Community Knowledge Mobilization and the Community Readiness Model Tool: A case study of diabetes in selected First Nations Communities in Canada

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Abstract

Background Chronic disease, such as type 2 diabetes, is a large concern for public health within developed nations, especially in First Nations communities, where rates are much higher than in non-Aboriginal populations. Successful interventions are always well tailored to their context, and participatory rural appraisal methods aid in this process of adaptation. Community readiness assessment is one example of how knowledge about the community landscape and context is created and mobilized for action. Despite the accessibility of this knowledge, there has been a large hurdle in implementing successful and sustainable programs and activities at the community level. Knowledge mobilization and knowledge translation strategies have the potential to increase mobilization within communities for prevention activities.

Objective To better understand the role of a research-developed tool for knowledge mobilization processes in First Nations communities. Of special interest is how the adapted Community Readiness Model (CRM) tool creates knowledge that can then be translated to action from the perspective of lay First Nations community members.

Methods Qualitative descriptive study based of focus group discussion.

Participants Community members from 6 First Nations communities recruited within Wave 1 of the FORGE-AHEAD research program.

Results Participants discussed the usefulness of the CRM tool around the following themes: key informants, community context, leadership, structure and organization of the tool, and mobilization using the Knowledge to Action (KTA) framework.

Conclusion Interpreting mobilization through the lens of the KTA cycle as a programming model highlighted the value of the CRM tool to the community, through providing knowledge about the community context, and acting as a catalyst for forward momentum down their mobilization

paths. With a few adaptations to better suit a First Nations community context, CRM tool would make an excellent contribution to the Participatory Rural Appraisal toolkit.

Contexte Les maladies chroniques, comme le diabète de type 2, est une grande préoccupation pour la santé publique dans les pays développés, en particulier dans les communautés des Premières Nations au Canada, où les taux sont beaucoup plus élevés que dans les populations non-autochtones. Les interventions réussies sont toujours bien adaptées à leur contexte et l'utilisation des méthodes d'évaluation participatives rurales aident dans ce processus d'adaptation. L'évaluation du modèle de préparation de la communauté (Community Readiness) est un exemple de la façon dont les connaissances sur le paysage et le contexte communautaire est créé. Malgré l'accessibilité de ces connaissances, il existe un écart dans la mise en œuvre des programmes et des activités réussies et durables au niveau de la communauté. Les stratégies de mobilisation des connaissances et l'application de ces connaissances ont le potentiel d'accroître la mobilisation au niveau des communautés pour les activités de prévention.

Objectif Afin de mieux comprendre le rôle d'un outil de recherche pour les processus de mobilisation des connaissances dans les communautés des Premières Nations au Canada. Un intérêt particulier est de savoir comment l'outil du modèle 'Community Readiness' (CRM) crée des connaissances qui peuvent ensuite être traduite à l'action dans la perspective de membres de la communauté des Premières nations laïcs.

Méthodes Étude descriptive qualitative fondée dans la discussion de groupe.

Participants Membres des 6 communautés Premières Nations choisi d'être partie de la vague 1 du programme de recherche FORGE AHEAD.

Résultats Les participants ont discuté sur l'utilité de l'outil ‘préparatifs du communauté’ autour des thèmes suivants: informateurs clés, le contexte communautaire, la direction, la structure et l'organisation de l'outil, et de mobilisation à l'aide du cadre de la ‘connaissance à l’action’..

Conclusion L’interprétation de la mobilisation à travers la lentille du cycle ‘connaissance à l’action’ comme un modèle de programmation a souligné la valeur de l'outil CRM à la communauté, en fournissant des connaissances sur le contexte communautaire, et d'agir comme un catalyseur pour continuer en avant sur leurs chemins de mobilisation. Avec quelques adaptations afin de mieux répondre un contexte de communauté des Premières Nations, l’outil de CRM ferait une excellente contribution à la boîte à outils d'évaluation rurale participative.

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Preface

This thesis was written according to the guidelines set out by McGill University for the submission of a document at the Master's level. As the MSc. candidate, I was primarily responsible for conceptualizing, designing and carrying out the research described in this thesis. Based on the literature review that I conducted and composed, I developed the specific study objectives for the research project and subsequent manuscript. I collected, transcribed and analyzed the data, as well as wrote the manuscript and other thesis sections.

The research was done in collaboration with the Transformation of Indigenous Primary Healthcare Delivery (FORGE AHEAD) research program under the primary investigator, Dr. Stewart Harris at the Centre for Studies in Family Medicine, Western Center for Public Health and Family Medicine, University of Western Ontario. The overall scope of this research was determined by myself and Jon Salsberg, and extended some of the original objectives of the FORGE AHEAD research program. Though the team at FORGE AHEAD did provide guidance, feedback and access to the data, the design and methodology underlying this research was my own.

Introduction

Chronic disease represents a significant public health concern within developed nations, including Canada. Part of the burden is the many modifiable risk factors present for chronic disease. Fortunately, this provides many points of contact where prevention interventions can dramatically improve health outcome, especially for diseases like type 2 diabetes. Despite the wealth of prevention research, there has been a large hurdle in implementing successful and sustainable programs and activities at the community level. As a result, there has been a relatively recent trend of investigation in implementation science exploring the concept of knowledge mobilization.

Knowledge mobilization is the process by which information is produced and subsequently used to encourage and produce action on a subject[1]. As stated by the Ontario Neurotrauma Foundation: "Knowledge Mobilization is getting the right information to the right people in the right format at the right time, so as to influence decision-making"[1]. Knowledge mobilization is considered one way of bridging the current practice, and the ideal, evidence-based standards of care[2]. An entire field of study, called implementation science, has been dedicated to this subject, especially in addressing the significant time lag between research evidence and its eventual use in clinical practice[3]. Currently this gap is clearly visible in health systems, and affects the health outcomes of all involved[4].

Knowledge mobilization is a concept known by many other names, most commonly 'knowledge exchange', or 'knowledge transfer'; one study identifies 29 different terms used in over 9 countries[5]. Though it is a very broad concept, this study will discuss knowledge mobilization within

the framework of knowledge translation. In Canada, the large body of work studying implementation science and knowledge mobilization is most often referenced as knowledge translation (KT). Additionally, KT has been widely discussed in the context of healthcare and quality improvement[6].

The Canadian Institutes of Health Research define knowledge translation (KT) as a 'dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health"[7]. Knowledge is also recognized as taking the form of more than just traditional study-derived evidence, for example: evaluation research findings, personal experiences and resource availabilities.

Graham et al [3] conducted a systematic review of frameworks used to describe the process by which research evidence (knowledge) was translated to practice, and identified 31 planned action theories using 16 different terms. What these theories had in common was their similarity in identifying steps or phases of planned action models. Graham and his colleagues synthesized this information into a conceptual framework known as the Knowledge to Action cycle (KTA) (See Appendix A). This model reflects the cyclical fashion of knowledge mobilization, as opposed to a linear, funnel-like flow of information[7].

The principle of knowledge translation can also be applied to the research process as a whole. This approach, called integrated knowledge translation (IKT) involves the end-users of the produced knowledge at all pertinent stages of the research project, from developing research questions to dissemination of results[7]. When working with end-users who have limited research

experience, IKT is founded on a participatory research approach. This approach can be seen as a systematic investigation, with the collaboration of those affected by the issue being studied, with a purpose of education, taking action or effecting social change[8]. Instead of researchers bringing only outside information of limited relevance, evidence will be discovered through working with members and with data that originates within the community itself[9]. Although participatory research can require extensive commitment of time, funding and resources by both researchers and community, building partnerships and fostering communication has been shown to increase the sustainability of intervention outcomes, enhance recruitment and most importantly, ensure culturally relevant and context-specific interventions[10].

Participatory research places an emphasis on capacity building and empowerment through research[11]. When a community has control over the research process it helps encourage participation and ensures the outcomes and results are considered valid for the context[12]. The transfer of knowledge and skills involved in this approach are an important aspect, one that may contribute to enhancing mobilization within a community[13]. This is especially relevant when addressing First Nations communities as it redresses past bad experiences with research[14].

When generating knowledge, those with and without research experience often turn to ‘toolkits’, such as available through Rapid Rural Appraisal (RRA) or Participatory Rural Appraisal (PRA). Rapid rural appraisal is a way to conduct a comprehensive environmental scan in a timely manner, without ignoring important information only available from certain perspectives[15]. Briefly, it should provide a snapshot of the resources and mobilization available in a community in a short period of time, using whatever resources are available, and critically ignoring information

not directly relevant to the identified issue. It can be recognized broadly from its use of qualitative methods of inquiry, and the involvement of end-users and other stakeholders in the information gathering process[16]. Rapid rural appraisal follows three principles: information must be understood from the community's perspective, data collection should meet a minimum standard or rigor, but not be an exhaustive process, and proceed with all timeliness by conducting data analysis while in the field[17]. Most importantly, the data collection process, like in program evaluation, is seen as a research process of its own right, and not just an exercise one must accomplish to arrive at other information[16].

While Rapid Rural Appraisal is a comprehensive field, there is less emphasis placed on aspects of facilitation, self-critical awareness and sharing of information between local peoples, stakeholders and facilitators[18]. That focus was shifter in the development of Participatory Rural Appraisal, an umbrella term covering the variety of methods and approaches that enable communities to share their knowledge of life and conditions, enhance and analyze this knowledge and plan for future action[9]. Initially developed and employed by NGOs, PRA aims to sustain local actions and institutions, while empowering local people to make key decisions. Besides the principles it shares with rapid rural appraisal, PRA stresses the importance of mobilization around an issue; the first step in any PRA toolkit is to encourage participation within the community, and plan methods that keep them interested throughout the process[17].

One such item in the participatory rural appraisal toolkit is the assessment of 'community readiness'. Community readiness describes how prepared a community is to address certain issues, and provides essential information to match intervention planning with the level of mobilization

available[19]. The link between developing intervention and policies that are consistent and appropriate with a community's level of readiness, and the cost-effectiveness and success of these initiatives has been addressed, primarily in the work of Jumper-Thurman, Plested, Edwards and Oetting[20]. They stress the importance of recognizing 'readiness' as a key difference separating the successful implementation of policies in one community as compared to another. Tailoring approaches ensures that the intervention efforts affect long-lasting change within the community, and helps prevent the waste of resources associated with a failed project. Kelly et al [21] compare the theory behind community readiness to that behind social marketing, using the analogy of knowing one's audience to better market products to them.

The Community Readiness Model (CRM) is a tool developed out of the Tri-Ethnic Center at Colorado State University using the readiness framework[22]. It involves using quantitative or qualitative data to asses readiness, and create a comprehensive, community-driven picture of commitment and resources across pertinent domains[23]. This method identifies and builds on strengths, resources and relationships already present within the community, and builds capacity through using the skills and assets of individuals, and existing relationship networks[11].

Though the CRM requires minimal expertise to use, it is still relatively resource-intensive for use in a research program following multiple communities across Canada. The Transformation of Indigenous Primary Healthcare Delivery (FORGE AHEAD) program is one such enterprise that aims to develop culturally appropriate, relevant and community-driven interventions to improve diabetes management in participating First Nations communities[24]. One phase of the FORGE

AHEAD program undertakes Community Readiness Consultations within participating communities and their community health centers.

FORGE AHEAD uses a participatory approach for several reasons, amongst them is promoting sustainability of any initiatives, and redressing previous negative experiences with research. As such, efforts were made to include First Nations collaborators at the steering level of the project, and have local community members take charge of the data collection process. While First Nations collaborators involved at the national steering level of the project had previous academic and research experience, most of the localized community-based representatives did not. This lack of experience made using some research tools inappropriate. In order to maximize ease of use and utility, the FORGE AHEAD team adapted the CRM tool for use within their program. With expert help from the Tri-Ethnic Center and First Nations collaborators, the steering committee adapted the CRM tool for use by minimally trained community facilitators. These facilitators then implemented the tool within their communities, and returned their results to the FORGE AHEAD team to be scored. Once result reports were disseminated to the community teams, they embarked on a process of discussion and quality-improvement planning to improve the prevention and care for diabetes within their contexts.

It is common for communities to employ research-developed tools to generate the evidence needed for action and change[25]. These tools, however, are usually intended for use by trained researchers, not community members with little or no research experience. Furthermore, use of these tools may be occurring within contexts for which they were not originally designed[25]. The purpose of this study, therefore, is to understand the role a research-developed tool plays in

knowledge mobilization processes in First Nations communities. In particular, how does the adapted Community Readiness Model tool create knowledge that can then be translated into action from the perspective of First Nations community members without a background in research? Furthermore, how do community members value the knowledge produced? This will be accomplished through an examination of the first six First Nations communities using the CRM tool through the FORGE AHEAD program. The experiences of these communities will be analyzed, and later compared to those of an exemplar First Nations community, Sandy Lake, Ontario, which had previously undergone a significant mobilization process using other methods of participatory rural appraisal.

Literature Review

According to a 2011 census, just over 1.4 million people in Canada self-identify as Aboriginal, accounting for 4.3% of the total Canadian population. Though this population is aging, it remains younger than the rest of the Canadians population; the median age being 26, 13 years younger than the median for non-Aboriginal Canadians. Additionally, children under 14 years of age account for just under one third of the Aboriginal population, representing 7.0% of all children in Canada[26]. Approximately one half of Aboriginal people live in urban areas, 31% live on designated territory of reserves, and the other 20% live in rural non-reserve areas[27]. Of those who self-identify as Aboriginal, 61% identify as First Nations, the rest as Inuit or Métis[26].

First Nations people living on-reserve assume a larger chronic disease burden than their non-Aboriginal counterparts. Circulatory-related causes of mortality represent 36% of total deaths for First Nations, compared to the 23% of total deaths for non-First Nation Canadians. Respiratory mortality is also disproportional, with 10% and 6% of total deaths in First Nations and other Canadians, respectively[28]. This burden is relatively recent, and appeared quite rapidly: in the 1980s, age standardized mortality rates for First Nations compared to the rest of Canada were lower in both males and females for all circulatory disease, including ischemic heart disease and strokes. By the 2000s, First Nations rates surpassed those of other Canadians in all but the rate of female ischemic heart disease[29]. Between 1991, and 2002-2003, the percentages of First Nations adults reporting at least one long-term health issue went from 31% to 67.3%[30].

