Struggles, strategies, and sequelae: A qualitative exploration of patient experience navigating the healthcare system

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Abstract

Background: Healthcare systems are complex. Patients require good health literacy to navigate successfully and obtain needed healthcare. Patients with social vulnerabilities, such as limited health literacy, low social support, low income, or limited language proficiency will experience greater challenges. Navigational failures may result in fragmented, inappropriate, or forgone care. Strengthening the capacity for patients to successfully navigate the healthcare system will lead to improved patient experience and appropriate use of health services. This study explored the experiences of primary care patients navigating the healthcare system and will inform the design of interventions to provide navigational support.

Objectives:

1. To identify the navigation barriers and challenges encountered by patients obtaining healthcare services.
2. To explore the strategies mobilized to address barriers and challenges, and any associated emotions and consequences from failed strategies.
3. To identify any actions by clinic staff that help patients navigate the healthcare system.

Methods: This qualitative needs assessment consisted of two sequential sub-studies: anticipated needs assessment and experienced needs assessment. The anticipated needs sub-study explored general navigational challenges experienced by patients when seeking recommended follow-up healthcare. During 5 half days, adult patients leaving their appointment were contacted (n=56) and those with a follow-up recommendation invited to participate (n=34). Semi-structured interviews (n=19) analyzed using content analysis, pointed to a minority that are likely to experience significant navigational challenges that lead to negative healthcare consequences. Consequently, the experienced needs sub-study recruited adult patients referred by their primary care provider as experiencing significant navigational challenges. Guided by Jobs To Be Done (JTBD) Theory, in-depth retrospective ethnographic interviews (n=7) explored the consequences and impact on care by focusing on the nuances of stories told by patients. Thematic content analysis and JTBD Theory were used to reveal the functional, emotional, and social Jobs to be Done underlying the navigational trajectory.

Results: The anticipated needs assessment found that all patients experienced frustration in getting follow-up services, many felt powerless, and a minority forwent services completely. Navigation challenges are exacerbated when support from social network is not available, and navigation is more challenging when patient-provider communication was weak and the reason for follow-up is not clear to the patient. Results obtained from the experienced needs assessment showed that although navigating the healthcare system is annoying, patients persevere for their own health (functional Job), for their commitment to a good patient-provider relationship (emotional Job), and the desire to be perceived as a good patient (social Job). Personal connection is a key strategy to overcoming hurdles. Social networks and communication with the care team supported perseverance through challenges.

Conclusion: Navigating the healthcare system is work. Patient motivation to persist through frustrations and challenges is strengthened by the clarity of the functional, emotional, and social Jobs that patients need to accomplish by getting recommended services. Ensuring that patients have a complete understanding of why they require a certain healthcare service, and its importance, is critical to improving patient adherence to obtaining the service. Social networks and connections are a key strategy mobilized to support healthcare system navigation. Human touch and communication with the entire care team drives patients to follow-up with recommended healthcare services and persist in overcoming navigational hurdles. Finally, more

robust support is needed for a portion of the patient population, mainly the socially vulnerable patients.

Résumé

Contexte : Le système de santé est complexe. Les patients doivent avoir de bonnes connaissances en matière de santé pour bien naviguer et obtenir les soins de santé dont ils ont besoin. Les échecs de navigation peuvent se traduire par des soins fragmentés, inappropriés ou oubliés. Renforcer la capacité des patients à bien s'orienter dans le système de santé permettra d'améliorer l'expérience des patients et l'utilisation appropriée des services de santé. Cette étude a examiné les expériences des patients en soins primaires qui naviguent dans le système de santé.

Objectifs :

1. Identifier les obstacles à la navigation et les défis rencontrés par les patients qui obtiennent des services de santé.
2. Explorer les stratégies mobilisées pour surmonter les barrières et les obstacles, ainsi que les émotions et les conséquences liées à l'échec de ces stratégies.
3. Identifier les interventions du personnel de la clinique qui aident les patients à naviguer dans le système de santé.

Méthodes : Cette étude qualitative d'évaluation des besoins se compose de deux sous-études séquentielles. La sous-étude sur les besoins **anticipés** a exploré les difficultés générales de navigation rencontrées par les patients lorsqu'ils tentent de faire le suivi des soins de santé recommandés par leur médecin. Pendant 5 demi-journées, tous les patients adultes quittant leur rendez-vous ont été contactés (n=56) et ceux ayant une recommandation de suivi de soins de santé ont été invités à participer à l’étude (n=34). L'analyse de contenu a été utilisée pour analyser les entretiens semi-structurés (n=19). La sous-étude sur les besoins **expérimentés** a recruté des patients adultes référés par leur médecin primaires comme étant confrontés à des difficultés de navigation importantes. Guidées par la théorie Jobs To Be Done (JTBD), des entrevues ethnographiques rétrospectives approfondies ont permis d'explorer les conséquences et l'impact des difficultés de navigation, de relever dans des histoires racontées par les patients les motivations (« Jobs ») fonctionnels, émotionnels et sociaux sous-jacentes à la trajectoire de navigation.

Résultats : Les résultats montrent que la navigation demande du travail et est frustrante. Les patients persévèrent face aux défis pour leur propre santé (fonctionnelle), pour leur engagement dans une bonne relation patient-fournisseur (émotionnelle) et pour le désir d'être perçu comme un bon patient (sociale). Le lien personnel est une stratégie clé pour surmonter les obstacles. Les réseaux sociaux et la communication avec l'équipe soignante encouragent la persévérance face aux difficultés de navigation.

Conclusion : Naviguer dans le système de santé est un travail. La motivation des patients à persister malgré les frustrations et les défis est renforcée par la clarté des buts (« Jobs ») fonctionnelles, émotionnelles et sociales qu'ils cherchent accomplir en obtenant les services recommandés. S'assurer que les patients comprennent parfaitement pourquoi ils ont besoin d'un certain service de santé et le niveau d'importance de ce service est essentiel pour renforcer la motivation des patients à l'obtention du service. Les réseaux sociaux sont une stratégie clé mobilisée pour soutenir la navigation dans le système de santé. Le contact humain et la communication avec l'équipe soignante incitent les patients à suivre les recommandés et les aident à surmonter les obstacles à la navigation. Enfin, un soutien plus solide est nécessaire pour une partie de la population de patients, principalement les patients socialement vulnérables.

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Clarification of terms and abbreviations

Anticipated needs assessment: The first of the two sequential sub-studies. The anticipated needs assessment explored general anticipated navigational challenges by patients recommended follow up healthcare services. Participants were recruited from the private GMF in St. Henri.

Experienced needs assessment: The second of the two sequential sub-studies. The experienced needs assessment explored significant challenges experienced by patients noticed to be struggling with healthcare navigation. Participants were referred by their providers and recruited from the teaching GMF in Côte-Des-Neiges.

Ongoing access to healthcare: Patient continuation of healthcare initiated by the provider, based on a need determined by the provider

Jobs To Be Done (JTBD): Theory predicting successful innovations, developed by Clayton Christensen of Harvard Business School. JTBD was used as a guiding theory for the experienced needs assessment and as a lens looking back on the anticipated needs assessment.

Clinic staff: We refer to clinic staff as patient-facing individuals working at the referenced clinic. This includes the provider, the care team, clerical, and administrative staff.

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Contribution of authors

Conceptualization and design of the study was done by Victoria Wicks and Dr. Jeannie Haggerty. Data analysis and interpretation was done by Victoria Wicks, supported by Dr. Jeannie Haggerty and Dr. Alayne Adams. All chapters of this thesis were written by Victoria Wicks, with feedback from Dr. Jeannie Haggerty and Dr. Alayne Adams. Additional input was given from thesis committee members Sonia Lussier and Dr. Maxine Dumas-Pilon.

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Introduction

Health care systems are complex. Interacting parts pose challenges for patients' orientation and navigational capacity within them. Consequently, challenges navigating the healthcare system impact patients' ability to obtain healthcare services, often resulting in fragmented, inappropriate, or forgone care (Brownstein et al., 2011; Calhoun et al., 2010; Carter et al., 2018; Comino et al., 2012; Mistry et al., 2021; Sofaer, 2009). Both access to healthcare and the patient experience contribute to a patient's ability to obtain healthcare services. Access can influence a patient's ability to obtain recommended healthcare and the patient experience can influence the motivation and commitment to follow through with a healthcare recommendation. Understanding the broader challenges that patients' face when accessing and navigating the healthcare system will contribute to the development of interventions to strengthen patient navigational capacity, ultimately leading to improved patient experience and appropriate use of health services.

In the context of healthcare, access broadly refers to the opportunity to use appropriate services proportional to needs (Daniels, 1982; Whitehead, 1992; Levesque et al., 2013). It is sequential and includes both the opportunity to reach appropriate healthcare services and the ability to obtain the services according to individual needs. (Levesque et al., 2013). It is dependent on the interface between population level characteristics such as income, education and attitude towards medical care, and system level characteristics such as organization and location of facilities (Aday and Anderson, 1974; Penchansky and Thomas, 1981). Individual experience can influence a patients' drive to follow through with a healthcare recommendation made by their doctor, and ease of access can influence a patient's actual ability to obtain the recommended care (National Academies of Science, 2018). Patient experience is shaped by the interaction of two aspects: functional and relational. Functional aspects of healthcare experience include the practical aspects, such as timeliness and continuity of care. The relational aspects of patient experience refer to the interpersonal relationships between patient and provider, such as display of empathy and inclusive shared decision making (Luxemburg et al., 2022). Patients' experiences accessing healthcare contribute to their satisfaction with the system and their likelihood to continue seeking healthcare (Luxemburg et al., 2022).

Navigational challenges impede access to healthcare as it impacts to opportunity to reach and obtain care. Navigational challenges are compounded for individuals with social vulnerabilities, such as limited health literacy, low social support, low income, or language proficiency. When patients experience navigational challenges in terms of obtaining healthcare, they are tasked with employing their own strategies to access appropriate healthcare and meet their health needs. Exploring and understanding patient stories related to challenges obtaining healthcare and how it is experienced, is essential for improving ongoing access to healthcare, building a trusting patient-provider relationship, empowering patients, and identifying areas for improvement, among others. There is limited research that explores what challenges patients' face when trying to obtain healthcare services, the implications of challenges and at what point they must implement their own strategies to obtain healthcare. There is a need to better understand how to support patients' journey through the healthcare system and to inform healthcare organizations how to better meet the needs of their patients and improve the patient experience. To support this, this study seeks to understand the consequences and challenges that patients' face when navigating the health system, with the following objectives:

1. To identify the navigation barriers and challenges encountered by patients obtaining healthcare services.

2. To explore the strategies mobilized to address barriers and challenges, and any associated emotions and consequences from failed strategies.
3. To identify any actions by clinic staff that help patients navigate the healthcare system.

Literature review

Access to healthcare

Key definitions

Access is a complex notion, defined and interpreted varyingly throughout the literature. Penchansky and Thomas (1981) acknowledge that many researchers are divided between access referring solely to direct entry into or use of the healthcare system, and access as a characterization of the factors that influence entry into the healthcare system and the use of the healthcare system. Levesque and colleagues (2013) synthesize the literature on the concept of access to healthcare and define access as "*the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care*". Access is achieved when the accessibility of health systems aligns with the abilities of populations (Levesque et al., 2013). Addressing Penchansky and Thomas (1981), two sub definitions should be considered to address access to healthcare: utilization and accessibility. Utilization refers to the successful use of appropriate healthcare services. Accessibility refers to the ease of obtaining healthcare services and everything that facilitates or hinders the ease of use (Anderson and Davidson, 2007; Sibley and Weiner, 2011).

It is important to also distinguish between first contact access and ongoing access. First contact access refers to any access to healthcare initiated and determined by the patient. First contact access is defined by Haggerty and colleagues (2007) as "*the ease with which a person can obtain needed care (including advice and support) from the practitioner of choice within a time frame appropriate to the urgency of the problem*". The term ongoing access is not well defined in the literature. It relates to the coordination and continuation of care, including needs, settings, and providers (Starfield, 2005). The distinguishing characteristic is that ongoing access is initiated by the provider, based on a need determined by the provider. This study focuses on primary care patients who have been recommended to obtain follow-up healthcare and is therefore concerned with challenges impacting ongoing access when providers perceive there to be a healthcare need.

Primary healthcare serves as patients' first point of contact with the healthcare system and supports entry into the rest of the healthcare system (Starfield et al., 2005). Especially for socially vulnerable populations, primary care increases access to healthcare services and supports an effective and efficient approach to improve population health at a lower cost, compared to specialist focused systems (Starfield et al., 2005; Kringos et al., 2013). Since the introduction of primary care in 1961, the term's definition has varied. In 1978 the Institute of Medicine (IOM) defined primary care as *"the provision of integrated, accessible healthcare services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients, and practicing in the context of family and community"* (IOM, 1994). Access to care and coordination of care, along with comprehensiveness, accountability and continuity of care are among the core attributes of primary care (Starfield et al., 2005). Coordination of care describes the amalgamation of a patient's healthcare conditions and needs, both within primary care and across other healthcare disciplines (O'Malley et al., 2009). Access to care and coordination of care as attributes of primary care are impacted by healthcare navigation. As healthcare systems are stretched and access is challenged, patients are tasked with navigating uncharted waters to achieve ongoing access within the healthcare system.

Key conceptual models of access

Levesque and colleagues (2013) conceptualize access to healthcare using five dimensions of service accessibility (approachability, acceptability, availability and accommodation, affordability, and appropriateness), and five dimensions of person abilities (ability to perceive, ability to seek, ability to reach, ability to pay and ability to engage). Healthcare accessibility is generated by the interaction between the dimensions of service accessibility and the dimensions of person abilities (Levesque et al., 2013). Access considers the demand features (person and populations) as well as the supply features (health systems and organizations) and is achieved when person level characteristics and health system characteristics intersect successfully. Levesque and colleagues (2013) demonstrate that access to healthcare includes the opportunity to recognize health needs, successfully seek and use healthcare services, and improve or maintain health using healthcare services. In their framework, on the supply-side, access includes the enabling of a person to take the appropriate steps that will support them in obtaining healthcare services. On the demand-side, access considers the barriers encountered at each step towards access.

Dimensions of accessibility

In the access framework mentioned above, five dimensions of service accessibility are described. Approachability refers to the identification that appropriate health services exist relative to the need of the person and that those services can be reached. Acceptability relates to personal autonomy and refers to the social and cultural factors that determine if an individual may or may not accept a service, Availability and accommodation refer to the physical reachability of healthcare services, to both the space and those working in healthcare roles, in a timely manner. Affordability acknowledges the financial capacity for people to mobilize resources and spend time to use appropriate services for healthcare. Finally, appropriateness is the suitability between individual needs and aspects of the service offered (Levesque et al., 2013).

Health equity in access

According to the Canadian Institute for Health Information Commonwealth Fund survey (2020) access to care is continuously a challenge in Canada. Access to healthcare is further challenged for those experiencing health inequities (Marmot et al., 2013). Equity in health care is defined as "*as equal access to available care for equal need, equal utilization for equal need, equal quality of care for all*" (Whitehead, 1992). Social determinants of health (SDH), such as income, education, geographic location, and gender contribute to health inequities and impact access to healthcare (WHO, 2008). Income and geographic location impact a patient's ability to commute to medical appointments or afford medical costs. Education impacts a patient's health literacy and therefore their ability to acquire health information or access resources (Sandhu et al., 2022). Access to healthcare is a challenge exacerbated by SDH and health inequities (Andermann, 2016).

Navigational impact on access

Patients who experience navigational difficulties also experience difficulties accessing healthcare (Sofaer, 2009; Griesse et al., 2020). The process of accessing healthcare services thus requires some degree of navigational ability. When patients lack navigational ability, their capacity to obtain ongoing access to healthcare is impeded. This became especially impactful when the COVID-19 pandemic occurred (Clark et al., 2020). The disruption of in-person health related services caused a rapid shift towards reliance on technology and digital literacy to obtain needed healthcare (Adams et al., 2023; Breton et al., 2021). This caused a shift towards navigation as a factor impacting access to healthcare and showed disadvantages for socially vulnerable populations, such as unequal access to technology and unequal capacity for using technology (Adams et al., 2023; Breton et al., 2021). This inequality is known as the digital divide, represented by lower rates of technology and digital adoption among older patients, those of lower socioeconomic status (SES) and racial/ethnic minority groups (Eberly et al., 2020). Research exploring disparities in access to healthcare among new immigrants to Canada, show that many of the disparities are navigational in nature (Bajgain et al., 2020). Similar findings were noted in a scoping review conducted by Kalich and colleagues (2016) to understand the barriers experienced by immigrants' in accessing healthcare services in Canada. One of the most common barriers to accessing healthcare was a lack of information regarding access and challenges navigating healthcare services. Barriers such as language and cultural customs in a new country further exacerbate navigational challenges. Additionally, a systematic review on chronic disease management found navigating the healthcare system to be one of the main barriers associated with accessing healthcare services in rural areas (Golembiewski et al., 2022).

Parchman and colleagues (2005) surveyed veterans with one or more chronic illnesses to better understand what attributes of primary care are related to hassles in the healthcare system. They found that patients with complex medical needs, such as chronic conditions, are at a greater risk of experiencing navigational challenges and that hassles associated with the healthcare system are inversely related to the level of coordination of care by primary care providers and the level of communication that the patient has with their primary care provider. Disparities in access to healthcare caused by navigational reliance has alarming implications. Increased inequities present between advantaged and disadvantaged populations as socially vulnerable patients disproportionately lose access to primary healthcare (Nouri et al., 2020). Although these disparities are explored, there is no literature quantifying the burden of suffering associated with navigational challenges impacting ability to obtain needed healthcare.

Theoretical Background

In the context of healthcare, the term navigation can be understood as charting from one destination to the next, often in the absence of directions. The destination may be known, but how to get there is unclear. For patients, navigating the healthcare system to obtain appropriate healthcare services is challenging. A high degree of health literacy, especially in the context of navigation, is required for first contact and ongoing access to healthcare (Griese et al., 2020). Navigational health literacy refers to the ability to use information that supports navigating the healthcare system, and to find appropriate care when needed and at the right location (Griese et al., 2020). SDH have a wide-ranging influence on health, health outcomes (Braveman and Gottlieb, 2014) and navigational health literacy (Griese et al., 2020).

With access and communication challenges present in the healthcare system, patients often rely on their social networks to support their health information needs (Tarrant et al., 2015). Patients are required to draw on their own knowledge of alternative services and the support of friends, colleagues, and relatives to navigate and access healthcare (Tarrant et al., 2015). Lack of social support is disadvantageous to patients as it is associated with delayed access to medical care, increased expenses and may contribute to poorer health outcomes (Reisinger, Moss and Clark., 2017). To best support patients in overcoming navigational challenges to obtaining healthcare services, it is critical to understand what challenges they are facing. The following section summarizes a review of the literature to answer the question of what challenges are patients faced with when trying to navigate the healthcare system to obtain healthcare services.

