, support to seniors, midwifery, breast cancer screening programs etc. In 1995/96, $5.326 million

was allocated to community-based initiatives through this program.

New Brunswick (NB)

NB is currently divided into seven health and community regions. Since 1992, eight Regional Hospital Corporations (RHC) operate 51 health care facilities. As well, RHCs oversee the Extra-Mural Program in each region, a product of the merger between RHCs and the Extra-Mural Hospital or the "hospital without walls". The Extra-Mural Program consists of a home care program established within the hospital system while remaining independent of any one hospital. It incorporates sixteen service delivery units. Special hospital facilities have also been designated as "centres of expertise". Notwithstanding, the focus in the NB health system is outpatient care. A maximum bed-to-population ratio has been fixed in each region; 37 acute care beds are provided to 1000 people. Other cutbacks include ceilings on individual physicians' incomes paid by Medicare. Savings will be dedicated to physician recruitment in rural areas.

Despite important reform initiatives, the province has begun to reinvest money into the health system. From 1996/97 to 1997/98, the budget for health and community services increased by $9.6 million, reaching a total $1.266 billion. In addition, on May 5, 1997, the government announced an increase of up to $12 million to be allocated to RHCs. In order to cultivate EBDM, the Provincial Utilization Management Coordinating Committee (PUMCC) – composed of representatives from the provincial health and community services department and professional associations – is attempting to develop

performance indicators for the Regional Hospital Corporation System. It is expected that the first set of indicators will be delivered in 1999.

Newfoundland

Since 1993, acute and long term care services have been reorganized under thirteen RHBs, composed of individuals from the region, who assist the community in determining health needs and developing programs and services. These RHBs replaced 39 independent boards. Four RHBs are responsible for institutional care, four for community health, and two integrated boards for both (in northern Newfoundland and Labrador). Four CHBs have been set up for the purposes of delivering community health services in the areas of health promotion, health protection, continuing care, drug dependency, mental health and consultation, self-help/advocacy, housing and transportation. At the primary care level, acute care services are provided by rural medical clinics and CHCs. Ambulatory care has also been enhanced by regional and provincial referral centres. A surge of 10 per cent in ambulatory care visits has been experienced over the last five years. In terms of tertiary care, hospital restructuring in St-John's, first announced in June 1995, has resulted in the centralization of hospital management through the Health Care Corporation (HCC) which administers all hospitals in the St-John's region through seventeen programs (ambulatory care, cardiology, critical and continuing care, laboratory services, medical care etc.).

In January 1997, the Central Newfoundland Health Services Review conducted by KPMG Management Consultants released their final report. Subsequent to the recommendations of this report, the 1997/98 budget increased funding to RHBs by $2 million and broadened their mandate to offer certain services previously offered by the Department of Social Services. On May 9 and 10, 1997, a Provincial Health Care Forum was held in St-John's. The Forum reflected the government's commitment to establishing partnerships with communities. Among other initiatives, the Forum recommended the establishment of community-based health centres and an advisory committee on health issues with public representation. In April 1998, a new Department of Health and Community Services was introduced whose focus is on macro-management policy issues and on working with regional boards.

Northwest Territories (NWT)

In June 1994, the NWT's Health and Social Services Department combined two departments into one for the purposes of service integration. These had not been united since 1977. In May 1997, Medical-Emerging International Inc. submitted a draft strategic plan to the territorial government for its consideration. The plan proposed a comprehensive framework for an Integrated Health and Social Services System (IHSSS). The IHSSS would provide for a continuum of care and a smooth transition after Nunavut is created. Funding would be allocated on a capitation basis, determined according to a rostered target population, to locally-based IHSS Authorities (IHSSAs) responsible for program and service delivery and fully responsible and accountable for the development

and control of budgets. There would, however, be a redistributive cost-sharing framework to assist smaller IHSSAs. IHSSAs would represent a public/private partnership. They would follow a federated holding model of governance: a formal reporting line is set up from each operating unit to the appointed IHSSA Board of Trustees. This model of governance would guarantee decentralized decision-making at the local level and a focus on population needs and monitoring at the Board level. CHCs would be renamed Health and Social Services Centres (HSSCs). Responsibility for the integrated information system, an essential building block for the IHSSS, would be centralized at the ministerial level. Such responsibilities would include: defining data fields for a system-wide electronic client/patient record; integrating existing databases through this record, support end-users at their site-of-service; monitoring health status and determinants; monitoring program activities and system expenditures in relation to trends; refining needs-adjuster in the funding formula.

In 1997, regional health and social services boards (RHSSBs) were formed to manage institutional and community health and social services. A new population-based funding allocation formula was phased into RHSSB operations in 1998/99. That same year, three new RHSSBs in Nunavut and nine regional and community HSSBs in Western NWT were founded. While RHSSB members are appointed by the Minister, it is claimed by the territorial government that community involvement is, nonetheless, an integral part of the regionalized health system: "Communities work with the department and the boards to identify local priorities and plan and deliver programs that meet their own

needs".

In late summer 1997, a discussion paper entitled Finding a Better Way: Health and Social Services Strategic Plan was published in order to direct public consultations coordinated by RHSSBs. The consultations were intended to produce recommendations for the development of a strategic plan, based on the following objectives: the ability of individuals to maintain health and well-being; sustainability of the system; increased coordination between people and organizations; increased local and regional control; enhanced and consistent skills of caregivers; and a transition plan for division (i.e. the creation on January 1, 1999, of Nunavut). The paper identified five basic principles guiding the process of health care reform: basic needs first, equitable access to services, a focus on prevention, individual responsibility and knowledge-based actions. A Strategic Initiatives Fund has been founded, following the public consultation process, to encourage RHSSBs to implement innovative, community-based service delivery arrangements according to these objectives and principles.

Nova Scotia (NS)

The 1997 NS Department of Health's Business Plan cited the following strategic goals: enhanced health status (achieved through individual and community responsibility), access to services, support for renewal of health and the health system (reorganization, rationalization, broader understanding of health, partnerships), sustainability, and EBDM. In order to ensure province-wide access to services, the Plan

recommended the implementation of regionalized clinical service plans that would stress seamless community-based service delivery for health care, particularly home care and long term care. The Plan suggested that a Provincial Advisory Council act as a public forum to discuss the following: a model of governance and operating principles for RHBs; a means of providing skills, technical support and information to RHB and Community Health Board (CHB) members; and, a policy framework on alternative models for physician remuneration and primary care delivery. The Council was established in 1998 in order to advise the Minister on general policy issues. It is composed of the Minister of Health and the chairpersons and CEOs of the RHBs and Non-Designated Organizations (NDO). Finally, the Plan proposed that EBDM be facilitated by an automated mechanism to collect home care information and by other improved information technology tools, databases and communication systems.

During the second phase of NS's health renewal, consisting of an eighteen-month period that began in 1996-97, hospital governance was transferred to four RHBs (Western, Northern, Central and Eastern), except for the four NDOs: the Queen Elizabeth II Health Sciences Centre, the Cape Breton Health Care Complex, the Isaac Walton Killam (IWK)-Grace created in May 1996, and the NS Hospital. Three of these facilities were recently created from hospital mergers, and three are teaching hospitals. *The Act to Establish RHBs* was assented to in September 1994. Since early April 1997, RHBs began to assume responsibility for certain primary care service delivery (drug dependency, public health) beyond hospital operations, with the assistance of a Primary Care

Transition Team. Home care is the next step in decentralization. The formal establishment of CHBs was delayed to ensure that a sound regional foundation was established. Citizen participation appears to have been an important part of building this foundation, as expressed by Health Minister Bernie Boudreau:

> We remain totally committed to community-based input in our health care decision-making. We hope to benefit from the varied experience gained by RHBs as they develop approaches to community involvement and advice. During the eighteen months we will be learning about and preparing for community-based health care planning, to get it right. (NS Department of Health, Health Reform 2)

34 CHBs were finally established to develop community health plans and local action strategies. With assistance from the Department of Health, planning tools and other educational materials were produced to guide RHBs and CHBs. In addition, the Deputy Minister set up a joint planning group made up of RHB members, RHB staff and Department staff to advise and support CHBs in their role as local planner. Finally, in October 1998, a Ministers Task Force on the Regionalized Health System was formed to review the current structure and provide recommendations to the Health Minister.

Public input was solicited on a discussion paper presented by the Department of Health entitled Good Medicine: Securing Doctors' Services for Nova Scotians. The paper studied different options in professional remuneration, education and training, health promotion and illness prevention. The Minister explained the incentive to launch the public consultation as follows: "For too long talks on physician issues have not been

open to public input and debate" (NS Department of Health, Public Asked 1). Community participation was again celebrated in the Building Health Communities initiative announced in April 1997. The initiative sought to develop a community health plan through "widespread community participation", guiding the actions of 20 CHBs that provide advice and direction to RHBs on the organization and delivery of services.

Ontario

In 1996/97 and 1997/98, the provincial government stabilized spending at $17.8 billion despite a reduction of $2.1 billion in federal transfer payments; it had initially promised that spending would be protected at $17.4 billion. An additional $2 billion was committed in 1997/98 to be allocated over the next five years to hospitals for severance labor adjustments, job retraining, educational and capital investments. It was intended as a transition fund in light of extensive hospital restructuring undertaken in Ontario by the Health Services Restructuring Commission (HSRC) since 1996. The Commission has issued reports relating to 22 communities. While hospitals have been the focus of the latest phase of Ontario health care reform, the Commission announced plans in early September 1997 to address primary care reform during the second phase of its four-year term. The Ontario Medical Association (OMA) is advocating a "reformed fee-for-service" model. According to this model, physician services are provided to a voluntary rostered population. Physicians then submit their rosters to the government which assesses the patient group for health needs, age and sex. Funding is determined following this assessment in addition to physicians' billing for services rendered. The model thus

combines a capitation structure with fee-for-service remuneration.

Perhaps as a result of the ambiguous success of DHCs in the past, the focus of current regionalization initiatives in Ontario is on streamlining services and creating one-stop shopping centres, as well as on the devolution of financial responsibility to municipalities, as opposed to promoting consumer involvement. A restructuring plan was announced in September 1997, whereby, the number of DHCs was reduced from 33 to 16. Hence, the geographic boundaries and population size of each district was greatly increased. While some barriers to integrated health system planning and delivery were removed, the DHC's restricted mandate did not change. In 1996, the Ontario Government opened 43 new Community Care Access Centres (CCACs) which replace 76 home care and placement coordination agencies. CCACs are presented as a means of "one-stop shopping" for long-term care. While municipalities were not required to contribute to the funding of the 99 homes for the aged which they operate, they must now provide 50 per cent of funding for these services. The government further intends to create an agency responsible for province-wide management of policies, special programs and evaluation of long-term care services. Consumers and providers will be consulted about the development of this agency; as well, consumers will make up a third of its board members. Municipalities are also expected to fully fund public health programs run by 42 boards of health, and land ambulance services, compared to previous arrangements where they contributed only 25 per cent to public health services and did not contribute to the cost of land ambulance services. They will also fund 100 per cent of

Homes for Special Care. According to the Ontario Ministry of Health, "[m]unicipalities will now have greater flexibility to tailor programs to local needs while maintaining provincial standards" (Community Health Services 2). But what the Ministry calls flexibility, the Ontario College of Family Physicians (OCFP) denounces as fragmentation, limited access and deterioration of services. The OCFP argues that delivery will be dependent on a municipality's ability to pay.

Announced by Health Minister Jim Wilson in February 1997, and recommended by the HSRC, 18 Rural and Northern Health Care Networks will be created to provide 24-hour access to care in remote communities to emergency and specialized services. Smaller rural hospitals will be permanently linked to at least one larger hospital with a fully staffed emergency department open 24 hours. The larger facility will also provide for clinical support and specialty services. Rural and northern hospitals located within 40 kilometres of each other will be connected to form regional networks consolidating administrative and support services, and perhaps even a common staff and governance. They will be linked to local DHCs and other health care providers and agencies. New technologies will gradually be phased-in to allow emergency care (medical information transfer from rural ambulances and helicopters to hospitals), telemedicine consultations, and education and training.

Prince Edward Island (PEI)

In October 1993, the PEI legislature assented a new *Health and Community Services Act*. The Act was based on Task Force recommendations for a renewed vision of health and the health system with a focus on the client, on the broad determinants of health, on regional governance, on community empowerment, on increased personal and community responsibility, on EBDM and needs-based planning, and on the pooling of human services funding. The 1993 Act founded five Regional Health Authorities Boards (RHABs) and two central bodies: the Health Policy Council for strategic planning and the Health and Community Services agency for budget allocation. RHABs are responsible for service delivery and management, needs assessment, human resources, priority setting, and resource allocation in the areas of health, social services, corrections, housing and employment. Other boards, including hospital boards, addiction services boards and the central Hospital and Health Services Commission, were abolished in favour of RHABs. Members of regional boards, seven of which are community members, are currently appointed by the Minister. However, by the fall of 2001, the five RHABs will be composed of three appointed and six elected members.

Following the election of the new government in November 1996, an Act was enacted to implement changes to the structure of the central components of the system in the spring of 1997. Furthermore, an extensive evaluation project was undertaken to assess the new health system and implement the new evidence-based approach to public policy development. Assisted by Health Canada and the Centre for Health Economics

and Policy Analysis (CHEPA), the project will evaluate the impact of decentralization, devolution and community involvement. For instance, a public survey was held in June 1997 to provide input on the effects of community involvement. One product of the evaluation project will be to devise decision-support tools to enhance the use of information by decision- and policy-makers. The final report of the Health System Evaluation Project is expected to be released in the fall of 1999.

Quebec

Released in 1989, a report entitled Improving Health and Well-Being in Quebec identified existing problems in the health system, setting the tone for future health care reform. Among the system's deficiencies were: cooption of the system by providers; neglect on the part of the Ministry of Health and Social Services to conduct evaluations; lack of cooperation between the public and private sectors, within the public sector, and between the public sector and community groups; deficiencies in terms of accessibility, quality and adaptability of services (particularly in the areas of geriatrics, aboriginal health, remote populations, and acute social problems); deficiencies in administrative and human resources management (including an overwhelming bureaucracy, lack of training and investment in human resource development etc.); reduction in federal transfer payments; absence of a relationship between increased expenditures and level of performance of the system. In August 1991, the role of regional advisory councils was expanded to include organizational functions, such as budget allocation, expenditure control and evaluation. Board membership was changed from professionals to people

outside the health and social services sector. Envelope funding replaced global budgets.

New strategic objectives were drafted to guide health system reform. These objectives were primarily focussed on the needs of citizens and on health and wellness. Key components of the reform process were identified as follows: outcomes-oriented action; adaptation of services to regional realities; intersectoral approach to client services; identification of the determining factors contributing to problems/deficiencies; reorientation of system management toward objectives of health and wellness; restructuration of system management according to activity sectors. A citizen-focussed system was defined in provincial public policy documents as a system that supports province-wide access to service integration and "one-stop shopping". In 1997, service delivery in Quebec was divided amongst 17 RBs and regional health and social services councils, 154 CHCs, 140 hospital centres, 19 child and youth protection centres, 104 rehabilitation centres and 384 long-term care and housing centres. While the total number of corporations has declined, mostly following mergers, the number of access points have been maintained. In 1993, there were 667 public institutions and 2084 service points, while, in 1998, 377 and 2109 respectively.

Saskatchewan

The current phase of health care reform in Saskatchewan began in 1992. The reform process has since followed five key principles: increased community involvement, emphasis on disease and accident prevention, healthy lifestyles and population health,

improved balance between institutional and home/community-based care, service integration and coordination for an efficient, client-centred system, sustainability through public funding. Having replaced 400 single-function boards, 32 DHBs plan, manage and operate province-wide service delivery according to these principles. Members of DHBs are elected and they hold open board meetings and public meetings to involve residents in health needs assessment and service planning.

A Health Renewal Working Group progress report released in October 1996 reported an increase in home care of 38 per cent that included an increase of 39 per cent of palliative care clients served at home and an increase of 83 per cent of acute care services provided at home. While 1200 unnecessary hospital beds have been closed, hospitals still accounted for 82 per cent of district budgets. The Working Group reported cost-savings of $1.67 billion since 1991/92. While the Group remained committed to a publicly funded health system, they have sponsored seven alternate physician payment pilot projects involving 25 family physicians serving 32,000 residents. The report attempted to forecast the main components of the Saskatchewan health system in 2005: CHCs addressing basic health needs through service integration[190]; telemedicine consultations with specialists; outpatient care; an emergency care network including a province-wide information network for accessing health records and outcomes; home care; supervised living and other housing options; prevention and multisectoral health planning; a team and holistic approach; and, public funding guided by sound investments

[190]There are currently 51 CHCs in rural Saskatchewan.

and clinical practice research. In fact, funding for community and home-based services did increase from 7 per cent of the total health care budget in 1991/92 to 10 percent in 1998/99, representing an increase of 116 per cent in expenditures for community and home-based services. Meanwhile, funding for institutional care was reduced from 37 per cent of the total health budget in 1991/92 to 35 per cent in 1998/99.

A benefit analysis prepared by Ernst and Young reported key benefits to improved information management in Saskatchewan's health system: improved decision-making, better diagnosis and care, reduced duplication of tests and procedures, better access and accuracy of information, reduced time spent on record management, improved nursing care, improved service delivery in rural areas, reduced isolation for rural physicians, and increased productivity due to service integration. The study identified the main factors critical to the achievement of benefits: stakeholder involvement, effective management of change, comprehensive training, and streamlining services and activities. Ernst and Young projected cost-savings of $58 million to $114 million per year.

Yukon

As of December 1995, there were 2 hospitals in the Yukon, 59 staffed beds, 4 nursing stations, 11 health centres, 98 licensed physicians and 26 dentists. The first phase of the new Whitehorse General Hospital was completed in December 1996. It was undertaken thanks to a one-time capital grant from the federal government totalling $47 million. The hospital contains 77 beds, a native healing centre and specialist clinics. The

Hospital Board has been severely criticized due to many deficiencies in the structure and operation of the hospital identified by workers and residents. Among these problems are chronic understaffing (from 5 to 2 nursing stations), the replacement of nurses with certified nurses assistants (non-patient care), the absence of a common pool of specialized nurses, the insufficient number of beds, the use of maintenance employees as security officers, the absence of an adequate psychiatry program and non-functional air systems responsible for some cases of overt carbon monoxide poisoning. On April 23, 1996, the Board announced the appointment of an independent team of reviewers composed of three outside medical and hospital operations consultants.

In April 1997, the administration and delivery of community health services were transferred back to the territorial government. There have been discussions in the Yukon Legislature regarding the institution of community health centres (CHCs) instigated by the Yukon Party. Notwithstanding, devolution is occurring with the self-government of the Council of Yukon Indians. Recognizing the great difficulties of recruiting physicians in rural and Northern communities, on August 21, 1997, the Yukon Government agreed to increase professional fees-per-service by 0.5 per cent for the next two years. The Department of Health and Social Services and the Yukon Medical Association have also devised a medical information plan. The Plan will allow more rapid reporting of test results, electronic billing for medical services and potential telemedicine connections between communities, Whitehorse and southern medical centres.

Appendix B: The Last Decade of Provincial and Territorial Government Policy Frameworks and Initiatives in the Domain of ICT[191]

The first Information Highway Ministers' Meeting was held in Winnipeg on September 30, 1996. The federal/provincial/territorial ministers reached a consensus on the need for selective government action to ensure universal access to the information highway. Thus, they agreed to develop collaborative approaches and actions to produce and maintain a viable network of public access points and communication networks in order to provide access to all communities in Canada. They also committed to a minimum level of privacy protection applicable across the country.

Alberta

A report of the Alberta Science and Research Authority (ASRA) describes the underlying principles of Alberta's infostructure: strong government leadership, partnerships, rapid development and technology diffusion, a "culture of use", infrastructure, training and education, and empowerment of Albertans. The report states: "Aggressive use of IT&T in Alberta will assist the government to achieve its basic goals of decentralization, and deficit and debt reduction while also generating important domestic and global economic growth opportunities." On November 12, 1998, the ASRA published another report outlining a strategy for ICT development in the province. It identifies four priorities: investment in education, development of the ICT

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[191] While initiatives in the field of education and culture will be presented, government-sponsored initiatives in health care will generally not be mentioned since these will be dealt with separately later in this chapter.

infrastructure, growth of investment in R&D, and growth in the ICT business sector. The ASRA seeks to connect 90 per cent of the population by 2001 by providing high-speed access to all schools, 95 per cent of businesses, and 80 per cent of residences.

British Columbia (BC)

On August 16, 1995, the Information and Technology Access Office (ITAO) was created to fulfill a government obligation under the Electronic Highway Accord. A product of deliberations in which community groups, industry, labor and government representatives were involved, the Accord set forth a vision of the future information society of British Columbia whose three objectives are universal access, industry competitiveness, and the effectiveness and efficiency of public services. The vision's main guiding principles are: a collaborative approach, public/private partnerships, a focus on individuals and communities, a recognition of fiscal realities and government leadership/shared responsibility. The Accord elaborates a two-sided approach to realizing the first objective of universal access: by providing for access as capacity and access as empowerment of individuals and communities. In responding to the call for access as capacity, the government will contribute to the building of a comprehensive, telecommunications backbone. In order to "empower" individuals and communities, the government will support public access points in libraries, schools etc., community networks, the development of content and services by educational, public centres (museums, science centres), the development of computer literacy and skills, and community input into the development of public information services. Examples of such

initiatives include the Communities Connect program, the Community Archives Network Funding program, a grant to the BC Community Network Association, the Provincial Learning Network etc.

In February 1996, the BC Archives and Records Services, the Information and Privacy Branch and Enquiry BC (toll-free telephone line for government information and referral services) came under the direction of the ITAO. Subsequently, the ITAO's mandate was extended to encompass all matters relating to provincial science and technology public policy; the new organization was named the Information, Science and Technology Agency (ISTA). It governs the Minister's Advisory Council on Information Technology and the Premier's Advisory Council on Science and Technology, among other bodies. It further administers the *Freedom of Information and Protection of Privacy Act* which regulates public access to government information. BC considers privacy to be a fundamental human rights issue. BC's Submission to Industry Canada Re: The Information Highway dated December 22, 1994, supports the adoption of the CSA's Model Privacy Code. In addition, the submission recommends the mandatory development of privacy-impact statements by government agencies and the private sector upon implementation of new information technology, the adoption of fair information practices, and the promotion of voluntary self-regulation based on these practices.

Manitoba

The Manitoba Information Highway Advisory Council (MIHAC) formulates IT&T public policy in seeking to increase Manitoba's competitive advantage. As a result of an investment of $600 million by the Manitoba Telephone System, the province has successfully achieved an individual telephone line service integration of 100 per cent with fully digital switching capacity, and the building of a comprehensive fibre-optics network. 96 per cent of Manitobans have toll-free access to the information highway through fibre-optic cables. Despite its insistence on adopting "the best regulation is the least regulation" approach, the MIHAC does not discount the need for strategic government action to protect the public interest against market abuses, as well as to provide for universal access and applications in education and health. The Council has recommended that public access to computer terminals, and associated technology, be implemented in every municipality by 1998 – including nursing stations – by non-profit, community-based computer organizations, such as Blue Sky Community Networks. The Council also strongly encourages community partnerships to coordinate and combine the use of resources. In summary, the Manitoba Government supports ". . . community intervention through public-interest groups, self-policing, established codes of ethics and public education [that] will provide the 'healthy' balance between free expression and community interests" (Johnston, Johnston and Handa 164).

New Brunswick (NB)

In 1993, the NB Task Force for the Information Highway introduced a strategy that positioned NB as both a "testbed" province, and the NB government as a model user. The NB Information Highway Secretariat favors private sector involvement in the growth of ICT. The NB Government also established a Task Force on Data Sharing and Protection of Personal Privacy. The Task Force presented a motion in March 1994 to create a Privacy Commissioner. A report by the Task Force, dated August 1994, recommends an independent adjudication process and the adoption of a Privacy Code to provide a consistent guide to information management practices. The draft Privacy Code reflects the following general principles: to limit data collection to relevant and necessary use; to ensure the accurate, complete and up-to-date nature of the information collected; to limit the use of information to the purposes stated at the time of collection; to provide for open and responsive access for individuals to their personal information; to maintain audit trails of access and use; and, to ensure the security of systems.

Newfoundland

The provincial government plays an instrumental role in the competitive growth of the ICT industry, as well as the adoption of ICT in social sectors. It has launched some strategic initiatives addressing both the needs of business and those of citizens and communities. For instance, the federal and provincial joint CAP will fund an additional 70 centres across the province by March 31, 2001. The number of CAP sites in the province will then total 150. Operation ONLINE (Opportunities for Newfoundland and

Labrador In The New Economy) Inc., a not-for-profit organization, is geared toward the channelling of public monies to stimulate the provincial information technology sector. It coordinates projects in training, distance learning and information technology supplier development, and the Educational Market Access Fund. The Fund assists the entry of locally produced multi-media courseware into the provincial education system.

Northwest Territories (NWT)

In 1994, a two-day "Connecting the North" Symposium was organized by the Inuit Broadcasting Corporation (IBC) involving 27 community discussion groups of ten members each spanning the Yukon, NWT, Nunavik (Quebec Inuit territory) and Labrador. The Symposium was intended as a forum to encourage public awareness and participation relating to the design, implementation and use of the information highway in Northern Canada. In the Symposium's Final Report published in 1995, key issues brought out during the discussions are listed: access[192], the impact of new technology on culture and language, training, increased accountability of service providers, research and development, and means of acquiring funding through partnerships and the redirection of public and private funds. As revealed by the community consultations conducted by IBC, much significance is attributed to the role of public regulatory bodies in supporting the principle of service universality and the mechanism of cross-subsidization. However,

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[192]Access to the Internet was first provided to NWT residents in October 1994 thanks to the efforts of the NTnet Society – formed, in June of that year, as a volunteer, community-owned, not-for-profit organization – and to a $160,000 grant received from CANARIE.

these consultations also insist that this principle and this mechanism, traditionally deployed to secure the monopoly of service providers, be used to potentially implement local ownership and control, diversity in R&D applications, and not-for-profit initiatives to provide "basic" services, these to be redefined by community members.

Prior to the CRTC hearing conducted in March 1995, the government of the NWT submitted a report commenting on national information highway policy, based on the Department of Education, Culture and Employment's strategic plan, released in 1994, and the IBC Symposium. The report was compiled following 18 months of public consultations. Its main recommendation was the creation of a "seamless network of community learning networks, providing an environment for life-long learning and personal development" (Government of the NWT, Connecting the North 2). Following recommendations of Nordicity Group Ltd. regarding the Development of a Business Case for a Digital Communications System, the territorial government issued a "Request for Proposals (RFP) For a Digital Communications Network" on May 6, 1996. The digital communications system, described in the RFP, would be made available to 58 NWT communities by 1999. Services provided would include: Internet access, government computing applications, telemedicine and tele-education applications through videoconferencing. The network is owned, operated and maintained by a private service provider with the GNWT acting as an "anchor tenant", guaranteeing a minimum amount of revenue. However, the network is designed as an open, modular and expandable network for other users to interconnect in the future. The network design accommodates

shared access by the government of the NWT and the Nunavut government. The contract was awarded on October 17, 1996, to Ardicom owned by Arctic Co-operatives Ltd. (largely Inuit-owned), NorthwesTel and Nasco.[193]

Nova Scotia

Established in 1995, the Technology and Science Secretariat (TSS) is aimed at instituting policies and strategic directions that will support employment, wealth creation, resource management and information technology capacity within government, commercialization plans, and ICT regulation. The TSS's key activities are to develop the government as a model user (e.g. Guidelines for Internet Use in the Nova Scotia Government, April 1997), to secure investment from industry and to organize joint science and technology development initiatives among public and private partners. Thus, the TSS is more so concerned with increasing the competitiveness of the province's ICT industry than with the integration of ICT in its social sectors.

Nunavut

Community-level delivery of services to the information highway is the approach favored by the Nunavut Implementation Commission (NIC), as intimated in two supplementary reports released in 1995 and 1996. In Nunavut Telecommunication

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[193]Nasco is a consortium of Aboriginal development corporations: the Nunasi Corporation (owned by all Inuit enrolled under the Nunavut Land Claim Agreement), the Denendeh Development Corporation, the Inuvaluit Development Corporation, and the Yukon Indian Development Corporation.

Needs, the NIC introduces the concept of CTSCs which it believes are key to building an integrated regional Nunavut economy. It further argues that CTSCs can overcome many barriers to rural telecommunications development, such as the lack of network infrastructure, severe limitations to accessible services, prohibitive equipment and services costs, and the lack of training and skills. Notwithstanding, the NWT government's implementation of the digital communications network in 1996 supplanted community-based initiatives recommended by the NIC. In response to the RFP launched by the NWT government, the NIC insisted on certain modifications to its technical, management and human resource specifications, foremost being the creation of 21 CTSCs by the year 2000. However, the NWT government claimed that transition funding approved by the federal government for the implementation of the Nunavut government would not be sufficient to account for the expenses associated with the information technology infrastructure desired by the NIC.

Ontario

The Information Highway Secretariat of the Ministry of Energy, Science and Technology adopts a stance in favor of competition in the ICT industry. To promote such competition, it administers some strategic initiatives intended for Ontario-based businesses, mainly the Telecommunications Access Partnerships (TAP) and the Interactive Digital Media Small Business Growth Fund. The $50M TAP program offers funding to participants willing to develop shared regional/community networks through public/private partnerships. These partnerships are directed toward improving business

dealings and building a province-wide, shared backbone network through successful research & development projects.

Prince Edward Island (PEI)

The Ministry of Technology and Environment assists information technology businesses and contributes to the integration of ICT in education and health. Beginning in 1995, 41 SchoolNet Digital Collections Projects and 18 CAP sites were established in the province by 1997. That year, the provincial government agreed to cost-share the CAP with the federal government. An additional 28 sites have since been founded. The provincial government now claims that no Islander is more than 15 minutes away from a public access point to the Internet.

Quebec

In July 1995, the final report of the Consultative Committee on the Information Highway was published. The Committee put forward a set of recommendations dealing with the following issues: a government strategy (formulated in 1996); the government as a model user; the connection of all schools by 1998; the integration of information technology in the schools' curriculum; distance education; the connection of all health care institutions by 2000 through regional networks; public education on the advantages of using ICT in health care and on security and confidentiality of electronic information; government support of pilot projects in health care; ICT use in continuing medical education and basic health care education; research and development; cultural history and

content (connection of museums, libraries etc. and online accessibility of their materials); affordable access; reengineering government. On August 2, 1995, a Ministerial Committee and an Inter-ministerial Committee on Information Technologies were created along with an Information Highway Secretariat. In April 1998, the Treasury Board Secretariat and Culture and Communications Ministry released a provincial policy on the information highway. Among its objectives, the policy proposes: to generalize the use of the information highway by providing community access points, public training and access to high-bandwidth; to prepare Quebec youth to use and develop ICT; to enhance Quebec cultural content on the information highway; to favor the use of ICT in economic development; to render the government more accessible to citizens and businesses.

Following the release of the provincial policy, the Information Highway Fund, introduced in 1994/95, was revised to encourage access, francophone content production and new economic development and employment opportunities. It was granted an additional $10 million to do so. Since it was first established, the Fund has contributed $70 million to the ICT industry, created 500 jobs and prompted $150 million in investments. More recently, in June 1999, the government launched a Forum on the Information Highway to promote discussion amongst non-government organizations with respect to ministerial priorities and the main issues related to the information highway, focussing on the economy, social sectors and research and development. While in 1998, the provincial government instituted an overall policy framework, in 1999, it stresses electronic commerce and security issues.

The right to privacy is stated in the Quebec Constitution. Furthermore, on June 15, 1993, the Quebec Government enacted Bill C-68, *An Act respecting the protection of personal information in the private sector*, to complement its *Freedom of information and Protection of Privacy Act* regulating the public sector. Bill C-68 goes so far as to regulate telemarketing's use of "nominative lists".

Saskatchewan

The Saskatchewan Communications Network (SCN) is a Crown Corporation that seeks to increase public access to information to sustain educational, cultural and social initiatives. The SCN is composed of a Training Network and a Broadcast Network. The Training Network delivers post-secondary and secondary classes to 180 classrooms in 146 communities and is made available to businesses and other organizations for satellite conferencing. In contrast, the Broadcast Network reaches approximately 700,000 residents through cable, wireless cable and satellite for the purposes of curriculum support programming, post-secondary credit classes and general educational and cultural programming.

Yukon

While I have been unable to obtain much information on the government's ICT policy, schools throughout the territory are connected to the Internet through YESnet (Yukon Educational Student Network). The network is an initiative cost-shared by the federal SchoolNet program and the Yukon Department of Education. The network was

launched in 1996 within the framework of the Schoolnet Grassroots Program that facilitates the use by teachers of the Internet in the context of learning activities with their students.

Appendix C: Provincial and Territorial Government Policy Frameworks and Initiatives in the Domain of Telehealth

A key vehicle for telehealth public policy development, initiated by the OHIH, consists of the Federal/Provincial/Territorial Chief Information Officers Forum founded in February 1998. It was recently expanded as the Federal/Provincial/Territorial Advisory Committee on the Health Infostructure. As of yet, the Committee has acted on the issues of Y2K, privacy and standards.

Alberta

In November 1995, Health Minister Halivar Jonson announced the creation of a province-wide health information technology system as a key initiative for 1997, as well as new legislation for the protection of health information. He received an anonymous donation of $14 million that stated two conditions: the donation would fund provincial telehealth development; the Alberta government must match the amount of the donation.[194] On January 28, 1996, committees were appointed to guide the development of the system including a Senior Reference Committee composed of physicians, nurses, members of RHAs, pharmacists, members of Cancer and Mental Health Boards, representatives of universities and faculties of medicine, of CIHI and Alberta Health. No citizens or community groups appear to have been involved except perhaps through RHA representation. On June 14, 1997, Alberta Health announced the selection of IBM

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[194]Total budget projections of Alberta Health for information management and technology range from $200 million to $300 million, corresponding to 1.5 per cent of its annual budget.

Canada Ltd to develop a blueprint for Alberta *Well*net, in cooperation with a consortium of companies including TELUS and three Alberta-based information management and technology firms specializing in systems integration for the health sector. The blueprint was completed in the Fall of 1997. In announcing the end of the selection process, the Chair of the Senior Reference Committee, Dr Tom Noseworthy "stressed the importance of moving ahead with the development of better systems to allow physicians, health authorities, nurses, pharmacists and researchers to access and share information so they can work together to improve health" (Alberta Health, Strategic Partner).

Alberta *Well*net's financial framework will allocate to each RHA a fixed amount of capital funds to develop telehealth applications, later to be sustained by additional operating subsidies. It is hoped that Alberta *Well*net will serve to improve community health needs assessment currently undertaken by Alberta's RHAs.[195] Hence, the implementation of ICT is configured in such a way as to advance the regionalized structure of the health system. The mission of Alberta *Well*net is stated as follows: "To enable better decisions, using integrated system-wide health information, to improve the health of Albertans and the management of the health system" (Alberta Wellnet).

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[195]The process of community health needs assessment in Alberta involves: collecting a solid base of information about health needs, environmental and behavioural influences on health, and community resources in the region; involving communities through planned input sessions; designing action plans and setting priorities to address needs; integrating regular monitoring and evaluation; and finally, building the resulting information into business cycle plans.

It is planned that 150 locations will be connected by the network. Currently, there are 20 pilot projects in place providing telepsychiatry, CME, telelearning and teleradiology services. Pilot projects that will be integrated in 1999-2000 include a pharmaceutical information network, an integrated cancer care network, expansion of the newborn registry for metabolic screening, financial applications in three RHAs, a province-wide Spatial Public Health Information Exchange (SPHINX), a province-wide system to integrate personal health information, a breast cancer screening registry, and eight new telehealth applications. A special billing code has been created to cover the remuneration of medical professionals. It is planned that a team of experts from the province's universities will be called on to evaluate the network's applications, taking into account financial indicators and the intangible benefits of telehealth. The province is, in fact, hosting the First Global Conference on the Evaluation and Diffusion of Telehealth in October 1999. Finally, new legislation was introduced for discussion in June 1997 known as Bill 30, the *Health Information Protection Act*. In December 1997, the Health Minister released a report reviewing comments on the draft bill. He chose to create a working committee and a steering committee to further review the issues and recommend further options for a policy framework on the protection of personal health information.

British Columbia

In June 1995, a consensus was reached and plans to integrate HealthNet/BC in the government's Health Information Management Project (HIMP) were initiated. Its two

main components were identified: an open data network and an information sharing facility. The consensus established the following principles to guide the implementation of the distinct network components: equal access (a decentralized network), standards-based, accessible information (subject to provisions of the *Freedom of Information and Protection of Privacy Legislation*[196]), data security and integrity, and cost-effectiveness. A list of potential participants to HealthNet/BC was provided: regional staff (RHBs, CHCs), the Health Ministry, physicians, hospitals, information and service providers of the private sector, laboratories, public and mental health providers, continuing and long term care facilities, municipal and civic governments, regional districts, pharmacists, and funded health agencies. Citizens and community members were not directly targetted. It was planned that access to the network would be restricted to this list of participants and offered through subscription applications on a "user pay" basis. Service delivery contracts were to be offered for basic connection services, the cost to be determined by provincial volumes. The cost of other services were to be set by the vendors.

Plans to develop several network applications were announced: the Healthnet/BC Connections Project (linking acute care hospitals and Ministry's offices such as RHBs and CHCs, and PharmaNet access for hospitals), the Client Registry (demographic information acquired through a Personal Health Number), PharmaNet (drug use and

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[196]On July 27, 1995, BC's Information and Privacy Commissioner, David H. Flaherty, presented BC's policy on the protection of health information at the Eighth World Congress on Medical Informatics. Since November 1994, all 100 provincial hospitals have been regulated by the *Freedom of Information and Protection of Privacy Act.*

interaction application, on-line claims adjudication), and Teleplan (electronic submission of physicians' claims). All pharmacies were connected to PharmaNet in September 1995. Annual cost-savings resulting from PharmaNet were projected in July 1995 at $1.5 million deriving from streamlined Pharmacare administration, and $10 million to $35 million deriving from the detection and prevention of prescription drug fraud, abuse and overuse. The results of the Healthnet/BC strategy are reported by the CCHSE as follows: the roll-out of a secure, private network linking health authorities for information exchange, pilot deployment of a client registry whose access is protected by the pilot use of a Public Key Infrastructure, the extension of PharmaNet to several hospital emergency rooms and cooperative pilot initiatives among health authorities offering physicians the opportunity to access health information electronically and securely exchange mental health information. Third parties who wish to develop Healthnet/BC applications must comply with standards set by the province's Health Information Standards Council, in addition to presenting a business case. These applications are not subject, however, to any performance measurement once they are operational.

Other provincial initiatives include an InterMinistry Telehealth Committee, formed in order to guide and coordinate telehealth-related projects undertaken in the province. It is expected that in building Healthnet/BC as the provincial backbone, telehealth applications and projects will be undertaken, especially once security and privacy issues are resolved. Currently, the St. Paul's Hospital, the Vancouver General Hospital and the University of BC Hospital are involved in piloting telehealth

applications that are not directly sponsored by the province. The BC Vital Statistics Agency continues to improve its on-line system known as VISION, and its electronic warehouse or VISTA. Finally, BC has taken the lead in the creation and operation of the Canadian Year 2000 National Clearing House for Health. Jointly funded by the federal/provincial/territorial governments, the clearing house will be operated under contract by the LGS Group Inc. of Montreal.

Manitoba

In 1995/96, Manitoba Health signed a multi-year contract with SmartHealth to put together a HIN as the backbone infrastructure on which a variety of applications can be piggy-backed. Its design consists of a secure Intranet only accessible to health care providers. It was expected to be completed by the end of the 1999 fiscal year. Its planning is guided by a Multi-Stakeholder Advisory Committee and mainly driven by the need to improve rural access to health services. A Crown Corporation was formed called the Health Information Services of Manitoba Corporation (HISM) to manage the network.

The year 1995/96 was also the first full year of operation of the Drug Programs Information Network (DPIN), the first functional HIN application. First activated on July 18, 1994, the DPIN manages prescription records, processes claims and provides real-time adjudication of Pharmacare reimbursement to patients and pharmacies. Before it is completed, it will have been extended to northern nursing stations, hospital pharmacies, and physicians' offices. While it was initially introduced to hospital emergency rooms

and admitting areas in five model sites across the province, it was implemented in all hospitals by the Fall of 1999. The network will also support a Decision Support System to serve as a clinical data repository to be piloted by the year 2000. A Diagnostic Services Information Network will also link laboratories across the province.

Other pilot projects have been initiated by Manitoba Health which involve information technology. The Continuing Care Management Information System has designed a Screening Assessment Care Planning Automated Tool (SACPAT). The system is supported through a Local Area Network and laptop computers and is used by health care workers to conduct interviews. The Winnipeg Regional Health and Family Services Mobile Workforce pilot project is also directed at improving the mobility of health care workers. It has equipped 45 providers with laptop computers and communication devices. With funding from Manitoba Health, the Manitoba Centre for Health Policy and Evaluation has produced a Population Health Information System named POPULIS. The system examines data on health and on the relationship between the use of services and health status. Past studies of POPULIS have consisted of analyses of the impact of health care reform initiatives on the quality of care. Lastly, with the development of the HIN, a Privacy and Confidentiality Committee with members from regulatory bodies and consumer groups[197] was formed. On December 17, 1997, the *Personal Health Information Act* was proclaimed.

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[197]Members of the Consumers Association of Canada, the Manitoba Association of Rights and Liberties and the Manitoba Society of Seniors were among the participants.

New Brunswick (NB)

In 1995, Premier Frank McKenna, in an address to Parliament, announced NB's future leadership in telehealth development. That same year, a strategic plan and Terms of Reference paper outlining the provincial government's involvement in telehealth were formulated. As well, a Telehealth Coordinating Committee was created. The government chose to support a decentralized framework for telehealth, encouraging hospitals, private sector partners and other facilities to undertake pilot projects. The framework is focussed on enhancing NB's competitive advantage in the field of ICT and on improving access to specialist services. According to a report on telemedicine released by the NB Department of Health and Community Services in January 1997, "[t]he process of reform which has been under way in New Brunswick for the last few years, combined with the government's commitment to the strategic use of technology, has created the right kind of atmosphere for the application of telemedicine" (Telemedicine Section 5). The report lists the most significant strengths and opportunities from which it can be concluded that NB is well-positioned strategically to undertake telemedicine: NB Tel's 100 per cent fibre-optic infrastructure, supplying the necessary bandwidth in rural and urban areas[198]; the government's readiness to act as a model user of ICT; health care regionalization that imposes a delivery and management network (e.g. fixed number of medical manpower); current telemedicine applications in

[198]Furthermore, the province is looking into developing a broad bandwidth infrastructure, presently testing some applications.

progress in RHCs[199]; and NB's leadership in distance education.

The provincial Wellnet serves as the backbone telecommunications infrastructure linking 61 locations. The following applications currently run on Wellnet: the province-wide Tele-Care network (a triage project operated by Clinidata), teleradiology (9 projects throughout the province), telecardiology (Vital-NB Health Centre), telepediatrics (Maritime Children's Telehealth Network), tele-neurosciences/psychiatry (RHC project), tele-homecare[200], a Client Service Delivery System, a multi-point tele-education network[201], and telenephrology (a RHC/Beauséjour project). Wellnet is a secure, private network. However, the government is testing a PKI infrastructure hoping to use the Internet in the future to deliver telehealth. In order to resolve other potential impediments to the advancement of telehealth, the government has published a recommended guide for telehealth remuneration listing which high-priority services will be reimbursed. Moreover, it has obtained telehealth liability coverage in the provincial insurance plan, as well as a ruling by the Canadian Medical Protective Association (CMPA) and the

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[199]For instance, the Atlantic Health Sciences Corporation operates a teleradiology project improving support to Grand Manan Island.

[200]NB was selected in the fall of 1996 as a site for the onset of Stentor's Beacon Initiative to conduct "in-the-home" telemedicine.

[201]TeleEducation NB is a province-wide videoconferencing network linking over 100 sites including eight RHCs. While it was used initially for the training of ambulance attendants, it has since been expanded to encompass university courses, CME delivered from Quebec and Nova Scotia, and administrative meetings. Audiographic tele-education sites have also been installed in the program offices of the Extra-Mural Hospital.

Association of Medical Colleges determining the extent of physician liability coverage.[202] The government considers the issue of privacy to be common to all electronic exchange of information and, therefore, is considering general privacy protection for all social and economic sectors. Having received a $30,000 grant from Health Canada, the government is setting up a committee to produce a standard evaluation framework for telehealth projects. Finally, it continues to promote public/private partnerships as a means to sustainability.

The NB Government has proposed the following vision to guide the integration of telemedicine: "Telemedicine will improve access to quality patient care, education and research services at an affordable and sustainable cost" (NB Department of Health and Community Services, Telemedicine Section 7). Telemedicine is part of a broader vision conceptualized by the NB Department of Health and Community Services for an integrated health care delivery system involving the strategic use of ICT: a comprehensive NB Care Network. The NB Care Network involves three categories of innovations in ICT: technologies designed to provide consumers with health information and increase popular participation in informed decision-making; technologies used to exchange information for administration; and, telemedicine technology. The second category refers to the use of the Hospital Financial and Utilization Management System (HFUMS). The report configuring the Care Network describes telemedicine as a "reengineering tool" to

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[202]Three conditions must be met to guarantee coverage: a provincial license, image quality that equals standard images, and patient consent for telehealth use.

be implemented within the context of health care reform (NB Department of Health and Community Services, Telemedicine Section 4). Telemedicine will serve to expand the responsibilities of the newly formed "centres of expertise" to cover activities such as peer review, remote consultations, practice guidelines, research, CME etc. With regards to its benefits for rural areas, the Department argues: "Rural hospitals and communities that have had to redefine a role for themselves within a radically different health care system are presented with unprecedented opportunities to 'find their niche' with the aid of telemedicine" (Telemedicine Section 5). Components of the Care Network that are already in place are: Wellnet administrative databases such as the aforementioned HFUMS, as well as the Regional Addictions Services System, the Extra-Mural Program Patient Unit Information System and the Medicare Administration and Technical Services (MATS) system; the Prescription Drug Program (a pilot project connecting 90 per cent of pharmacies); and, Tele-care (a free, dial-up, 24-hour, bilingual, nurse information triage network).

Newfoundland

On October 8, 1996, the Newfoundland and Labrador Centre for Health Information (NLCHI) was founded with the primary objective of drafting recommendations relating to an integrated and comprehensive ICT system for health and social services. The Centre itself is the result of 26 recommendations presented by the Provincial Task Force on Health Information. The task force was composed of members from the Department of Health, the Treasury Board and the Newfoundland and Labrador

Health Care Association. From these recommendations, the Department of Health elaborated a seven-year strategic health information plan, of which the Centre is the first phase. Viewed as an essential step in health system reform, the Centre will improve EBDM, as stated by former Health Minister Lloyd Matthews, by "[c]oordinating health information and databases [that] will assist government health providers, consumers and special interest groups in making more informed decisions about health care" (Newfoundland Department of Health, New Centre). Citizens are part of the Centre's Board of Management. The 1996/97 budget dedicated $9.4 million to the Centre. Total public expenditures directed toward the Centre over the next few years is expected to reach $50 million.

In October 1998, the Centre released a business plan for a province-wide health information network. It recommended eleven applications, the first two to be introduced shortly: a Unique Identifier System, personal medication dispensing history, personal diagnostic service history, diagnostic service requester decision support, personal medication regimen, personal health information profile, physician practice pattern profiling, clinical decision support tools, telehealth, a Human Resource Management Information System, and enhancements to the recently implemented Client and Referral Management System. The Centre projects a one-time cost for implementing the first two applications of $10 million, and annual operating costs of $1.5 million. Notwithstanding, a main driver for the network, the Centre suggests, are estimated costs savings to the government of $5 million over five years.

Aside from the establishment of the Centre, the provincial government has stood on the sidelines of telehealth development in the province. Rather, Memorial University's TETRA/Telemedicine Centre has played a crucial role in the advancement of telehealth in Canada. Relying on external funding sources, such as a recent grant from the European Space Agency or a user-pay basis, it has innovatively undertaken distance CME and teleconsultations in several specialty areas. As well, some regional health boards have funded telehealth applications within their own budgets. Payment schedules for teleradiology and telepsychiatry were instituted in the context of pilot projects organized by Memorial University. A more extensive remuneration policy has been drafted for consideration by the government and by the provincial Medicare Commission. The Centre has also drafted a privacy policy.

Northwest Territories (NWT)

Network 99 consists of a health and social services computer network that links every community since April 1999. It includes WellCom (a record-keeping and electronic data transfer system for CHC management) and a Child Welfare Information System (a record-keeping system for child welfare cases). Network 99 built a telehealth system used primarily for teleconsultation. In its first phase begun in 1997, Westnet connects the Yellowknife General Hospital and two other health care centres in the NWT to conduct teleconsultations in orthopaedics and internal medicine. Its second phase will involve telepsychiatry, teledermatology, telegeriatrics and distance trauma consultations.

Nova Scotia (NS)

In early 1997, the NS Department of Health released the results of an evaluation conducted on a telemedicine pilot project linking hospitals in Guysborough, Sheet Harbor and North Sydney to specialists in radiology and dermatology located at the Queen Elizabeth II Health Sciences Centre in Halifax. The project had also organized 12 CME sessions held from January to June 1996, focussing on team building amongst a variety of health care providers (physicians, nurses and social workers). The evaluation found that out of five emergency cases where teleradiology was used, in three of those cases the virtual presence of the radiologist alleviated the need for transportation to a regional health care facility. Furthermore, the study concluded that practitioners adapted easily to the applications and had a high level of acceptance of the technology.

On September 23, 1997, Premier Russell MacLellan proudly announced the creation of the first province-wide computer-based telemedicine network in Canada. The NS Telehealth Network connects every hospital in the province and span 43 sites. It represents a public and private partnership worth $8 million. The first stage was undertaken by the Dalhousie University Medical School and the second stage is operated and managed by NS companies: TecKnowledge Health Care Systems Inc. and MT&T. However, the Community Health and Epidemiology Department of Dalhousie University continues to be involved in bi-annual performance measurement that does not incorporate a cost-benefit analysis. The NS Government is confident that the network has export capabilities, but generally perceives it as a supplemental cost to health care delivery.

Innovatively, part of the network is connected to St. Kitts, an island in the Carribean, to provide teleradiology and tele-ophthalmology services.

Currently operating on the network are the following applications: CME, administrative systems, teleconsultations (in psychology, dermatology, emergency medicine, oncology), grand rounds to regional hospitals, and nurses education. Each application must respond favorably to criteria set by an advisory committee (needs assessments, local buy-in, cost-effectiveness, strategic contribution to the overall network design). The committee prioritizes emergency ward and clinical applications over administrative and CME applications. The government negotiated revised fee structures to accommodate telehealth service delivery. While radiologists and general practitioners receive the same amount of remuneration in a teleconsultation, specialists who participate in a teleconsultation are paid a supplemental detention fee to accommodate for the additional time required. The government also received a letter from the CMPA ensuring that no special liability risks are incurred in teleconsultations by medical practitioners.

Nunavut

The Baffin Health Network links Pond Inlet, Kimmirut, Iqaluit, and three tertiary care centres in the Ottawa region (the University of Ottawa Heart Institute, the Children's Hospital of Eastern Ontario and the Civic Hospital). The network serves to conduct teleconsultations in mental health, family medicine and ENT, and to provide professional support to nurses working in isolated areas. The first phase of the Network faced serious

technical impediments, while 50 per cent of its $1 million start-up budget was expended on training, evaluation and other non-technical activities.

Ontario

Announced by Health Minister Jim Wilson in February 1997, the Rural and Northern Health Care Framework will build networks to provide 24-hour access to care in remote communities to emergency and specialized services. Smaller rural hospitals will be permanently linked to at least one larger hospital with a fully staffed emergency department. The larger facility will also provide clinical support and specialty services. Rural and northern hospitals located within 40 kilometres of each other will be connected to form regional networks consolidating administrative and support services and perhaps even sharing staff and governing structure. They will be linked to local DHCs and other health care providers and agencies. New technologies will gradually be phased-in to allow emergency care (the transfer of medical information from rural ambulances and helicopters to hospitals), telemedicine consultations, and education and training.

Health Information Partnerships have been formed between DHCs, Public Health Units (PHU) and academic science centres in Ontario regions. These partnerships have been complemented by ICT networks, such as the Central West Health Planning Information Network that links seven PHUs, seven DHCs and McMaster University's Faculty of Health Sciences. The goal of these partnerships is to coordinate health assessment, planning and population-based health information research conducted by

local planning and service delivery bodies.

Funding to launch the first phase of the Ontario Smart System is in the process of being approved. The system is envisioned as a core ICT infrastructure for the delivery of health services across the province, driven by rationalization rather than application development. If realized, it will connect all hospitals and CCACs. The government also projects that cost savings totalling $100 million will ensue from integrating existing laboratory testing networks. At present, the government estimates that while over sixty independent networks are being operated in the province, forty of these are health care related.[203]

In June 1996, the Ontario Ministry of Health distributed a consultation paper entitled A Legal Framework for Health Information. The paper criticizes current privacy protection laws for their restrictive application to discrete health care relationships and to health records instead of to the information contained in those records. It states:

> As a result, health information that is protected when in the custody of a physician or hospital may be free of legal protection when it is disclosed for other uses; for example, to an insurance company. A legal framework that protects confidentiality to health information could be tied to, and follow, such information throughout its use and disclosure. (Ontario Ministry of Health, Legal

[203]For example, all pharmacies are presently connected to the province-wide Health Network.

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Public feedback was accepted regarding the paper's recommendations until July 31, 1996. The legal framework responding to this feedback is still under development.

Prince Edward Island (PEI)

In 1993, the PEI Health and Community Services Department began strategic planning of an Island Health Information System (IHIS). The objectives of the IHIS are service delivery, the exchange of patient care information and information for planning, evaluation and research. The original strategic plan for IHIS, entitled VISION 2000, was developed by HealthVision, a California-based company. The vision included the following components: community-based networks to link providers locally, regionally and nationally; the clinical use of these networks; access to information for providers at the point of care; strict confidentiality and security guidelines and procedures; access for providers to institutionally-based systems; data exchange standards; a central data repository; a patient profile that includes medication, lab results and diagnostic images; service event tracking; assistance and care plan tracking; individual and family tracking; consumer access to health promotion and prevention information; access options such as e-mail, distance education, conferencing, training etc.

In 1995, the IHIS conducted its first live application. By 1997, a solid foundation was in place for the building of an integrated, province-wide health information system for health and social services. Currently, the IHIS runs the following applications: the

provision of a personal health number, financial/enterprise automated systems, payroll/human resources automated systems, a PharmaNet, the management of medical records and the pharmacy informatics program. The IHIS also integrates a system for physician billing, a social services medical information system, a senior assessment database and a health needs index. Hence, the IHIS is oriented toward rationalized administration and EBDM rather than toward developing clinical applications.

In 1997, a review of the Strategic Plan was launched. It identified five key applications for the future: a case management system, a patient care system, a laboratory information system, a radiology information system and a clinical information system. The review featured a cost analysis reporting a total investment from 94/95 to 97/98 of $10.1 million and future investments ranging from $5.8 million to $8.6 million. The review concluded that such an investment could not be justified by the state for a population of 135,000. The PEI Government chose to enter into a public-private partnership for the purposes of increasing the province's competitiveness in the field of telehealth by creating economic development opportunities, and of minimizing the financial impact of the IHIS. The government established a Memorandum of Understanding with Cebra Inc., a subsidiary of the Bank of Montreal. Cebra will first conduct made-in-PEI business cases for the five key areas identified in the review. It will search for "best-of-breed" solutions, integrate and adapt these for efficient and effective implementation of the IHIS. Cebra is motivated to participate in the IHIS initiative to develop a competitive advantage in regional, national and international markets.

Quebec

In the mid-1970's, information technology in the Quebec health system served the operational needs of institutions. In the early 1980's, it responded to the needs of clinical-administrative systems. By 1989, its implementation was described as diverse, incompatible, dependent and inflationary. On August 2, 1995, a Ministerial Committee and an Inter-ministerial Committee on Information Technologies were created along with an Information Highway Secretariat. The secretariat released an implementation strategy in April 1996 that outlined the context of information technology in the health system. It also identified four strategic objectives for an "Inforoute Santé" that would complement key components of health system reform: to produce population-based information on resource allocation, health and social problems, risk factors, known intervention models, and existing programs; to increase patient autonomy and improve decision-making; information networking among consumers, professionals, institutions, regional boards, for improved access to, and management of, services; to pilot security mechanisms (smart cards); to be active in telediagnostic, telemedicine and teleservice. The secretariat favors a technical architecture that incorporates convivial user-system interfaces, client-server models, open systems, portability, connectivity, and interoperability. In order to build this architecture, the Ministry of Health and Social Services intends to build partnerships with industry for a shared investment, in exchange of providing support for commercialization and exporting.

In July 1996, the Ministry of Health and Social Services conducted a study on public reactions to the information technology implementation strategy. 96 per cent of respondents agreed with the strategy, but 55 per cent admitted they were not sufficiently informed. In response to the public consultations conducted in 1995/96 and the results of the July 1996 study, the Ministry of Health and Social Services drafted an integrated action plan for the implementation of the information highway in the health and social services system. The plan is also based on pilot project evaluations. According to the plan, during 1997, direct information services were to be made available to the citizen to improve his/her decision-making powers, his/her health and well-being, and his/her position within a reformed health system. This would be accomplished through open networks such as community networks and the Internet. The 1996/97 budget dispensed a global amount totalling $19 million for technical infrastructure, and $5 million for information highway pilot projects.

At the end of 1997, the Ministry released a provincial policy coordinating the implementation of telemedicine, telediagnostic and teleservice. This policy has, as of yet, not been implemented in any systematic way. Instead, pilot projects continue to be operated across the province, partly funded by the government and mostly by the Information Highway Fund. The Quebec Inter-regional Telemedicine Network began its first phase in June 1996 by linking the Hotel-Dieu Pavilion of the Montreal University Hospital, St-Mary's Hospital located in Three-Rivers, and hospitals in Joliette and Rouyn-Noranda. Funded by the Information Highway Fund, teleconsultations have been

conducted over the network in the areas of radiology, anaesthetics, dermatology, psychiatry and cardiology. Trials in CME have also taken place. The East Quebec Network, funded by CANARIE and the Information Highway Fund, connected the Laval University Pavilion of the Quebec Universities Hospital and hospitals of Rimouski, Seven Islands, Chandler, Riviere-du-Loup, St-Georges, Madeleine Islands, Maria, St-Anne-des-Monts, Mont-Joli, Matane, Gaspe and Amqui. Teleconsultations in cardiology, pediatrics and radiology have been tested. The Minister of Health and Social Services directly granted $4.7 million to the Quebec Pediatric Telemedicine Service connecting four tertiary care centres, 28 other provincial health care centres and two northern health centres. Pediatric cardiology consultations are delivered at a distance through the network. Plans have recently been announced to expand the network to over 70 sites. Finally, the Provincial Mother-Child Network operated by the St-Justine Hospital in Montreal was funded by the Fonds d'Adaptation des Services de Santé when it was launched in June 1997. Active in the Laval, Valleyfield and St-Jerome regions, it offers services in infectious disease, obstetrics, gynaecology and intensive care. It may expand to include telepsychiatry, teleradiology and the exchange of EMRs.

Quebec is planning to develop and implement smart card technology province-wide. In addition to being concerned with security measures, Quebec has the most comprehensive legislative protection of personal privacy in the country, and perhaps even internationally. As well, Quebec has granted legal protection to the doctor-patient privilege almost equivalent to that of the solicitor-client privilege.

Saskatchewan

On August 25, 1997, the Government of Saskatchewan announced its commitment of $40 million over the next two years to provide for the implementation of the Saskatchewan Health Information Network (SHIN) over SaskTel's existing fibre-optic network. The investment will be used to develop individual EMRs, to link health district professionals, and to deploy software in the ordering, recording and monitoring of health services. SHIN is operated by a Crown corporation, but is managed by a Board of Directors composed of representatives from government, the Saskatchewan Association of Health Organizations, DHBs and health professional organizations. The board is publicly accountable for expenditures. The Science Applications International Corporation was selected to lead the implementation of SHIN (to begin in the Fall of 1999) but it is not represented on the board.

In July 1996, a Telemedicine Steering Committee was formed to direct telemedicine projects of the SHIN.[204] Three telehealth pilot projects have since been funded. A real-time videoconferencing network, the Northern Telehealth Network, connects nine sites in La Ronge, North Battleford, Ile-à-la-Crosse, Prince Albert, Meadow Lake, Nipawin, Saskatoon, and two nursing stations, to conduct teleconsultations and share information in the specialties of child psychiatry, dermatology, ultrasound, teleradiology and CME. Computing Devices Canada is the

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[204]There are no citizen nor community members directly participating in the Committee, except potentially through their role in DHBs.

technical supplier (hardware and software) of the network. The network is also partly funded by CANARIE. The Southwest Rural Physician Network is geared toward the exchange of EMRs by physicians in the Southwest Health District, involving 34 workstations. Internet applications will be developed for public and professional education in several districts. Projects will be evaluated upon completion. Fee structures were revised to accommodate telehealth consultations, supplementing time-related payments.

At present, personal information held by the Saskatchewan Government is protected by the *Freedom of Information and Protection of Privacy Act*. The implementation of SHIN has prompted action to extend privacy protection to the private sector. Three steps will be undertaken by the government: the drafting of an open statement of principles consistent with internationally accepted fair information practices; the enactment of legislation formulated with public input; and the establishment of structures for accountability (a designated public authority, the use of aggregate standards or de-personalized information, audits, enforcement mechanisms). Draft legislation was presented to Parliament in the Spring of 1999.

Yukon

The Department of Health and Social Services and the Yukon Medical Association devised a medical information plan, allowing for faster reporting of test results, electronic billing for medical services and potential telemedicine connections

between communities, Whitehorse and southern medical centres. Currently, the Whitehorse General Hospital is receiving teleradiology and tele-ultrasound consultations from the Vancouver General Hospital and an Alberta health care facility under a two year contract specifying liability, payment and jurisdictional arrangements. Recently, a pilot project connected the Whitehorse General Hospital with rural communities in order to deliver teleconsultations in the areas of dermatology, rehabilitation, occupational therapy and physiotherapy. The project was funded by CANARIE ($150,000), NorthwesTel ($180,000) and the Yukon Government ($260,000). It was governed by a Project Committee composed of members from NorthwesTel, the Yukon Departments of Informatics and of Health and Social Services, and one physician. The project was completed in June 1999 and subjected to a comprehensive evaluation. Presently, the government is revising fee structures to compensate physicians for the additional time spent on teleconsultations. Liability issues are resolved with a Consent of Treatment and Diagnosis Form signed by each patient prior to receiving a teleconsultation.

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