The prevalence of diabetes in First Nations people living on-reserve is considered the largest area of concern. In 2010, the Public Health Agency of Canada listed diabetes prevalence in on-reserve

First Nations adults as the highest in Canada, with an average of 17.2%; the next highest was listed as First Nations people living off-reserve with an average of 10.3%. When adjusted for age, the diabetes rates are 3.6 and 5.3 times higher for men and women respectively in First Nations men and woman than their non-Aboriginal Canadian counterparts[31]. These findings are consistent with elevated and largely disproportionate rates found in other Indigenous groups around the world, such as American Indians, Australian Aboriginals and the New Zealand Maori and Pacific Islanders, when compared to their non-Indigenous counterparts[32].

This high prevalence of disease imposes a large financial burden on the federal healthcare system that services First Nations communities. When admitted to hospital, these patients with diabetes tend to have more complications, tend to stay longer and use more of the hospital's resources compared with non-Aboriginal diabetes patients[31]. While financial costs are also incurred by individuals, some of the consequences of diabetes in a community cannot be expressed numerically. Limited mobility, and the need for individuals to often travel outside the community for treatment results in the loss of community Elders[33]. Having diabetes has also been linked to greater social isolation, not speaking First Nations languages or achieving a higher than high-school education level[34].

It is important to note that the incidence of type 1 diabetes is extremely rare in this population, even in children, and the vast majority of cases represented are type 2 diabetes[35]. The highest disproportion noticeable in Canada is between the James Bay Cree and their non-Aboriginal Canadian counterparts in Quebec at 19.1% and 5.1% respectively[36]. Another large difference is the age at which individuals develop the disease. In a study by Dyck et al [35] looking at the epi-

demiology of diabetes in First Nations people in Canada, they found that most new cases appeared in the 40-49 age group, as opposed to the >70 age group in the rest of Canada. Young and his colleagues found the same trend in age of onset, as well as the rising prevalence of gestational diabetes. In Ontario and Quebec, up to 13% of pregnancies are affected by gestational diabetes, and among Aboriginal women over the age of 35, just under half of pregnancies are associated with either pre-existing of gestational diabetes[31]. Gestational diabetes in the mother is also a significant risk factor for eventual once of type 2 diabetes in the child. Dean et al [37] even discovered the presence of type 2 diabetes in children aged 8 to 17 years in a northern Ojibwa-Cree community.

Along with the higher prevalence rate comes an especially poor prognosis and progression of the disease, and it quite often leads to serious complications, such as retinopathy, end-stage renal failure and cardiovascular disease[32]. In one First Nations community in Quebec, over 60% of patients had at least one serious complication[31], while a 2002-2003 study found that 89% of First Nations adults reported at least one adverse health complication due to their diabetes, and almost a quarter reported four or more[36]. A second study from 2008-2010 showed a continues high prevalence of problems with the kidney, circulation, lower limbs and infection for First Nations individuals living on-reserve with diabetes[36].

When compared to the general population, rates of end-stage renal failure among First Nations people with diabetes were over twice as large (24% and 56%)[32]. Even compared to other indigenous groups around the world, First Nations in Canada demonstrate the highest rates of retinopathy (34% to 40%), neuropathy (9.6% to 46.3%) and lower extremity amputations (36.1%).

These differences are thought to be attributable to: “an earlier age of diabetes onset, a greater severity of the disease, reduced access to health services due to geographical barriers, and an increased number of risk factors for other chronic diseases” by the Public Health Agency of Canada[36].

Since diabetes can only be treated, and not cured, through pharmacological means, most of the current diabetes interventions focus on prevention and healthy living strategies to try and reduce the severity and risk of complications of the disease. The Centers for Disease Control and Prevention define three different types of prevention: primary, secondary and tertiary[38]. Primary prevention targets the entire community environment in efforts to keep diabetes from occurring in the first place. Secondary prevention occurs once an individual already has diabetes, however using prompt and appropriate management, the impact of the disease can be lessened. Tertiary prevention is called for in the cases of individuals who have been living with fully developed diabetes, and includes attempts to prevent side effects and minimize consequences of the disease.

While individualized interventions have shown successful prevention for high risk individuals, they are costly, and do not take into account the social and environmental factors affecting an individual’s health[39]. Within First Nations communities, diabetes interventions become more sustainable when implemented by the community as a whole, in a community-based manner to address both individual and environmental factors. As such, an understanding the problem diabetes poses for First Nations communities also requires an exploration of the presence of increased risk factors present within the community as a whole.

Historically, there has been a large shift in physical activity levels and food consumption in First Nations communities[40]. The main risk factor for diabetes, obesity, has rates that vary by region and community, but they have been shown to reach anywhere from 47.7% [41] up to 64% [30] in First Nations children. An increased reliance on store-bought food decreased the need for high-energy activities such as hunting, and made access to foods high in fat and sugar easier to access than their healthier counterparts[31]. Other socioeconomic factors such as the exorbitant price of fresh produce in rural and remote communities, and the lack of infrastructure to support physical activities, contribute to the high levels of obesity and obesity-related diseases, such as type 2 diabetes[41].

While there is some evidence pointing to an increased genetic predisposition to obesity [42], results are inconclusive, and do not explain the large gaps in nutrition and exercise[40]. Smoking is also a large contributor to the risk of developing chronic disease; about 1/5 of youth in First Nations communities smoke tobacco in a manner inconsistent with traditional usage and the peak age for taking up this habit is only 16 years old[30]. Maternal health is another area where interventions could target to achieve high results. Between high levels of gestational diabetes, smoking while pregnant, and the protective effect of breastfeeding on childhood obesity, maternal health has also become a community health problem[30]. Given the nature of this diabetes epidemic, interventions and programming must take ecological action, targeting not only the health of the individual but also the surrounding impacting environments which includes the community[43]. In order for this kind of action to occur, community members must perceive diabetes as not something an individual must live with, but rather a collective problem that can be treated and prevented[44].

Despite the importance of diabetes chronic care and prevention, it is unsatisfactorily incomplete for many on-reserve First Nations patients[45]. Past literature has examined several barriers to both healthcare provision and prevention programming for diabetes. When addressing care provision, systemic and environmental factors are identified by Minore et al [13], Harris et al [45] and Rosecrans et al [46] as being barriers to effective care provision. High turnover of nurses, doctors and social program leaders causes interruptions in care provision and slows down the process significantly, causing fragmented care[45].

Issues pertaining to low socioeconomic status and rural communities are also identified. In the case of these barriers, current interventions are at fault for not properly addressing these concerns during development[46]. Harris continues to criticize current interventions for their sole focus on acute care, and lack of culturally relevant policies[45]. Shaw et, al. adds that interventions surrounding education, the confounding effects of co-morbidities and social support are also lacing, but that the presence of a strong sense of self-efficacy improved health outcomes, especially when combined with social support from family members and the community at large[47]. Bhattacharyya et al [48] grouped perceived barriers from a health care provider perspective into four main categories, ranked by importance: patient, provider, systematic and environmental factors. The highest ranking factors belonged to the 'patient' group: motivation to adopt healthy lifestyles, adherence to treatment, and motivation to seek preventative care. Systemic factors, like easy access to facilities, and funding availability ranked relatively low in comparison. The penchant for 'blaming the victim' found in many rural Aboriginal communities is problematized

in the discussion of this study, and the identification of high staff-turnover may contribute to this context.

When addressing prevention and other community-based intervention activities, barriers are mentioned, though not as often. Daniel et al [49] cited an apparent lack of interest on behalf of community members as often being another barrier to secondary prevention programs. Facilitators, however, are often cited or expanded upon. Two systematic reviews by Merzel and D'Afflitti [50] list reasons for intervention failure, including a lack of community participation. With lack of participation comes a low level of community penetration and intervention exposure across the community, demonstrating the difficulty of engaging populations enough to cause sustained behavioral change in the absence of community buy-in. Some of the causes for this lack of participation are a difference in goal and priorities between researchers and community members, insufficient timeline to properly engage and form partnerships with stakeholders, and not ensuring sustainability of interventions in the long-term. One thing the authors did note was the success of HIV prevention programs, mainly due to the formative research conducted to properly tailor programs to target populations and the emphasis on changing social norms.

Similarly, Ho et al [41] suggest that skill-based activities within the community increase levels of self-efficacy, and subsequently increase intentions to perform healthy behaviors. Referring to the Kahnawake Schools' Diabetes Prevention Project (KSDPP), Bisset et al [44] identified facilitators and techniques, such as culturally inviting and relevant education sessions, that led to their program's success. Mostly they attribute the high level of community ownership to the ability to engage and involve community members throughout Kahnawake. Levesque et al [51] add that

this approach, with an emphasis on environmental change, multi-sectorial collaboration and community partnerships, leads to the enhancement of the health on an entire population.

Research and intervention studies in diabetes have been in place for decades; many recent projects demonstrate awareness of the potential barriers and actively work to overcome them. Yet the prevalence rates of diabetes in most First Nations communities keep rising[52]. Dyck and his colleagues who ascertained that throughout their study period (1980-2005), the diabetes prevalence rate had increased by 10.8% in women, and by 11.1% in men, compared to 3.5% and 4.2% respectively for Canadians[35]. Though the literature has a great record of interventions currently in place, there are no clear answers as to why they have yet to achieve a significant difference in health outcomes. Participatory research methods are cited as increasing ownership and engagement of the community, leading to sustained outcomes. For example, Kahnawake has sophisticated and sustained prevention efforts in place [53] and also has not seen the rise in incidence and prevalence observed in other communities[54]; yet has had difficulty providing evidence that implies causation between these two facts.

Complicating the issue further is the host of other critical issues currently faced by First Nations peoples living on reserves that may take precedent and divert efforts away from chronic disease prevention. Suicide and injury rates are significantly higher in these communities, especially in youth, compared to the rest of Canada[55]. High rates of alcoholism, smoking, drug use, violence, depression and child abuse are also among the most pressing problems faced by those living on First Nations reserves[56]. These issues pose a serious and often more immediate concern

due to their potential for mortality, and use many of the medical and social resources available in these typically remote and isolated communities.

It is clear in the literature that that implementing programs and training personnel becomes inefficient and burdensome, especially in already overwhelmed community institutions, unless properly tailored to each individual community's abilities[57]. Merkel and D'Asslitti cite insufficient tailoring of interventions as one of the reasons behind community-based health promotion projects having only a limited impact[50]. Creating tailored and specific interventions that match with community priorities and resources ensures that the sustainability of projects that ensure long-lasting change within the community, and helps prevent the waste of resources associated with a failed project[19]. There is, however, a lack of research focusing on how to best use each community's current resources and capacity for mobilization in the context of chronic disease prevention and care. This community context can also be referred to as the community landscape.

Assessing Community Landscapes

How to best evaluate the community landscape and context is the first step in addressing this issue. One method is that of rural appraisal, originating out of the field of agriculture and rural development[58]. Dissatisfaction with the usual use of quantitative survey questionnaires to elucidate information led to the development of this conceptual framework[15]. These long surveys often took too long for effectual use in decision-making. What rapid rural appraisal offered researchers went beyond simply a quicker means of data collection and put an emphasis on

community participation and interdisciplinary input. This emphasis shifted the nature of information gathering from leaders and elites to the poor and under-serviced[59].

Rapid Rural Appraisal (RRA) utilizes an available 'toolkit' of qualitative methods that have been shown to work rigorously. Interviews are the first key component, and often form the basis for any secondary inquiries. These interviews can take many forms: semi-structured or structured, focus groups, or even the collection of oral case histories. Second is the use of visualization methods, including but not limited to creating rankings, matrices, maps and seasonal calendars. Indeed rural appraisal bears many similarities to the concept of ethnography from the field of anthropology; early iterations of rapid assessment methods include 'Rapid Assessment Procedures' from medical anthropology, and 'Rapid Ethnographic Assessment'[60].

Rapid rural appraisal has been shown to be useful in a biomedical context; however, it can result in the following bias limitations. Bias during data collection can occur when culturally inappropriate measures are being used, or the interviewer's subjectivity manipulates the data to more closely resemble their worldview[15]. When data collection is completed by health professionals, there is the potential for limiting the amount of community participation, and a loss of information on how the community conceptualizes and gathers information[15]. This disconnect between researcher and the context they studied led to the development of Participatory Rural Appraisal (PRA). Using a participatory research approach to the process of rural appraisal engages end-users and stakeholders in all aspects of the research process, addressing many of the above bias limitations, while also promoting engagement and ownership of the results.

Community based participatory research originated in health promotion research, especially for chronic disease prevention such as type 2 diabetes[12]. Israel et al [11] found this approach was critical in reconciling differing perspectives between, for example, the researchers and Aboriginal community members. They also found that having members be involved in all aspects of the intervention, from planning to execution or data collection, enhanced the results. According to them, increased community participation at the planning stages allows for the anticipation of problems, tailored and targeting interventions and increased community buy-in[12].

Another study, the Canadian First Nations Diabetes Clinical Management Evaluation Study (CIRCLE), used a community-based participatory research approach to elucidate current clinical guidelines in treating diabetes in First Nations communities[61]. Current projects using this participatory style of research include the afore-mentioned Kahnawake Schools' Diabetes Prevention Project (KSDPP) and the Sandy Lake Health and Diabetes Project[62]. KSDPP succeeded in their strategy of employing community knowledge and expertise while promoting community capacity, and currently has the support of the community in making diabetes and associated wellbeing an important issue to members[63].

Inspired by community based participatory research, participatory rural appraisal has been used in many health contexts with success. Chambers lists several projects including those examining disease problem ranking, planning health projects and women's reproductive health[18]. The First Nations Diabetes Prevention Project used many items from the participatory rural appraisal toolkit to asses community level resources and needs for diabetes prevention and management: semi-structured interview, observations, seasonal calendars and community mapping for exam-

ple[39]. The inspiration behind using participatory research was not only to achieve more relevant and accurate data, but also to encourage further engagement of the communities being studied with the research project. How exactly participatory rural appraisal achieves this goal, has not been studied.

One specific method borne of participatory rural appraisal is the assessment of 'community readiness', as used in the Community Readiness Model developed out of the Tri-Ethnic Center at Colorado State University. The tool is used to measure levels of community readiness in a multidimensional manner: the final tool utilizes nine stages of readiness (no awareness, denial/resistance, vague awareness, preplanning, preparation, initiation, stabilization, confirmation/expansion, community ownership) to rank six dimensions of knowledge: the community's knowledge of the problem, current efforts aimed at addressing the problem, the community's knowledge of current efforts, leadership taken in these efforts, community climate and resources that have been put towards the efforts[19]. The tool requires few resources as only a handful of respondents are necessary, and interview structure can be adapted to structured or semi-structured formats. Lastly, the tool can be applied within a community-based participatory research approach, with community members acting as interviewers with only minimal training and no loss of rigor[64].