Search strategy

The search was conducted from January 2023 to February 2023. The databases PubMed, Google Scholar, and MEDLINE were searched using relevant subject headings. Multiple searches were conducted for literature familiarization in the domains related to the research topic, including access to healthcare, patient navigation and challenges associated with healthcare navigation. The literature review focused mainly on the following research question: What are the consequences and challenges that patients' face when navigating the health system to obtain healthcare services? All articles were screened for relevance by title and abstract. Relevant articles that were read in full appear in the references of this thesis. This study explores challenges faced by primary care patients when navigating the healthcare system to obtain recommended services. As such, articles that highlighted the experience or impact of navigational challenges faced by patients were included. To understand the context and provide background on the topic, the literature review also included articles documenting patient navigation in primary care and access to healthcare restricted by navigational challenges related to health equity. Articles were included if they adopted a qualitative, quantitative, or mixed methods approach. Articles were excluded if they met any of the following criteria: (1) healthcare challenges unrelated to healthcare navigation. (2) articles published earlier than 35 years ago, considering the relevancy of data. (3) articles published in languages other than English.

Overview of healthcare navigation

Patient navigation programs

Patient navigation programs were first introduced in New York in the 1990s. Developed originally as a strategy to address gaps in cancer care for vulnerable populations, patient navigation was implemented to respond to cases of late-stage cancer presentation credited, in part, to individual challenges understanding and accessing complex care services (Robinson-White et al., 2010). The original concept of navigation used individual navigators to support patients in eliminating barriers to obtaining cancer care such as medical system barriers, information barriers, financial and emotional barriers (Freeman and Rodriguez, 2011). Patient navigators are often lay peers who have similar experiences to the patients whom they are supporting and as a result may respond empathetically to the needs (Repper and Carter, 2011). Patient navigators are equipped to help patients overcome barriers and achieve access and continuity of care as they experience the complex healthcare system by improving their individual health self-efficacy and competence in obtaining appropriate services (Hoon Tan et al., 2015).

In the context of primary care, patient navigation supports complex patients in overcoming barriers in healthcare services (Carter et al., 2018). Patients with high social vulnerabilities are more susceptible to negative healthcare events (Haggerty at al., 2020; Grabovschi et al., 2013) experience more challenges obtaining healthcare services (Haggerty et al., 2020; Ryan et al., 2016; Begley et al., 2011; Lasser et al., 2006) and often have higher unmet social and emotional needs (Haggerty et al., 2020). These are the same patients who have the greatest benefits from navigational support (Freund, 2016). There is increasing evidence to support the movement to incorporate patient navigators into care teams (Carter et al., 2018; Ferrante et al., 2010; Mistry et al., 2021).

Navigational accessibility

Several of the dimensions of accessibility within the access framework proposed by Levesque and colleagues (2013) include navigational aspects where barriers or hurdles challenging access to healthcare may be encountered. The dimensions of accessibility and their relationship to navigation are explored below.

Approachability

Transparency and health literacy

Transparency, information regarding services and health literacy are among some of the system level factors related to approachability (Levesque et al., 2013). The interface between navigational approachability of health systems and a patient's ability to perceive, is what influences their perception of needs and desire for care. Patients report barriers to obtaining their recommended healthcare as they lack the information required to contact or access resources (Sandhu et al., 2022). Patients who report experiencing barriers related to incomplete information about the resources available to them highlights how critical it is to present healthcare recommendations and health service information to patients in way that is both understandable and comprehensible. In situations where patients leave a clinical encounter with an action to take but lack the steps and strategies to achieve that action, or the understanding of why they must act, noncompliance and/or falling out of the health system may result (Brandenburg et al., 2015; Jefferson et al., 2019; Sandhu et al., 2022). Supporting patients' health literacy is critical to improve their ability to identify when they require healthcare services and what resources are available to support them in obtaining the services.

Communication and information

For many patients, especially those who have high social vulnerabilities, and minimal support and resources available for them, the peace of mind associated with having trusted personnel to rely on for informational needs can help bridge gaps in ongoing care (Tarrant et al., 2015). Communication with providers and care team members can support approachability as it relates to transparency and access to ongoing care through the ability to obtain information regarding services. When patients are provided with complete information from the referring physician, and have trust in their physician, coordination of care and transparency are improved (Ireson et al., 2009). It has been noted that brief interactions with nonphysician care team members, creates a sense of personalized care for patients through communication and rapport (Brown et al., 2015; Ngo Bikoko Piemeu et al., 2021). Informational and relational support offered to patients on an individualized basis, supplementary to their encounters with care providers, can help patients better understand their health needs and how to support those needs (Lafortune et al., 2015; Ngo Bikoko Piemeu et al., 2021). The complexity of the system results in a stronger need for individual contact with a care team member to help patients navigate the healthcare system. Enhanced communication through means of clear language, explanation, ensuring understanding and providing opportunity for additional information or clarification can support the approachability of healthcare systems as perceived by patients (Politi and Street, 2010). Patient portals are a promising solution for comprehensive communication and dissemination of information between provider and patient, if they are accessible, usable, and understandable for patients (Hefner et al., 2019; Portz et al., 2019).

Availability and accommodation

Although grouped together as a dimension of access to healthcare, in the context of navigation, availability and accommodation may be looked at separately. Availability, as it refers to the physical reachability and existence of health services, should be considered separate from accommodation, which refers to organizational processes of health services, such as booking systems and telephone services as well as patient ability to accommodate to the processes

(Penchansky and Thomas, 1981). Navigational availability and accommodation relate to the interface between the organization and characteristics of healthcare facilities, local urban and rural contexts, and the patient's ability to reach them. In the context of navigation, both availability and accommodation depend on the different needs of patients.

Reaching availability

Availability describes the existence of healthcare resources with enough capacity to provide healthcare services (Levesque et al., 2013). Patients experience various geographic barriers to obtaining care as they are tasked with travelling to appointments (Syed et al., 2014; Lum et al., 2016; Bajgain et al., 2020, Ngwakongnwi et al., 2012). Difficulties with transportation is a reported barrier among patients trying to access desired services (Kalich et al., 2016; De Vries McClintock et al., 2017; Ryan et al., 2016). Patients experience differences in attaining accommodation based on if they and their healthcare provider are situated in rural or urban settings (Haggerty et al., 2014). Haggerty and colleagues (2014) found that distance to healthcare was primarily seen as a barrier for urban residents who require public transportation, strained by income and mobility.

Time constraints contribute to navigational challenges associated with the availability of care. Primary healthcare and ambulatory clinics often follow the schedule of regular working hours (9-5pm, Monday to Friday) which as a result, creates challenges for patients who have competing priorities and cannot afford to take additional time of work to attend appointments (Jefferson et al., 2019; Sandhu et al., 2022). Additionally, primary care practices may only open their phone lines during working hours, which challenges patients trying to access the clinic by telephone after hours. Patients experience difficulties contacting and obtaining timely appointments and are often tasked with accepting appointments at challenging times, requiring time off work to accommodate the appointment time and travel time (Lafortune et al., 2015). Studies suggest tangible strategies to allow for accessible communication between patient and the care team may improve the use of appropriate medical services, especially for patients with social vulnerabilities (Ryan et al., 2016; Mackichan et al., 2017).

Finding accommodation

Accommodation is a barrier to accessing healthcare when the need outweighs the capacity. With the challenges that healthcare systems are facing related to capacity, many patients experience long wait times or lack of service availability when obtaining follow-up care (Pandey et al., 2021). Due to healthcare service barriers, some patients forego scheduling appointments all together and risk falling out of the health system (Jefferson et al., 2019). The impact of long wait times due to accommodation barriers does not only affect individuals with chronic conditions, but those with acute and non-urgent conditions as well (Brandenburg et al., 2015; Lafortune et al., 2015). Patients who have nonurgent needs and experience long wait times have a higher rate of appointment no-shows and noncompliance to treatment (Brandenburg et al., 2015). It has been noted that rates of no-shows increase as the time between the scheduled appointment and the actual appointment increases (Lacy et al., 2004). Noncompliance of healthcare recommendations and no-show for appointments may lead to accounts of falling out of the health system.

Similarly, patients experience accommodation challenges using online portals or reaching clinics by telephone to obtain or cancel appointments. When the frustration of being unable to cancel their appointment becomes too severe, patients give up on trying and decide to miss the appointment altogether, resulting in consequences such as non-attendance and a wasted appointment slot, for both patient and care team (Frost et al., 2017).

Affordability

Affordability as a dimension of accessibility relates to the direct costs of healthcare services as well as the indirect costs cascading from healthcare service use and the opportunity costs related to loss of income. In terms of navigation, affordability considers health-related costs, financial health literacy and the cost of technology.

Direct costs

Canada's publicly funded healthcare system provides universal coverage for healthcare services based on need, rather than individual ability to pay (Government of Canada, 2011). Direct costs may be associated with the cost of treatments and interventions as well as costs incurred by the patient, such as costs of medication, household support and health-related activities (Goossens et al., 2000). Health and financial literacy impact access to healthcare in the domain of affordability and require navigational ability. According to the Institute of Medicine (US) Committee on Health Literacy (2004) health and financial literacy refer to the ability to make sense of and utilize health and financial information to access and promote good health and financial outcomes. Among cognitively healthy older adults, higher levels of financial and health literacy lead to more appropriate decision making specifically in terms of health maintenance and health insurance plans (James et al., 2012). Ability to navigate financial information related to healthcare is critical.

Indirect costs

Indirect costs impact patients in a similar manner to accommodation. Having to take time off from work to support a healthcare need results in indirect costs by means of reduction in pay, cost of transportation, and childcare costs for families who may need to hire someone to watch their kids while they attend a healthcare appointment (Goossens et al., 2000). Transit options vary in rural and urban locations, the availability and cost of transit to healthcare clinics and pharmacies are indirect expenses impacting access to healthcare (Syed et al., 2014). Technology is another indirect cost to healthcare. The increasing use of technology in healthcare and automated responses can save time and money, but often at the expense of the most vulnerable (Foo et al., 2020). Education level, literacy, income bracket and technological skills are all factors which impact the uptake and use of digital health technologies (Perzynski et al., 2017; O'Connor et al., 2016). The uptake of digital technologies, such as patient portals is heavily dependent on the interaction of personal, technological, and contextual factors (Azzopardi-Muscat and Sorensen, 2019). Increased technology use to access healthcare services can exacerbate existing disparities by limiting access to individuals who are technology literate and those who can afford technology (Goldzweig et al., 2013; Perzynski et al., 2017; Anthony et al., 2018; Hefner et al., 2019). Financial stress is a common barrier among socially vulnerable populations and further compounds navigational challenges (Kalich et al., 2016).

Study context

This study is a component of a larger project that adapts and spreads a Volunteer Navigator intervention, in which trained volunteers reach out to referred patients by telephone to provide personalized support for accessing healthcare services (Haggerty et al., 2023). As outlined below, the light-touch navigation support is well suited to be delivered by volunteers, when there is a specific need, but it has encountered problems when adapted to reliance on clinician referrals.

The initial intervention was piloted in the context of a Canada-Australia action research program, "Innovative Models Promoting Access-to-Care Transformation (IMPACT),", a 5-year (2013–2018) project aimed to improve access to appropriate primary care for vulnerable populations (Haggerty at al., 2023). Action research engages researchers and practitioners in identifying and tackling a local need through cycles of problem identification, intervention and learning by collaborating to design, implement, and intervene (Avison et al., 1999). In the context of the pilot study, an access problem had been persistent for decades in Quebec, where approximately 25% of the population was unattached to a family physician (Statistics Canada, 2014). Even after years of waiting on the centralized list for family physicians, the *Guichet d'accès aux médecins de famille* (GAMF), approximately 30% of persons assigned to a new doctor were being returned to the waiting list (Haggerty et al., 2023). It was noted that those being returned to the waiting list were more likely to be persons from socially and materially deprived neighborhoods. The most common reasons for being returned to the GAMF were because new patients could not be contacted or did not attend their first visit. Interviews with persons in socially and materially deprived neighborhoods showed that they did not understand the message received from the clinic nor the consequences of not attending a visit which they did not request (Haggerty et al., 2023).

Consequently, the intervention team obtained patient names directly from the GAMF for participating Family Medicine Groups (GMF) and trained lay volunteer navigators (*guides bénévoles*) to reach out by telephone to newly assigned patients. The volunteers stressed the importance of attending the first visit, offered logistical information for reaching the clinic, and provided patients with visit-preparation tips and materials. During the 4-month trial, volunteer navigators provided support to 108 patients, of whom 54 participated in the study. Interviews revealed that patients appreciated the service and entered the new patient-physician relationship with a high degree of trust and engagement. At the three-month follow-up, surveyed patients reported significant reductions in emergency room use (from 19% to 11%), significant reduction in unmet needs for care (from 50% to 16%), and statistically significant improvements in reported ease of navigating the health system and explaining their needs to health professionals (Haggerty et al., 2023).

Following the momentum of the IMPACT project, key decision makers recommended continuing the intervention but adjusting the program so that navigation support be extended beyond orientation for new patients to include navigation support for established patients. They also recommended that clinicians be the principal referrers to refer patients who needed support. In 2019, funding was obtained to spread the Volunteer Patient Navigator project to other clinics in Montreal (Haggerty et al., 2023). Following the pandemic lockdown, the project resumed in 2021, with Volunteer Navigators offering new patient orientation to a newly opened private Family Medicine Group (GMF) clinic in St. Henri, and then to a teaching GMF in the multicultural neighborhood of Côte-des-Neiges.

Overview of Volunteer Patient Navigator service

When patients are challenged with navigating the healthcare system, they may not follow through on referred or recommended services and consequently hinder opportunities to regain or maintain health. When clinicians or administrative staff detect primary care patients requiring navigation support, they may refer them to the Volunteer Patient Navigation service through various avenues. The referral form includes patient information relevant to the navigator and includes patient assent to share information with the volunteer (Appendix VI). Once the complete referral is received by the coordinator, they dispatch the referral to the appropriate patient navigator who will reach out to the patient (up to 5 attempts). Upon successful contact with the referred patient, navigators will help patients build autonomy by offering them information on available resources, helping them prepare for medical appointments, and supporting them after appointments. Patient navigators use the Connect platform to maintain logbooks of calls with patients, capturing the result of the call, including the information provided and assent to be contacted for future research. The coordinator reviews the logbooks and meets with navigators to share experiences and discuss calls.

Problem statement

Despite the significant impact of the pilot intervention, clinician referrals to the Volunteer Patient Navigation (VPN) program were minimal. Clinicians said they could only detect the patients with navigation challenges after they fail to obtain recommended services. Patients who fail to obtain recommended healthcare services may experience worsened health conditions as their care trajectory is slowed or halted. The premise of the service design was that clinicians would be able to prospectively detect patients who require navigational support before they leave the clinical encounter and refer them for navigational support. The underuse of the referral system not only put patients at risk for failure to obtain care, but the reduced demand for navigational support made it difficult to maintain the motivation of our volunteer navigators.

An understanding of why patients fail to obtain recommended services was necessary to inform clinicians on how to detect patients experiencing navigational difficulties before they leave the clinical encounter. A needs assessment was employed to understand patient navigation needs, experiences, and the impact of navigational challenges, with a view to inform service design.

The objectives of this study are:

1. To identify the navigation barriers and challenges encountered by patients obtaining healthcare services.
2. To explore the strategies mobilized to address barriers and challenges, and any associated emotions and consequences from failed strategies.
3. To identify any actions by clinic staff that help patients navigate the healthcare system.

Methods

Study overview and setting

This study is a qualitative needs assessment, comprised of two sequential sub-studies exploring navigational challenges experienced by primary care patients: 1) anticipated navigational needs 2) experienced navigational needs. The anticipated needs assessment explored general navigational challenges anticipated by patients who have been recommended follow up healthcare services (henceforth, "anticipated needs"). Participants were recruited from the private GMF in St. Henri. Data was collected using semi-structured individual interviews with patients leaving clinical encounters in a primary care setting, with a referral to obtain additional services (i.e., register on the patient portal; get diagnostic tests; referral to specialist or other health and social services;). Analysis uncovered the frustrations of navigation and resulting impact on healthcare, but an additional sub-study was needed to further explore the experiences of the minority of patients experiencing significant navigational challenges. The experienced needs assessment explored participant perceptions of significant navigational challenges and the impact on healthcare (henceforth, "experienced needs"). Participants were recruited from the teaching clinic in Cote-des-Neiges. Data was collected using retrospective ethnographic interviews. Thematic content analysis and Jobs To Be Done (JTBD) Theory guided the analysis of the experienced needs assessment. The experienced needs assessment built on the findings of the anticipated needs assessment. The methods for each sub-study are presented separately and in detail below.

Anticipated needs assessment

Rational for study method

In the context of healthcare, needs assessments systematically ensure that health resources are used efficiently to improve the health of the population (Wright, Williamson and Wilkinson, 1998). Needs assessment are useful in assessing the extent and nature of the needs of a target population to inform the design of programs of services to respond to the needs (Wright, Williamson and Wilkinson, 1998). The qualitative approach to a needs assessment captures subtleties of individual feelings, sequence of actions and subjective experiences of healthcare that would not be detected in quantitative indicators such as reported difficulty obtaining services or unmet needs for care (Fossey et al., 2002). This needs assessment was used to assess patient navigational needs. A "Rapid Identification of Themes from Audio Recordings (RITA)" approach was employed for data analysis (Neal et al., 2015). Given the resource intensive nature of in-depth analyses of verbatim transcripts, rapid analysis can produce quick and valid information to respond to ongoing implementation needs and challenges. A large benefit to using RITA is the speed of coding time. Where a traditional transcription estimates to take 600% to 700% of the time of the interview, segmental transcription, as used in RITA, takes approximately 13% of the interview time (Neal et al., 2015). A comparison of findings between rapid analysis and in-depth transcription analysis shows that rapid analysis supports providing actionable findings and recommendations while keeping rigor intact, if consistent with project needs (Gale et al., 2019). Rapid analysis involves transcribing data in the form of minute-by-minute summaries. The process involves systematically capturing a summary of the data obtained during a specific time frame. Through summary transcripts, the researcher can balance attention to both transcription and nonverbal information, creating more fulsome data analyses (Neal et al., 2015). The use of summary transcriptions allow for expedition of results while preserving the richness of the data. The RITA method was consistent with the study needs of expediting analysis and result dissemination to clinician referrers for ongoing implementation of the VPN service.

Study population

For the anticipated needs sub-study, the target population is primary care patients potentially needing navigational support for obtaining services recommended by clinicians; the study population was drawn from a consecutive series of adult primary care patients leaving their clinic appointment at the private GMF, with a referral to obtain additional health services. Participants were eligible if they were 18 years or older, French, or English-speaking, and a current or newly assigned patient with a recommendation by their family physician to obtain a follow-up service. Patients had varying levels of social vulnerabilities and were between 22-77 years old. The study population was recruited from patients who had recommended follow up care to obtain and could provide insight into their anticipated needs for navigational support.