There are many examples of how this tool has been used successfully in evaluating community readiness across a wide spectrum of field. York et al [65] used the CRM to evaluate the effectiveness of implementing various 'smoke-free' policies. The tool was used in West Virginia as a precursor to setting up various physical activity programs aimed at older adults suffering from

arthritis[66]. Ehlers et al [67] conducted a series of investigations in different school stakeholders before, and after the implementation of the 'Ready for Recess' program. Other fields of application in recent years include that of HIV/AIDS treatment [68], public housing initiatives [69] and obesity prevention[70].

Though community readiness has been assessed multiple times for various social and health related problems, it has been implemented with less frequency in Aboriginal communities, in both Canada and the United States. Of the incidences where it has been used with these populations it tends to be used for chronic disease treatment or prevention efforts. The most common use is surrounding HIV/AIDS prevention. Thurman et al [20], Nebelkopf et al [71], and the Canadian Aboriginal AIDS Network [72] all used the CRM tool to address HIV/AIDS in American Indians, and First Nations people in Canada. Other chronic diseases, such as cardiovascular disease in the Choctaw Nation of Oklahoma have also been addressed using the CRM tool[73]. The community readiness model has been used only once, however, in diabetes prevention research with Aboriginal communities in the United States or Canada, when Helitzer et al [74] tested stage-of-change measures for being indicative of attendance to diabetes intervention sessions. Though stage-of-change measures can asses some aspects of community readiness, it is by no means a complete survey[75].

Not examined in the literature is the level of ownership towards the data provided by the Community Readiness Model tool as felt by the communities using the information. As seen in participatory research approaches, ownership of the data leads to engagement with the research, and sustained program outcomes[76]. In this study, the outcome of interest is sustained community

mobilization around diabetes. Community mobilization is understood to be the process by which a community unites to gather resources for the development of sustainable change initiatives. Though it may be triggered by outside sources, mobilization is primarily seen as bring internal to the community, and hinges on the ability of members to take ownership over the decision-making process[77]. While the mobilization process has been examined among First Nations communities in Canada[44], it is still not very well understood. Though there has been some limited study on how mobilization processes unfold[78], there is a gap in knowing what language to use in conceptualizing and describing the mobilization trajectory.

There is a link between readiness assessment and community mobilization, yet it is not easily defined. Clearly awareness of a community's resources makes future leverage of these resources in support of interventions easier. Edwards et al [19] gives the example of how the community readiness tool was used to develop different media-based interventions for mobilization depending on their stage of readiness. In another study, the identification of a lack of community resources using the CRM tool was one of the crucial findings, prompting various efforts to increase available resources to those communities[79]. The primary contribution of the community readiness model seems to be the creation of knowledge that can be used by community members in preparing their own intervention strategies, based on these, and other findings[68]. What is less clear is what exactly this knowledge should encompass, and when and how this knowledge is used by community members.

Also not explained in the literature is exactly how this knowledge is transformed into action. Graham et al [5] propose a model for how research knowledge can be translated into practice,

called the Knowledge to Action (KTA) cycle (See Appendix A). The KTA cycle is comprised of two main components: knowledge creation and the action cycle. The knowledge component acts as a funnel to refine and synthesize information so as to provide the most useful results to individuals most likely to use them. Straus [80] divides available evidence into three different levels: first generation knowledge comes directly from primary studies, such as RCTs. Second generation knowledge is more synthesized, such as scoping and systematic reviews, while third generation knowledge comes from tools or products made following the principles of effective knowledge translation. These tools and products are easy to read, understand and use, and include clinical practice guidelines or decision aids[80].

The action component of the knowledge to action cycle covers the activities of implementation of application of knowledge. Organized into a cycle, it begins with the identification of the knowledge to action gap. This step is actually comprised of three sub-steps: identify the problem, identify/review/select knowledge and identify the know/do gap. Knowledge is then adapted to the local context, where feasibility and relevance is evaluated. Barriers to and facilitators for knowledge use are then sought out, after which interventions are selected, tailored and implemented. The last phases have to do with the evaluation and modification of interventions: monitoring knowledge use, evaluating outcomes, and sustaining knowledge use[5]. It is important to note that knowledge component can be applied separately to every piece of the action component, hence its appearance of a rotating triangle within the action cycle.

The role of the knowledge to action cycle can be better understood when contrasted with another theory, that of quality improvement. Quality improvement is ‘the effort to increase or improve

the degree to which health services increase the likelihood of desired health outcomes and are consistent with current professional knowledge"[81]. While both KTA and quality improvement have at their roots the desire to lessen the disparities between evidence and professional practice, quality improvement is more local and less generalizable than knowledge translation. Quality improvement is also increasingly linked with determining ways to improve patient safety and quality of care, as opposed to translating evidence to practice. Systematic reviews found that quality improvement initiatives took form through a wide array of activities, produced mixed and inconsistent findings and demonstrated limited effectiveness for long-term projects and change[81]. Knowledge translation on the other hand, aims to produce more generalizable results that are sustainable in the long-term through its constant cyclical reevaluation[5].

Mobilization is a very complex issue that is not very well understood, making it harder for communities to conceptualize their own mobilization trajectories. Interpreting mobilization through the lens of a model that provides structure and organization to this process could help in understanding and replicating mobilization in new settings. The Knowledge to Action cycle is essentially a programming model that provides users with a guide in creating knowledge, and then translating that knowledge into deliberate change in practice[5]. In mapping the Community Readiness Model tool onto the Knowledge component of this model, and mobilization processes onto the Action cycle, then the contributions of the CRM tool to mobilization can be elucidated.

Participatory rural appraisal methods or community readiness assessment tools are often developed with the sole purpose of providing information about a certain point in time, and are not intended as a catalyst for change within the community. Yet if these tools are to be of value to

more than just the researcher perspective of participatory rural appraisal projects, the community should be able to make use of the results in future mobilization stages. As seen above, the knowledge to action cycle is easily applied to myriad health issues. What has not been studied is the application of KTA to the actual process of mobilization: by investigating how knowledge created by the CRM tool is used for mobilization, the tool can be tailored, if necessary, for optimal use by community members.

The research questions addressed in this thesis are:

1) How does a community interpret the results of a research-developed tool to best fit their mobilization trajectory?

2) How do community members value the knowledge created from the adapted Community Readiness Model tool?

3) To what extent can this kind of tool be an appropriate part of a participatory rural appraisal process?

Methods

Design

This project will use a qualitative description research design. Qualitative description, according to Sandelowski, entails "a kind of interpretation that is low-inference" and "the presentation of the facts of the case in everyday language"[82]. As natural inquiry has defined itself as the "commitment to studying something in its natural state, or as it is, to the extent that this is possible in a research enterprise" [82], this framework is most appropriate for answering the above research questions. Data will be collected during the dissemination of results of the Community Readiness Model (CRM) tool to each respective community within the FORGE-AHEAD project. Thematic content analysis will be then undertaken to understand how communities interpret and restructure the results to fit their own personal mobilization trajectories.

As a student affiliated with the FORGE-AHEAD research program, access to these participating communities, their corresponding ethics review boards and the data obtained through the CRM tool has been granted. Since the CRM tool is the only validated method of establishing a readiness score that can be compared back to the readiness model framework, it is the ideal candidate for study as an essential component of participatory rural appraisal. In order to best examine the impact the use of the CRM tool has on mobilization across the full spectrum on readiness, the breakout sessions of all participating communities will be examined.

FORGE-AHEAD

This project took place within 'Wave 1' of the FORGE AHEAD research program. Each wave consists of three consecutive cycles of readiness evaluation and action planning. During the first

cycle, an adapted CRM tool was implemented within Community Teams of 4-6 individuals, led by a community facilitator. Members of the FORGE AHEAD research team then independently scored the surveys and prepared a report to return to each community. All members of the Community Team were invited to a 2-day workshop in London, Ontario to participate in a Quality Improvement Workshop and receive their results. Once communities received their results, they participated in a series of 4 breakout sessions, in which they were encourage to discuss their results, and to begin setting priorities and action plans for enacting change within their communities. FORGE AHEAD is using the tool as a means to support future quality improvement activities, whereas this thesis focuses on the creation and use of community-specific knowledge by members.

The CRM currently being used by the FORGE AHEAD research program was adapted with the help of experts from the Tri-Ethnic Center, University of Colorado. Instead of measuring six dimensions of knowledge, the underlying framework of readiness was altered to reflect two: knowledge readiness and action readiness. The nine stages of readiness in the original tool were compressed down to 5 and 6 respectively (see Appendix B). Readiness was still evaluated in a multidimensional fashion, however instead of using the interview format, a mixed-methods questionnaire was employed. The questionnaire was divided into two sections; the first asked the participant to reply from the perspective of the community as a whole, while the second asked the participant to use the perspective of the leadership in the community. For each question, participants had to choose their level of readiness following a set of statements corresponding to each item on the compressed readiness scale. They were then asked to provide any details or examples

pertaining to their response in a short-answer box below. For a sample page of the questionnaire, see Appendix C.

Once completed, a readiness report for each individual community could be prepared. The average score for each question was calculated across the community, then all scores within each section were averaged out across the community, for the final 'Overall Readiness Score'. Qualitative responses were summarized and anonymized, and presented next to their corresponding question scores. A list of who participants identified as community leaders was also provided.

The sampling method of the original CRM method was only altered slightly; instead of key respondents chosen to provide information on the community, participants were members of a 'Community Team'. These team members not only filled out the questionnaires, but received the reports and were asked to use them as the basis of their action planning.

Following the distribution of results, Community Teams participated in a series of five breakout sessions aimed at promoting discussion on the readiness report results, and prompting initial planning of interventions and activities. Two sessions were held on the first day, focusing on using the report to identify community priorities, and set goals for intervention planning. The second day featured sessions focused on establishing 'Plan, Study, Do, Act' (PDSA) cycles for future action to be implemented by the Community Teams. The PDSA cycles were the model chosen by FORGE AHEAD to frame action planning, and the discussion during these sessions

was prompted by the need to develop hypothetical scenarios that could be put in place once Community Teams returned to their communities.

Setting and Participants

There are 6 communities recruited into Wave 1 of the FORGE AHEAD research program. These communities are spread across Alberta, Manitoba, Quebec and Newfoundland, and represent First Nations from Algonquian, Iroquois and Athapaskan cultural-linguistic groups. While some of these communities are located in close proximity to large cities such as Calgary and Montreal, others are considered quite rural. All the communities have identified diabetes as problem within their community, and wished to join the project, and this was an inclusion criteria for recruitment. Conditions for recruitment into the FORGE AHEAD research program included the requirement that they identify diabetes as a priority issue within their communities.

Community Teams are composed of a single facilitator, chosen to liaise between the FORGE AHEAD team and the Community Advisory Boards, community and clinical teams within each participating community. Facilitators received training during an in-person workshop in London, Ontario in September 2015, and support via teleconference throughout the duration of the project. All Community Team members either work or reside in the community, and were chosen to represent different aspects of the healthcare groups present in their communities. Members include community health workers, nurses, dietitians, Elders, residents living with diabetes and social workers. Of the community teams, a total of 30 participants attended the Readiness workshop, and all provided consent to participate in this project. Of the participants, 24 were female,

accounting for 80%, and approximately 2/3 self-identified as being First Nations. All participants currently lived or worked on recognized reserve territory.

Data Collection

Each community participated in a series of five breakout session led by that community's facilitator, who had been given training in how to lead the discussion on the interpretation of these results. Guidance during these sessions was provided in the form of slide presentations displayed and controlled by the community facilitator, and the presence of a moderator. The moderator's role was to take notes on the sessions for future use by the FORGE AHEAD team, and to help community facilitators troubleshoot and solve and issues that arose. FORGE AHEAD steering committee staff would occasionally enter the room, either when summoned to answer a question, or to observe the sessions and ensure they remained on topic.

These sessions were audio-recorded and transcribed with identifying information removed from participants to ensure confidentiality. Dialogue associated with community facilitators, moderators or the FORGE AHEAD steering community were given identifying markers. Individual members of the Community Teams were not otherwise differentiated on the transcripts.

Data Analysis

The data analysis used thematic description and content analysis to interpret the data. The breakout session transcripts were coded and analyzed using thematic content analysis, as defined by Hsieh and Shannon: "a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or

patterns"[83]. Qualitative description relies on thematic coding and the use of constant comparative methods borrowed from grounded theory [84]. In this way, texts are read, creating codes and code hierarchies that are continuously revised as they are applied to new text. NVivo software was used to conduct the coding, and produce coding reports. A mixed-mode approach was employed: six deductive codes were supported by emergent inductive codes. All codes were in turn grouped into overarching thematic categories, describing the phenomenon under study, as described by Lofland [85]. These themes were then applied to the Knowledge to Action (KTA) framework, which was used to help interpret the data.

After preliminary data analysis was completed for each breakout session, coding reports were prepared with each code listed alongside a description of that code, the coding frequency and distribution of the code among breakout sessions. Text excerpts applicable to each code were included in this report. All potentially identifying information was removed from these coding reports before dissemination.

Participating community members were asked to provide feedback on these reports, and suggest other codes or ways of understanding the data. Breakout session moderators and FORGE AHEAD steering committee members were also asked to participate in this exercise. The aim of their contribution was to ensure coding reliability through 'virtual' double-coding. It would also have reduced coding bias, and ensure the analysis remained grounded in the cultural reality of each community, and that potentially harmful misinterpretation of the data did not occur. Limitations in time and resources resulted in the FORGE AHEAD and Community Team members and being unable to contribute directly in this double-coding process, and could only provide limited

input. Instead, issues of coding reliability and thematic interpretation were resolved with the aid of the thesis advisory committee.

Participatory Research

Due to the damaging historical relationship between First Nations people and researchers in Canada, the FORGE-AHEAD study employed the strategies of participatory research. First Nations representatives sit on the steering committee for each project stage of the FORGE-AHEAD project, and all material is passed through community-specific Community Advisory Boards (CABs) or the Health Council for approval.

A participatory approach was chosen for this study as well, partially again due to the involvement of First Nations communities, and partially for the other benefits provided by using such an approach. Stakeholders for this research were the FORGE AHEAD Steering Committee, and the participating Community Team members.

This study sought stakeholder input at various stages wherever was feasible and stakeholder time and resources allowed. The process of data collection was extensively discussed with the FORGE AHEAD Steering Committee, and both they and the Community Teams were invited to provide feedback on the preliminary findings and analysis of the data. A member of the FORGE AHEAD Steering Committee was also invited, and accepted, to sit on the thesis committee for this project. All possible efforts were made to avoid over-burdening research participants from both studies, and the findings of this study will be disseminated to the individual communities in a comprehensive manner.

Ethics

Ethics approval for this project was obtained from the McGill University Faculty of Medicine Institutional Review Board (IRB) (Appendix D) and the University of Western Ontario Ethics Board, as an addendum to the FORGE AHEAD research program (Appendix E). Information letters and consent forms (Appendix F) were distributed to all participants during the workshop, which covered the special considerations required when working with First Nations communities as stipulated by the Canadian Institutes of Health Research[86].

Results

Emergent Thematic Groups

The qualitative analysis carried out was aimed at discovering the use and value to the community of the knowledge created by the adapted Community Readiness Model tool. Information relating to the mobilization process was interpreted through use of the Knowledge to Action cycle framework. Forty-five codes were identified in total. Six deductive codes were established at the beginning of the coding process to provide a broad framework for the inductive analysis: 'Interpretation of Results', 'Local Knowledge', 'Mobilization', 'Restructuring of 'Results', 'Tool as Guide' and 'Understanding of Results'. The inductive approach used in data analysis yielded 39 others codes (See Table 1). Four thematic groups emerged from the codes used: Community Representation, Leadership, Community Context, and Structure/Organization of Tool. In order to analyze the information on mobilization and knowledge use, related codes were superimposed onto the Knowledge to Action cycle model.

Table 1: Codes by Thematic Group

Thematic Group	Codes	Description
Community Representation	Speaking for Group Personal Perspective Who is Using Tool Difficulty Completing Tool	Composition of the Community Teams, and how well they were able to represent the perspective of the community.
Leadership	Leadership Changing Opinions Personal Perspective Speaking for Group	Issues regarding the leadership aspect of the readiness assessment.

Community Context	Local Knowledge Accuracy Relating to Other Frameworks Relevance Tool Overlooked Something Timing Tool as Outsider Contextualized Results Disagreement with Tool Interpretation of Results	How well the CRM tool as adapted to fit a First Nations context.
Struc-ture/Organization of Tool	Understanding of Results Ease of Use Facilitator Understanding How Tool Works Tool Too Lengthy Community and Clinical Division Forward Momentum Local Knowledge	Issues relating to how well the underlying model and scale was understood and interpreted in the adapted CRM tool.
Knowledge to Action Cycle		
Identify Problem	Tool as Guide Tool as Springboard Tool as Vehicle Local Knowledge Contextualized Results Lack of Guidance Tool as Evidence Perceived Value Mobilization	
Determine the Know/Do Gap	Mobilization Lack of Guidance Limit Discussion Perceived Value Starting Points Restructuring of Results Tool as Guide Perceived Value Making it Fit Forward Momentum	
Identify, Review and Select Knowledge	Restructuring of Results Contextualized Results Lack of Guidance Unexpected Results Other Community Inspiration Tool as Evidence Starting Point If/Then Tool as Guide Limit Discussion Perceived Value Mobilization Forward Momentum Tool as Spring Board	

Adapt Knowledge to Local Context	Community and Clinical Division Forward Momentum Audience Community Context Using Local Resources Mobilization Ownership Contextualized Results
Asses Barri-ers/Facilitators to Knowledge Use	Barrier or Facilitator Community Context Bringing on Board

Community Representation

Community facilitators were encouraged to select participants for the readiness assessment based on whom they felt would best contribute to the activities of the Community Team. Instructions for selection were purposely left vague to avoid influencing the community facilitators' choices. Upon discussion of the results, however, this strategy was perceived by the facilitators as problematic. When considering the issue of appropriate community representation, the facilitators debated whether the correct people were chosen to represent the community, and how well were they able to do so. For example, Community Teams immediately identified an under-representation of men and Elders. As was stated:

> I think men are a little more reluctant to have that discussion with illness prevention… as opposed to women. Hence we're all women sitting here!
> We don't have men! I always think that... they're not represented very well in communities. {Community member}

Having an Elder's voice present in the room was especially missed as an individual affected by future mobilization efforts, as well as for feedback on the accuracy of the report in assessing the community landscape.

The over-representation of members who came from a health promotion or medical background was also recognized. For example:

> [I am] kind of putting my own input as a registered nurse, so I just kind of think [the results] might have been skewed a little bit. {Community Member}

While it was useful from an intervention planning perspective to have so many participants from a health care background, it posed a problem for the accurate assessment of community knowledge on different aspects of diabetes.

> But you know if you look at it, if you look at who you're talking to in health care… the people we surround ourselves with is kind of who we're basing it. {Community Member}

The impact of this over-representation was generally viewed as raising the scores somewhat above what would be accurate for the community's level of knowledge; however after discussing the matter further, the community generally agreed that the majority of scores should be left un-changed.

The lack of variation on the Community Team was not perceived as a problem when it came to the ability of the community team to communicate with their fellow community members.

> And we gotta remember too, you identified best with the youth, and they identify with you right? And so you'd have the schools, and you… could do Elders, because you identify with them, and then also with your clients, in your program too. So like there's different populations we could be reaching just here in this room.
>
> Yes, we could reach pretty much every demographic in our community. {Community Members}

There was a recognized division between Aboriginal community members and non-Aboriginals who worked within the community.

> I think sometimes our people are the ones that can reach people, you know? {Community Member}

And,

> Being white in that community, some people don't want to talk to me because I'm a white guy. {Community Member}

Community members furthermore experienced difficulty when asked to speak on behalf of others in the community, as opposed to giving only their own opinion. Previous personal experiences with health care provision was one facet of this issue.

> We're trying to come in from the cultural [perspective.]
>
> But you can't, you know? Like it's part of who you are, it's still part of your lived history, so you still have that affecting perhaps your perception. So yeah, what you have to say is valuable, but you know on my part…cause I really tried to answer it like I'm not a health care person, not looking at the health care person, and it was really hard. {Community Member}

Participants from different sectors naturally responded differently. For example, based on their professional experiences and access to community health data, participants from the health services sector identified and ranked priorities differently than other community members.

> One of the things we identified was the even though the community may feel that diabetes is [health] priority number 5 or number 6, we know as a health agency that diabetes is number 1, because we deal with these individuals, our data supports that individuals are coming in for this. {Community Member}

Overall the Community Teams tended to be composed of mainly women, with a background in healthcare provision. Despite the underrepresentation of men and Elders, the Community Teams maintained that they were able to reach out to all members of the community. There was an acknowledgement that having experience in health care provision may have skewed the community scores higher, yet after discussing the results, the Community Team felt the scores were relatively accurate.

Leadership

Arguably the largest hurdle to answering the adapted Community Readiness Model tool was not answering from the community perspective, but that of the leadership. Participants expressed not only a reluctance to speak on behalf of their leadership, but even in guessing what the leaders may think about a certain issue.

> The man who spoke today about the leadership part of this… I think that's the point he was trying to make, that we can't gauge what we think the leaders know, and I think that was kind of, this part of it anyways, was a little difficult for myself. {Community Facilitator}

One community member expressed this discomfort in speaking on behalf of community leadership by stating:

> …we're walking a fine line by telling other people what they think or feel about something. {Community Member}

To begin with, communities often had great difficulty identifying who the word 'leadership' was supposed to represent.

> Yeah, that kind of threw me off, like when I was talking about community leaders, like I was kind of vague with that. {Community Member}

Some immediately assumed a political definition, such as the Chief and Council of each community.

> But you know, implying as a leader, it made me think of politicians right away. {Community Member}

Chief and Council were not the only leaders identified. Others included more traditional (usually male) household leaders, role-models, teachers and health workers, among others. Informal leadership included individuals who simply had influence in the community, no matter the reason behind their authority.

> There's always different forms of leadership as well too right? … Like we could look at political leaders, we could look at household leaders, you know we could look at an older brother, we could… it goes all through the community right? {Community Member}

Additionally, some perceived that leaders were being categorized as separate from the community. This dichotomy caused confusion and was at times deemed inappropriate within the community context.

> Maybe the committee can look at the definition of leadership? Cause that separation between member and leader, what does that entail? {Community Member}

The question of who the 'leadership' entailed was considered an issue distinct to these communities, since in such small and contained communities, political leadership is directly implicated in the decision-making of all aspects of community life.

> It would have been different if we lived in a city… our bosses would have been the automatic leader, not the mayor or anything, not the premier. {Community Member}

Participants subsequently had difficulty answering and scoring questions from leadership perspective.

> There's two different leaders we are looking at, like the health director and the chief and council. Our health director is very active, doing something about diabetes, but chief and council are not too much. {Community Member}

Reconciling these differences in knowledge and experience between different types of leaders into a single answer was also difficult.

> Yeah, I think that group definitely has less knowledge compared to like, what I also consider leadership as the youth and stuff which has an increased knowledge. It's harder for me to kind of get an average number. {Community Member}

Reflected in this division of knowledge was the perception that political leaders were not the champions of diabetes prevention and care.

> I changed my score on that you know, because, you know I was thinking about the band council first, like chief and council, then I said, what do they know about diabetes? All they care is about this, this and that. Never about diabetes. Then again, they look at people in other leadership [roles], like [program] leaders. I am a leader, I know I understand diabetes well. So I changed my score. But if I were to think about the council I would probably put 0. {Community Member}

Community Teams did acknowledge that political leaders' lack of knowledge or involvement was due in part to the fact that diabetes awareness was not seen as being part of their responsibilities, or that they had other job priorities and responsibilities that took precedence.

> Many community leaders work full time and are unable to volunteer. {Community Member}

And,

> I'm sorry, and as a community leader identified in here, I know that I do try to be involved with providing education in the community and in the diabetes program, but I also have a job description and requirements that I have to meet, and so as much as I try to be in the community, I also have other responsibilities [that are] mandatory for me to take care of. {Community Member}

In fact, far from blaming their political leaders, there was an emphasis on supporting and engaging the leadership.

> I feel there is a bit of disconnect between leadership and community members. It makes it easier for us, we hear 'oh where's the leadership.' So we put a lot of blame on them, I think, for the way things are. They can't be everywhere, they can't solve everything, so how can we connect to even support our leaders, right? {Community Facilitator}

Some of the questions in the questionnaire were identified as being inappropriate given the context of leadership.

> Although I'm not a huge part of defending the leadership, the way these questions are organized sort of set them up to not succeed eh? I think the questions are a little bit slanted. {Community Member}

Despite the demonstration of solidarity, Community Teams identified the need to increase the amount of support community leaders had for, and encourage their involvement in, planning and implementing interventions.

> If the majority of the membership in a community listen, and adhere to what the leaders have to say, it doesn't matter how many volunteers you have, how many dedicated community members you have, but if the leadership has a voice and says something, the community will follow what that leader has to say. {Community Member}

Engaging the leadership was deemed important not only for their potential as role-models, but for action and sustainability. Leaders were perceived to have the ability to ensure continued funding for programs and interventions. They were also seen as able to block or prevent activities from happening within the community.

> You want to add leadership, directors, managers, because they're all the ones that we have to, we have to convince [of] this…
> 'Cause they have the bucks.
> Yeah, they have the bucks.
> …
> And not only that, they have the ability to say no! They can take a look at the video, and say no, that's not what we want our people to see. {Community Members}

The definition of community 'leadership' was purposely left broad by the FORGE-AHEAD steering group. This was intended to provoke discussion and allow the community to define their own criteria for leadership. While there was certainly discussion on the matter, the lack of definition became a barrier to answering the questionnaire.

> I think they should have been more specific in their questions… That was where I had a lot of trouble. {Community Member}

Speaking for community leaders caused more discomfort than representing community-wide opinions. Defining who community leaders were was the first hurdle, and once this had occurred, reconciling the experiences of different types of leadership still needed to take place. Community leader buy-in and involvement was recognized as being important, yet the community teams were very careful not to blame their leaders. Rather they recognized the presence of other responsibilities or priorities that leaders faced daily.

Community Context

The adaptations made to the Community Readiness Model tool generally were perceived to fit with a First Nations community context.

> The scale actually does reflect our Nation. {Community Member}

Aside from two communities that chose to alter their readiness score for one of the assessment questions, the Community Teams recognized the report as accurately reflecting the views of respondents to the questionnaire.

> Yeah the numbers will be pretty accurate.
>
> Nothing popped out like 'are you kidding me'? {Community Members}

The tool was not seen as overlooking any important aspects of community life, and overall it was perceived as being a comprehensive method of self-reflection on the community landscape.

> The questionnaire covered all bases, you know in terms of what sort of measures are in place in the community. You kind of had to be specific. {Community Member}

At time, the language used by the tool was problematic. The term 'resource' is one such example. For the most part, 'resources' was interpreted as meaning financial support, however when used to describe other resources, it became less relevant to the community context.

> When I think of these groups, I think of getting them involved in programs. Resources just sounds a little more disconnected to me. {Community Member}

The term was seen as increasingly less pertinent when applied to community members not in leadership role:

> Yeah, because here is says to get community people to get resources right? And how are you going to do that? … Nobody is going to come out and say they have a resource, they found something, like [come] to our office and share it. {Community Member}

The largest perceived shortcoming of the tool was the focus on diabetes-specific knowledge and action. Most of the programs already established in the community focus on general health and wellbeing, or target improving health status across a variety of chronic diseases. These preexisting programs and services were seen as relevant and appropriate for diabetes prevention; and the CRM tool was perceived as not acknowledging them simply because they were not specifically branded as 'diabetes prevention.'

> [We] do offer a lot of good programs, that influence the general wellness and health of the community, but they're not diabetes specific. {Community Member}

Despite this lack of specificity, no one expressed a desire to limit mobilization or action planning in that way.

> We can't just say we'll go back and you know what, we'll do all the diabetes. Don't worry about people with high blood pressure, don't worry about high cholesterol. {Community Facilitator}

In fact, programs were embraced when they were seen to have an impact on more than just diabetes care or prevention.