Recruitment and sampling

The anticipated needs sub-study occurred from May 2022 through June 2022. Recruitment took place in person at the clinic on 5 half days, representing different clinic times (Monday morning, Tuesday afternoon, Wednesday morning and afternoon, and Thursday afternoon). Posters were dispersed around the clinic and letters were distributed to patients upon arrival at the clinic indicating the clinics involvement in a study and that patients had the option to participate or not. During the recruitment days, all patients exiting their appointment were approached by the research student (n=56) (consecutive patient series), providing a representative sample of patients in the waiting room for that clinic half-day. Patients were asked if their family physician had recommended them to obtain follow-up healthcare services, spoke

French or English and if they were over the age of 18. Eligible patients were given the opportunity to participate by providing assent to be contacted for a telephone interview at a later date (n=34). Consultations with patient partners informed us that it often takes several days after the primary care appointment for patients to reflect on what they need to do to obtain their follow-up healthcare services. Nineteen patients were successfully contacted for the telephone interview 3-5 days after their clinical visit. Patients were asked if they preferred to be contacted in the morning, afternoon, or evening and the researcher respected this request.

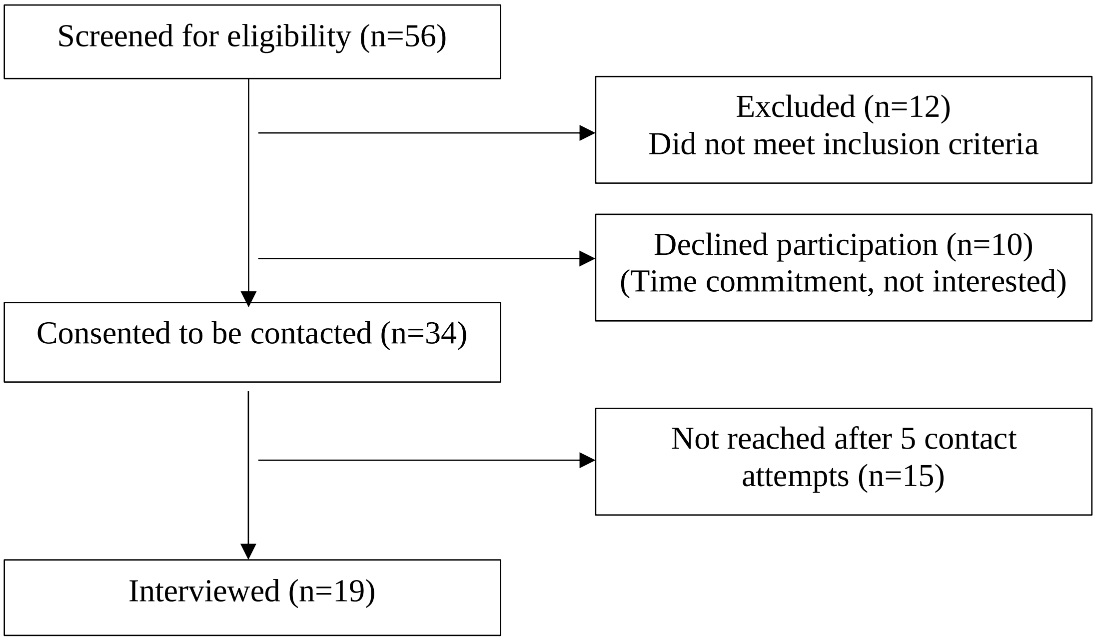

Figure 1- Selection diagram for anticipated needs assessment

Data collection

The researcher interviewed 19 participants using a semi-structured telephone interview guide (Appendix IV). At the time of interview the research student provided an in-depth explanation of the study and offered participants the opportunity to ask questions prior to obtaining and recording verbal informed consent. All participants were given the opportunity to complete the interview in English or French, per their preference. The interviews lasted between

13 and 27 minutes. Closed ended sociodemographic questions were posed (age, level of education, general health, and ability to find health information by themselves) to begin the interview. Subsequent questions pertained to follow-up service(s) recommended to the patient, their experience and emotions concerning accessing the service(s), and their insights on a volunteer navigation service. The interview guide was initially developed with a patient partner involved in the project and refined by the research team over the first several interviews. Following completion of the interview, post-interview memos and field notes were completed. Data collection was concluded after 19 interviews when theoretical saturation was reached, and no new or novel findings emerged. All interviews were transcribed in English. All French interviews were translated to English during summary transcription, however French quotes used in the results were kept in the original language.

Data analysis and management

Standard ethical practice was used for data management. Data protection and confidentiality was ensured. Pseudonyms were used throughout data transcription and reporting to preserve participant’s anonymity. One of the particularities with RITA is that analysis begins with data management as data is summarized into smaller segments from the interviews. Deviating from the guidelines set out by Neal and colleagues (2015), the interviews were transcribed question-by-question, rather than minute-by-minute. Participant responses were often of short interval, so this adaptation enabled the data to remain contextualized. The research team began analysis by familiarizing themselves with the data. Based on the study objectives and foci, initial deductive codes were developed. To ensure data was interpreted the same way, two research team members independently reviewed the transcripts and generated a set of inductive codes. The study team then consolidated the codes, and a codebook was developed. The codebook was used by each research team member to code the transcripts independently and systematically. Coding conflicts between research team members were discussed and resolved. Codes were categorized together, and emerging patterns were identified. Notable emphasis was placed on understanding the magnitude and frequency of challenges experienced by participants and the resulting emotions experienced. Data was originally analysed for content and then looked at thematically as themes were identified, refined, and defined from the observed patterns within and across interviews. Team based coding, independent field notes and prolonged engagement with data assured researcher neutrality and objectivity with data analysis.

Experienced needs assessment

Rational for study method

The rational for the experienced needs assessment was determined after completion of the anticipated needs assessment. The information gathered from semi-structured interviews in the anticipated needs study was too structured and not rich enough for a needs assessment. The structured questions left little room to uncover challenges and did not explore the complexities of the navigational struggle that patients are facing. In the anticipated needs assessment, participants were asked to think prospectively about how they would obtain the care recommended to them and consequently the data focused too heavily on a need that participants were not yet aware they had or had yet to explore. To produce richer, less speculative data, the investigators reoriented their approach to focus on a past healthcare experience among patients identified with significant navigational needs in the experienced needs assessment.

A retrospective ethnographic approach was taken to explore individual experiences and choices in depth and in context. Ethnographic retrospective interviews are used in JTBD interviewing to explore participant’s struggles and uncover the causal driver behind their choices. JTBD encourages the participant or user, to tell their story, and the researcher seeks to understand what job the participant or user is trying to accomplish. JTBD interviewing focuses on a balance between structure and flexibility, the participant must begin to ramble and share details that may appear irrelevant on the surface, for the real struggle and consequences to emerge. Participants were told to think of their interview as a documentary of their experience. They were asked to share as much detail as possible as it is significant in the creation of meaning.

Christensen and colleagues (2016) use the term "Jobs" as a short and simple way of describing "*what an individual seeks to accomplish in a given circumstance*". The circumstance, along with the dimensions of the Job are significant in understanding what the true Job to be Done is. Christensen and colleagues (2016) argue that there will always be three reoccurring Jobs; the functional Job, which is the obvious one, the task-related goal the individual wants to accomplish. The emotional Job, which is how the individual seeks to feel when making progress in the circumstance, and the social Job, which considers how the individual wants to be seen or perceived by others. Jobs and the decisional process that takes place when an individual works towards a goal, are often difficult to understand as the emotional and social Jobs are not obvious, even to the individual concerned.

While needs cannot be dismissed in the understanding of behaviour, they are far too generic to explain behavior (Christensen, Waldeck and Fogg, 2017). Where a traditional needs assessment may be employed to seek an understanding of what the functional Job is, it often fails to ignore the emotional and social Jobs. The highly structured and prospective interviewing approach used in the anticipated needs assessment did not allow for a deep enough exploration of navigational challenges experienced by patients. For the experienced needs assessment, retrospective ethnography supported an understanding of the context of individual navigational challenges, the forces driving individual choices and the solutions hired by individuals to get their healthcare Job done. In both assessments, using JTBD to uncover the functional, social, and emotional Jobs to be Done helped deepen the understanding of patient needs and support the development of solutions.

Study population

The study population consisted of primary care patients detected by their primary care provider as having significant navigational challenges. Participants were recruited from a GMF teaching clinic in the Montreal borough of Côte-des-Neiges. Eligible patients were 18 years or older, French, or English speaking, a primary care patient and experiencing significant navigational challenges, as perceived by the primary care provider. Participants in the experienced needs assessment also had varying levels of social vulnerabilities and were between 39-80 years old.

Recruitment and sampling

The experienced needs sub-study occurred from April 2023 through June 2023. Clinicians were asked to detect patients with navigational challenges such as trouble using online platforms or portals, failing to get recommended services, using private healthcare services etc. Those patients were purposefully selected and invited to participate. The primary care provider introduced the study to the patient and obtained verbal consent to be contacted by the researcher. The contact information for verbally assenting patients was securely shared (n=22) and the researcher contacted the assenting patients to arrange an interview. Up to five contact attempts were made with patients, leaving a message each time. Patients who were interested and eligible were scheduled for an interview, either in-person, virtual or by phone with the researcher. Seven participants were successfully interviewed (Figure 2).

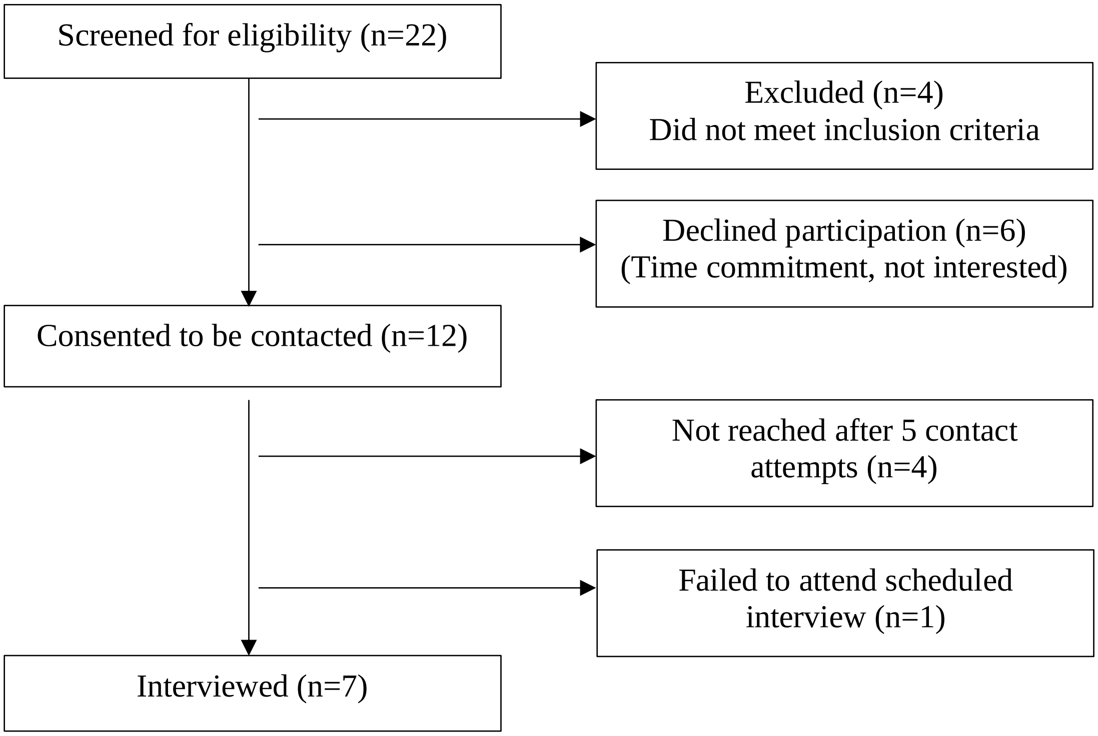

Figure 2 - Selection diagram for experienced needs assessment

Data collection

In the experienced needs assessment, 7 primary care patients participated in in-depth interviews. Participants were sent the informed consent package ahead of time to review and at the time of the interview, the interviewer explained the study and offered the participant the opportunity to ask questions (Appendix II). Participants were informed of their individual rights and informed consent was obtained verbally for virtual or phone interviews, and in writing for in-person interviews. All informed consent was recorded. All interviews were conducted in English, as per participant preference. The interviews lasted between 33 and 57 minutes.

Retrospective ethnographic interviewing was supported by the interview guide and interviewing technique as participants were invited to recall and share a story (Appendix III).

The interviewer set the context to resemble a conversation, to establish comfort and rapport. The participant was invited to share a story of their healthcare experience, providing in-depth and rich information (Green and Thorogood, 2018). As participants shared their stories, the interviewer began drawing a story timeline. The interviewer continuously probed for more detail by asking the participant to share additional information that would be added to the story timeline. Although information was not elicited linearly, the timeline supported specific probes and details related to the participant's story. Throughout the interview, emotion and nonverbal communication was observation and noted.

Similar to the anticipated needs sub-study, the experienced needs assessment began by seeking sociodemographic information about participant perceptions of their general health, and ability to find health information by themselves using survey style closed ended questions. The interviewer started the interview by asking participants what the term 'navigating the healthcare system' means to them. Participants were asked to recall and tell a story of a time they were required to navigate the healthcare system to obtain recommended healthcare services. The interviewer would jump in to pose questions that would elicit more detail pertaining to the social, emotional, and functional dimensions of the circumstance. Study objectives were kept in mind as participants were probed to think about the problems and challenges they faced in getting healthcare services and the resulting steps and strategies they implemented (if any). The interviewer also elicited information regarding support that patients obtained from social networks and the care team. The interview concluded with questions pertaining to social vulnerabilities including participant perceptions of their general health, and ability to find health information by themselves. Following the completion of the interview, a JTBD timeline analysis and field notes were completed.

Data analysis and management

Standard ethical practice was used for data management and data protection, and confidentiality were ensured. Pseudonyms for both participants and care team members were employed to preserve anonymity. Transcripts were uploaded to the data analysis software Dedoose, to manage and organize the data. Data was first transcribed verbatim, and memos of emotion and nonverbal communication were analyzed for context. Enhancing verbatim transcription by including accounts of nonverbal communication support the meaning and significance of what is being said by participants (Poland, 1995). Data familiarization involved the researcher reading transcriptions repeatedly and taking detailed notes on initial insights and potential patterns in the data. First level analysis involved coding transcripts using deductive codes informed by the literature review, the preliminary results from the anticipated needs assessment and the experienced needs assessment study objectives. Inductive codes emerged as the researcher interpretively watched video recordings, reviewed the post-interview JTBD timeline analysis and field notes while reading transcriptions to keep the data contextualized. For the second level of analysis, primary codes and excerpts were downloaded and categorised by valence where applicable and were further clustered and categorized based on the examination of how they arrayed across and between participants. For the third level of analysis, a conceptual data matrix was created based on JTBD Theory. JTBD progress-making forces diagrams (Figure 3) and timelines were created for each participant, analyzed, and compared with codes. Themes were then generated inductively based on coded data and patterns, with notable citations indicated for each. For example, emotions, which derived as a primary code, were coded first as the emotion itself. Secondly it was coded by valence, and thirdly it was fit within the progress-making force diagram as an internal motivation that represented progress to be done. It was in the third level of analysis that the role of the emotional Job, representing how someone wants to feel while progressing towards their goal, became clear.

Push → *External things that push patient to start*	Struggle moment	Pull → *Internal motivation to persevere. i.e. progress patient is trying to make (Job to be Done)*
← Habits *Comfort of old way that make patient want to give up*		← Anxieties *Worries that make patient want to give up*

Figure 3 – JTBD progress-making forces diagram

Analysis synthesis

A final level of analysis was completed across both sub-studies to gain a deeper level of insight into the navigational challenges faced by patients. Analysis of results from the anticipated needs assessment and the experienced needs assessment were synthesized inductively and iteratively following Immersive-Crystallization guidelines set out by Borkan (2022). Analysis began with the researcher fully immersing themself in the data to gain exposure and early insights. Suspending the immersion process, the researcher began reflecting and articulating trends in both sets of results through the process of Crystallization (Borkan, 2022). Crystallization merged analytical thinking with holistic experience as sub-study patterns, memos, field notes and results were synthesized, and patterns within and across both sub-studies were analyzed. Data analysis of the anticipated needs assessment was initially analysed for content, then was revisited holistically to look for theme coherence after completion of the experienced needs assessment and guided by the JTBD framework.

Ethical considerations

Ethical approval was obtained by the St. Mary's Hospital Research Ethics Board (reference number SMHC-13-30). Approval for both sub-studies was obtained as an amendment to IMPACT project (modification #11 and #13 of MP-18-2014-477).

There were no known risks to participating in this study. All methods were carried out in accordance with relevant guidelines and regulations. Precautionary measures were put in place in the case that any questions may have created discomfort for the participant. The interviewer participated in a Mental Health First Aid Training course prior to conducting the experienced needs assessment to enhance empathetic interviewing and develop tools to support participants in the case of a mental health emergency. Participants were informed of their right to refuse to answer any questions or withdraw from the study at any point without consequence. Participants were provided with the contact information of the primary investigator, as well as the number for the Service Quality and Complaints Commission. To ensure that the rights and dignity of all participants are respected, the research student clearly explained the purpose of the study and the consent process in lay person's language. All participants were able to give informed consent, and informed consent was obtained from every participant. All participants were informed of their voluntary participation, and that they may decide at any time, to not respond or withdraw from the study. Participants were assured that all information obtained from them, including their name and contact information, remained confidential, and was not associated with any of the data they provided. Only members of the research team had access to the interview recordings. All notes and recordings will be destroyed at a maximum of 5 years after the study is completed.

Results

Twenty-six interviews were conducted across both sub-studies. Nineteen were part of the anticipated needs assessment and seven were part of the experienced needs assessment. Characteristics of participants in both needs assessments are described in Table 1. Most participants in the anticipated needs assessment identified as a woman, were between the ages of 35-54 and had been a patient of their family physician for 5 or more years. In the experienced needs assessment, most participants identified as a woman, were 55 years or older and had been a patient of their family physician for 5 or more years. In both sub-studies, nearly half of the participants were immigrants to Canada and several participants experienced at least one social vulnerability.

Table 1: Characteristics of participants for assessment of anticipated needs and experienced needs.

Characteristic	ANTICIPATED NEEDS (n=19)			EXPERIENCED NEEDS (n=7)	
	n	Per cent		n	Per cent
Sociodemographics					
Gender					
Man	3	16%		2	29%
Woman	16	84%		5	71%
Age					
18 to 34 years	1	5%		0	0%
35 to 54 years	11	58%		3	43%
55 years and older	7	37%		4	57%
Born in Canada					
Yes	12	63%		4	57%
Health and healthcare					
Number years with family doctor					
less than 6 months	5	26%		0	0%
6 months to 11 months	0	0%		1	14%
1 year to 4 years	3	16%		0	0%
5 years or more	11	58%		6	86%
Perception of general health					
Excellent	2	11%		2	29%
Very good	10	53%		3	43%
Good	5	26%		1	14%
Fair or Poor	2	10%		1	14%
Ease of obtaining health information by your self					
Very easy	6	31%		4	57%
Moderately easy	10	53%		2	29%
Not very or not at all easy	3	16%		1	14%
Social vulnerabilities					
Highest level of education					
Graduate or professional degree	6	31%		3	43%
Bachelor's degree	10	53%		2	28%
Community or technical college or less	3	16%		2	28%
Social network: Persons to confide in					
More than one	16	84%		6	86%
One	3	16%		0	0%
None	0	0%		1	14%
Social network: persons who can help with activities of daily living					
More than one	8	42%		5	71%
One	5	26%		2	29%
None	6	31%		0	0%
Perceived financial status					
Comfortable	15	79%		6	86%
Tight	3	16%		1	14%
Very tight or Poor	1	5%		0	0%

General observations from assessment of anticipated needs

All participants experienced frustration in obtaining recommended follow-up healthcare and some felt lost and powerless in situations of navigation. A minority of participants forwent the recommended service completely and were unwilling to return to their doctor in cases of extreme navigational frustrations.

> *"But what can you do after the fact really, other than complain and not visit again"*
> *Anticipated needs, Rachel, 41*

Commitment to navigating and following-up with recommended healthcare services seemed to be motivated when clinicians provided patients with tangible actions, emphasized the importance of the referral, and explicitly stated why the referral was required, and when reception staff provided support to patients.

> *"Calling to get an ultrasound appointment was completely impossible because no one would pick up the phone. So, I brought the requisition back with me to the clinic and the doctor recommended having the clinic staff fax it over and that worked out way better because I got a phone call a few hours later and was able to make the appointment"*
> *Anticipated needs, Vera, 36*

Patients who are new to the healthcare system such as newly assigned primary care patients and recent immigrants, patients who have limited health-related French or English language proficiency or patients who have low social support appeared most likely to feel lost and need navigational support.

> *"If you're sick, and you don't know what's wrong with you, and people are explaining to you in another language, it doesn't work... people are going to be very anxious"*
> *Anticipated needs, Anne, 75*

Many participants had not yet begun the process to obtaining their recommended follow-up healthcare services, nor had they even begun to think about it. As a result, participants were unaware of the challenges they may encounter obtaining ongoing access and underestimated the time commitment and work that it would take to obtain the recommended follow-up.

Emerging results across both sub-studies

All participants in the anticipated needs assessment had been tasked by their provider with obtaining a recommendation or referral for their own healthcare. All participants in the experienced needs assessment had come up against significant navigational challenges, as perceived by their primary care provider. Most participants in both sub-studies shared strategies that they mobilize to address navigational challenges, and some expressed the ways in which clinic staff support their navigational journey. Nearly all participants expressed their emotions, both positive and negative surrounding navigation and the challenges experienced.

The overall findings of this study suggest that healthcare system navigation is work that requires time and commitment. Patients persist in the work of chartering their way through the healthcare system because they have a Job to do. Christensen and colleagues (2016) suggest that a Job represents the progress than an individual is trying to make in a given circumstance. The task of navigating the healthcare system is experienced universally as frustrating work for patients, but the functional, emotional, and social Jobs to be Done support perseverance through frustrations. Personal connection and the human touch are key strategies to support the work of navigation through social networks and communication with care team members. The main findings are summarized in Table 2.

Table 2: Theme identification

Themes	Theme description	Sub-theme
Navigation is experienced universally as frustrating work	The task of navigating the healthcare system requires work on behalf of the patient. The work is frustrating and for some patients it is so hard that it results in a real struggle	Navigation is a significant struggle for few

Three reoccurring Jobs to be Done motivate the work of navigation	Jobs to be Done are functional, emotional, and social goals that motivate patients to work at navigating the healthcare system and try different strategies for success	Functional Job of optimizing health
		Emotional Job of attending to the patient-provider relationship
		Social Job of being seen as a good patient
Personal connection is a key strategy to overcome hurdles in the work of navigation	Patients are required to use their connections; personal, social, and relational to support them as they navigate the healthcare system	Using social network to get ahead
		Communication with the care team supports ongoing access

Navigation is experienced universally as frustrating work

Findings from both sub-studies suggest that among all participants, navigating the healthcare system is experienced as frustrating work. Hurdles are constantly encountered, and strategies are required to overcome the hurdles. Participants shared their own personal definitions of the term 'navigating the healthcare system'. To most participants, navigation meant working their way through the healthcare system, finding a way to contact with a healthcare provider, or using resources to obtain a healthcare service.

> *"Getting my way through the system. That's how I understand it (navigating the healthcare system). Whether it's being able to book an appointment, to modify the date of my appointment and knowing how I can change the date in case anything happens… to have some information, medical information, or assistance getting through the system, to talk to a doctor or nurse"*
>
> *Experienced needs, Natasha, 46*

Patients reported having to work to navigate the healthcare system. They shared many accounts of spending considerable amount of time on the phone trying to reach a clinic, online trying to navigate a platform, or simply trying to understand the steps to obtain ongoing access to healthcare. When using online platforms, participants reported difficulty determining which one to use (ex: Clic Santé or the clinic portal), and how to use them. Across the entire study, many participants found the process of accessing information online overwhelming due to the vast amount of information available and reported spending a significant amount of time trying to find a way to schedule an appointment or reach the appropriate service. These hurdles led to frustration and a fragmented care experience as patients resorted to emergency rooms or delayed care, impeding ongoing access to care.

> *"It just doesn't make sense. You can't get emails or just a call directly to someone. Everything is really, really, hard (to navigate). So, because of that, everything takes time. And then the time creates new problems in the delay of care."*
>
> *Experienced needs, Stacy, 62*

Work was often accompanied by expressions of frustration. In the anticipated needs assessment, frustration was reported as the most frequently evoked emotion related to challenges with obtaining follow-up healthcare services.

> *"It's more frustrating than anything else. You see, it's not user friendly. It's like you're trying to get an appointment for… You know you're trying to find where to do it. But it's not easy, and that's where I think it's frustrating."*
>
> *Anticipated needs, Victor, 46*

Participants reported having to re-start the healthcare seeking process several times, which resulted in increased frustration at each unsuccessful attempt. Feelings of frustration often led to feelings of lostness and uncertainty as time progressed.

> *"Okay, frustrated… I was…. annoyed, very frustrated, and… frustrated… I didn't know where to turn. Should I call a clinic? Where should I call? I looked up some clinics online. Do I go into a walk-in clinic somewhere totally different? Or should I take him to the urgent care clinic, which sometimes I did…"*
>
> *Experienced needs, David, 52*

Navigation is a significant struggle for few

Although frustration was experienced universally among participants, it was evident from the anticipated needs assessment that adequate workarounds were put in place. Several participants mentioned feeling sorry for patients who don't have support or the means to navigate the system, alluding to other patients who experience real struggle.

> *"I'm still able to go, come back, walk... I have a husband who takes me by car. I can afford a taxi. I can do it. Everyone can't. I have the time. I'm in a very um, great position that I can do all this and still find a way, in the long run, to get to where I want to go. Not everyone can.*
>
> *Experienced needs, Alexia, 80*

Participants in both sub-studies mentioned knowing the challenges that elderly and socially vulnerable patients face, and how it is important to navigate the system using the appropriate means and indirectly supporting other patients. Those participants expressed that for them, navigation is work and frustrations are present, but they do not struggle.

> *"I do think that the phone system should remain for people at the age of my father, for people, you know people that have no other opportunities to book an appointment"*
>
> *Experienced needs., Natasha, 46*

> *"It's hard for them (older patients) to navigate the system and I can't imagine my mom waiting every single time on the phone for like 15 minutes and then (for them to) repeat the same thing and she won't understand that she needs to fax it or like, send an e-mail. I mean if you're not tech savvy... Never going to figure it out, you know like. No way."*
>
> *Anticipated needs, Valerie, 36*

In one case in the anticipated needs assessment, a participant who is an employee in the healthcare system, expressed concern for recent immigrants and socially vulnerable populations who struggle with understanding the healthcare system and ultimately end up utilizing healthcare services inappropriately.

> *"A lot of people that I find that come to the emergency oftentimes are immigrants. They don't know how the Quebec healthcare system works. So, they just come to the emergency, but then once they come to the emergency and they get, you know, eventually served, they use that as their primary care. It's the people that you know, had trouble getting access to their family doctor, they think that the emergency is the only door that could get them an appointment"*
>
> *Anticipated needs, Kate, 45*

Only a select number of participants experienced significant navigational frustration to the extent that it became a real struggle. For those who struggle, they appear to abandon the task more easily because the progress-making forces pushing and pulling them forward, are not strong enough compared to the anxieties, habits and struggles pulling them back.

Three reoccurring Jobs to be Done motivate the work of navigation

Jobs represent the goal an individual is trying to achieve in a given circumstance (Christensen et al., 2016). Jobs include tasks to complete or work to do and they are sometimes frustrating, annoying, or stressful. For participants, navigating the healthcare system is a Job that requires work. Many Jobs are required to support the goal an individual is trying to achieve but three distinct Jobs recurrently supported participants work of navigation.

The circumstance, along with the functional, emotional, and social Jobs to be Done support the work that an individual must do to achieve their goal (Christensen et al., 2016). JTBD interviewing brings clarity to the Job individuals are trying to achieve as they themselves are rarely explicitly aware of their intended progress. This became evident in the experienced needs assessment through detailed retrospective storytelling, JTBD timelines and progress-making forces diagrams. As patients charter their way through the healthcare system, they encounter hurdles which hinder their ability to get to the destination. Hurdles were encountered among almost all participants across the entire study. Motivated by their Job to be Done, all participants discussed overcoming those hurdles in some capacity. Participants from the experienced needs assessment described in detail the workaround solutions they adopt to support getting to their destination.

When individuals encounter hurdles impacting their progress towards the Job to be Done, workaround solutions are provoked. The various dimensions of the Job intrinsically motivate individuals to commit to goal they are trying to achieve. Participants are motivated to successfully obtain ongoing access to healthcare when healthcare is recommended by their provider. The importance of following through on a recommendation and doing whatever necessary to get it done successfully was communicated.

> *"It's important. She's my family doctor and needs to know all about me. I would have tried all other ways. I would have gone to the pharmacy, showed him my prescription from California. I would have tried anything"*
>
> *Experienced needs, Alexia, 80*

Persistence in working towards the goal is a function of the strength of the functional, emotional, and social Jobs to be Done. The identification of pushes and pulls through progress-making force diagrams identify the main Job participants are trying to accomplish and demonstrate what supports individual persistence through navigational work.

Functional Job of optimizing health

The functional Job to be Done is the task-related goal to be achieved. Christensen and colleagues (2016) explain that the functional Job is stable over time and independent of any social and emotional dimensions. In this context it is the concrete health related goal being strived for, the goal that is obvious to the individual. For participants, the functional Job to be Done is to support their own health needs and optimize their health.

Participants in both sub-studies frequently expressed challenges reaching the clinic by phone or using online portals. When challenges are encountered participants feel frustrated and irritated but manage to find ways to obtain care. In all scenarios, participants would use workaround solutions to reach the clinic. When participants have progress to make and it isn't obvious how to get the Job done, they engage in workarounds. Motivated by their functional Job to be Done, participants want to support their own health and healthcare trajectory. In the experienced needs assessment, participants frequently expressed going in person to the clinic to book appointments when contact challenges arose.

> *"I don't even go on the phone. I tried. I go (in person) … It takes me less time than waiting on the phone. I tried calling once, twice, three times. It was impossible. I was talking to a friend who works in here (clinic) and she said, "go to the department and make the appointment", and I came. It took me 5 minutes".*
>
> *Experienced needs, Michael, 77)*

Many participants noted the significant amount of time that is takes to navigate the healthcare system. A few participants indicated having to take time off work to have sufficient time to be able to book an appointment.

Participants use other resources to support themselves in obtaining healthcare. Participants in both sub-studies expressed using workarounds such as the emergency room in situations where they were unable to reach their family physician. Participants often know when their healthcare situation is an emergency and when it is not, but the goal of getting the Job done makes them persevere in taking necessary measures.

"Sometimes we need an appointment right away, and we can't get it, and we end up in the emergency, which we overload the emergency, whereas if we had possibly spoken to the doctor, something else could have been arranged"

Experienced needs, David, 52

One participant in the anticipated needs assessment was unable to reach her provider for an urgent question regarding medication she was taking. Consequently, she went to the emergency room. At the emergency she was met with disapproval by the attending physician as he expressed that her situation would have been more appropriately dealt with by her family physician.

> *"Où est ton médecin générale, pourquoi tu viens à l'hôpital pour quelque chose comme ça ?"*
> *"Where is your general practitioner, why did you come to the hospital for something like this?"*

Anticipated needs, Melissa, 72

Emotional Job of attending to the patient-provider relationship

At the surface level, a less obvious Job to be Done is the emotional Job. The emotional Job represents how someone wants to feel while progressing towards their goal. The emotional importance of following through on a doctor's recommendation is driven by the participants' desire to build or maintain a good patient-provider relationship. Patients want to support themselves but also to support the relationship they have with their family physician. Upon exploring the strategies that patients mobilize to address navigational challenges and the associated emotions, the influence of the emotional Job became evident. Patients were motivated to follow the healthcare recommendations made by their doctor to support the relationship they have with that doctor. Their commitment to the relationship with their doctor became a driving factor to persevere through navigational challenges, especially when patients had not yet fully internalized the health reasons for their functional Job.

It was observed that for many participants, the emotional Job became the principal motivation for navigational work. This was especially evident in participants who didn't fully understand why they needed the recommended follow-up healthcare and when patients didn't understand the health implications of their functional Job. As a result, the main motivation for participants to follow through on health recommendations was to maintain a good patient-provider relationship. Participants in the experienced needs assessment expressed great trust in their providers which enabled perseverance through navigational challenges.

> *"Whatever they (primary care provider) tell you, you take that advice with your eyes closed."*
>
> *Experienced needs, Michael, 77*

> *"I mean how can I not share with her my health, if I want her to take care of, you know, to take care of what I need, she has to know everything"*
>
> *Experienced needs, Alexia, 80*

It is evident that when participants trust their provider, their relationship and continuous care over time is supported. When participants follow through with healthcare recommendations, it shows the provider that they can trust their patients to support themselves as well. Participants felt that providers have a responsibility to care for them, but equally that patients have a responsibility to care for themselves, which includes following through on advice, even if they do not completely understand why. In one case in the anticipated needs assessment, a participant expressed the importance of advocating for themselves and how supportive and responsive providers can be when patients explain their concerns.

> *"I'm really quite verbal and good at advocating for myself… I've learned to advocate for myself… Doctors are responsive if you ask the questions and for the information"*
>
> *Anticipated needs, Darcy, 41*

As time passes and patients build a relationship with their family physicians, they develop a deeper connection with that provider. As family physicians provide a range of healthcare support to patients through the lifecycle, patients develop a sense of attachment unique to that provider. In one case a participant was seeking emotional support from her provider following a traumatic incident. The family physician was on leave and the participant felt significant emotional distress not being able to confide in the provider they trust the most.

> *"I didn't think that it was something for a replacement doctor. It was information, and I found that it was very important information that I didn't want to pass through too many avenues. You know… I wanted it to go straight to her… I just wanted to inform her, and I, I didn't think that it would make sense for anybody else to, to… speak to anybody else"*
>
> *Experienced needs, Claudia, 57*

For several participants in the experienced needs assessment, their emotions were supported when making progress by having a collaborative relationship with their family physician.

Participants persevered through the navigational challenges to reciprocally support their partnership with the family physician and to support their emotions while making progress.

> *"I think it's important to collaborate fully with any doctor. I mean, you cannot expect them to have results if you don't participate. You, I mean, you know, if they give you, prescribe you some medication and you do not take it, you cannot expect to be cured if you don't do."*
>
> *Experienced needs., Alexia, 80*

> *"The other thing about being a good patient is when you see your doctor to try and be precise about your symptoms or issues, which is hard. But to give all the right data…. You need to ask the right questions"*
>
> *Experienced needs., Stacy, 62*

Participants described the strength of their connection with the family doctors and the impact that family doctors have on them through their deep understanding of the whole patient. Many of the participants have been long-time patients of their family physician. They expressed their gratitude for having a stable provider with whom they feel comfortable sharing their health concerns and seeking their support. All participants spoke very highly of their primary care providers and the connection they feel to them.

> *"She knows everyone's case by heart, like she knows your soul. So, if you talk to her (family physician) about something, she listens"*
>
> *Experienced needs, Claudia, 57*

Social Job of being seen as a good patient

The social Job represents how someone wants to be perceived by others. Commonly articulated by participants from the experienced needs assessment is the desire to be perceived by others as a good patient while making progress towards their health goals. The others include clinic staff, friends, or family. In several cases, participants alluded to wanting to be perceived by their care team as "the good patient". For many patients that meant being proactive, gathering information through online sources or through their networks prior to their appointment. For participants, being a good patient also meant knowing when it was appropriate to seek support from their provider and knowing what means to use to contact their care team.

> *"I wanted to see if I stabilized properly, and I took my BP (blood pressure) on a regular basis and showed her the results. I brought all my paperwork that was given to me by the hospital, by the doctors. So, she has all my test results and everything"*
>
> *Experienced needs, Alexia, 80*

In the experienced needs assessment, when participants spoke about social support, it was evident that they valued their networks' perception of them, especially when some of their social connections work in the healthcare field and are a trusted resource.

> "*Very important (to follow doctor friends' advice). You know, you try to take their advice… and you follow it. They know the medical, the medicine, the chemistry. And it's out of friendship that they give you that advice. It's not business for them. It's human service.*"
>
> *Experienced needs, Michael, 77*

> *"I would talk to a friend who's also a doctor. He's a childhood friend. And if we have a problem, we go through him sometimes. I reach out to him. But this is a completely different relationship. This is a friendly one, no problem. I can call or text and he will reply and help"*
>
> *Experienced needs, Alexia, 80*

Personal connection is a key strategy to overcome hurdles in the work of navigation

Patients adopt various workaround solutions to overcome the navigational hurdles that impede their ability to obtain ongoing access to healthcare. The most successful workarounds were obtained with the support of connections, especially from social networks or through communication with the care team. In both sub-studies, participants discussed how their personal, medical, and social networks supported them in obtaining ongoing access to healthcare.

In a digital age, human contact is becoming less available and accessible. Many participants expressed uncertainty when using online platforms and leaving voicemails at the clinic, given fears that no one would receive them, and their request would be lost in the system.

> "*Calling a human person, them responding and giving me an answer, even if the appointment is going to be in a month. Somebody who will listen and tell me what to do.*

> *It's the fact that there is no one there, there is no contact, no contact anymore. It's very, very hard. And as I say, I can understand things, you know. And deal with the many things that you have to go through before reaching. But it's that you reach nothing. Almost no human contact anymore"*
>
> *Experienced needs, Alexia, 80*

> *"Just go in person because it's easier. Because at least you deal, if they have to deal with someone, when you're there, they can't hang up on you"*
>
> *Experienced needs, Stacy, 62*

Many participants are caregivers for older family members. Several explained that elderly patients appreciate the opportunity to speak to someone, either in person or by phone, to book appointments or ask questions. Participants noted the power of the human touch in supporting patients to overcome navigational hurdles and supporting their healthcare experience.

> *"My father, when he tries to navigate through the system, he wants to talk to someone. So I would figure, I might as well leave the line open for people his age or his generation, or people that that don't have access to the internet…"*
>
> *Experienced needs, Natasha, 46*

Using social network to get ahead

Most participants across the anticipated needs assessment and all participants in the experienced needs assessment mentioned using their social networks as a strategy to support them in obtaining ongoing access to healthcare. It was evident that participants with a strong social network have a much higher success rate with obtaining follow-up healthcare and experience less challenges with regards to navigating the healthcare system.