> I thought it was like specific to [diabetics], but you know it's kind of nice to know that it's more broad, like diabetic or not diabetic. It's kind of like health promotion. {Community Member}

A focus on general health and wellness was reflected in the goals and objectives set by communities:

> What are you trying to accomplish?
>
> Healthy living. {Community Members}

Community Teams largely ignored the categorization of programs or interventions as being diabetes-specific, and focused instead on those that addressed general health and wellbeing. To be considered an appropriate tool for community members to use without much prior training, the Community Readiness Model tool should pay special attention to the language employed. A disconnect regarding the definition of 'resource' from a researcher versus a community member perspective was also found. Otherwise, the tool had been adapted well to fit the context of First Nations communities in Canada, and the scores were seen as accurately portraying the community landscape.

Structure and Organization of the Tool

Though the original Community Readiness Model tool provided purely qualitative data, the adapted version provided a quantitative result, on a 0/1 - 5 scale. Overall this scale was very well received, and intuitively understood by community members. Low scores were interpreted to be indicators of where action planning and mobilization should be centered, as opposed to making the community feel blamed or stigmatized.

> Overall, [our scores] weren't horrible… I'm not saying horrible like the number's bad, but there were some things we could improve on. {Community Facilitator}

And,

> The score doesn't mean anything except we gotta do some work. {Community Facilitator}

Low scores also helped identify priority areas:

> There may be lots of areas you want to improve on, but there's certain areas you think you'll get the most benefit out of. {Community Facilitator}

The possibility that a community could improve its score proved to be a motivating factor in many instances.

> If we can continue uphill… we want every [score] to be 5. We want every one of them to be a 5, and be a priority and everybody to be healthy. {Community Member}

There was some variation in the extent to which Community Teams used the qualitative summaries provided with each score. Certain Community Teams either did not have very much data or

did not consult that section of the results report. Those teams that did, found that the qualitative data justified the numerical score, and provided a better understanding of what the questions were encompassing. Qualitative findings were especially useful in the few cases where it became difficult to distinguish between questions.

> Sometimes the official definition doesn't really sound quite right, but if you read it with the [summary] next to it, and it's like 'oh yeah, okay yeah'. {Community Member}

Both professional health care providers and lay community members identified the need to bridge the gap between strictly community-oriented goals, and those of the clinical team. This was raised in reference to the knowledge contributed by each team's questionnaire.

> [The clinical team has] different questionnaires too? … Maybe that's something we need to do when we get back home, meet the clinical team. {Community Member}

Communication and partnerships between teams was also seen as important.

> I think that's kind of the main objective of why we're here, is to bridge that gap between community leaders and clinical leaders, and to have them working together on an ongoing side-by-side basis. {Community Facilitator}

Communication and collaboration between clinical and community aspects was not a new concept, rather seen as something "we've always done in the past" {Community Member}.

The Community Team felt they had more to offer the Clinical Team than they would receive in return.

> There's some community things you can do to improve adherence, in terms of education… that would increase knowledge in one area and have direct impact on whether they feel the need to be coming in to their appointments. {Community Member}

Community facilitators were trained in data collection and dissemination of results during the September workshops, and displayed competence in how the tool functioned when leading the sessions on their own. However, in the presence of FORGE AHEAD team members, especially those who were present during the initial training, the community facilitators deferred to the FORGE AHEAD team when questions about the tool arose.

> So we had a 4, and I'm thinking the 4 is the individual scores? Is that what that means, the 4s?
>
> Yep, so the members that, everyone that answered that question, that was the average… {Community Member, FORGE AHEAD Team Member}

Community facilitators not only deferred to FORGE AHEAD team members, but they also asked many more questions themselves about aspects of the tool they had covered in training.

> Some of them attend the diabetes programs, the community leaders, or should we pick a lower score? What would majority mean? What percentage would that be?
>
> Generally majority is 50% and up.
>
> Really? So half of the community leaders. {Community Facilitator, FORGE AHEAD Team Member}

When alone with the community, in the presence of a moderator who was not part of the main FORGE AHEAD team, community facilitators demonstrated a much stronger sense of understanding and confidence about how the tool functioned.

Regardless of the variation in community facilitator understanding of the tool, participants generally felt the scale used was intuitive, with qualitative data adding a positive impact when present. The division between clinical and community-level interventions and programs acknowledged, but was seen as unnecessary and potentially even detrimental to establishing relationships between organizations in the community.

The Knowledge to Action (KTA) Cycle

To best describe how the results of the tool were used by community members to begin or enhance mobilization around the issue, codes were matched to stages of the KTA cycle (Appendix A). Briefly, the KTA stages relevant to the current findings are: identify problem; identify, review and select knowledge; determine the know/do gap, adapt knowledge to local context and asses barriers and facilitators to knowledge use.

Identify Problem

One of the goals behind using an adapted CRM tool was to aid members in pinpointing areas for improvement within their communities.

> Think back, and look through [the readiness report], I would suggest before you go too far in here, and develop a great idea, if it's not something that's identified as a need from a readiness standpoint, are [you] going down the right path?… Look for the readiness scores. {FORGE AHEAD Team Member}

The results were used to help rank priority areas on which to focus interventions and activities. Low scores were especially useful in identifying areas of weakness within the community.

> The point of this is just to think about which areas do we think we could make the most progress in, and that's sometimes, often some of the areas you may have scored weaker on, you know, that's not happening as strongly in the community. {Community Facilitator}

The explicit use of examples stated in the readiness report was not the only way community members identified areas of importance. Discussion would often diverge into problems not identified by the tool. These issues were usually community-specific barriers to either intervention planning, or mobilization in general. As one community member stated:

> Also you have to remember too that even with the resources and the information that's out there, you have to realize the amount of people that don't even know how to read or write! And that's a big issue too. {Community Member}

Snowballing, or the transition from an issue mentioned in the report to another not covered by the report was a way to articulate areas that the readiness assessment would otherwise not have captured. Even without having an associated score, many of these issues became a part of the discussion surrounding priorities and action-planning within the community.

> When we're talking about advertising, and not just the fitness programs, but advertising in general, that's one thing we're trying to do based out of our offices, advertise our services more. So community members are aware of what's going on and what type of resources we provide at [community] counseling and support services. {Community Member}

While the report did serve as the starting point for the breakout sessions, it was the conversation itself, including digressions, that was identified as being valuable.

> Well obviously just by talking we have our priorities, we already know some of our priorities, right what we have to do. {Community Facilitator}

Community members saw the report as more than just a prompt to guide the conversation. It was also helpful in breaking a large and almost unfathomable goal into smaller pieces.

> I think what happens is when we're dealing with a lot of different committees and stuff like that, that's generally what happens, cause it's almost like you know, you almost have to know what's going on in the community, because it's, it is such a big community with so many different things that are all attached here and goes there. And you know, it's really important to have that as an overall [view]. And then, like you said, zero in on [one aspect], something small… {Community Member}

This guidance was especially helpful, as many participants felt overwhelmed by the daunting task set before them:

> There's so many things we need to improve, I just wonder where we're gonna start. {Community Facilitator}

Overall, the readiness report served as a guide for community members to approach the monumental task of mobilizing around diabetes. Its main function seemed to be in identifying issues that inspired discussion, and in keeping the goal of mobilization in sight. Community members seemed to appreciate the flexibility of allowing the conversation to flow over areas not covered by the report, but also having a physical guide to refer back to.

Identify, Review and Select Knowledge

After identifying community needs, the next step towards mobilization was to address the Community Team's ability to determining the feasibility of their goals and enact change. Toward the-

se ends, the CRM results can be seen as a summation of community knowledge. Since many priorities had been identified using the results of the readiness report, participants were faced with the challenge of funneling the wealth of information into more manageable and tangible goals.

> So what you need to do, we need to funnel it down, and have a clear statement of what we're doing. And that's when we're going to start going into our ideas, and small bites and small chunks. Because there's so many things to think about, and I dunno if you guys saw, you were talking, 'yeah but there's this, and there's that and barrier and this and this and that, and how are we gonna get there. We have to incorporate all these things', it became too big. So then it's: okay, how do we funnel it…
>
> We have so much information but there's a saturation, like you're saying, so I guess part of the things we could work on is pinpointing specific information? And maybe giving smaller little bites for everything…{Community Member}

This often involved reprioritizing categories as identified in the report. This reprioritization tended to neglect the actual numerical scores, and at times involved amalgamating categories into one larger issue.

> So we agree that community and leadership participation is the most important priority. And with that comes more knowledge and awareness of our programs, and we start with this.
> Yeah, cause it's almost like … a cause and effect of one thing, you can almost look at it like that.
> They're not really mutually exclusive.
>
> …
>
> Put them together, as [priority number] 3. We don't have to pick one or the other do we?
> These two?
> Yeah… programs and resources… I don't see them acting that differently {Community Members}

An important hurdle for Community Teams to overcome was building and maintaining enthusiasm and momentum for the task. Having a series of goals to target and move through was identified as making this task more approachable.

> And it's good because we have a moderate term goal with getting a [long-term] goal. Because, well we need these kinds of things. It's hard to get the momentum going if we don't have them right away. {Community Member}

The discussion on community leader involvement seemed to have the most positive impact when it came to momentum:

> But that's was just my thought, when you were talking about the distinguishing between having community involved in these programs and having leadership involved-
> …
> Ya it gets the ball rolling. It gets things going and running, which I think would then increase community participation as a whole. {Community Members}

Another contribution of the readiness results report to mobilization was in serving as a justification for improvement in the community.

> It's just that now this will become a project the will give us a little more initiative, a little more push, to say ok, realistically now we need to do this, and we can tie it in, and have achievable outcomes, and objectives because, as opposed to just sitting with the staff and just saying we need to change this, it's a good tool for me to use with the rest of the staff as well, to be able to say, okay, this is not just me saying I don't think you're doing enough in your job area, this is a part of the project that we're doing, and we're identifying [needs] from the community, and from everybody that's participating in this, this is where we have some gaps. And this is how now we can look at improving. {Community Member}

Although there was less reliance on the readiness report as a guide in this stage, it still contributed by supporting the continued re-evaluation of community priorities and goals. Along with narrowing the scope and focusing planning, community members also began to apply the knowledge produced by the results to mobilization of people outside the Community Team.

Determine the Know/Do Gap

Part of determining what specific actions would be taken in each community requires establishing a vision for what successful mobilization around the issue would look like. This was not articulated directly during the breakout sessions, however a rough picture of what would indicate successful community mobilization could be pieced together. Examples include, leadership support and buy-in, permanent funding, and the involvement of other community groups and organizations in planning and executing activities. As there was no portion of the breakout sessions dedicated to discussing potential quality indicators, much of this aspect was only touched upon briefly, and within the scope of other topics.

When it came to identifying gaps to target for action-planning, the tool once again proved to be a guide.

> … we said we need to do the community awareness, education, knowledge first, because it was identified in our readiness report, now it wasn't low, but it wasn't a 4, we want ours to be a 4 and 5, so when we do our survey again, we should be able to say yes, the community knows about diabetes, and programming, and about general knowledge about diabetes. {Community Member; Community D}

Adapt Knowledge to Local Context

Three common sub-themes emerged when examining how each community adapted their mobilization process to the local community context. The first was that of needing community-wide support and acceptance, in order to move forward.

> And our goal is always to get community mobilized and involved. If we can,-
> That's the goal of the whole community.
> -if we can get that going, we've got lift-off! {Community Members}

> So one of the things you have to do in our community is that we need to talk to, we need to give them the idea, to show them, not to, to allow them to, what we call buy-in to the project. If they don't buy-into it, forget it, we might as well go do something else. {Community Member}

This was important not only at a community level, but for individuals as well.

> I think that the biggest thing we need to do is get the community people to take ownership of their health. {Community Member}

One common way of promoting community buy-in was using local resources and other community members to help carry the message of their planned programs.

> Well, hoping by using local resources, like our youth, [that] people will have more of a connection to the [project].
> And local, local testimonials so we can back that up when people ask. {Community Members}

Buy-in could also be increased through involving community members in the planning and implementation of projects.

> It's like our housing too right? You provide community with housing, they haven't taken the effort to assist in building that house, they haven't taken the effort to appreciating that house that they've

> gotten for free, and so it's the same with our walking trail, you turn around and you have an incentive to do something, you involve the people in something. Because you know what? When you take a community as huge as ours, and you involve people in the community and you have a variety selection of people involved in that project, chances are you'll have more appreciation of the project than you would if somebody comes in and builds it for you. So you need to involve the community in decisions that need to be made, involve them in the actions in order for them to appreciate them. {Community Member}

The second sub-theme, of collaboration and integration of existing community programs and organizations, was also identified as increasing community support and acceptance.

> Because even if I see it now, there's a lot going on in the community, this we can all agree on, there's so many areas through the community where we kind of need to collaborate. {Community Member}

How exactly Community Teams were supposed to go about bringing together these separate efforts was not always clear, yet doing so was still identified as being an important task. Some even went as far as to identify a lack of collaboration and integration as a barrier to mobilization.

> Like the Cree Health Board, the Cree School Board, the leaders there, they should be involved. You know we're all working on the same goal, the well-being of the people. But if we don't, if we cannot work together, then we're not going to go far with trying to go forward. {Community Member}

Communication was often cited as needing to improve, in order to increase collaboration, yet historical legacies make this a challenge. The impact of the residential school system is still being felt throughout the communities, especially when it comes to inter-generational communication. Literacy rates, and the language of communication are aspects of this communication barrier.

> Then you always have to remember too that our people are a silent people. And there is so many areas of communication that are not being met because of the Indian Residential School system, where the parents, I found that, and my mum is a prime example right? She has been in there since she was a child, never knew her, her parents, but the thing was that she was never able to communicate, even in the school. So when she came out, she couldn't communicate with her children, she couldn't communicate anywhere even with her family. So when it came to us as children, we still haven't learned that communication skills with our kids, cause it passes on, and you're stuck in the system. So what we need to do is create a system where communication has to be key in our communities, because people always say well let's hold this conference, let's hold that conference, but they have to be constantly reminded on daily basis, what they need to do is to communicate as a nation. Because often in our nation, communication is a big key. And it's often ignored. I see on our TVs in our nation all over the place, you know blurbs of what's going on, but it's a blurb, there's nobody speaking in Cree, there's nobody speaking in English, to say this is what's happening tomorrow, you have to read it. Well if you have a nation that has a literacy problem, half of them are not going to relate to it. {Community Member}

The third sub-theme, that of which audience to target with intervention planning and mobilization efforts, was again similar across participating communities. Youth were identified across the board as key players in reaching the larger community audience. Teaching youth was something that was not only seen as easier to do, but also had consequences in the form of the ripple-effect: children would role-model for their parents, but even directly teach their parents the important health lessons.

> If you want to try to change the mentality of people, you got to start with working with children, and their families. If you're gonna start trying to change the way of thinking of people in the older ones, that's gonna take forever. {Community Member}

and

> Yeah, so I'm starting to see that more and more in our community, where a lot of the kids are starting to role model their parents, and

> teach their parents. Because of the things that they're learning in school, and all the resources we are providing for them, if the parents aren't teaching them, and the kids are teaching them, at least you just start from somewhere. {Community Member}

Mobilizing and involving youth was also seen as a way to reach the leadership, and showcasing the importance of improving health conditions in the community.

> This is what [the youth] want to see happen in their community, and they are going to present this idea to the leadership, whether it happens or not, which it probably won't, which is unfortunate, that's you know, that's the way it is sometimes, but at least they know, hey, our youth are really thinking of positive change in the community… {Community Member}

There was, however, some disagreement when it came to distinguishing between members who either had, or did not have, diabetes. Some Community Teams felt it better to keep target audiences for programs broad so as to avoid any marginalization or stigmatization of attending members. The idea of promoting general health and wellbeing, as opposed to interventions that were diabetes-specific arose again in this context.

> But I feel with First Nations people when you separate one group, you know, you're high risk diabetes, you're diabetic, they're not inclined to give that information cause they're still kind of marginalized. If you can include the whole group, then people will be more likely; even though it people are not pre-diabetic, they know somebody who might, whose diabetic.
>
> Yeah, so everyone is really affected, like and also too, you don't want to isolate one group either cause then other people won't feel like they are able to attend programs and stuff, when really it should just be open to the entire community. {Community Members}

Other communities thought the issue of diabetes should be addressed head on. They believed that the best way to reach individuals with diabetes, would be to create programs and interventions specifically for them.

> I wrote for DM2, but actually we should call it another way, because I don't think if it's called that way, diabetic people are not gonna be coming, because they are going to be shy, or feel ashamed or whatever you know. We have to find another name…
> Why do I feel the opposite?… I think sometimes it could be [aimed] for people who are diabetic.
> …
> Ok, so you think we should call a cat, a cat. {Community Members}

In most cases the minor disagreement over the target audience for programming was solved by resolving to keep these programs open to everyone, but to also advertise and make a pointed effort to reach and involve those with diabetes.

Adapting the mobilization process to the local context raised issues endemic to First Nations communities: communication issues, stigmatization and the importance of youth outreach. Involving the community as a whole, and increasing buy-in from both the community and leadership sides was another recurrent theme. Though communities explored common themes in regards to adapting their mobilization process, the specific manifestation of each issue within the community, and the proposed solutions were all unique.

Asses Barriers/Facilitators to Knowledge Use

Barriers to and facilitators of mobilization emerged organically during the entire duration of the break out sessions, and appeared most often in conjunction with discussion of the community

context. The ability to engage the community in the first place was seen as a barrier to continued momentum.

> We always hit a brick wall when it's working, working with others. I know eh? It's always a brick wall when you're trying to get them becoming more involved, so how would you do that? {Community Member}

This was seen as much at the individual community member level, as with the leadership.

> Ya because sometimes [community members] don't want to come out, some of them are so shy, and they don't want to speak up. {Community Member}

Securing funding was also identified as a major barrier to mobilization; another issue stemming from a lack of leadership involvement.

> Because the reality is people need to pay out of pocket, and/or we need funding. Everybody is looking for funding, their program doesn't run off anybody's budget, and so to start a program like this, it's gonna be those leaders, are they going to, is there real buy-in? Are they going to put money in? {Community Member}

One of the facilitators to improving leadership engagement was the collaboration of organizations and community groups.

> No no, when the grassroots are the front line people, they really start working together, sooner or later those who sit in the top office with the window, they end up talking. It just kind of happens that way, it's you know 'oh ya ya ya'. Cause that's our job to report back.
> …
> So when you're involving more management and more programs it becomes more collaborative, it becomes more out there and accessible to community.

> So increase collaboration between organizations as well. That's pretty useful…
> Just having these meetings can help with that, cause we've got all these different groups, talking and expanding.{Community Member}

In fact collaboration was viewed as so important, that a lack of collaboration was seen as another barrier.

> Ya ya for sure, cause there are people who backed off anyways, and I mean, for example if you guys want to work on developing a traditional food shop, you're not gonna be able to do that alone. We'll have to go to the band, and involve other people, so ya, we can go and get help, we're not gonna do that just the three of us. It's impossible, we'll need help from other people. So it's like our committee is going to be the one that brings out the idea, and tries to have things going, but then afterwards if you need help, we're gonna go from there. {Community Member}

The largest barrier to mobilization at the community level was promoting the initial engagement and ownership with community members and leadership. Facilitating this process was thought to be collaboration between organizations, and grass roots initiatives that would raise the priority of diabetes in the eyes of leadership, and allow for more funding and subsequent momentum.

The Knowledge to Action cycle proved to be appropriate lens through which to examine the knowledge creation and mobilization process that Community Teams underwent. The most energy was used for discussing the first aspect of the cycle, identifying the knowledge to action gap (identify the problem, identify/review/select knowledge and identify the know/do gap). In general, the readiness reports acted as framework within which Community Teams could move back and forth on the Action Cycle without losing their focus. It also helped serve as motivation to

move forwards on the Action Cycle, and to prompt discussion of areas not covered by the adapted Community Readiness Model tool.

Discussion

The purpose of this study was to better understand how community readiness knowledge is used by community members and community-based service providers in precipitating and guiding their mobilization process for diabetes prevention and care. A better understanding of how this knowledge is used will contribute to tailoring readiness assessments, and other participatory rural appraisal techniques, not only within a First Nations context, but to broader communities in general. Examining how mobilization processes unfold will also help in identifying what kind of information is needed to facilitate the process, and when it should be applied.

Mobilization through the KTA Cycle

Examining the community mobilization process through the lens of the Knowledge to Action (KTA) Cycle framework was a fitting method for understanding that process and the contribution made by the Community Readiness Model tool. When seen as a programming model, the KTA Cycle is intended to act as a guide in taking research evidence and applying it to a specific context in order to facilitate the uptake of best practices[87]. The KTA Cycle does not appear to have been used to describe a process of mobilization before, and this study illustrated how the KTA Cycle can be used to guide a knowledge mobilization process where the source of evidence is community knowledge rather than simply a literature review.

Knowledge Creation

The knowledge creation process that produced the community readiness assessment reports can be described using the terminology developed by Graham et al [5]. The process begins with knowledge inquiry, when a wide range of evidence or information is developed about the subject

at hand. This knowledge is then synthesized, funneled and tailored to apply to the necessary context. Finally, the tailored knowledge is used to generate tools and products, such as reports, practice guidelines, maps or seasonal calendars[80]. Community primary data collection using the CRM questionnaire constitutes the stage of *knowledge inquiry*. This first phase required taking the vast amount of information available about the community, and choosing what was most appropriate to answer the questions asked in the readiness assessment. The *knowledge synthesis* process was mostly done by the FORGE AHEAD research team. Though not a systematic review or meta-analysis as generally described for this stage of the KTA Cycle, the team summarized both the qualitative and quantitative data present, to create a profile of each of the six communities. Continuing down the funnel of knowledge production, the readiness assessment report was created, an example of a *knowledge tool or product* seen in the third phase.

This method of distilling knowledge is similar, to that used by other forms of Participatory Rural Appraisal. The use of third generation knowledge tool or products, is a common theme in PRA, and speaks to the importance of incorporating knowledge translation practices into research. Participatory research in general incorporates knowledge translation into the beginning of every research project, in order to promote engagement with end-users as they develop their own knowledge. FORGE AHEAD succeeded in this aspect, as having the readiness report to use before and during the mobilization process proved to be valuable to the Community Teams as discussed below.

Action Cycle

The means by which Community Teams advanced through the action cycle matched well with the steps described by the model's creators. The knowledge creation process contributed to every step, and there was much movement back and forth between phases of the action cycle, as expected in the model[5]. This was seen in the findings, particularly during the first step. The discussion surrounding problem areas identified by community members and where action and intervention planning should be focused, was spread over nearly all of the five breakout sessions, with different iterations being discussed back and forth on the cycle as goals were refined. Linear progression between steps was seen mostly between the 'adapt knowledge to local context' and 'identify barriers and facilitators' steps, although even there movement back to the initial step was common.

During the breakout sessions, community mobilization did not progress further than the KTA Cycle stage of *identifying barriers and facilitators*. In order to progress to the subsequent stages of *tailoring* and *implementing knowledge* for mobilization activities, a physical presence in the community and the inclusion of other identified individuals would be required. Even the discussion surrounding barriers to and facilitators of mobilization was restricted mainly to hypothetical terms. From this it can be inferred that there is a limit to how much can accomplished in the planning stages without gathering further information. While the exercise of discussing steps further along the action cycle was useful for keeping community members engaged and motivated during the mobilization process, it provided very little forward momentum. More generally, effective knowledge mobilization requires a presence in the physical setting, and time for exploration of future steps, in order to proceed[88].

There was one aspect of the action cycle, establishing the Know/Do Gap, that did not match as well to the discussions held during the breakout sessions. While i*dentifying the problem* and *identify, review, select knowledge* were well accounted for, there was little explicit articulation of what successful mobilization would look like, nor the identification of potential quality indicators that could be used to track progress. Both exercises are necessary for *determine the Know/Do gap,* and Community Teams only addressed these issues briefly and in very vague terms. This may have been due in part to the lack of moderator guidance towards this goal. While moderators prompted community members to try to visualize measurable indicators for specific interventions, there was no guidance towards picturing similar measures for the mobilization process as a whole. This occurred since reflection on the mobilization process was never a substantial goal of the sessions.

Lack of guidance in this step may also have hindered Community Teams' forward progress on the action cycle. When the KTA cycle was formulated, it used concepts and ideas from various theories of change to create a new, more holistic theory of planned action[5]. Using the KTA cycle as a guide for action would have ensured that Community Teams at least proceed through a discussion on this step. This indicates that though mobilization processes may emerge organically, they could be facilitated and promoted by using established programming models, such as the KTA cycle.

Another potential reason for the absence of dedicated conversation on the this issue is the fact that the mobilization process is poorly understood[89], and rarely studied, making the process of

determining what successful mobilization looks like largely arbitrary. A way to avoid this 'guesswork' in the future could be to introduce examples of other First Nations community mobilization success stories into the bank of resources available to communities at this stage in their process. As indicated in the findings, seeing what other communities were doing to improve diabetes prevention and care initiatives served as an inspiration, motivation and reference point when participants were discussing their own projects.

Sandy Lake First Nation

One community that documented its successful mobilization trajectory is Sandy Lake First Nation. Sandy Lake is located about 2000 km northwest of Toronto, Ontario. It is a small Oji-Cree community, accessible only by air for more than ten months of the year[33]. With one of the highest rates of diabetes found worldwide [90], this community initiated action on the 'problem of diabetes', recruited help from outside researchers, and now has one of the most sophisticated diabetes prevention and care infrastructures in place in a First Nations community in Canada[33]. The process of their mobilization was extensively studied in an unpublished report by M. Cargo et al [91].

There are many similarities between the mobilization path of Sandy Lake First Nation and the communities in this study, such as the identification of children and youth as one of the main targets of any intervention planning, and the involvement of grass roots and other community organizations as critical to community engagement. Lastly, the need for community leadership buy-in was necessary across all the communities. Differences existed as well. For example, non-community members had much more involvement in the planning stages in Sandy Lake than in

FORGE AHEAD. When community members replaced outsiders, the level of ownership and trust felt by the community towards the Sandy Lake research project immediately increased.

Cargo et al [91] interpret the mobilization trajectory of Sandy Lake First Nation through a slightly modified Community Readiness Model framework, not the Knowledge to Action Cycle. It is still possible, however, to see several of the key elements of the KTA cycle present in Sandy Lake. Similar to how the FORGE AHEAD communities shifted between stages of the action cycle in their discussions, the Sandy Lake Health and Diabetes Project (SLHDP) team moved back and forth between raising awareness, planning and implementation of activity stages. The authors noted an iterative – rather than linear – progression through the mobilization process. SLHDP also employed a needs assessment methodology to act as a guide in establishing the best way to address diabetes in their community. This supports the idea that mobilization is best understood through the lens of a programming model like the Knowledge to Action cycle.

In their report, Cargo et al [91] further describe the role of 'critical events'. Critical events are defined as those that precipitate and influence progression down the mobilization trajectory. They act as a catalyst in moving communities forward, and can be either one large event, or several smaller ones that combine into an effect large enough to push the community into the next phase of mobilization. One example of such a critical event in SLHDP was the dissemination of results of a needs assessment study they conducted to adjust and diversify their interventions. If we apply the same concept of critical events to mobilization within participating FORGE AHEAD communities, the dissemination of CRM assessment results can be seen as a 'critical

event'. This would indicate that the value of this tool lies not only in providing information about the community, but in propelling these Community Teams forward on their mobilization paths.

Value of the Community Readiness Model Tool

From the analysis of the community breakout sessions, the perceived value and contribution of the tool to the mobilization process was two-fold. First, it provided knowledge about the community context. Second, it acted as a catalyst for further action. The value of the tool to Community Teams in this context also shed light on the contribution an environmental scan such as this readiness assessment provided to mobilization processes in other settings.

The results of the tool provided information on the community context in a number of ways. Firstly, the tool provided an overview of strengths and limitations in the community when it came to diabetes prevention and care programming, as well as general knowledge about the disease throughout the community. Using these results, community members were able to find gaps, and prioritize filling them according to the needs of the community. The readiness reports also provided a compilation of existing programs and services, which in most cases did not exist for all the diabetes or wellness activities, programs and projects ongoing within the communities.

The process of answering the questionnaire set in motion a critical reflection on the community landscape within the Community Teams. This reflection continued even after results were disseminated; in many instances the discussion turned to topics that were not present in the report. The flexibility of the breakout sessions allowed the report to serve as a foundation for 'snowballing' on related issues that the tool did not identify. Participatory research methods are intended

to achieve this goals. Through engagement with the community over results, discussion is inevitably prompted, and an informal process of gathering information about the community landscape is undergone[92]. A formalized research tool can provide a written report that organizes the community information, and presents it in a manner that is understood, breaking down the mass of information into more manageable components of a larger whole. Reporting and returning results in such a fashion guides and limits discussion to the goals at hand, streamlining the knowledge to action process.

The information surrounding community landscapes provided by the adapted Community Readiness Model tool is similar to that sought by other methods of Participatory Rural Appraisal[93]. Community Teams were able used this information to launch into a reflection and subsequent discussion on the issue of diabetes, and embark on the mobilization process that would allow them to take action within their communities. Presenting the results using the readiness scale added extra impetus to forward movement on the KTA cycle. The identification of community limitations and gaps using a scale implied a need to move ‘up’, and score ‘higher’ in future iterations of the community readiness assessment.

In general, this adapted Community Readiness Model tool would serve as an appropriate addition to the Participatory Rural Appraisal toolkit. The questionnaire was able to uncover relevant and useful knowledge that was then used to directly influence the mobilization of these communities. The tool could be used in a participatory research setting, and its ease-of-use by community members without a background in research contributed to the assessment of its value.

Adjustments to the adapted Community Readiness Model Tool

While the tool did prove to be of value, there were still some aspects that did not quite fit a First Nations context. If the tool is to be used in the future with other First Nations communities, these issues should be addressed and the readiness assessment adjusted. These adjustments also shed light on how First Nations communities create and consider knowledge in their decision-making processes.

Community Representation

One of the issues identified by the Community Teams was the lack of male and Elder representation, both on the committee and as participants in the readiness survey. Looking at the breakdown of the Community Teams, there were 24 female participants, to only six male participants. Five of the six community facilitators were also female. The Community Teams were selected for the most part on the basis of professional roles within the community, hence the inclusion of the four men who filled roles in health organizations in their respective communities. When it came to positions unaffiliated with a professional role, such as the one reserved for community member feedback, chosen community members were predominantly female.

Having a balanced representation of participants is particularly important for achieving the aims of Participatory Research[94]. The composition of those guiding the research should match that of those who are affected by the issue under study. In this case men, and especially Elders, represent a significant proportion of First Nations community members who have diabetes.

While the issue of how to solve a lack of Elder representation was relatively simple to solve, that of male input was not. Community facilitators easily suggested asking an Elder to be a part of the team, or if they could not, perhaps getting them to complete a readiness questionnaire. Doing the same for a male perspective, however, was not suggested. This was likely a reflection of the larger issue of male underrepresentation in health care within the community, as opposed to simply an issue with how the Community Teams were formed, or the questionnaire disseminated.

The present finding on the underrepresentation of men is not exceptional, and is seen more broadly in the literature on First Nations and Indigenous health. In Northern Alberta, for example, the Diabetes Outreach Van Enhancement (DOVE) study found that 76% of Aboriginal participants were female, as opposed to only 49% of Non-Aboriginal participants[95]. In a study of Canadian 'quitline' use for smoking cessation, there was again a higher proportion of female users in Aboriginal populations (69.6%) as opposed to non-Aboriginal (62.2%)[96]. A microanalysis of an Aboriginal men's health group in Australia reported a similar initial hesitancy of men to be involved in improving their own personal health, never mind involved in improving health at the community level[97].

Another imbalance in representation was present in the number of individuals who worked in health care. Here again, merely recruiting other individuals to sit on the Community Team was not considered. Barriers to recruitment for volunteers from other non-professional community positions may have been due to prior engagements and other responsibilities. However, it was more likely due to the desire to form an ideal Community Team. Since the individuals answering

the readiness assessment questionnaire would be the same individuals involved in action planning, facilitators may have felt the need to encourage participation in those who were already interested in diabetes, and who could easily contribute to the action-planning phase of the FORGE AHEAD research program.

The gaps in community representation found in this study speak to the broader issue of choosing appropriate stakeholders when undergoing participatory research projects[98]. Often the choice of who to involve in projects is limited to the so-called 'easy' selection of individuals who could contribute to the research process. More difficult to include would be those individuals whose influence and participation are still critical to consider, yet may be seen as having less to contribute at face-value. As seen in this study, an environmental scan such as the readiness assessment can aid in identifying pivotal groups that need to be involved in order for mobilization to proceed.

A way to avoid representation bias in the future would be to keep the formation of the Community Team separate from the recruitment of questionnaire respondents. While individuals on the community team could have each completed the adapted community readiness tool, the questionnaire could also have been circulated to leaders, Elders and community members who would not be required to sit on the Community Team. Sampling for the tool could then more closely take into account the initial sampling strategy of the Community Readiness Model[22]. Doing so would still allow for necessary stakeholders to contribute input, yet not be compelled to participate in the overall governance of the project if they did not desire to do so. This flexibility of involvement can be applied to any participatory project setting.

Speaking for the Group

It is considered culturally inappropriate for First Nations community members to represent and speak on behalf of others. According to Dr. Horn-Miller, an expert in traditional community governance and Indigenous ways of knowing, "when we speak, it is important to acknowledge that it is presentation of an individual voice, and not that of anyone else. You cannot speak for another person, you cannot subsume their voice into your own"[99]. As reflected in the findings, being asked to ignore a teaching many individuals were raised on, and to represent the community as a whole made some participants uncomfortable, and may have also contributed to a skew in the community readiness scores. An even further exacerbated sense of discomfort applied to questions that asked community members to speak about what their leaders thought or felt. Again, increasing the sample size and variety of participants, especially including leadership into this sample, may help mitigate the effects of this culturally inappropriate question for the context.

Leadership

The definition of 'leadership' within the community was intentionally left broad by the FORGE-AHEAD steering group, with the intention of provoking discussion and allowing the community to define their own criteria for leadership. While there was certainly discussion on the matter, the lack of definition proved to be a significant barrier in answering the questionnaire. Much of this difficulty arose since many of the leaders identified had very different positions and roles in the community. Given this variety of lived experiences, answering questions from a single 'leadership' perspective was problematic.

Given the discussion surrounding leadership, there seemed to be two categories of leadership that played different roles in the mobilization process. The first would be the political definition of leadership, the Chief and Council as stipulated by the Indian Act[100]. Although this category seems intuitive, it can be perceived as problematic by community members. Chief and Council as a representative authority was imposed upon First Nations communities by the Federal government of Canada in the Indian Act. In establishing this uniform method of governance, the Indian Act removed many important principles of traditional governance, including the requirement for community participation in decision-making in many instances[101]. Even in the cases where 'custom' forms of governance were establish, many First Nations individuals would not equate the current governance system with their traditional methods[102]. As such, there are many cases where the legal, federally-endorsed leadership within a community may not have the trust or support of the community, or even be seen as the legitimate leaders of the community[102].

The second category of leaders includes those individuals that could act as champions for mobilization around diabetes prevention or care, and lend their support to new and continuing initiatives. Their involvement is important in gaining and maintaining momentum for community-wide engagement and mobilization. It is clear there is a need for this level of leadership if mobilization efforts are to succeed. Cargo and colleagues [91] acknowledged the contribution to mobilization made by a community champion. Using a different term, Israel et al [11] also identified support from respected individuals within the community as being a facilitator to effective community-based research projects.

The borders between the two types of leadership are fluid, and ideally, political leadership should be counted among the second group of community supporters as well. As seen in the findings, political leaders' other community responsibilities and priorities are barriers for this happening without external encouragement. One key community goal was to count political leadership as champions and supporters of diabetes prevention and care.

Given the nature of this division of leadership, and the importance of including both aspects in mobilization planning, it follows that both be addressed by the readiness assessment questionnaire. Restricting the definition of leadership to political leaders, specifically the Chief and Council, produced the most useful information on community limitations and gaps in knowledge and services around diabetes. From a knowledge mobilization perspective, identifying individuals in positions of authority who have the ability to approve, disapprove or rescind program initiatives was an important aspect for the readiness assessment to capture.

On the other hand, discussion of potential supporters, champions and role-models, came about most often when the communities were asked to identify and list leaders in their community regarding diabetes. In order to not confuse this exercise with the section targeting the political leadership, it could perhaps be moved to the end, or another section of the CRM tool. Explicit definitions of each type of leadership should be provided at every stage of the questionnaire. It is important that guidance in identifying potential champions be included in any form of environmental scan if the information is to be used as a mobilization facilitation tool.

Study Limitations

Participation in this study was restricted to communities already recruited by the FORGE AHEAD research program. As such, the selected communities may not represent an exact cross-section of the wide variety of First Nations communities in Canada. Additionally, all communities recruited by FORGE AHEAD must have identified diabetes as being an important issue in their community, due to the participatory nature of the program. This immediately situated these communities on an already established mobilization trajectory. The findings of this study therefore do not represent communities who have yet to begin mobilizing around an issue.

Lastly, all participating communities received the same readiness report template, and very similar guidance during the breakout sessions. This may have contributed to a lack of variation in mobilization processes across these communities.

Though efforts were made to obtain feedback on the findings and analysis presented in this study, no stakeholder response was received. Findings were distributed to the Community Teams, moderators, and the FORGE AHEAD steering committee. Limitations in time and resources meant that individuals on the FORGE AHEAD team were occupied with other program tasks and unable to contribute directly to interpretation of findings. Communication with the Community Teams was limited to email, making it difficult to reach participants, even after multiple efforts. Issues of coding reliability and thematic interpretation were therefore resolved through discussions between the principal author and her advisory committee, with only limited input from FORGE AHEAD or community representatives.

Future Research

Given the nature of the breakout sessions, it was impossible for Community Teams to address all the steps in the KTA Cycle. Future research may want to focus on the implementation of mobilization efforts within the physical communities, in order to study the progression of mobilization trajectories further along the KTA Cycle. Generating a more complete picture of the mobilization process will aid in further understanding how programming models can facilitate mobilization. It will also potentially elucidate further guidelines or recommendations on what kind of knowledge is required during mobilization, and when it should be gathered and applied.

Conclusion

The purpose of this study was to better understand how knowledge created by the adapted Community Readiness Model tool is used by community members to give rise to and guide their mobilization process for diabetes prevention and care. Using the Knowledge to Action cycle as an interpretive lens demonstrated that the mobilization processes of these communities fit well into the template of a programming model. Within this framework, the readiness report was an example of a *knowledge tool or product*, and was of value to the community through providing knowledge about the community context, and acting as a catalyst for forward momentum down their mobilization paths. This demonstrates that a research-developed tool can provide useful written reports that organize community information, while presenting it in a manner that breaks down the mass of information into more manageable components. Reporting and returning results in such a fashion guides and limits discussion to the goals at hand, streamlining the mobilization process.

Due to the information it was capable of providing regarding the community landscape, this adapted Community Readiness Model tool would serve as an appropriate addition to the Participatory Rural Appraisal toolkit. The process of answering the questionnaire set in motion a critical reflection on the community landscape, and it's ease-of-use allowed for the tool to be implemented by community members without a previous background in research. In order to improve its applicability to a First Nations context, adjustments should be made such as increasing the sample size and variety of participants, avoiding culturally inappropriate questions and creating a clearer definition of the term 'leadership'.

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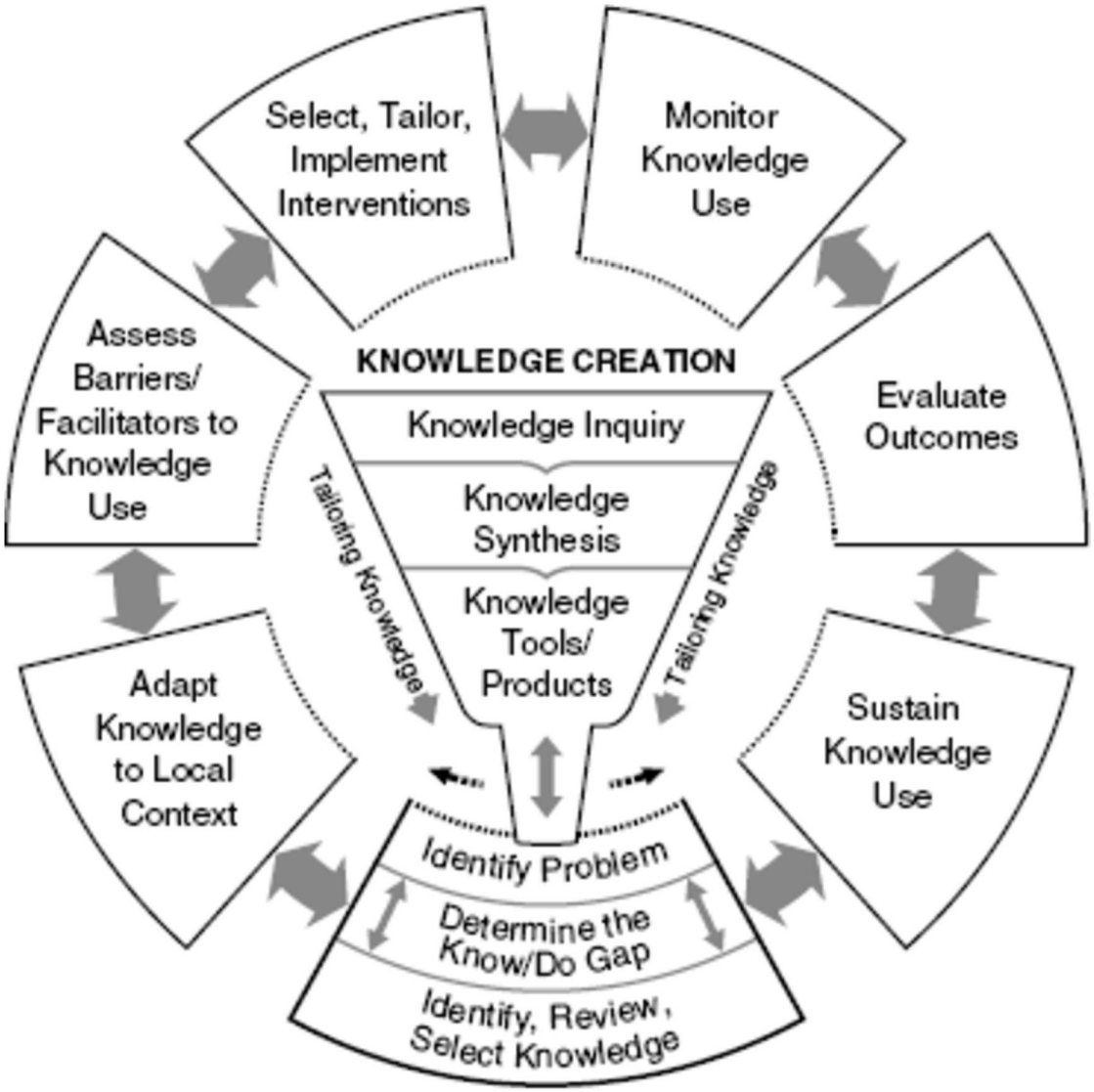
Appendix A: The Knowledge to Action Cycle [5]



Appendix B: Readiness Level Score Definitions in the modified CRM tool **[24]**

Table 1: Overall Readiness Scales and Definitions			
KNOWLEDGE READINESS SCALE		**ACTION READINESS SCALE**	
		0	**NO ACTION** - nothing is being done about diabetes.
1	**NO AWARENESS** - Not recognised as an issue, no awareness of the issue.	1	**PREPARATION** – community members and leaders are active in terms of planning efforts, or trying to get efforts started. This includes involvement in getting resources for efforts. No efforts are operating yet.
2	**APATHY/RESISTENCE** – has minimal knowledge and/or wrong information. There is some basic awareness of the issue, but not important enough to do anything.	2	**INITIATION** – activities are underway with some community member and leader involvement. And some resources are used and assigned to efforts.
3	**AWARENESS** – there is some knowledge and awareness of the issue, and as a result people would like something to be done. However other community priorities stop diabetes from being an important issue.	3	**STABILIZATION** – activities are actively supported by leaders and community members in key roles, including some work to find and secure resources.
4	**SUPPORT**–Diabetes is a priority. There is enough knowledge to act with likelihood of good success. Solid understanding of diabetes and its local impact	4	**CONFIRMATION/EXPANSION** - efforts are in place and may have expanded, and community members and community leaders play key roles in efforts. Resources have been increased, some resources are secure, and some evaluation of resources takes place.
5	**DETAILED AWARENESS** –Diabetes is a significant and ongoing priority. Know the effects of disease and how to evaluate knowledge about diabetes.	5	**OWNERSHIP** – diabetes efforts are now ongoing, with community leaders and community members highly involved. Some resources are secure, and efforts will likely continue into the future. The success of diabetes efforts can be used as an example to help other community issues.

Appendix C: Sample page from the modified CRM questionnaire **[24]**

2. a) What do the majority (at least half) of community members know about how diabetes affects your community? (Please mark an ☒ in only one box)

Nothing - they have never heard of diabetes or think that diabetes does NOT affect anybody in your community.	☐
Very little – they may know there are some people living with diabetes in your community, but they may not know how many. They may also think that diabetes affects individuals but not your community as a whole.	☐
A little –they may have an idea of how many people are living with diabetes and that diabetes affects your community as a whole, but they are likely unsure how or how much it affects your community.	☐
Some –they may know how many people are living with diabetes, and have some understanding of ways in which it affects your community (for example, making other health problems worse, stress on families, or can limit work and recreation).	☐
A lot – they may have a clear understanding of how diabetes affects your community, as well as some knowledge of the 'bigger picture' such as the fact that First Nations peoples have higher rates of diabetes or that other health issues (for example, obesity, smoking, heart disease) can affect or be affected by diabetes.	☐

2. b) Please provide any information or examples you think are important to better describe your community members' knowledge of how diabetes affects your community.

Appendix D: McGill University Institutional Review Board Approval

McGill

Faculty of Medicine
3655 Promenade Sir William Osler #633
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler #633
Montréal, QC H3G 1Y6

Fax/Télécopieur: (514) 398-3870
Tél/Tel: (514) 398-3124

23 January 2015

Dr. Gillian Bartlett-Esquilant
Department of Family Medicine
Participatory Research at McGill University (PRAM)
5858 Ch. de la Côte des Neiges, Suite 300
Montreal QC H3S 1Z1

RE: **IRB Study Number A12-B60-14A**
Community mobilization and the community readiness model tool: a case study of diabetes in selected First Nations communities in Canada

Dear Dr. Bartlett,

Thank you for responding to the IRB's correspondence concerning the 1 December 2014 full Board review of the above-referenced. This study was reviewed on behalf of Masters Student, Rachel Simmons.

The submitted response and revisions are acceptable. Final ethics approval for this study is provided on 23 January 2015:

- Thesis Protocol, version October 2014;
- Information Letter to Community Team Members and Community Team Consent Form, IRB dated January 2015.

The ethics approval for this study is valid until **December 2015.** The Certificate of Ethical Acceptability is enclosed.

All research involving human subjects is required to undergo an annual ethics review as stipulated in Federal and Provincial documents guiding and regulating human subjects research. This annual review is scheduled according to the date of initial approval and it is the responsibility of the investigator to submit a completed application form for Continuing Ethics Review to the IRB prior to the stop date of the study's ethics approval. A copy of the Continuing Review form is available on the IRB website at: http://www.mcgill.ca/medresearch/ethics/.

Any modifications or unanticipated developments that may occur to the study prior to the annual review must be reported to the IRB promptly. Study modifications cannot be implemented prior to ethics review and approval of the change.

The IRB has assigned this study the following **IRB Study Number: A12-B60-14A.** Please reference this number for all correspondence with our office.

Regards,

Roberta Palmour, PhD
Chair
Institutional Review Board

Appendix E: University of Western Ontario Institutional Review Board Approval

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Amendment Approval Notice

Principal Investigator: Dr. Stewart Harris
Department & Institution: Schulich School of Medicine and Dentistry\Epidemiology & Biostatistics,Western University

HSREB File Number: 103865
Study Title: Transformation of Indigenous Primary Healthcare Delivery (FORGE AHEAD): Community-driven Innovations and Scale-up Toolkits
Sponsor: AstraZeneca Canada Inc.

HSREB Amendment Approval Date: December 22, 2014
HSREB Expiry Date: June 17, 2015

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Revised Letter of Information & Consent	Community Mobilization Assessment	2014/11/18
Other	Workshop 1 Agenda - Community Team	2014/11/18
Other	Workshop 1 Agenda - Clinical Team	2014/11/18
Instruments	Team Functioning Questionnaire	2014/11/13
Instruments	Primary Healthcare Delivery Questionnaire	2014/11/13
Instruments	Clinical Readiness Report - Clinical Team	2014/11/18
Instruments	Clinical Readiness Report - Community Facilitators	2014/11/18
Instruments	Community Readiness Report - Community Team	2014/11/18
Instruments	Community Readiness Report - Community Facilitators	2014/11/18
Instruments	FORGE AHEAD Clinical Indicators for Surveillance	2014/11/18
Instruments	Appendix 15_Clinical Readiness Questionnaire	2014/11/18
Instruments	Appendix 13_Community Questionnaire	2014/11/18
Revised Western University Protocol	Protocol	2014/11/18

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the amendment to the above named study, as of the HSREB Amendment Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer to Contact for Further Information

Erika Basile ebasile@uwo.ca	Grace Kelly grace.kelly@uwo.ca	Mina Mekhail mmekhail@uwo.ca	Vikki Tran vikki.tran@uwo.ca

This is an official document. Please retain the original in your files.

Appendix F**: Study Information Letter and Consent Form**

Transformation of Indigenous Primary Healthcare Delivery (FORGE AHEAD): Community-driven Innovations and Scale-up Toolkits

Centre for Studies in Family Medicine • Schulich School of Medicine & Dentistry • Western University • Western Centre for Public Health & Family Medicine • 1151 Richmond St., • London, Ontario, Canada • N6A 3K7• t. 519-858-5028• f. 519-858-5029• toll-free 1-855-858-6872

JANUARY 27, 2015

Dear community team member,

I, Rachel Simmons, would like to invite you to participate in my Masters thesis project – Community Mobilization and the Community Readiness Questionnaire. This project will take place within the framework of the FORGE AHEAD program. Providing the appropriate diabetes care and management strategies is important in First Nations communities in Canada. Unfortunately, it is very hard to figure out what kind of programs will work in each different community, since the environments are all so different. As part of FORGE AHEAD, you will be using the Community Readiness Questionnaire to assess what exactly the environment of your community is, and how ready you are to start diabetes prevention and care programs (Community Readiness Consultations). This questionnaire has been used before in First Nations communities in Canada, but never for diabetes. I am interested in finding out whether this questionnaire is helpful to community members when they start planning their own programs, and how members use the results of this questionnaire to further change in their communities.

Your community facilitator will explain this project to you during the Quality Improvement Initiative workshop #1 for the FORGE AHEAD program. They will be able to provide any further information, support and to answer any questions your community team members might have regarding your participation in this project.

The enclosed letter of information describes the project, and which FORGE AHEAD activities it will encompass. All of the activities have been designed to collect important information in a way that requires the least amount of your time and effort.

If you have any questions, please do not hesitate to contact me or the other members of the thesis committee. Direct contact information for those affiliated with McGill University is available on the department website at http://www.mcgill.ca/familymed/research-grad/research/faculty. For general inquiries, please contact rachel.simmons@mail.mcgill.ca or call 514-966-6199.
Thank you again for your participation in this most important program of research!

Yours truly,

Rachel Simmons

MSc. (c), Department of Family Medicine,

McGill University and Participatory Research at McGill

Letter of Information for Community Team Members: Community Mobilization and the Community Readiness Quesitonniare

Investigators:

Rachel Simmons, MSc (c)	McGill University, Montreal, QC
Gillian Bartlett, PhD	McGill University, Montreal, QC
Jon Salsberg, MA, PhD (c.)	McGill University, Montreal, QC
Peter Nugus, MAHons, MEd, PhD	McGill University, Montreal, QC
Linda Stanley, PhD	Colorado State University, Fort Collins, CO

Contact person:

Rachel Simmons	(514) 966 6199, rachel.simmons@mail.mcgill.ca

You are invited to participate in this Masters' thesis component of the FORGE AHEAD Community Team activities – Community Mobilization and the Community Readiness Questionnaire. This letter has been designed to provide you with the information you need to make an informed decision about whether to participate in this project. If you have any questions please do not hesitate to contact our team.

PURPOSE:

To determine whether the Community Readiness Questionnaire is helpful to community members when they start planning their own programs, and how members use the results of this questionnaire to further change in their communities.

ACTIVITIES & PROCEDURES:

For this study I will be observing the Community Readiness Consultation sessions during the January 2015 quality improvement workshop #1 for FORGE AHEAD. As a member of the Community Team from your community, you have already had the chance to answer the Community Readiness Questionnaire. Your community facilitator will receive the results, and pass them on to you and your fellow members. There will be a brief presentation on what the results and scores mean during the Community Readiness Consultation sessions, then you will be invited to participate in a group discussion surrounding what your community results mean to you, and how

you will move forwards with the rest of the project. Participation in these sessions was addressed in the consent form you signed with the FORGE AHEAD program.

For this project, your consent is being asked to record these sessions. The contents will be analyzed and used as evidence for the above purpose. Your community team's results for this project will be shared with you.

The results will be used to address the question of how the questionnaire results are interpreted and used by community members. No data collected will be shared with anyone outside the FORGE AHEAD program. A summary of the results will be shared with the communities, and will be seen by those involved in the McGill thesis review process. Explicit permission will be sought from relevant Community Advisory Boards for any further use or sharing of the results.

CONFIDENTIALITY AND PRIVACY:

All of the data collected for this study will be kept strictly confidential. The recording of the sessions will be transcribed word for word, however all names will be removed, and participants will be identified using a numerical ID. Data will be stored according to the procedures outlined by the FORGE AHEAD Program:

> All information obtained for the program is confidential. Community information (data) belongs to each community. Your individual data will remain confidential. Only authorized FORGE AHEAD team members will have access to your individual answers for research purposes. Communities will have access to and receive a summary of the results of their community team's information. Regional and national summary results may be used in workshops in the FORGE AHEAD program. Individual community results will NOT be shared with other communities, agencies, etc. The regional and national summary reports will not include your name or any other information that identifies you. The information will be kept with your community and the FORGE AHEAD research team. Information (data) will be stored in a password-protected database or stored in a locked filing cabinet in London, Ontario at the Centre for Studies of Family Medicine.

BENEFITS:

There is also no direct benefit from participating in this project. If you chose to participate, you will help increase the amount of information available on the use of the Community Readiness Questionnaire in First Nations communities. This could potentially help with the future use of and improvements to this questionnaire.

RISKS AND DISCOMFORTS:

Program activities may make you think about topics and issues you have not thought about before; otherwise, there are no known risks related to participating in program activities.

REIMBURSEMENT:

There is no compensation offered for participation in this project.

Centre for Studies in Family Medicine • Schulich School of Medicine & Dentistry • Western University • Western Centre for Public Health & Family Medicine • 1151 Richmond St., • London, Ontario, Canada • N6A 3K7• t. 519-858-5028• f. 519-858-5029• toll-free 1-855-858-6872

VOLUNTARY PARTICIPATION:

Participation in this project is voluntary. You may refuse to participate and you may refuse to be recorded at any time.

CONTACT PERSONS FOR QUESTIONS:

If you have any questions regarding your participation in this program, please contact Rachel Simmons at 514-966-6199, or rachel.simmons@mail.mcgill.ca, or Jon Salsberg at 514.398.1357, or jon.salsberg@mcgill.ca.

If you have any questions regarding how this project relates to FORGE AHEAD, please do not hesitate to contact Dr. Stewart Harris (Principal Investigator), 519-858-5028 or Mariam Naqshbandi Hayward (Program Coordinator) 519-661-2111 ext 22115, at the Centre for Studies in Family Medicine of The University of Western Ontario. For general inquiries, please contact FORGEAHEAD@schulich.uwo.ca or call toll-free at 1-855-858-6872.

If you have any questions regarding your rights as a research participant, or the conduct of the study, you may contact the Office of Research Ethics, 519-661-3036, ethics@uwo.ca. This person is not involved in the study and contacting them will not affect your participation in the study.

This is your copy of the Letter of Information to keep for your records.

Centre for Studies in Family Medicine • Schulich School of Medicine & Dentistry • Western University • Western Centre for Public Health & Family Medicine • 1151 Richmond St., • London, Ontario, Canada • N6A 3K7• t. 519-858-5028• f. 519-858-5029• toll-free 1-855-858-6872

Community Team Consent Form

I have read the letter of information and the nature of the study has been clearly explained to me. All of my questions have been answered to my satisfaction.

Please date, print and sign your name below and return this form to Rachel Simmons by January 27, 2015.

☐ I consent to allowing my participation in the FORGE AHEAD Community Readiness Consultation sessions at the January 2015 quality improvement workshop to be recorded and used for analysis.

Participant's Name: _____

Participant's Signature: _____

Date: _____