> *"I'll ask around too, but I'll, I'll pretty often do both actually. I'll talk to people around me about it and double check online"*
>
> *Experienced needs, Natasha, 46*

In one case, highlighted in the anticipated needs assessment, a patient was required to use her social network to obtain a specialist appointment. The participant had been a long-time patient of a dermatologist who, when retired disbanded his clinic leaving many patients without a doctor.

The participant used her sister as a referral when she contacted a new dermatologist to inquire about becoming a patient, but not without challenge.

> *"I asked my sister who had one, a teaching dermatologist at the MUHC. So, she gave me his name and number and I called. At first, they were reluctant to take me on as a new patient but because I told them my sister had been seeing this doctor for a number of years, they took me on. I needed to go to my sister, a family member, because I didn't know where to start"*
>
> *Anticipated needs, Rachel, 76*

A few participants in the anticipated needs assessment admitted to using their privileged position within the healthcare field when seeking healthcare or healthcare information.

> *"Of the list of resources, they (the clinic) gave me, I called, and I went on their websites to see if I could take an appointment online... I also tried to call the hospitals that I'm working at… I would say, I work as a health professional, can you squeeze me in for an ultrasound... and still that didn't work... so, it's kind of discouraging"*
>
> *Anticipated needs, Valerie, 36*

> *"I use all the resources, so I don't just speak to the doctor (right away). I usually speak to the pharmacist, and obviously I work in the in the (healthcare) environment. So yeah, sometimes I speak with colleagues, fellow doctors..."*
>
> *Anticipated needs, Kate, 45*

In both sub-studies, the importance of having a social network, such as friends, family, or colleagues to reach out to for information regarding ongoing access to healthcare was prevalent. Participants in both sub-studies expressed concern for patients who have limited or no access to a social network, especially a network in healthcare.

> *"You know someone that's coming from the outside would, would probably have more trouble knowing how to follow up and stuff"*
>
> *Anticipated needs, Kate, 45*

Communication with the care team supports ongoing access

The care team plays a significant role in informing the Job to be Done. Several participants in both sub-studies discussed the personal contact they have with their provider or care team by means of phone or email. Participants expressed immense gratitude to their care team for being available directly or reaching out to support them when they require healthcare.

> *"St. Mary's had set up a wonderful nurse… I had her direct line, of course she'd call me back very shortly... I had her cell phone, and she either answered or she called… you could leave a message and she called you right back. She knew the history, and she knew everything"*
>
> *Experienced needs, David, 52*

> *"I have a nice network of physicians, a care team… having those connections help"*
>
> *Anticipated needs, Darcy, 41*

Participants mentioned the support that their doctors give to them by taking the time to provide guidance on navigation during the clinical encounter. Participants explained that their providers are very informative and provide resources for navigational support when referring to specialists. However, in some cases, participants expressed concern about the amount of time that providers spend with them on navigation directly or explaining how to navigate. One participant felt as though his need for navigational support consumed valuable provider time:

> *"This took a lot of extra time for her, during which she could have seen other patients…"*
>
> *Experienced needs, Richard, 59*

Conversely, when communication with providers or the care team is unavailable, access to healthcare is hindered. One participant reported being unable to book an appointment with their doctor in a reasonable amount of time and as a result, felt disconnected and unattached from the primary healthcare system.

> *"I just needed a doctor to call me back to discuss what I should do. Get some advice. And, and what I found with family medicine lately is they, the doctor looks at their schedule, and says, no, can't see you for a month… And their overloaded of course… But this makes you feel like you don't have a doctor…*
>
> *Experienced needs, David, 52*

In sum, across the entire study navigation was expressed universally as frustrating work. Some participants experienced significant struggle with navigation. The functional, emotional, and social Jobs to be Done supported work and perseverance despite frustrations. Striving for improved health outcomes when health is suffering is the essence of the functional Job. Building strong relationships and connections with providers encourage patients to work through navigational challenges and is the emotional Job. Additionally, the perception of oneself by others in the social network and being seen as ‘the good patient’ constitutes the social Job. Finally, personal connection is a key strategy mobilized to successfully navigate the healthcare system. Social networks and communication with the primary care team supported navigational work and participants Jobs to be Done.

Discussion

These two sequential qualitative sub-studies explored the navigational challenges experienced by patients in obtaining healthcare services recommended by their primary care provider. It was found that navigating the health system is work, though the degree of work experienced varies by patient. The retrospective ethnographic exploration of the sub-group of patients with experienced navigational needs discerned three recurring Jobs to be Done which motivate the work of navigation: 1) the functional Job of obtaining a service to optimize health; 2) the emotional Job of building a good patient-provider relationship; and 3) the social Job of being perceived by clinic staff, family and friends as a good patient who follows through on advice. Strong communication with the care team - which for patients includes clinic staff - plays a critical role in framing the Jobs to be Done and informing strategies for the navigational work. While patients use a variety of navigational strategies and workaround solutions, it was found that the patient's social network is the first line of defense when they encounter barriers. Consequently, access may depend on the size and influence of the social network. Each of these findings are discussed in detail below.

Navigating the healthcare system is work

Navigating the healthcare system is time consuming and frustrating for patients. The burden of treatment in healthcare is defined by the work required and the associated effect on patient wellbeing and functioning (Eton et al., 2012). To obtain ongoing access to healthcare requires considerable work on behalf of the patient and the complexity and degree of work involved is a barrier (Dixon-Woods et al., 2006). Further, a high degree of health literacy is required to be able to navigate the healthcare system and obtain ongoing access to healthcare

(Griese et al., 2020). Patients are tasked with intentionally working to improve their health literacy, to understand medical information and to engage with healthcare services. The degree of work required varies in magnitude, depending on the individual and their characteristics and circumstances. For socially vulnerable patients, work is additionally burdening due to the misalignment of their competencies and needs as compared to those of healthcare organizations (Dixon-Woods et al., 2006). The work and responsibilities of being a patient, including navigating the healthcare system, as well as having the capacity, resources, and reediness to address the work and responsibilities, must be balanced. When patient workload exceeds the capacity of the patient to engage in the workload, disruptions in health and healthcare may occur. Navigation is required to maintain the balance of workload and capacity, and work is required to be able to navigate the healthcare system.

Jobs to be Done motivate the work of navigation

The Job that patients are working towards is distinct from the work they are doing. Work represents the task that the patient is engaging in and the Job to be Done is the goal they are striving to achieve by doing the work. Based on the JTBD Theory, the importance of the various Jobs motivate the individual to perform the work (Christensen et al., 2016). The functional, emotional, and social Jobs will be reoccurring among patients but varying between patients. The importance of each Job is what leads patients to engage in a behavior change and is what determines their persistence and degree of work to get the Job done. JTBD Theory seeks to understand consumer behavior by looking at the Jobs they need done, and as such, bears some similarities to the Theory of Planned Behavior, which looks at various chronological constructs representing control over behavior change, to predict individual intention to make a change (Ajzen, 1991). JTBD Theory is a novel approach in healthcare and has not been used – to our knowledge – to inform the work of access. Using JTBD Theory elicits the various functional, emotional, and social Jobs and the motivation to work towards the Job becomes apparent.

Study results revealing the role of the care team in shaping the participants Job to be Done demonstrated how predominant the emotional and social Jobs are for many patients. This relates to the notion of being 'the good patient' and maintaining a good patient-provider relationship. In terms of behavior, patients are regarded unfavorably when they fail to conform to the provider recommendations (Kelly and May, 1981). When patients are unaware of why they must obtain a healthcare service or follow-up with the recommendation made by their provider, they may simply conform to the recommendation for their emotional and social Jobs, regardless of how much work is required. When patients have a clearer understanding of their health needs and why it is important to follow provider recommendations, they are more likely to internalize the goal and work towards their functional Job to be Done as well as the emotional and social Jobs.

Social networks are a key strategy to support healthcare system navigation

When access to healthcare is challenged and navigational difficulties are continuously present, patients are reliant on their social networks to support their health information needs and connect them with healthcare providers or services (Tarrant et al., 2015). Patients who lack social support are at a disadvantage as they experience longer wait times, delays in accessing medical care, higher medical expenses, and ultimately poorer health outcomes (Reisinger, Moss and Clark., 2017). The extension of a patient's social network is the principal strategy used to navigate the healthcare system. The social rank, influence, and size of network influences access and those without social networks will experience a greater degree of burden and struggle. Social determinants of health lead to additional equity implications associated with the degree of work required to get a Job done. Patients who experience more than one social vulnerability will have more hurdles to overcome and experience problematic access to healthcare (Haggerty et al., 2020). Social networks serve as a principal strategy to support healthcare system navigation and ongoing access to healthcare.

Communication with the care team and clinic staff facilitates the work of navigation

Navigational challenges related to communication exacerbate the work required of a patient when healthcare services are recommended. For example, limited health literacy can impede communication between patient and provider. Patients must clearly understand the health information they are obtaining in order to be motivated to take necessary actions and work to follow through with the actions (Graham and Brookey, 2008). Providers, the care team, and clinic staff, including clerical and administrative employees, can support navigation through communication, by emphasizing why follow-up healthcare is required and ensuring patients understand follow-up instructions. When there is poor communication between the patient and physician or if the reason and importance of obtaining the follow-up service is not clear, patients are less motivated to persevere through challenges. Clear communication with the care team and clinic staff facilitates anticipated navigational challenges. When clinicians give tangible, concrete actions, and say why the actions are important, or when they refer patients to clinic staff for help, their perseverance to navigate and obtain needed care is strengthened.

Most often, clerical, and administrative staff are the first point of contact for patients obtaining healthcare. Patients see clerical and administrative staff as part of the care team. They support and advocate for patients by ways of providing information or brokering healthcare for patients who need additional support outside of the clinical encounter (Neweult et al., 2015). Collaboration, communication, and teamwork with providers and clinic staff support the Job to be Done. A strong patient-provider relationship and relationship with clinic staff is a valuable resource in helping patients overcome navigational hurdles.

Limitations

Although the findings of this study largely support existing literature on the challenges faced by patients when accessing ongoing care, we recognize that potential challenges and experiences identified are necessarily partial. This study reflects the experiences of a relatively small sample size, especially in the experienced needs assessment but the depth and richness of the data is a strength unique to the study.

Memory bias is a limitation of this study. In the anticipated needs assessment participants were asked to think back on a time when they experienced navigational challenges. The recalled emotions may have been minimized as challenges appear mitigated after the service is received and “all’s well that ends well”. Similarity, several of the participants in the anticipated needs assessment reported that they had yet to attempt to obtain the healthcare recommendation made by their provider. This meant that the actual experience was not able to be assessed which led to descriptions of hypothetical needs. This finding prompted a more targeted approach to recruitment for the experienced needs assessment, however some participants in the experienced needs assessment had difficulty remembering specific details of their navigational experience, as probed by the interviewer.

Additionally, this study may have been affected by social desirability bias. All participants in the experienced needs assessment were recommended to the study by their primary care provider. As a result, participants may be reluctant to share certain details of their care experience to be perceived positively and as a ‘good patient’.

Implications for future research

There are many opportunities for future research following this study. The findings present an interesting initial exploration of healthcare navigation challenges as experienced by patients in the primary care system. Targeting a larger population of individuals with diverse social vulnerabilities, or individuals who do not have a primary care provider may generate compelling findings that reflect a range of experiences in accessing primary healthcare. Further work is needed to gain insights on these populations and better understand how navigation services could be tailored to best support the patients who experience the greatest challenges.

This study demonstrates the value of using various and diverse methods in healthcare research. The use of JTBD methods rooted in business innovations used patient narratives to produce rich insights regarding the “Job” of navigation as both work and desired goal, and how it might be better supported by the healthcare system. It would be interesting to continue exploring the use of JTBD Theory as an approach in healthcare research and continue the exploration of access to healthcare from the consumers lens, as a Job to be Done.

Implications for the Patient Navigator Service

As mentioned previously, the context for this study was a Volunteer Patient Navigator service that was being established to help patients referred by their primary care doctors, to navigate the healthcare system. The purpose was to better understand patients’ navigational needs, when and how they are expressed, and any clues we could provide to primary care doctors to about who is likely to need a navigation referral.

These two needs assessment sub-studies provided our team with a much more nuanced appreciation for the complexity of the work of navigation and the types of solutions that are likely to respond to patient needs. Although patients’ previous experience leads them to anticipate that navigation will require time and commitment and is likely to be experienced as annoying, the vast majority nonetheless managed to obtain needed services through a ‘muddling through’ approach that taps into their personal or their social network’s experience. Consequently, our personalized Volunteer Patient Navigation service may be unnecessary for certain patients whose “workarounds” are sufficient. Nonetheless, it is evident that patients would benefit from being pointed to a resource such as a website that provides road maps for getting recommended services, including alternate options, much like a Google Maps for navigating the health system.

For those with identified difficulty navigating the healthcare system, the in-depth ethnographic interviews and JTBD analytic framework provided a new appreciation of the importance of the human touch, and hence the relevance of something like a personalized Patient Navigation service as an adjunct to mass digital solutions. Insights regarding the importance of people’s emotional and social goals in providing motivation to persist in the work of navigation, also have implications for the tone and approach that navigators need to use to interact with and support patients who are having trouble.

Finally, this study gave us a better appreciation for how difficult it is for primary care providers to pick up cues of anticipated navigation difficulty. The work of navigation is not only outside the purview of clinicians or clinic staff, but is also under-estimated by patients themselves. This inhibits patient ability to provide cues indicating navigational needs to their provider during the clinical encounter. In our interview of anticipated navigation needs, few patients anticipated having any difficulty, and virtually none had elaborated a concrete action plan to start the process. Only during the interview, when recalling previous experience, did they begin to anticipate the annoyance of the work of navigation. Our study also demonstrates that patients expect the staff at their clinic to be the initial source of guidance when they run into navigational hurdles. So, a feature of a digital and personalized Patient Navigation service is that clinic staff, especially front office staff, be empowered to provide information about services and make referrals to the personalizes support when needed.

Implications for clinical practice

When working towards successful healthcare system navigation, the destination may be known, but how to get there is often unclear. The patient partner on this thesis committee provided an important insight on the importance of clinicians telling patients *why* they need the recommended healthcare service. As we noted, in the absence of a well-formed functional health goal, the patient will rely on the emotional and social goals. From the perspective of the patient partner, the motivation to 'be a good patient' is not always in the best interest of the patient because it does not really engage them as a partner in their own care. Becoming a partner involves addressing the power difference in the patient-physician relationship, especially in the asymmetry of information. Giving information about why care is needed not only helps the patient internalize the functional Job for the work of navigation but also engages them more broadly in advocacy for their own care.

Reflection

It is interesting to reflect on the experience of conducting, executing, and analyzing each sub-study of this needs assessment. The anticipated needs assessment was semi-structured with little room to venture away from the interview guide and explore or unpack interesting points raised by participants. Although the interview guide was developed to address the objectives for the study, looking back we realize that there was potential for deeper exploration. This is critical in qualitative work where exploration and understanding are a focus of the research.

Interviewing for the experienced needs assessment brought a new perspective on qualitative interviewing as it positioned the interviewee as the leader, guiding the interview as they told their story. This unstructured ethnographic format let the interviewee share their experience in the most meaningful way to themselves. Interviewees were suggested to share as many details as possible and told that nothing was insignificant. This directive gave the interviewer the opportunity to dive deeper on significant or “unpackable” words that the interviewee would say by asking them to elaborate, allowing the researcher to explore the participants Job to be Done. The retrospective ethnography allowed for true experience to emerge and for the participant to reflect on concrete situations.

Much of the richness of the data from the experienced needs assessment came from the details and emotions that presented using the method of retrospective ethnographies. This valuable learning led to a second “look-back” at the anticipated needs assessment to find previously undetected nuances in the interviews, after completion of the experienced needs assessment. The richness of ethnographies and storytelling provided strong insight into the experiences and struggles of navigation and the underlying Jobs to be Done that patients are faced with.

It is important to acknowledge identity and positionality as a researcher and the potential influences on the conduct, collection, and analysis of the data. Following the JTBD interviewing style, the researcher positioned themselves to think and listen from the participants perspective. As the interview progressed, the interviewer would encourage deeper reflection and details to document the participant’s story. The researcher asked participant to clarify or explain a statement to promote the participant being the expert of their story. As researchers, academic background and experience plays a role in shaping the research process. Power dynamics may impact the research process and data obtained. By positioning the interviewee as the expert of the story, the researcher can establish a collaborative relationship with the participant, valuing their perspective and positioning them as equal. As emotions were evoked during the interviews, the researcher used their own lived experiences to relate and empathize with participants, fostering a safe and inclusive sharing space.

Conclusion

Healthcare system navigation requires work. It is universally frustrating for patients, but the functional, emotional, and social Jobs push patients to work through those challenges. For some patients, navigation is a real struggle in which significant consequences occur. For patients experiencing navigational challenges, frustrations are mitigated by the functional Job of wanting to optimize their health. Patients are motivated to pursue their healthcare needs for the emotional Job of wanting to support a good relationship with their provider and are driven by the social Job of wanting to be perceived by others as a good patient. Finally, patients utilize their social networks and communication with the care team and clinic staff as strategies and facilitators to support navigation.

The results of this study highlight navigational challenges faced by primary care patients and may support solutions to help patients navigate the healthcare system and obtain ongoing access to healthcare with greater ease. Results also indicate the need for the development and implementation of interventions to better support and educate patients and their care teams. Understanding and acknowledging the navigational challenges that patients face when accessing ongoing healthcare services and exploring solutions to support patients will help bridge gaps in primary healthcare delivery and improve equity of access to primary healthcare. There is value in providing personalized support to patients who are challenged by the degree of work required in navigating the healthcare system, through human touch. There is space to improve the coordination and continuity of ongoing access to healthcare for individual patients already in the primary care system by understanding their Job to be Done, communicating clear healthcare information, and the provision of human support.

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Appendices

Appendix I: REB Approval Letters

Centre intégré
universitaire de santé
et de services sociaux
de l'Ouest-de-
l'Île-de-Montréal
Québec

Additional information and/or miscellaneous communications

Protocol title: **Innovative models promoting access and coverage team (IMPACT): Supporting the implementation of organizational innovations in community-based primary health care to improve population coverage and access to vulnerable groups**

Project number(s): **MP-18-2014-477, SMHC-13-30**
Form: **F2H-3130**
Nagano identifier: **SMHC-13-30**
First submit date: **2023-03-20**
Principal investigator: **Dr. Jeannie Haggerty, PhD**
Last submit date: **2023-04-25**
Project's REB approbation date: **2013-11-04**
Form status: **Form approved**

Review and Decision- Research Review Office

1.

Details concerning the REB decision:

Approved - delegated review

It was determined that the review of this submission (e.g.: amendment, annual report, termination report, resubmission/response to comments or notification) could be delegated in accordance to article 6.12 of the Tri-Council Policy Statement (TCPS 2 2022) because there were no changes affecting the level of risk for your project.

Subcommittee Biomedical

Please note that this decision is valid for the following participating site(s):

CIUSSS-OMTL

2.

Date of the REB final decision & signature

2023-05-01

Signature

Rebecca MacDonald, MA
Agente de planification, programmation et recherche – éthique de la recherche
Direction des affaires universitaires, enseignement et recherche
CIUSSS de l'Ouest-de-l'Île-de-Montréal

Comments from the REB Chair / Vice Chair:

R. MacDonald is signing on behalf of the delegated member who sent her approval via email.

3.

Approved documents

Approved protocol or bank framework

SMHC-13-30_AmendedProtocol_Modification13_V2.docx

Approved ICFs for use at the CIUSSS ODIM - EN & FR

SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx

SMHC-13-30_ICF_En.docx

SMHC-13-30_ICF_Fr.docx

SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx

General Information

1. **Indicate the full title of the research study in French**

Projet IMPACT (Modèles novateurs favorisant l'accès aux services de santé): Appuyer la mise en œuvre d'innovations organisationnelles en soins de santé de première ligne pour améliorer l'accès aux services de santé pour les groupes vulnérables.

2. **Indicate the full title of the research study in English**

Innovative models promoting access and coverage team (IMPACT): Supporting the implementation of organizational innovations in community-based primary health care to improve population coverage and access to vulnerable groups

3. **Indicate the name of the local Principal Investigator responsible for the project**

Haggerty, Jeannie

Study status

1.

The request concerns:

one or more participating institutions

Indicate the site(s) affected by the amendment

CIUSSS-OMTL

Indicate the current status of the research project at this establishment

Project is in progress and recruitment is ongoing

Notification details

1.

Briefly describe the nature of the information or correspondence:

Addition of in-person interviewing to the protocol and in-person informed consent (Fr and En). Addition of zoom interviewing and video recording to the verbal consent form, and to the study information forms given to participants who choose to be interviewed by zoom.

---

2. **Does this new information or correspondence have an impact on the project?**

☑ Yes
☐ No, for your information

Impact on:

☐ Approval of the project
☐ Project continuation/study procedures
☑ Changes are required to study documents
☐ Participant integrity or safety
☐ Other

Please specify the coming changes to the documents:

Addition of the option to interview in-person or by zoom (participant choice) and in-person informed consent form. Addition of video recording to the verbal consent form, and to the study information forms given to participants who choose to be interviewed by zoom

---

3. **Please attach all relevant documents to this notification, if applicable.**

SMHC-13-30_AmendedProtocol_Modification13_V2.docx

SMHC-13-30_ICF_Fr.docx

SMHC-13-30_ICF_En.docx

SMHC-13-30_verbal informed consent_En_Fr.docx

SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx

SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx

Exchanged comments history

REB office Regarding the use of an online platform for the interviews, please add the following 2023-04-25 statement to section '5. Risks associated with the research project' of all the ICFs: Due 10:54 to the potentially identifying nature of the online interview, there is a risk of reidentification and breach of confidentiality. However, measures are in place to minimize these risks.'

Researchers 2023-04-25 Thank you. All French and English ICF forms and forms for patients have been updated to include the statement, including the verbal ICF form. 14:32

Signature

1. **Add here any additional confidential information that you wish to transmit to the office of the REB.**

We would like to invite participants to interview in-person or by zoom if they prefer. If in-person is the preferred choice, then we will provide them with the ICF form to review and sign at the time of the interview. If zoom is the preferred choice we have added video recording to the verbal consent form and to the study information forms given to participants.

2. **I certify that the information provided on this form is correct.**

Victoria Wicks
2023-04-11 13:09

Centre intégré
universitaire de santé
et de services sociaux
de l'Ouest-de-
l'Île-de-Montréal
Québec

Project number(s): **MP-18-2014-477, SMHC-13-30**
Nagano identifier: **SMHC-13-30**
Form: **F2H-3130**
Transmission date : : **2023-05-01 10:48**

File transmission report to participating centers

The REB decision regarding the notification form F2H-3130 is sent to you in this mailing. Files related to this notification are also sent to you as described below.

Files linked to this notification and transmitted by the REB :

- SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx / SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx
- SMHC-13-30_ICF_Fr.docx / SMHC-13-30_ICF_Fr.docx
- SMHC-13-30_ICF_En.docx / SMHC-13-30_ICF_En.docx
- SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx / SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx
- SMHC-13-30_AmendedProtocol_Modification13_V2.docx / SMHC-13-30_AmendedProtocol_Modification13_V2.docx

Files linked to this notification and transmitted by the REB to the answering site only :

No elements

Files linked to this notification and NOT transmitted by the REB :

- SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx / SMHC-13-30_CIUSSS_REB_form for patients_Fr_V2.docx
- SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx / SMHC-13-30_CIUSSS_REB_form for patients_En_V2.docx
- SMHC-13-30_verbal informed consent_En_Fr.docx / SMHC-13-30_verbal informed consent_En_Fr.docx
- SMHC-13-30_ICF_En.docx / SMHC-13-30_ICF_En.docx
- SMHC-13-30_ICF_Fr.docx / SMHC-13-30_ICF_Fr.docx

The files sent with this notification can be viewed directly in the project, under the "Uploaded files" tab, in the files category called "Fichiers reliés aux suivis du CÉRÉ".

Comments (from REB evaluator) regarding transmitted files :

Centre intégré universitaire de santé et de services sociaux de l'Ouest-de-l'Île-de-Montréal
Québec

Centre de recherche de St. Mary

BY E-MAIL ONLY

January 3, 2020

Jeannie Haggerty, PhD
Principal Investigator
McGill Research Chair
Family and Community Medicine
St. Mary's Research Centre

RE: Approval of amendment (#11) of multicenter protocol: SMHC-13-30
Entitled: *Innovative Models Promoting Access-to-Care Transformation (IMPACT): Supporting the Implementation of Organisational Innovations in Community-Based Primary Health Care to Improve Population Coverage and Access for Vulnerable Groups.*
Principal Investigator: Dr. Jeannie Haggerty
Sponsored by: Instituts de recherche en santé du Canada / Fonds de recherche du Québec - Santé

Dear Dr. Haggerty,

This is to confirm receipt of your amendment received September 19, 2019 for the above-mentioned protocol. Please be advised that the Chair of the Research Ethics Committee (REC) provided expedited approval for your amendment on October 16, 2019. It was determined that the review of this amendment could be delegated in accordance to article 6.12 of the Tri-Council Policy Statement (TCPS2) because there were no changes affecting the level of risk for your project. The amendment will be recorded at the following meeting of the St. Mary's Research Ethics Committee.

Approved documents:

- Budget_SpreadNavigationSupportV2, undated;
- SMHC-13-30 FormE 20191016 signed, dated: October 16, 2019;
- PLIQC_AmendedProtocol_Evaluation_2019-09-18 (1), dated: September 18, 2019.

This approval is valid within the following institutions that have provided a letter of authorisation:

- St. Mary's Hospital Center, an installation of CIUSSS de l'Ouest-de-l'Île-de-Montréal – local investigator: Jeannie Haggerty (authorised November 4, 2013);
- CLSC- St-Hubert, an installation of CISSS du Montérégie-Centre – local investigator: Mylaine Breton (June 11, 2015).
- Hôpital Pierre-Boucher, an installation of CISSS du Montérégie-Est – local investigator: MarieHélèn Côté Sauvé (authorised August 21, 2015)

Should you have any questions or require additional information, please do not hesitate to contact me at (514) 345-3511, ext. 3698.

Thank you for your attention to this matter,

Télécopieur : 514 734-2652 www.ciusss-ouestmtl.gouv.qc.ca

Fredrick Vokey, MA
Agent de planification, programmation et recherche – éthique de la recherche
Direction des affaires universitaires, enseignement et recherche
Centre intégré universitaire de santé et de services sociaux de l'Ouest-de-l'Île-de-Montréal

On behalf of :
Jessica Kovitz-Lensch, MD, FRCPC
Chair, Research Ethics Committee
St. Mary's Hospital Center

encl: Approved Documents (zipped)

CC:
Mme Christine Beaulieu, Coordinatrice de recherche
Mme Jocelyne Bonin, Personne mandatée, CISSS de la Montérégie-Est
Mme Suzanne Descent, Assistante de recherche
Mme Emilie Dionne, Coordinatrice de recherche
Mme Cloé Rodrigue, Personne Mandatée, CISSS de la Montérégie-Centre
Mme Hélèn Langelier, Coordinatrice du Comité d'Éthique de la Recherche, CISSS de la Montérégie-Centre

4710 St-Ambroise, suite 100
Montréal Quebec, H4C 2C7
tel: 514-317-9887
fax: 514-317-9343
www.cliniqueindigo.ca

Clinique Indigo

Montreal, April 20, 2022

Jeannie Haggerty, PhD
St. Mary's Research Centre
Montreal, Quebec
Sent by email: Jeanie.haggerty@mcgill

Dear Dr. Haggerty,

As clinic directors at Clinique Indigo, we have reviewed your proposal for the Assessment of Patient Navigation Needs, and we agree that the study processes meet requirements for feasibility and ethical protection of patients, and consequently we are able to approve that this study be conducted at Clinique Indigo with our patients.

In particular we have verified the following

1 Feasibility - the study processes are feasible for the clinic and.

- ☐ The process of informing and recruiting patients does not interfere with the tasks of clinic personnel related to patient care.
- ☐ The method of recruiting patients in the clinic will not will not interfere with patient care
- ☐ The study does not require clinic resources that are destined to clinical care of patients.

2. Ethical protection of patients:

- ☐ The method of recruiting patients does not put undue pressure on them to participate.
- ☐ Patients have ample opportunity to voluntarily accept or refuse participation.
- ☐ The process for obtaining informed consent can be verified independently (i.e. it is recorded)
- ☐ The proposed interview questions are respectful to both patients and Clinique Indigo.

Please inform us of any changes made to the study itself. We believe that the results will help us improve the care to our patients. We are looking forward to seeing the results.

Maxine Dumas Pilon, MD
Co-founder, Indigo Clinic

Appendix II: Assessment of Experienced Needs Informed Consent Form

Centre intégré
universitaire de santé
et de services sociaux
de l'Ouest-de-
l'Île-de-Montréal
Québec

Title of the research project:	*IMPACT: Supporting the Implementation of Organisational Innovations in Community-Based Primary Health Care to Improve Population Coverage and Access for Vulnerable Groups*
Principal investigator:	Dr. Jeannie Haggerty
Member(s) of research staff:	Victoria Wicks

St. Mary's Research Centre
Connect

Patient needs for Navigating the Health Services
Lighting the way to care

1. Introduction

We invite you to participate in a research project. However, before agreeing to participate in this project, please take the time to read, understand and carefully consider the following information.

This form may contain words you do not understand. We invite you to ask any questions that you may have to the researcher in charge of this project or to a member of its research staff and to ask them to explain anything that is not clear.

2. Nature and objectives of the research project

The purpose of this study is to explore the lived experiences that patients face when obtaining follow up health services recommeneded by their primary care provider, and the functional, emotional, and social consequences associated with these experiences and how patients address them. The results will be used to better understand the needs of patients and inform a patient navigation service that aids patients in overcoming barriers with accessing health services.

For the realization of this research project, we plan to recruit 20-25 participants and interview 10-15 of those eligible participants. Participants must be at least 18 years of age.

3. Conduct of the research project

3.1 Location of the research project, duration and number of visits

This research project will take place at GMF-U St. Mary's Hospital (SMH)

3.2 Nature of your participation

If you agree to be contacted, a research assistant will call you for a short interview, within the next 3-5 business days. The research assissant will gives you a little more information, and you will have the chance to accept or refuse the interview. If you provide your consent to participate, your participation in this study will consist of one short interview and a few simple questions about your demographics (I.e., your age, level of education, general health, and ability to find health information by yourself). This interview will be recorded and stored on a secure, password-protected platform. The interview will allow us to better understand your ability to obtain health services recommended by your doctor and whether you could benefit from navigational support. The interview will be completed over the phone with the researcher and will take about 30-45 minutes.

4. Disadvantages associated with the research project

There are no known disadvantages associated to your participation in this study. There are some questions that may make you feel discomfrotable, you always have the right to refuse to answer. The information provided will not have any negative impact of the services you receive from the medical clinic.

5. Risks associated with the research project

There are no known risks associated to your participation in this study. The information provided will not have any negative impact of the services you receive from the medical clinic.

Due to the potentially identifying nature of the online interview, there is a risk of re-identification and breach of confidentiality. However, measures are in place to minimize these risks.

6. Benefits associated with the research project You will receive no personal benefit from your participation in this research project. However, we hope the results obtained will contribute to the advancement of scientific knowledge in this area of research.

7. Voluntary participation and possibility of withdrawal

Your participation in this research study is voluntary. Therefore, you may refuse to participate. You may also withdraw at any time, without giving any reasons, by informing the doctor in charge of this research study or a member of the research team.

Your decision not to participate in the study, or to withdraw from it, will have no impact on the quality of care and services to which you are otherwise entitled, or on your relationship with the teams providing them.

The researcher in charge of this research study, the Research Ethics Board, the funding agency, or the sponsor may put an end to your participation without your consent. This may happen if new findings or information indicate that participation in this research study is no longer in your best interests, if you do not follow study instructions, or if there are administrative reasons to terminate the study.

You have the right to modulate your withdrawal from the study at any time. If you withdraw or are withdrawn from the study, no further data will be collected. The information and, audio recordings, images and MRI already collected for the study will be destroyed by the research team to ensure your withdrawal.

Finally, any new findings acquired during the course of the study that could influence your decision to continue your participation will be shared with you quickly.

8. Confidentiality

During your participation in this study, the researcher in charge of the study and the research team will collect, in a study file, the information about you needed to meet the scientific objectives of the study.

All study data collected during this research study (including personal information) will remain confidential to the extent provided by law. You will be identified by a code number only. The key to the code linking your name to your study file will be kept by the researcher in charge of this study. No identifying information will be captured, nor analyzed. All electronic information will be kept on the research team's password-protected computers.

Study data will be stored for at least 7 years following the end of the study by the researcher in charge of this research study, after which it will be destroyed

11. Compensation

You will not receive financial compensation for participating in this research study.

12. Should you suffer any harm

Should you suffer harm or discomfort during this research study, you will receive all the care and services required by your state of health. By agreeing to participate in this research study, you are not waiving any of your rights nor discharging the doctor involved in the study, or the institution of their civil and professional responsibilities.

13. Contact information

If you have any questions or if you have a problem that you think might be related to your participation in this research study, or if you would like to withdraw, you may communicate with the researcher in charge of this research study or with someone on the research team at the following number: 647-235-1015 or email address: victoria.wicks@mail.mcgill.ca

14. Complaints

For any questions regarding your rights as a research participant in this study, or if you have comments or wish to file a complaint, you may communicate with:

Commissioner for Complaints and Quality Services CIUSSS de l'Ouest-de-l'Île-de-Montréal at 1-844-630-5125 or by email at commissariat.plaintes.comtl@ssss.gouv.qc.ca .

15. Declaration of interests

The principal investigator states that s/he has no personal interest that could conflict with his/her role as a researcher.**16. Monitoring of the ethical aspects of the research project**

The Research Ethics Board of the CIUSSS de l'Ouest-de-l'île-de-Montréal has given ethics approval to this research study and is responsible for monitoring the study at all participating institutions in the health and social services network in Quebec.

Additional consent options:

Audio recording

Do you accept to be audio recorded during interviews? The audio recordings (either stored in digital files or audio tapes) will be included in your research file and be kept for a maximum period of 7 years after the end of the study by the researcher responsible for this research project. Content of the tape(s) may be published or scientifically discussed, but it will not be possible to identify you.

☐ Yes ☐ No

Video recording

Do you accept to be video recorded (which includes audio recording) during interviews? The video recordings (either stored in digital giles or video tapes) will be included in the research files and be kept for a maximum period of 7 years after the end of the study by the researcher responsible for this research project. Content of the tape(s) may be published or scientifically discussed, but it will not be possible to identify yourself.
☐ Yes ☐ No

Declaration of Consent

Title of research project: *IMPACT: Supporting the lmplementation of Organisational Innovations in Community-Based Primary Health Care to lmprove Population Coverage and Access for Vulnerable Groups*

Signature of participant

I have reviewed the Informed Consent Form. Both the research study and the Informed Consent Form were explained to me. My questions were answered, and I was given sufficient time to decide. After reflection, I consent to participate in this research study in accordance with the conditions stated above.

Name and signature of participant Date

AND

I have explained the research study and the terms of this Informed Consent Form to the research participant, and I answered all questions asked.

Name and signature of the person obtaining consent Date

AND

I certify that this Informed Consent Form was explained to the research participant, and that the participant’s questions were answered.

I undertake, together with the research team, to respect what was agreed upon in the Informed Consent Form, and to give a signed and dated copy of this form to the research participant.]

Name and signature of the Principal Investigator Date

Centre intégré
universitaire de santé
et de services sociaux
de l'Ouest-de-
l'Île-de-Montréal
Québec

Title of the research project:	*IMPACT: Appuyer la mise en œuvre d'innovations organisationnelles en soins de santé de première ligne pour améliorer l'accès aux services de santé pour les groupes vulnérables.*
Principal investigator:	Dr. Jeannie Haggerty
Member(s) of research staff:	Victoria Wicks

St. Mary's Research Centre
Connect

Patient needs for Navigating the Health Services
Lighting the way to care

1. Introduction

Nous vous invitons à participer à un projet de recherche. Toutefois, avant d'accepter de participer à ce projet, veuillez prendre le temps de lire, de comprendre et d'examiner attentivement les informations suivantes.

Ce formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes vos questions au chercheur responsable de ce projet ou à un membre de son personnel de recherche et à leur demander d'expliquer tout ce qui n'est pas clair.

2. Objectif de l'Étude

L'objectif de cette étude est d'explorer les expériences vécues par les patients lorsqu'ils obtiennent des services de suivi de santé recommandés par leur prestataire de soins primaires, ainsi que les conséquences fonctionnelles, émotionnelles et sociales associées à ces expériences et la façon dont les patients les abordent. Les résultats seront utilisés pour mieux comprendre les besoins des patients et informer un service d'orientation des patients qui les aide à surmonter les obstacles à l'accès aux services de santé.

Pour la réalisation de ce projet de recherche, nous prévoyons de recruter 20-25 participants et d'interviewer 10-15 de ces participants éligibles. Les participants doivent être âgés d'au moins 18 ans.

3. Déroulement du projet de recherche

3.1 Lieu du projet de recherche, durée et nombre de visites

Ce projet de recherche se déroulera au GMF-U St. Mary's Hospital (SMH).

3.2 Nature de votre participation

Si vous acceptez d'être contacté, un assistant de recherche va fair un court entrvue avec vous, dans les 3 à 5 jours ouvrables suivants. Une fois que l'assistant de recherche vous aura contacté, vous aura donné quelques informations supplémentaires, vous aurez la possibilité d'accepter ou de refuser l'entrevue. Si vous donnez votre consentement à participer, votre participation à cette étude consistera en un court entrevue et quelques questions simples sur vos données démographiques (c'est-à-dire votre âge, votre niveau d'éducation, votre état de santé général et votre capacité à trouver des informations sur la santé par vous-même). Cet entrevue nous permettra de mieux comprendre votre capacité à obtenir les services de santé recommandés par votre médecin et de savoir si vous pourriez bénéficier d'une aide à la navigation. L'entrevue se déroulera avec le chercheur et durera environ 30 à 45 minutes.

4. Désavantages associés au projet de recherche

Il n'y a pas d'inconvénients connus associés à votre participation à cette étude. Certaines questions peuvent vous rendre mal à l'aise, vous avez toujours le droit de refuser de répondre. Les informations fournies n'auront pas d'impact négatif sur les services que vous recevez de la clinique médicale.

5. Risques associés au projet de recherche

Il n'y a auque risque ou d'inconfort connu associé à votre participation à cette étude. Les informations fournies n'auront aucun impact négatif sur les services que vous recevez de la clinique médicale.

En raison de la nature potentiellement identifiante de l'entretien en ligne, il existe un risque de ré-identification et de violation de la confidentialité. Toutefois, des mesures sont en place pour minimiser ces risques.

6. Avantages associés au projet de recherche

Vous ne recevrez aucune compensation pour votre participation à cette étude. Cependant, les résultats de l'étude peuvent contribuer à améliorer les soins de santé pour d'autres patients.

7. Participation volontaire et possibilité de retrait

Votre participation à cette étude de recherche est volontaire. Vous pouvez donc refuser d'y participer. Vous pouvez également vous retirer à tout moment, sans donner de raisons, en informant le médecin responsable de cette étude de recherche ou un membre de l'équipe de recherche.

Votre décision de ne pas participer à l'étude, ou de vous en retirer, n'aura aucun impact sur la qualité des soins et des services auxquels vous avez droit par ailleurs, ni sur vos relations avec les équipes qui les dispensent.

Le chercheur en charge de cette étude, le comité d'éthique de la recherche, l'agence de financement ou le sponsor peuvent mettre fin à votre participation sans votre consentement. Cela peut se produire si de nouvelles découvertes ou informations indiquent que la participation à cette étude de recherche n'est plus dans votre intérêt, si vous ne suivez pas les instructions de l'étude ou s'il existe des raisons administratives de mettre fin à l'étude.

Vous avez le droit de moduler votre retrait de l'étude à tout moment. Si vous vous retirez ou êtes retiré de l'étude, aucune autre donnée ne sera collectée. Les informations et, les enregistrements audio, les images et l'IRM déjà collectés pour l'étude seront détruits par l'équipe de recherche afin de garantir votre retrait.

Enfin, toute nouvelle découverte acquise au cours de l'étude qui pourrait influencer votre décision de poursuivre votre participation vous sera communiquée rapidement.

8. Confidentialité

Pendant votre participation à cette étude, le chercheur responsable de l'étude et l'équipe de recherche recueilleront, dans un dossier d'étude, les informations vous concernant nécessaires pour atteindre les objectifs scientifiques de l'étude.

Toutes les données recueillies au cours de cette étude de recherche (y compris les informations personnelles) resteront confidentielles dans les limites prévues par la loi. Vous ne serez identifié que par un numéro de code. La clé du code reliant votre nom à votre dossier d'étude sera conservée par le chercheur en charge de cette étude. Aucune information d'identification ne sera saisie, ni analysée. Toutes les informations électroniques seront conservées sur les ordinateurs de l'équipe de recherche, protégés par un mot de passe.

Les données de l'étude seront conservées pendant au moins 7 ans après la fin de l'étude par le chercheur responsable de cette étude, après quoi elles seront détruites.

9. Compensation

Vous ne recevrez aucune compensation financière pour votre participation à cette étude de recherche.

10. Si vous subissez un préjudice

Si vous subissez un préjudice ou une gêne au cours de cette étude, vous recevrez tous les soins et services requis par votre état de santé. En acceptant de participer à cette étude, vous ne renoncez à aucun de vos droits et ne déchargez pas le médecin participant à l'étude ou l'institution de leurs responsabilités civiles et professionnelles.

11. Informations de contact

Si vous avez des questions ou si vous avez un problème que vous pensez être lié à votre participation à cette étude de recherche, ou si vous souhaitez vous retirer, vous pouvez communiquer avec le chercheur responsable de cette étude de recherche ou avec un membre de l'équipe de recherche au numéro suivant : 647-235-1015.

12. Plaintes

Pour toute question concernant vos droits en tant que participant à cette étude, ou si vous avez des commentaires ou souhaitez déposer une plainte, vous pouvez communiquer avec :

Commissaire aux plaintes et aux services de qualité CIUSSS de l'Ouest-de-l'Île-de-Montréal au 1-844-630-5125 ou par courriel à commissariat.plaintes.comtl@ssss.gouv.qc.ca .

13. Déclaration d'intérêts

Le chercheur principal déclare qu'il n'a aucun intérêt personnel qui pourrait entrer en conflit avec son rôle de chercheur.

14. Suivi des aspects éthiques du projet de recherche

Le Comité d'éthique de la recherche du CIUSSS de l'Ouest-de-l'île-de-Montréal a donné son approbation éthique à cette recherche et est responsable du suivi de l'étude dans tous les établissements participants du réseau de la santé et des services sociaux du Québec.

Consentements spécifiques facultatifs :

Enregistrement audio

Acceptez-vous d'être enregistré lors des entretiens? Les enregistrements (cassettes ou fichier numérique) seront incluses dans votre dossier de recherche et seront conservées pendant une durée maximale de 7 ans après la fin de l'étude par le chercheur responsable de ce projet de recherche. Le contenu de la ou des bandes peut être publié ou discuté scientifiquement, mais il ne sera pas possible de vous identifier.

☐ Oui ☐ Non

Enregistrement vidéo

Acceptez-vous d'être filmé (ce qui comprend l'enregistrement audio) pendant les entretiens? Les enregistrements (cassettes ou fichier numérique) seront incluses dans les dossiers de recherche et seront conservées pendant une période maximale de 7 ans après la fin de l'étude par le chercheur responsable de ce projet de recherche. Le contenu de la ou des bandes peut être publié ou discuté scientifiquement, mais il ne sera pas possible de vous identifier.

☐ Oui ☐ Non

Déclaration de consentement

Titre du projet de recherche: *IMPACT: Appuyer la mise en œuvre d'innovations organisationnelles en soins de santé de première ligne pour améliorer l'accès aux services de santé pour les groupes vulnérables.*

Signature du participant

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m’a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées.

Nom du participant Signature Date

ET

*Signature de la personne qui **obtient** le consentement*

J’ai expliqué au participant le projet de recherche et le présent formulaire d’information et de consentement et j’ai répondu aux questions qu’il m’a posées.

Nom de la personne qui obtient le consentement Signature Date

ET

Engagement** du chercheur **responsable

Je certifie qu’on a expliqué au participant le présent formulaire d’information et de consentement et que l’on a répondu aux questions qu'il avait.
Je m’engage, avec l’équipe de recherche, à respecter ce qui a été convenu au formulaire d’information et de consentement et à en remettre une copie signée et datée au participant.]

Nom du chercheur responsable Signature Date

Appendix III: Assessment of Experienced Needs Interview Guide

INTERVIEW STARTS

VERBAL INFORMED CONSENT AND CONSENT TO RECORD

Before we start, I must record this information to meet legal requirements for obtaining your informed consent to participate. **Is it okay that I record this interview?**

RECORDING STARTS

Have you had a chance to read through the papers that I gave you at the clinic which explain the study?

Do you have any questions about any of the information on the papers?

Have you been given enough information to decide about whether to participate or not?

- If no, explore any questions and clarify
- If yes, ask:

Do you consent freely and voluntarily to participate in this interview?

Socio-demographic information on patient. Fill in the personal survey questions,
Before we start, I have a few questions about you that will set the context for some of the other questions I will ask.

Survey - Demographic questions

Who is your doctor at St. Mary's Family Medicine Center? _________________

How many years have you been a patient of this doctor?

- Less than 6 months
- 6 months to 1 year
- 1 to 5 years
- 5 years or more

What is your year of birth: ___________

Were you born in Canada?

☐ Yes
☐ No

If no, in what year did you first come to Canada to live? _____________________

Do you identify as an indigenous person?

☐ No
☐ Yes, and If yes:
   ☐ Indigenous First Nation Status
   ☐ Indigenous First Nation Non-Status
   ☐ Indigenous Metis

☐ Indigenous Inuit
☐ Self-Identifying Indigenous

Compared to other people your age, in general, would you say your health is:

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

In general, how easy is it for you to get health information by yourself? Would you say:

☐ Very easy
☐ Moderately easy
☐ Not very easy
☐ Not easy at all

How would you describe your gender?
○ Man ○ Woman ○ Non-Binary ○ Transgender ○ Two-spirited ○ Prefer not to say ○ Specify ____________

INTERVIEW: Understanding patients current navigational flow and support needs

Introduction:

Now, I would like to talk to you about your experience in the healthcare system. But firstly, I must make it clear that giving your honest answers to my questions won't affect your care any way, and details of any medical information you share stays between us. This also applies if you decide not to talk to me. None of the information you share with me will be shared back to your Doctor.

I want you to help me understand your healthcare story. You doctor recommended we speak to you because they believe you have experienced difficulties with getting follow-up care. We know that the healthcare system is complex and can be tricky to understand and we are looking into solutions that may help patients use the healthcare system but to do that, we need to know what **challenges you face that might get in the way of obtaining care, what works or what doesn't work for you and how it impacts your healthcare.**

Imagine that we are shooting a documentary and want to capture what your story of getting needed healthcare looks like. We don't have a long list of questions, and there are no right or wrong answers, we just want to better understand your story

Circumstance
Asked above in socio-demographic questions

Decision to seek recommended follow-up care

1. Let's start with the term navigation, what does "navigating the healthcare system" mean to you?
    a. do you remember any situations where you have had to "navigate the healthcare system" to get follow-up care by your doctor (ex: tests, exam, referral…)
        i. can you tell me about when your doctor recommended this?
            1. *time? virtual? in person?*
            2. this might be a bad question, but can you tell me a bit about why your doctor recommended it? what was happening with your health at the time… work? family?

Circumstance creates context

2. So, your doctor recommended that you get X… because of Y… Can you tell me more about the time when you decided to try and get the care your doctor recommended – *Details*
    i. Let's think back, tell me about what the day look like? (time of day, location, alone?)
    ii. Tell me about the steps did you take? What exactly did it look like (go in depth here, step-by-step)
    iii. what options did you consider at first? and after?
    iv. Successful/unsuccessful?

Pushes and Pulls

3. Tell me any problems/challenges you encountered when trying to get the (follow up care)? *PUSHES*
    a. Tell me about what made it difficult?
    b. What happened? What did you do to try and resolve it? Where you able to obtain the follow-up care?
    c. What were you feeling while dealing with this problem?

4. What kinds of supports do you seek when you experience challenges related to your healthcare?
    a. Tell me about what kinds of resources or information are you using?
    b. Tell me about who usually helps you (if anyone) and what is your relationship to them?

5. If you could imagine an ideal experience of seeking and receiving follow-up care, what would it look like?

6. Finally, what does it mean to you to "be a good patient"
    a. why is it important for you to get this follow up care?

7. Did you realize anything new while you were talking to me? anything interesting that you're taking away from this? or questions for me?

To finish up, I have a few more specific questions which may make you uncomfortable, you always have the right to refuse to answer.

What is the highest level of education you have completed?

- o Completed a graduate or professional degree (Master, MD, DDS, DMD, DVM, OD, PhD)
- o Completed a bachelor’s degree (e.g. B.A., B.Sc.,B.S.N.)
- o Had some university education or completed a community college, technical college, or postsecondary program (e.g. trade, technical or vocational school, CEGEP)
- o Completed secondary school or high school
- o Did not complete secondary school or high school

I**f you needed it, how many persons, family or friends do you have who could help you with activities of daily living (e.g. dressing, driving)?** *Would you say:*

☐ More than one
☐ One
☐ None

How many persons, family or friends do you have who you can confide in or talk to about your problems? *Would you say:*

☐ More than one
☐ One
☐ None

What phrase best describes your financial situation? *Would you say:*

- o Comfortable
- o Tight
- o Very tight
- o Poor

Thank you again for your time. If you have any concerns about this study, the number to contact is on the information sheet you were given at St. Mary's Family Medicine Centre. Finally, if you think a volunteer could help you, I can give you the number to call: 514 554-2566.

FIELD NOTE: ASSESSMENT

Interviewer initials:	
Date, time called	
Language	
Initials and First Name or Name used:	
Phone number	
Contact sheet number (PG#-PT#)	
Unique identity code	

(Contact_PT_RA)	
Agreement to record	**Yes** ○ **No** ○ **Withdrawn** ○
Informed consent obtained	**Yes** ○ **No** ○ **Withdrawn** ○

Doctor:

Appendix IV: Assessment of Anticipated Needs Verbal Informed Consent and Interview Guide

Interview Script and verbal informed consent

Good morning Mr. /Ms. _________. A couple of days ago at *Clinic Name* you gave us your permission to contact you for a short interview. Is this a good time to talk?

Introduce self: Name, St. Mary's Research Centre. We are doing a study to understand challenges patients face when they are getting health services or tests that their doctor has recommended.

Informed consent.

Before we start, I want give you a chance to accept or refuse to participate in this interview. I have to record this information to meet legal requirements for obtaining your informed consent to participate.
Is it OK to record? *If not, continue with consent but you need to take notes.*

Have you had a chance to review the pamphlet we gave you about the study?
If needed repeat study objective, above

This interview will be your whole participation in this study. It take about 15 minutes of your time. There are no known risks of participating, but if there are questions that make you uncomfortable – remember you always have the right to refuse to answer.

You will not receive a benefit for participating, but the results will help us make accessing healthcare better for other patients. But if you think you need help getting needed healthcare I will be happy to refer you to our patient navigator service.

If you have any concerns or complaints about the study or the way you are treated, the information of the person you can contact is on the sheet I gave you at the clinic.

This interview will be completely confidential. The recording will be stored in a secure platform. No one but the research staff will listen to the recording, and we will not use your name in any notes we take for analysis or in any results we share. You can request a report of our results from clinic staff within the next month or so.

Your decision to participate or not is entirely voluntary, and will not affect in any way the care that you receive at Clinique Indigo.

Have you been given enough information to make a decision about whether to participate or not?

If no, explore any questions and clarify
If yes, ask:

Do you consent freely and voluntarily to participate in this interview to explore your needs about finding your way in the health system?

If no, then thank the person and hang up. Make sure your hang up is recorded.

If yes, proceed with the interview guide.

Socio demographic information on patient. F*ill in the personal survey questions,*
Before we start, I have a few questions about you that will set the context for some of the other questions I will ask.

Main questions	**Secondary or follow up questions**
You told us that the doctor had recommended some more health services like getting tests, or referrals or accessing resources.	Can you tell me briefly what was recommended? Is this this first time you've been recommended this/these health service(s) <u>How clear is it you, what you need to do next?</u> Would it help you to actually look at the papers you were given?
If yes, understand completely, What makes it clear for you? Has there ever been a time when you were unclear of what you needed to do next for your follow up recommendation?	(Explore what makes it easy for them, what helped at the clinic). Probes o Done this before: tell me about the first time. o Someone helps o Always find it easy Can you think of anything that the doctor or clinic staff did or said that made it clear what you need to do? o How did it feel (look for specific expressions that provide a clue into the magnitude of the stress it represents to patients (lost, panicky, bothered, frustrated etc) o What did you do to solve the problem? o What happened?
Can you tell me specifically what is not clear?	(probe for specifics about what is not clear) • At what point did you realize that you did not understand. (As soon as you get home, one or two days after, just during this interview) • How does this make you feel? (explore specific emotionally-charged expressions, magnitude of the stress (irritated, confused, lost, panicky, bothered, frustrated angry etc) • What is your plan now about what to do next? o What are you doing to resolve that problem? o Next steps o What kind of resources or information are you using to find your way ? • What happens when you don't find your way or when it is hard?

	• Can you think of anything that your doctor or clinic staff could have done or did to clarify things for you?

Exploring perception of volunteer patient navigator service

Currently, we have a pilot project where volunteers reach out to patients by telephone to help patients find their way in the health system.
• Were there times that it will be helpful for you?
• If someone was to call you to help you follow through with what your doctor recommended, what could they help with?

Patients can be referred to the service by your doctor or even the clinic secretary. you can also call a number to leave a message so someone can reach out to you.
• What do you think about that? How would your doctor know that you need help?

Volunteers help patients get on electronic platforms to get services, can explain how specialist referrals work, and even help prepare visits to the doctor.

- How helpful would that be to you or to other patients?
- Could you think the type of things that you will need?

Patient characteristics of social vulnerability
Finally, just to finish I have a few more simple questions that I want to ask. The answers will help us get more information about the type of patients who will most benefit from the patient navigation services. The questions may seem quite personal! You always have the choice not to answer.

(fill the survey questions in the field notes.)

Thank you again for your time. If you have any concerns about this study, the number to contact is on the pamphlet you were given at the Clinic. The results of this study will be available at the Clinic upon completion of the study. Finally, if you think a volunteer could help you, I would be happy to give you the number to call: 514 554-2566.

Scénario d'entrevue et consentement éclairé verbal

Bonjour M. / Mme _________. Il y a quelques jours à la *Nom du Clinique* , vous nous avez donné la permission de vous contacter pour une courte entrevue. Est-ce que c'est un bon moment pour se parler?

Présentez-vous : Nom, Centre de recherche de St. Mary. Nous effectuons une étude pour comprendre les défis que rencontrent les patients lorsqu'ils ont besoin de services de santé demandés par leur médecin.

Consentement éclairé

Avant de débuter, j'aimerais vous offrir la chance d'accepter ou de refuser de participer à cette entrevue. Je dois enregistrer cette information pour répondre aux normes légales pour l'obtention du consentement éclairé de la participation. **Est-ce que c'est correct si j'enregistre?** *(Sinon, continuez, mais vous devez prendre des notes)*

Est-ce que vous avez eu la chance de lire le dépliant que nous vous avons remis à propos de notre étude?
(Si nécessaire, mentionnez brièvement l'objectif de l'étude, mentionné ci-dessus)

Cette entrevue sera votre unique participation à l'étude et prendra environ 15 minutes. Il n'y a aucun risque à participer, mais s'il y a des questions qui vous rendent inconfortable, rappelez-vous que vous avez le droit de refuser de répondre.

Vous ne recevrez aucune compensation pour votre participation, mais les résultats pourraient nous aider à rendre l'accès aux services de santé plus facile pour d'autres patients. Si vous croyez avoir besoin d'aide pour recevoir des soins de santé, il me ferait plaisir de vous référer à notre service de patients navigateurs.

Si vous avez des préoccupations ou des plaintes à formuler à propos de cette étude ou la façon dont vous avez été traité.e, l'information sur la personne à contacter se trouve sur la feuille que vous avez reçue à la clinique. (voici le numéro de téléphone 1-844-630-5125)

Cette entrevue est entièrement confidentielle et l'enregistrement sera sauvegardé sur une plateforme sécurisée. Les enregistrements seront écoutés seulement par le personnel de recherche et aucun nom ne sera utilisé dans les notes d'analyse ou dans les résultats partagés. Vous pourrez demander le rapport de nos résultats au personnel de la Clinique dans les prochains mois.

Votre participation est entièrement volontaire et n'affectera en rien les soins que vous recevez à la Clinique Indigo.

Avez-vous eu suffisamment d'information pour prendre la décision de participer ou non?
    Sinon, explorer toutes questions et clarifier
    Si oui, demander :

Est-ce que vous consentez librement et volontairement à participer à cette entrevue pour explorer vos besoins à vous repérer dans le système de santé?

Sinon, remercier la personne et terminer l'appel. Assurez-vous d'enregistrer lorsque vous raccrochez.
Si oui, continuer avec le guide d'entrevue.

Information sociodémographique du patient *(remplir les questions dans « personal survey »)*
Pour commencer, je vais vous poser quelques questions pour mettre en contexte la suite de l'entrevue.

Questions principales	**Questions secondaires ou suivis**
Vous avez mentionné que le médecin vous avait donné des suivis comme des tests, des références ou l'accès à des ressources.	Pourriez-vous me dire brièvement ce que vous a été recommandé? Est-ce que c'est la première fois que vous deviez faire cette recommandation? Est-ce que la prochaine étape à suivre est clair pour vous? Est-ce que ça vous aiderait d'avoir les documents remis sous les yeux?
Ques-qui la rend clair pour vous? *Continuez avec* - Est-ce que vous pourriez me parler d'un épisode ou vous ne saviez pas quoi faire?	*(Explorer ce qui facilite les gestes à poser, ce que la clinique a fait)* o déjà fait ça auparavant? Parlez-moi de la première fois. o Quelqu'un vous a aidé o Toujours été facile o Est-ce que vous pensez à quelque chose que le médecin ou le personnel de la Clinique a fait qui vous a aidé à comprendre ce que vous avez à faire? Comment vous sentiez-vous? (observer, pour vous donner une idée de l'ampleur du stress pour le patient (perdu.e, en panique, importuné.e, frustré.e, etc.) o Qu'avez-vous fait pour résoudre le problème o Que s'est-il passé?
Si le patient ne comprend pas parfaitement *ou* *une fois précédente ou le patient ne comprenait pas quoi faire (dire les questions au passé si requis)*	• Pourriez-vous me dire précisément ce que vous ne comprenez pas? *(explorer les aspects spécifiques de ce qui n'est pas clair)* • À quel moment avez-vous réalisé que vous n'aviez pas compris? (Aussitôt arrivé.e à la maison, dans le bureau du médecin, un ou deux jours plus tard, pendant l'entrevue…) • Comment vous sentez-vous à ce sujet? *(explorer les expressions spécifiques qui donnent une idée de ce que ça représente pour le patient (perdu.e, en panique, importuné.e, frustré.e, etc.)*

	• Qu'est-ce que vous prévoyez faire à partir de maintenant? o Qu'allez-vous faire pour résoudre le problème? o Prochaines étapes o Quel type de ressources ou d'information utiliserez-vous pour vous repérer? • Qu'est-ce qui se passe quand vous n'y arrivez pas ou c'est difficile? o Pensez-vous à quelque chose que le médecin ou le personnel auraient pu faire pour vous aider à comprendre?

Explorer la perception du service de patients navigateurs bénévoles

Présentement, nous faisons un projet pilote dans lequel les bénévoles appellent les patients par téléphone pour les aider à se repérer dans le système de santé.
o Est-ce qu'il y aurait eu des moments où ça aurait pu vous être utile?
o Si quelqu'un vous appelait pour vous aider à suivre les recommandations de votre médecin, comment pourrait-il vous aider ?

Les patients peuvent être référés au service par le médecin ou même la secrétaire médicale, ou vous pouvez également appeler un numéro pour que quelqu'un vous contacte.
• Qu'est-ce que vous en pensez? **Comment votre médecin pourrait-il savoir que vous avez besoin d'aide?**

Les bénévoles aident les patients à accéder aux plateformes électroniques pour obtenir des services, peuvent expliquer comment le système de référence des professionnels fonctionne et même les aider à préparer leur rendez-vous avec le médecin

- Est-ce que ce service pourrait vous être utile ou être utile à d'autres patients?
- Pouvez-vous penser à autre chose qui pourrait faire une différence?

Une dernière question – Si vous pouviez dire une chose à votre médecin sur le processus pour accéder aux services demandés, quelle serait-elle?

Caractéristiques des patients en lien avec la vulnérabilité sociale

Finalement, pour terminer, j'ai quelques questions à vous poser. Les réponses vont nous donnerde l'information sur le type de patients qui pourraient bénéficier le plus de notre service de bénévoles navigateurs. Les questions peuvent vous sembler plus personnelles. Vous avez toujours le choix de ne pas y répondre. *(Remplir le questionnaire dans le document « field notes »)*

Je vous remercie à nouveau pour votre temps. Si vous avez des préoccupations sur cette étude, le numéro à contacter est sur le dépliant qu'on vous a remis à la Clinique. Le résultat de cette étude sera disponible à la Clinique. Et finalement, si vous pensez qu'un bénévole pourrait vous aider, je peux vous donner le numéro à joindre : 514 554-2566.

Appendix V: Codebook

Assessment of Anticipated Needs Codebook

1.0 Challenges accessing referred services

1.1 Sofy
  Any reference to using the patient portal system, Sofy.
  *Indicated valence (positive/negative).

1.2 Referral system
  Any reference to making contact for referral (online or by telephone), indicated positively or negatively.

1.3 Wait times
  Any indication of wait times regarding referral or indication of experiencing delays when trying to book a referral.

1.4 Language
  Any reference to language impacting access to services or their care experience.
  *Indicate valence (positive/negative).

1.5 Challenge using technology
  Any referencing of experiencing technological challenges - not related to Sofy or online platforms.
  Ex: using a computer

1.6 Availability of information
  Any reference to the adequacy of information obtained regarding referral.
  Ex: Too much information or not enough information.

1.7 Online platforms (Navigating them)
  Participant indicates challenges navigating/using online platforms.
  Ex: Which platform to use

1.8 Poor Communication
  Participant makes reference to poor or miscommunication between self and practitioner

1.9 Not listened to
  Participant indicates that practitioner did not listen to them and their needs were not met
  Ex: HCP did not take the time to listen to what the patient had to say during encounter

1.10 Lack of Follow-up
  Any reference to inadequate follow-up with patients by practitioners
  Ex: patients not being followed up with frequently during pregnancy

1.11 Challenges commuting to appointments
  Any reference to challenges patients face getting to and from appointments
  Ex: living outside of Montreal and having to commute into the city

1.12 Fragmented Care
  Any reference to fragmented or incomplete care
  Ex: unable to find a family doctor for children

2.0 Relative ease of accessing referred services

2.1 Done it before
  Participant indicates they faced no challenges when accessing/following up on the referred services/actions.

2.2 Familiar with the healthcare system

Participants indicate they know/have experience with the healthcare system, making it easy to navigate.

2.3 Tangible/concrete action.

Participants indicate they were given a specific action to take.

Ex: a specific phone number to call.

2.4 HCP Explains Care + Takes Time

Participant indicates that their HCP spends time explaining care and ensuring they understand

2.5 Patient Advocates

Any reference patient makes to advocating for themself or taking lead action for their healthcare

2.6 Information Easy & Available

Participant indicates that information is easy and available to access

2.7 Personal Network

Participant makes reference to having a strong support network to help access/understand care

2.8 Not yet aware of potential challenges

Participant is not yet aware of any potential challenges they may face with accessing follow-up care

Ex: has not tried to obtain an appointment yet

2.9 Receptionist explains

Clinic receptionist explained or clarified patients questions regarding obtaining follow-up care

2.10 Doctor made appointment

Participants doctor made the appointment for them

3.0 Responsibility

3.1 Responsibility of Patient

Participants indicate that patients should have a greater role/responsibility in their care.

3.2 Responsibility of Physician

Participant indicates that physicians should have a greater role/responsibility in helping patients navigate/access their care.

3.3 Responsibility of clinic/healthcare system

Participants indicate that clinics/systems should have a greater role/responsibility in helping patients navigate/access their care.

4.0 Emotions

Participant makes a reference to emotion regarding their experience in accessing follow-up service/referral.

4.1 Frustrated

Patient expresses feelings of frustration

4.2 Discourage

Patient expresses feeling discouraged

4.3 Dismissal of feelings

Patient expresses feeling as though their feelings were dismissed

4.4 Unnerving
    Patient expresses feeling unnerved
4.5 Irritated
    Patient expresses feeling irritated
4.6 Lost
    Patient expresses feeling lost in the healthcare system
4.7 Powerless
    Patient expresses feelings of powerlessness
4.8 Ashamed
    Patient expresses feeling ashamed
4.9 Bothersome to doctor
    Patient expresses feeling like they are bothersome or burdening to their doctor
4.10 Stressed
    Patient indicates feelings of stress or stressful situations

<u>5.0 Consequences/ease of access</u>

5.1 Unintended misuse of healthcare services
    Participant reports they used a service that was deemed not appropriate for their need.
5.2 Non-compliance (4.3 Non-compliance)
    Participants reports that they did not comply with recommendations
    Ex: did not follow through with obtaining follow-up care

<u>6.0 Utility of volunteer patient navigator services</u>

6.1 Not useful - understand healthcare system
    Participant reports that VPN service would not be useful for them as they fully understand the healthcare system
6.2 Not useful - personal network
    Participant reports that VPN service would not be useful for them as they have a strong personal network that can support them
6.3 Helpful
    Patient makes any general reference to the VPN service being helpful for themselves or other patients
6.4 Useful - family physician
    Patient makes reference to the usefulness of the VPN service in helping patients obtain a family doctor
6.5 Useful - phone number to call if patient has questions
    Patient makes reference to the usefulness of the VPN service having a phone number for patients to call if they have questions
    Ex: useful if patients realize they have unanswered questions after they have left their appointment
6.6 Useful - language/translation
    Refers to patient suggestions concerning matching patients-physician in terms of language. Also includes any reference to the language challenges with Quebec more broadly.
6.7 Useful - limited network

  Refers to patients who have limited support networks and would benefit from peer support

6.8 Useful - Emotional support
  Patient makes reference to the usefulness of the VPN service in providing patients with emotional support

6.9 Useful - Prepare for appointment
  Patient makes reference to the usefulness of the VPN service in helping patients prepare for upcoming appointments
  Ex: reminders of what patients should bring with them or have prepared ahead of time

6.10 Useful - help with technology
  Patient makes reference to the usefulness of the VPN service in assisting patient with technology or online platforms
  Ex: booking appointments on Sofy

6.11 Useful - reminder about appointment
  Patient makes reference to the usefulness of VPN to remind patients that they have an upcoming appointment

6.12 Useful - book appointment
  Patient makes reference to the usefulness of VPN in assisting patients with booking online appointments

6.13 Useful - provide healthcare info
  Refers to the use of VPN services in providing lay healthcare information

6.14 Useful - Help find the location
  Refers to the use of VPN services in helping patients find the location of the clinic that they are receiving care at

6.15 Useful - Save time
  Any broad refers to the use of VPN services in saving time
  Ex: saving time for patients who have to work all day

Assessment of Experienced Needs Codebook

1.0 Getting help

Strategies mobilized by participant to obtain primary healthcare or the recommended healthcare by a primary care provider

1.1 Call clinic

Any reference to calling the clinic as a way of obtaining ongoing access to healthcare

1.2 Confirm information

Any reference to seeking clarity to confirm information

1.3 Direct contact with care team

Any reference to having direct contact with provider or care team, via email, phone or portal

1.4 Forgo care

Any reference to giving up, forgoing care

1.5 Go in-person

Any reference to going in person to get support or to speak with someone face to face

1.6 Going to emergency

Any reference to going to emergency when primary care appointments are not available

1.7 Private sector

Any reference to going into the private sector to obtain healthcare

1.8 Social support

Any reference to using social support network to obtain healthcare, support or information

2.0 Hurdles to getting care

Hurdles or challenges associated with obtaining primary care or recommended healthcare by a primary care provider

2.1 Barriers to getting care

Any reference to experienced barriers or challenges associated with obtaining primary care or recommended healthcare by a primary care provider

2.2 Availability of appointments

Reference to lack of availability for appointments

2.3 Cost of care

Reference to paying to get care or paying for something related to getting care

2.4 Perception by others

Reference to fearing how others might perceive the participant

2.5 Geographic barriers

Reference to challenges patients face, related to the geographic location of appointments

2.6 Instability with care team

Reference to lack of permanency with provider or care team members, rotating physicians seeing patients

2.7 Lack of human contact

Reference to not being able to speak to a human

2.8 Online portals

Reference to challenges using online portals or online platforms

2.9 Reaching the clinic

Any indication of inability to reach the clinic (by phone or email) or indication of experiencing delays due to challenges contacting clinic

2.10 Technology

Reference to limited access to technology to support obtaining appointments

2.11 Time sensitive

Reference to time sensitive needs, requiring service quicker than obtainable

2.12 Transferred to limbo

Reference to being transferred to other sources, departments, lines, or loss of transmitted information... when original contact is unreachable

2.13 Wait times

Reference to long waiting times for appointments

2.14 Working hours

Reference to challenges contacting health services during working hours

3.0 Link with care team

Link between the patient and the care team

3.1 Good patient

Any reference to patient perception of what makes a good patient

3.2 Collaborate with doctor

Any reference to collaborating with doctor, trusting them and following their recommendations for healthcare

3.3 Informed patient

Any reference to being an informed patient, talking to provider and asking questions for clarity

3.4 Knowing when to seek care

Any reference to knowing the appropriate times and ways to seek healthcare from doctor

3.5 Respecting wait times

Any reference to understanding and respecting wait times and delays

3.6 Type of visit

Any reference to understanding what visit type is appropriate for the health needs

3.7 Partnership with provider

Any reference to the relationship between the patient and the primary care provider

3.8 Connection with care team

Any reference to the connection between patient and care team (care team includes providers, nurses, healthcare professionals and clinic staff)

3.9 Communication with care team

Any reference to communication with the care team or level of comfort with communication based on relationship

3.10 Listening to provider

Any reference to respecting providers education and knowledge and listening to their recommendations

3.11 Power of interactions

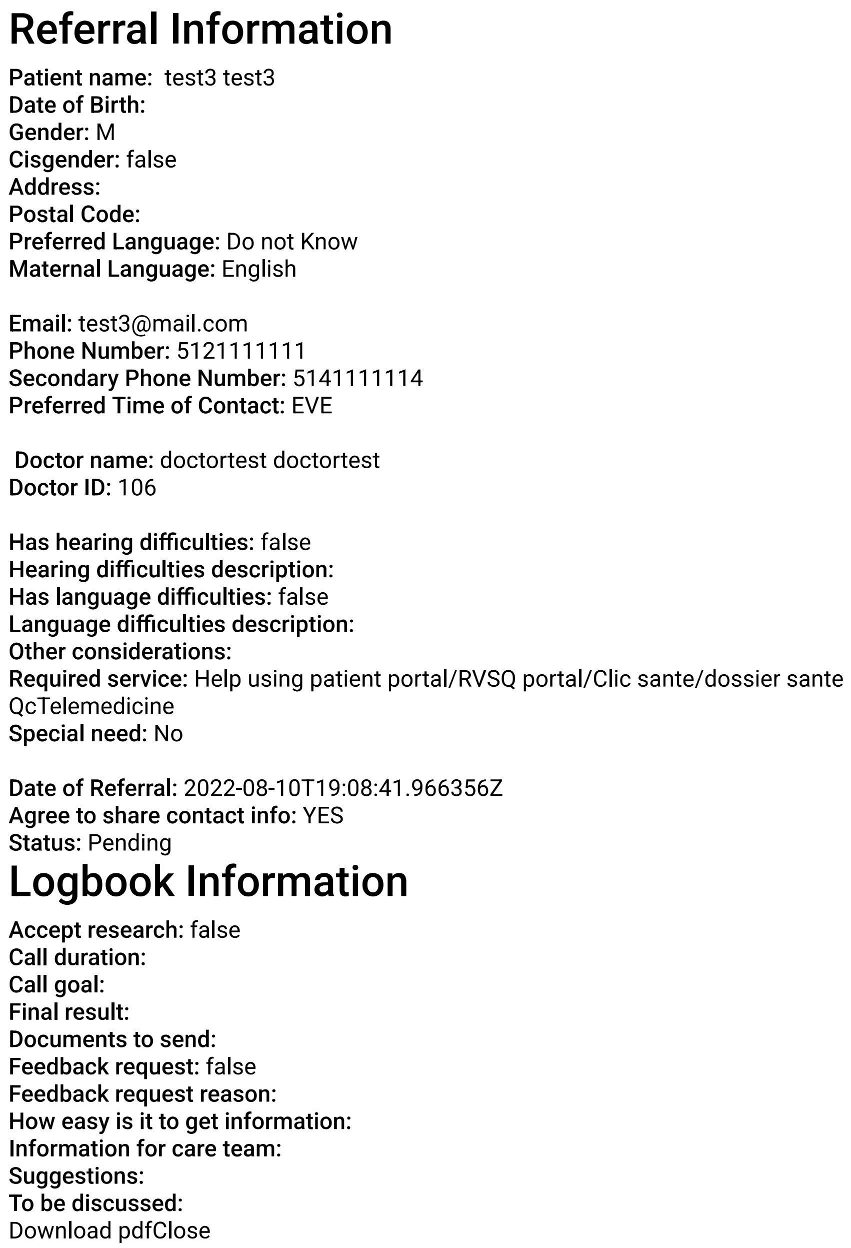
Any reference to continuous interactions between patient and care team, including clinic staff, nurses, and providers

4.0 Emotions

Emotions felt by participant related to obtaining healthcare

4.1 Frustrated
    Patient expresses feelings of frustration
4.2 Discourage
    Patient expresses feeling discouraged
4.3 Angry
    Patient expresses feeling angry
4.4 Anxious
    Patient expresses feeling anxious
4.5 Fear
    Patient expresses feeling fearful
4.6 Helpless
    Patient expresses feeling helpless
4.7 Control
    Patient expresses feeling in control of healthcare, and obtaining care
4.8 Panic
    Patient expresses feeling panicked
4.9 Uncertain
    Patient expresses feelings of uncertainty or confusion
4.10. Trust
    Patient expresses having trust in their provider and/or care team

Appendix VI: Connect platform referral



Referral Information

Patient name: test3 test3
Date of Birth:
Gender: M
Cisgender: false
Address:
Postal Code:
Preferred Language: Do not Know
Maternal Language: English

Email: test3@mail.com
Phone Number: 5121111111
Secondary Phone Number: 5141111114
Preferred Time of Contact: EVE

Doctor name: doctortest doctortest
Doctor ID: 106

Has hearing difficulties: false
Hearing difficulties description:
Has language difficulties: false
Language difficulties description:
Other considerations:
Required service: Help using patient portal/RVSQ portal/Clic sante/dossier sante QcTelemedicine
Special need: No

Date of Referral: 2022-08-10T19:08:41.966356Z
Agree to share contact info: YES
Status: Pending

Logbook Information

Accept research: false
Call duration:
Call goal:
Final result:
Documents to send:
Feedback request: false
Feedback request reason:
How easy is it to get information:
Information for care team:
Suggestions:
To be discussed: