Aboriginal Community-Based Primary Health Care Research: Developing Community Driven Primary Health Care Research Priorities

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Aboriginal Health Services
# Table of Contents

**INTRODUCTION** 5  
**COMMUNITY DRIVEN PRIMARY HEALTH CARE RESEARCH WITH ABORIGINAL PEOPLE: SETTING PRIORITIES AND CREATING MECHANISMS FOR CHANGE** 6  
- Literature Review 6  
- Primary Health Care Research 7  
- Aboriginal Health Care Research and Community Collaboration 8  
- Aboriginal Community Partnerships and Primary Care 8  
- Primary Health Care Priority Setting with Aboriginal Communities 9  
- Linking Primary Health Care Research with Primary Health Care System Change 11  
**METHODOLOGY** 13  
- Project Summary 13  
- Participants 13  
- Procedure 14  
**RESULTS** 15  
- Key Findings, Building Research Relationships in Aboriginal Communities 15  
- Future Research Directions 18  
- Mental Health & Substance Use 22  
- Primary Health Care 22  
- Public Health 23  
- Prevention 24  
- Indigenous Cultural Competency and Human Resources 25  
- What is working in Communities 26  
**CONCLUSIONS & DISCUSSION** 27  
**NEXT STEPS** 28  
- Partnerships for Meaningful Research 28  
- Partnerships for Primary Health Care Improvement 29  
**REFERENCES** 30
Executive Summary

Project Background

In 2011, a Canadian Institutes for Health Research (CIHR) Community Based Primary Health Care Planning grant was initiated in partnership with Fraser Health Aboriginal Health and Simon Fraser University, Faculty of Health Sciences. The overall goal of the project was to document Aboriginal community priorities around improving access to primary health care for Aboriginal people in the Fraser region. More specifically, to identify community research priorities around the barriers and facilitators to primary care, develop research partnerships with First Nations communities, university researchers and health care government decision makers and develop future plans for collaborative participatory community research in this region. A multi-disciplinary research team was assembled and the Fraser Salish Caucus approved the research study.

Study Design Overview

A series of 11 community meetings were held in the Fraser region communities between July 2012 and December 2012. Meetings were organized and community members were invited to participate with assistance of the community hub coordinators in each region. Participants of community meetings included: community members, health directors, health service providers, mental health workers, youth, Elders, nurse practitioners, community health workers, council members and band members. Participants were asked open ended questions in three key areas: primary health care needs, primary health care research priorities, and primary health care research and community relationships.

Key Findings and Recommendations

Results of the community meetings were categorized and organized into themes specific to recommendations for conducting research with Aboriginal communities, service gaps and challenges and primary health research priorities.

Research with Aboriginal communities:

Some key recommendations were made for conducting research with Aboriginal communities within the Fraser region. Participants recommended that researchers focus on building relationships, engaging community members and using a methodology that fits with the community’s needs. Engaging communities and leadership from the beginning of the project and bringing awareness and knowledge to the community was mentioned. Working with the health team and building trust with community members was a key theme.
Service Gaps and Challenges:
When discussing primary health care research often community members shifted the discussion to talk about key service gaps and challenges that are immediate priorities in the community. Access and transportation were key issues mentioned in all community meetings. Other key gaps identified included: lack of culturally competent care, human resources, mental health service need, addictions service need, emergency and crisis services, lack of access to specialist care and community capacity for health promotion and prevention.

Primary Health Research Priorities:
Primary health care research priorities were organized into 4 theme areas: (1) Mental Health and Substance use, (2) Primary Health Care, (3) Public Health and Prevention and (4) Human Resources and Indigenous Cultural Competency. Access to mental health and substance use services on reserve is a key issue; more support for families dealing with a family member that has mental health or substance use issues was frequently mentioned. Access and transportation to family doctors, specialists and emergency services was a key primary health care issue. Communities called for increased prevention and health promotion initiatives including a focus on chronic disease prevention and management. A high turnover of staff and lack of culturally competent staff in communities was a key issue mentioned in community meetings.

Next steps include building upon existing research partnerships and pursuing the development of further research aimed at addressing the primary health care issues identified by communities in this project. Community participants called for research that will lead to health reform and policy change and improve their access to culturally appropriate and effective services. It is increasingly important that communities drive the research agenda and that future research projects aim to build research capacity within communities. The partnerships developed as part of this project will be leveraged to support and partner with communities to develop and carry out research projects that are of interest to them with a focus on creating change and addressing barriers that communities have identified.
Introduction

This report describes the Community Based Primary Health Care Project undertaken as part of a CIHR Planning Grant initiated in 2011. The goal of the grant was to address the following question ‘What are Aboriginal community priorities around improving access to primary health care for Aboriginal people in the Fraser Health region?’ A series of 11 community meetings were held in the Fraser region to discuss Primary Health Care research priorities with a number of community representatives. The themes that emerged from these meetings are organized into 4 key areas: Mental Health and Substance Use, Primary Health Care, Public Health and Prevention, and Human Resources and Indigenous Cultural Competency. Community discussion participants identified a number of key priorities for research in these areas as well as identified gaps to accessing services in these priority areas. The creation of partnerships for research in Aboriginal communities was also discussed in the community discussions and will be described in this report.
Community Driven Primary Health Care Research with Aboriginal People: Setting Priorities and Creating Mechanisms for Change

Literature Review

Primary health care is often referred to as the foundation of our health care system in Canada and access to effective primary health care is often used as an indicator of population health worldwide (Barclay & Fletcher, 2010). Russell and Colleagues (2007) in a report for the Canadian Health Services Research Foundation define primary health care (PHC) as “a set of universally accessible first level services that promote health, prevent disease, and provide diagnostic, curative, rehabilitative, supportive and palliative services” (p.6). Often the term primary health care is used to refer to family doctors and other practitioners that provide first point of contact services and on a broader level it can refer to an approach to health service delivery at the individual and population level with public health functions (Russell et al., 2007).

It has been widely acknowledged that Aboriginal people, inclusive of First Nations, Metis and Inuit peoples bear a disproportionate burden of disease in Canada (Reading & Wein, 2009; Adelson, 2005). The health disparities that exist between Aboriginal people and their non-Aboriginal counterparts result from the historical context of the relationship between Aboriginal people and the Canadian nation-state and the social and political inequities that resulted (Adelson, 2005). Although Aboriginal Canadians, like all Canadians, have “access” to health care the Aboriginal population specifically have been provided services through a health delivery system that is fragmented and jurisdictionally ambiguous (Reading & Wein, 2009; Lavoie, 2004). In order to improve access and delivery of primary health care services for Aboriginal communities, research must be conducted that investigates community-specific barriers to access and provides applied recommendations for change. In order to create primary health care that is responsive to Aboriginal community needs, it is essential that Aboriginal communities themselves drive the primary health care research agenda.

Primary Health Care Research

The Canadian Health Services Research Foundation (CHSRF)(2007) published a report on mapping the future of primary health care research in Canada. This report found a significant disconnect between the support for renewing and revitalizing primary health care and linked support for PHC research. A lack of funding for PHC research and career development was identified. Generating high quality knowledge in PHC is complicated by the limited availability of PHC data, lack of PHC research support and lack of a common vision for PHC research. The authors conclude that this lack of capacity for generating knowledge in PHC will limit Canada’s ability to create meaningful changes to the PHC system and improve outcomes (Russell, Geneau, Johnston, Liddy, Hogg, & Hogan, 2007).
Aboriginal Health Care Research and Community Collaboration

Health research with Indigenous people has a tarnished reputation resulting from a history of researchers conducting research in communities and leaving with research results that amount to little or no impact on the health and well being of community members. Historically research has been used as a way to further advance colonial control (Cochran, et al., 2008). Community based participatory research has often been suggested as a methodology to engage research participants in the research process. Health research has often documented the problems in Indigenous communities using inappropriate methods. Indigenous ways of knowing and Indigenous methods are often not valued in Western research paradigms (Cochran, et al, 2008). There is an urgent need for research that incorporates community participation in meaningful ways and acknowledges that Indigenous ways of knowing constitutes a valid research data source. Cochran (2008) recommends that researchers conducting participatory studies in Indigenous communities must incorporate capacity building, which may include allowing communities to participate in the design and development of research studies. Community participation in all aspects of a research study is inclusive of establishing research priorities to be investigated for community well being, thereby ensuring that research is relevant to community needs and priorities.

Dudgeon, Kelly & Walker (2010) argue that genuine collaborative relationships and partnerships in Indigenous research and setting the health agenda at all levels is essential to closing the gap in health for Aboriginal and Torres Islander People in Australia. Research methodologies can be restructured so that the focus of the research is on the process of conducting the research rather than only on research outcomes. Collaborations for research may be difficult in early stages when time and patience is required to build trust. Since research has historically been a powerful part of colonial agendas it is essential that research agendas are created using Indigenous methodologies and with Indigenous people critically engaged to ensure research reflects their interests.

Anderson, Shepherd & Salisbury (2006) explored through a qualitative study the process of engaging and involving the public in planning for primary health care. Involving the public in the creation of primary health care policy can be seen as a way to ensure that services match the needs of communities while increasing accountability to local health services and empowering participants (Anderson, Shepherd, & Salisbury, 2006). Several themes were identified including: process, partnership and power, all of which are interrelated and impact how people participate in the process. Involving community members in decision-making involved a number of approaches to engage communities and innovative approaches to incorporate community views and create a sustainable and shared vision. Chiarella, Salvage & McInnes (2010), describe an active relationship between health professionals and community members as the ‘coproduction of health’. Coproduction in health requires long-term relationships between the service provider and members of the community where all parties make significant contributions. Providing community members or primary health care consumers with the necessary information and skills can empower them to create ways to maintain health within their communities. Chiarella, Salvage & McInnes describe a model of participation from the 1960’s called the Arnstein model which asserts that participation can be described on a continuum from non-participation to full participation and then decision making powers. With the ultimate goal of community empowerment there are several stages of community engagement along the continuum: information, consultation and partnership. As communities become empowered through participation and increased control there is a greater impact on health status, improving health service outcomes and reducing health inequities (Chiarella, Salvage & McInnes, 2010).
Issues of access to culturally appropriate health care for urban dwelling Aboriginal people have been described in previous studies. Aboriginal clients have reported lack of trust for their health care providers and experiencing barriers in accessing the system, with discrimination and racism being a commonly experienced barrier (Sookraj et al., 2010). Sookraj, Hutchinson, Evans, & Murphy (2010) conducted a participatory qualitative study investigating the challenges that organizations experience in delivering health and social services and facilitating access to mainstream services for Aboriginal people in three small cities in BC. Findings outlined that Aboriginal people access a diverse constellation of health services including private, public and services within the Aboriginal community. Administrators from several urban Aboriginal organizations outlined a number of challenges to delivering culturally appropriate services, particularly turbulent economic and political environments combined with human resources challenges (Sookraj et al., 2010). It is important to highlight the vast diversity in services accessed in different Aboriginal communities and in urban and rural settings, which further highlights the need for community driven research priority setting in order to gain greater insight into community needs and the barriers each community faces in accessing care.

Aboriginal Community Partnerships and Primary Care

Building partnerships is a process that is fundamental to working towards improving health outcomes in Aboriginal communities. Partnerships allow for Aboriginal community input and influence into the health care planning process. In Australia, Aboriginal Community Controlled Health Services (ACCHSs) deliver comprehensive primary health care to Aboriginal people. A partnership approach between ACCHSs and the government has been essential to improving health outcomes with ACCHS collaboration at all levels of the health care system including delivery of services and policy (Bailey & Hunt, 2012). The benefits of establishing partnerships for improving Aboriginal health have been well documented in international literature and are most effective when built upon the foundation of self-determination. The United Nations Declaration on the Rights of Indigenous peoples places self-determination at the forefront and calls for consultation with Indigenous peoples on administrative or legislative measures that affect them (Bailey & Hunt, 2012). Bailey & Hunt (2012) outline some characteristics that are key to developing effective partnerships. Partnership is more than consultation or the creation of advisory groups but involves considerable involvement at all stages.

Key characteristics of successful partnerships include:

- Respect, trust and mutual understanding between all partners
- An acceptance that different parties will have different roles and responsibilities
- Provision of adequate resources to all partners
- Realistic and specific objectives, usually ones that each partner organization would not be able to meet by working alone
- A process of review and evaluation which is both qualitative and quantitative and which assesses the partnership process as well as its outcomes.

(Bailey & Hunt, 2012, p.50).

Achieving health equity for Aboriginal peoples requires strong partnership building for primary health care planning with a partnership approach that incorporates principles of self determination, human rights approaches, clear descriptions of what is required to improve the health of Aboriginal peoples and clear roles and responsibilities for all stakeholders involved.
Primary Health Care Priority Setting with Aboriginal Communities

In more recent years priority setting has become a more important and acknowledged part of the health care system with a key aspect being the involvement of public values in assessments and setting priorities for change (Lomas, Fulop, Gagnon & Allen, 2003). Priority setting has gone through at least 4 major changes with the first change being a shift from the idea that priority setting can be done through use of a rational set of linear rules. The second major change involved the use of multidimensional approaches rather than strictly economic appraisals and the introduction of participatory action research (McDonald & Ollerenshaw, 2006). The third change focused on the consumer driven movement in health care and the inclusion of community voice in decision-making. The fourth change declared a commitment to setting priorities in a collaborative way and through minimizing power imbalances encouraging active participation (McDonald & Ollerenshaw, 2006). In priority setting for primary health care the process is important as well as ensuring that the views of the users of the system are incorporated while preventing domination from any particular group. Lomas et al. (2003) identify two approaches for setting priorities in health research: technical assessments and interpretive assessments. The technical approach is dependent on data and involves setting priorities based on population data, prevalence information and data on costs and use. Although this type of assessment is necessary it includes value assumptions that may not reflect those of the patients or population who use the services. Interpretive approaches allow for multiple objectives guided by multiple assumptions and relies more on the subjective priorities of the system users. Interpretive processes in priority setting are only as good as the stakeholders that are involved and who has a voice in making the changes to the system. The priorities identified by the policy makers, researchers or health bureaucrats often differ greatly from the consumers of the health services (Lomas, Fulop, Gagnon & Allen, 2003). There is no easy way to determine who is “right” or whose values should be valued more. However interpretive approaches can be used to blend the subjective inputs with existing health data.

McDonald & Ollerenshaw (2011) conducted a study using reflective practice for primary health care priority setting in Australia. The project examined real world experiences of practitioners and decision makers in priority setting, which led to the creation of a priority-setting framework to be used in community settings. The researchers found that 13 factors were key influences in setting priorities for primary health care:

1. Data comparison to determine health needs in the area
2. Moving upstream to target social determinants of health
   1. Identifying the scale of the problem
   2. Impact of the problem (morbidity and mortality)
   3. Aligning priority with government priorities and targets
   4. Maintaining progress with existing community health plan initiatives
   5. Available resources to solve problems
   6. Considering the values of all members
   7. Consumer voice and consumer action
   8. Assessing the financial cost of not addressing the problem
   9. Leveraging off other concurrent initiatives
10. Potential to produce improvement (immediate and sustained)
11. Strength of evidence base (degree of certainty to produce improvements)
(McDonald & Ollerenshaw, 2011)

Setting priorities for applied health services research requires identifying areas where the research will result in improved service delivery and benefits to the organization. Lomas et al.
(2003), propose a “listening model” for priority setting. The listening model brings together research funders, researchers and the users of the research to listen to one another in order to arrive at relevant research priorities that can be incorporated into practice. The six steps of the listening model involve: identifying stakeholders for consultation including the users of the research; identifying and assembling the data needed for the consultation; designing and completing the consultation with the stakeholders to identify issues of priority for the next 5 years; validating the identified priorities by comparing to other sources of information; translating priority issues into priority research themes and validating priority research themes with stakeholders to guarantee they truly reflect their views.

In setting primary health care research priorities there is an obligation that the focus and results of the research are reflective of the needs of the community represented by the research (Smith, Mitton, Peacock, Cornelissen & MacLeod, 2009). Little research has investigated how primary health care priorities are set and outlined the processes for how the service users’ perspectives are incorporated into developing research agendas. In forums held with decision maker partners from the 6 British Columbia health authorities the challenges of priority setting was discussed. Participants discussed that there is pressure to engage the public in decision-making and priority setting however the exact process for how to conduct this type of public engagement is not clearly outlined, more specifically how to incorporate the public’s input into
evidence. Participants mentioned that engaging the public or community who use the services is time consuming, costly and it is unclear to what extent the public should be involved in these decisions. However, it was also noted that the process of public engagement in the priority setting process is a way to test whether decision maker priorities are a reflection of what the community members see as being priorities (Smith, Mitton, Peacock, Cornelissen & MacLeod, 2009). Further inquiry is needed to develop frameworks for public involvement in primary health care research priority setting and guides for using this input as evidence for decision-making.

Brands and Gooda (2006), describe a unique model of partnership for Aboriginal health research in Australia. The Cooperative Research Centre for Aboriginal Health (CRCAH) includes partnerships of universities, research institutions and the users of the research and each partner is financially invested in the goals of the partnership. This partnership completed a project which synthesized and summarized areas of research reform in Indigenous health that were yet to be achieved, which included: Indigenous control over the research agenda and processes, improved processes for quality control, consultation and transferring research findings into policy and practice (Brands & Gooda, 2006). Although this study was conducted among Australian Indigenous communities many of these same elements of Indigenous research reform are often discussed among Canadian Indigenous communities. CRCAH undertook priority setting research to ensure that their research would be relevant to potential users rather than purely driven by researchers’ interests. Some identified characteristics of successful research in Indigenous health contexts were: stakeholders or users of the research involved throughout, research outcomes focused from the start, strong relationships between researchers and users of research, targeting multiple levels of change and high quality research (Brands & Gooda, 2006). Furthermore CRCAH found that some key barriers to ensuring that Aboriginal people guide the research agenda are: power imbalances between Indigenous and non-Indigenous, undervaluing of Indigenous perspectives and knowledge, and the overarching system of research that is Western dominated and investigator driven (Brands & Gooda, 2006). CRCAH uses a board to set research priorities which has representation from the Aboriginal health sector, research users and government organizations. Research users also have involvement in the development of research proposals, protocols and input into methods and research questions. A CRCAH interdisciplinary group of reviewers oversees each project under development in contrast to the peer review process, this ensures that projects with Aboriginal researchers and research methods are also valued in this area of research (Brands & Gooda, 2006). The interdisciplinary, community based and cooperative nature of the CRCAH makes it a promising model to be applied to building research capacity and conducting Aboriginal community driven and relevant research in the Fraser Health region.

Linking Primary Health Care Research with Primary Health Care System Change

Transforming knowledge into action for primary health care reform is a well-known challenge. Internationally countries with capacity to address the systematic determinants of health, stronger primary health care systems and effective management of chronic disease have lower costs and better health indicators (Armstrong & Kendall, 2010). In Canada, strategies are needed to support the improvement of the primary health care system and there is now an increased focus on evidence-based decision-making. Despite recommended evidence-based policy there remains a lag between knowledge creation and innovation in policy and practice. Transformation based on evidence requires key change agents within the system and the full engagement of community and clinical sectors (Armstrong & Kendall, 2010). New and innovative ways of sharing knowledge and disseminating information between silos are required. Additionally, research
needs to become increasingly relevant to practitioners and policy makers in order to make a real impact in primary health care policy.

High quality research on primary health care designed for and delivered to Aboriginal communities is urgently required. Best et al. (2012) state that an evidence base is needed in order to achieve large system transformation. The authors define large system transformation as: “interventions aimed at coordinated, system wide change affecting multiple organizations and care providers, with the goal of significant improvements in the efficiency of health care delivery, the quality of patient care, and population-level patient outcomes.” (Best et al., 2012, p.422). Efforts towards large-scale system transformation should focus more on iterative planning cycles that focus on shifting the system through changing how people do their work within the system rather than focusing on meeting specific targets. Best et al (2012) conducted a systematic review on knowledge of large system transformation. Their key findings included five simple rules to large system transformation: (1) engage individuals at all levels in leading change efforts; (2) establish feedback loops and choose evaluation and measurement methods carefully; (3) attend to history or the context of the system; (4) engage physicians; and (5) involve patients and families (Best et al., 2012). Further refinement of research methodologies is required in order to investigate large system transformation in more depth; the authors call for comparative case study investigations to compare and contrast lessons learned.

Evidence has shown that transforming health care services based on evidence is more successful when face-to-face methods are used and when decision makers are involved in the research process (Dobbins et al., 2008). A knowledge broker (KB) is an emerging method to increase collaboration between researchers and end users as well as increasing evidence-based decision-making. A knowledge broker links end users of services and researchers and develops a mutual understanding of goals and cultures. The users of services identify issues and problems for which solutions are needed. Use of this method of engagement can facilitate the identification, interpretation and translation of research into policy and practice (Dobbins et. al., 2012). A KB has multiple other roles; they facilitate knowledge exchange, build rapport with community and forge new connections and relationships across multiple different jurisdictions and disciplines. A KB can take many forms and can be an individual, a group or an organization. However, in each case the KB is linked to the users of services and focuses on integrating evidence into policy decision-making. Furthermore, the KB role involves synthesizing community health data and local knowledge to assist in translation to policy and practice. Research demonstrating the effectiveness of KBs is relatively new however anecdotal evidence suggests this is an effective and promising approach for translating the service user’s needs into practice and establishing system change (Dobbins et al., 2012).

Knowledge networks are formal networks that bring together experts in different fields around a common issue. Knowledge networks are usually multi-disciplinary and offer a participatory approach to address primary health care issues or unmet need (Armstrong & Kendall, 2010). Knowledge networks can respond to local challenges and support learning of all members however these networks while guided and governed by members must be structured in order to make innovation in practice and develop solutions. The knowledge networks have a united sense of purpose and support interdisciplinary learning. Networks have been identified as a way of achieving greater research impact on policy and practice. Typically community is left out of the knowledge translation process; knowledge networks may be an innovative way to bring Aboriginal communities, researchers and policy makers together to make community driven change to primary health care programming and practice.
Methodology

Project Summary

A 2011 CIHR Community Based Primary Health Care Planning Grant initiated the current project. The overall goal of the project was to address the following question: What are Aboriginal community priorities around improving access to primary health care for Aboriginal people in the Fraser Health region? Specific objectives to achieve this goal were:

1. Identify Fraser Health Aboriginal communities’ research priorities around the barriers and facilitators to accessing primary health care;
2. Develop research partnerships inclusive of First Nations communities, First Nations Leadership, university-based researchers, and health care and government decision-makers to address the priorities identified in objective 1; and
3. In collaboration with First Nations community research partners, develop a methodology to address the priorities identified in objective 1.

Participants

Research partnerships were developed through a variety of meetings including a presentation on the research project at the Fraser Caucus meeting on March 15, 2012. At this time the focus was to seek further participation from community members in the Fraser region to take part in the research group to guide the project. Several community members demonstrated interest in becoming further involved and joined the research group; furthermore, the Fraser Caucus demonstrated their overall support for the project going forward within the region.

A series of 11 community meetings were held in the Fraser Health region between July 4, 2012 and December 4, 2012. Meetings were organized with assistance of the Community Hub Coordinators within each region. Community meetings were held within each community with a variety of participants including: community members, health directors, health service providers, mental health workers, youth, Elders, nurse practitioners, community health workers, council members and band members. Outlined below are the communities that participated in the meetings:

<table>
<thead>
<tr>
<th>Participating Communities</th>
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<tr>
<td>Sumas First Nation</td>
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<tr>
<td>Skawahlook First Nation</td>
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<tr>
<td>Spuzzum</td>
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<tr>
<td>Leq’a:mel First Nation</td>
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<tr>
<td>Seabird Island</td>
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<tr>
<td>Mission Friendship Centre</td>
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Procedure

Meeting participants were asked a series of open-ended questions in three key areas:

- Primary health care needs
- Primary health care research priorities
- Primary health care research and community relationships

The community meetings were open discussion format allowing participants to guide conversations based on what they determined as priority discussion items and issues around primary health care in their communities.

A follow up community meeting was held on April 17th, 2013 with participants from all communities represented in this research project invited to hear findings and provide further input into the report. The input from the follow-up community meeting was incorporated into the research findings reported.
Results

The results of the community discussions were organized by key themes and categorized into the following theme areas: building research relationships with Aboriginal communities, research methodology for conducting research with Aboriginal communities, and future research directions. In each of the community discussions both the primary health care research priorities and gaps and challenges to accessing primary health care services in Fraser Health communities were discussed. These themes were organized into 4 main categories: 1. Mental Health and Substance Use; 2. Primary Health Care; 3. Public Health/Prevention; and 4. Human Resources/Indigenous Cultural Competency.

Key Findings

Building Research Relationships in Aboriginal Communities

Building research relationships with Aboriginal communities is a key area of focus in discussions of conducting primary health care research in the Fraser Health region. Aboriginal communities have been “researched to death” and often communities do not get to see direct results of research that they participate in. For researchers coming from outside of the Aboriginal communities it is a balance between the values placed on research by academic settings and the values of the community (Cochran et al., 2008). Cochran et al (2008) discussed the importance of considering Indigenous ways of knowing when developing research methods for projects to be conducted with Aboriginal communities. Participatory and community based research that incorporates Indigenous methods has become increasingly important in order to combat research fatigue in communities and ensure results are reflective of community needs. Conducting research within Aboriginal communities requires building positive and collaborative research relationships as well as using research methodologies that are valued by communities and encourage active community participation, partnership and collaboration.

Figure 1 represents key themes discussed by community members on the topic of building research relationships with Aboriginal communities for primary health care research. Some key themes that emerged were to engage the community in respectful ways by coming to the community with a sense of humility, creativity and flexibility. Engaging the community hubs, community leaders, family leaders, community members and specifically youth is key. A key theme mentioned was a focus on outcomes of research. Researchers have come to communities with the intention of completing research projects that don’t demonstrate direct results that the community will benefit from. Aboriginal communities are interested in conducting research that leads to real world results and will allow for changes in addressing the gaps and challenges they face in accessing and utilizing culturally appropriate primary health care services.

Figure 2 represents key themes discussed about research methodology when working with Aboriginal communities conducting primary health care research. Showing at the outset that the research has a clear purpose, will incorporate community viewpoints and provide solutions for the community was discussed. In addition, having an interdisciplinary research team was mentioned as being important to the community. Participants recommended that researchers
focus on the process of research and using creative ways of learning. Spending time in the community is important, and engaging Elders, youth and children in the research as well. Spending time to start the conversation and allow community members to tell their stories and be heard should be a key aspect of any primary health care research study conducted with Aboriginal communities.

Figure 1: Word cloud representing Building Research Relationships themes from Fraser Health Region community meetings

Figure 2: Word cloud representing Research Methodology themes from Fraser Health Region community meetings
Recommendations for Conducting Research with Aboriginal Communities in the Fraser Health Region

Building Relationships
- Engage Communities from the beginning of the project
- Engage Leadership
- Community awareness of the project
- Work with the health team
- Bring awareness and knowledge to the community
- Build trust

Engaging Community Members
- Engage Family leaders to recruit participants to engage
- Reassure community members that there will be outcomes that result from the research
- Communicate to all community members through publications (e.g., community newsletter)
- Engage community hub coordinators
- Engage research leaders from within community to develop community engagement strategies
- Develop a community communication strategy for communicating research activities and findings

Methodology
- Create a diverse and interdisciplinary research team
- Adequately represent community viewpoints
- Include Elders
- Information gathering instead of consultations
- Incorporate feedback processes into project
- Ensure project has impact for future generations - contribution to the community
- Engage youth and children in the research process
- Conduct research that creates capacity to generate funding for communities and provide solutions to problems
- Show a clear research purpose and outcomes
- Spend time in the community
- Present results back to the community
Future Research Directions

Future research directions include investigating innovative ways to provide transportation and health care to communities that face geographic barriers to primary care and specialist services. Within-community solutions must be identified so that community members no longer have to travel long distances to access basic medical care and face long waits for emergency or crisis services. Use of emergency room services when there was no access to a primary care physician was also mentioned in community dialogue. Future research must investigate ways to provide communities with regular access to a primary care physician or nurse practitioner and provide continuity of care. Community members identified their interest in engaging in health promotion and prevention activities. Creating culturally relevant and culturally appropriate health promotion and prevention initiatives is a key interest. Finding new ways to bring together traditional views of mental wellness and substance use with traditional medical models and offering this type of program within an on-reserve setting is a key priority. In all community meetings a number of specific health issues were recommended to be a focus of future research including:

- Environmental health - toxins/drinking water
- Housing
- Cancer
- Asthma/allergies/lung conditions
- Autoimmune disorders
- Smoking and obesity
- Heart disease and stroke
- Arthritis
- Alzheimer’s and dementia
- Youth health issues – addiction and mental health

Community members called for research to investigate why rates of these health issues might be on the rise, ways to prevent or stem the increase in incidence of these conditions and research that can provide community solutions to deal with these problems.

Identified Service Gaps and Challenges:

In community meetings participants were asked about their thoughts on primary health care research priorities. In every meeting the discussion evolved from discussing health research specific priorities to discussing some key gaps and challenges that communities face in accessing primary health care services.

Community members outlined numerous barriers they experience in accessing the primary health care services they need. A key theme mentioned in every community is the issue of access. Many communities face geographical barriers to accessing the services they need with many community members travelling long distances for basic primary health care. Community members called for increased cultural competency of primary care providers in their regions. Experiences with primary health care providers were described where continuity of care, cultural competence and comprehensive care was lacking. Access to addictions and substance use services in communities was a key priority. It was often mentioned that the families of community members with mental health or addictions issues require additional support and in many cases it is important that the individual is able to receive the addictions or mental health support they need from within their home community and with their own cultural elements interwoven within programming. A key theme mentioned was a focus on youth health. Community members see the youth as their future and see them struggling to find their way. It was mentioned that youth could benefit from more health promotion and prevention programming. Youth initiatives that promote
holistic wellness as well as having a key focus on promoting mental health and preventing substance use was mentioned as a key priority. Community members also called for involving the youth in research initiatives.

**Key Service Gaps Identified:**

- Access and transportation
- Lack of culturally competent care
- Human resources and initiatives to decrease staff turnover
- Lack of mental health services on-reserve
- Lack of addictions services on-reserve
- Lack of services that promote youth wellness
- Lack of emergency and crisis services
- Lack of access to specialist care
- Lack of community capacity for health promotion and prevention
- Maternal and child health – pre/post natal care

Despite community members identifying a number of gaps and barriers to primary care many communities offer their members a number of primary health care services that provide excellent care. However, communities in the more remote areas require additional support in overcoming some of the barriers they face in accessing basic primary care. Access was discussed in terms of geographical availability as well as access to culturally relevant or culturally competent care. In communities where transportation to services is an issue access to emergency services is also a key barrier to care. Police and ambulance services are not providing responsive care to more remote communities and often because of community infrastructure have difficulty finding addresses or homes that have made the emergency call. Participants called for a system to be developed that can help emergency services navigate on the reserve and provide more timely and responsive service. Access to substance use and mental health care on reserve was mentioned in most communities. It is important that options for care are offered for community members that allow them to reside within their home communities and work through their recovery while also able to receive support and assistance from their family and community support systems.
Fraser Health Region Community Primary Health Care Research Priorities

<table>
<thead>
<tr>
<th>Themes</th>
<th>1. Mental Health &amp; Substance Use</th>
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<tbody>
<tr>
<td></td>
<td>• Access to mental health care – counselor</td>
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<td></td>
<td>• Youth mental health and wellness</td>
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<td>• Mental health prevention</td>
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<td>• Support for families dealing with mental illness or addiction</td>
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<td>• Addictions screening and treatment services</td>
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<td>• Connection between housing and mental health</td>
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<td>• Education on the health effects of alcohol and drugs</td>
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<td></td>
<td>• Suicide prevention and crisis management</td>
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<td>• Addressing stigma</td>
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<td>• Trauma</td>
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<td>• Support for those who have had abuse</td>
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<td>• Drug use in the community</td>
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<td>• Schizophrenia</td>
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<td>• Social assistance for those with mental illness</td>
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<td></td>
<td>• Peer support models for those with mental illness</td>
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<td>• Supporting children’s self esteem and mental health</td>
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<table>
<thead>
<tr>
<th>Themes</th>
<th>2. Primary Health Care</th>
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<tbody>
<tr>
<td></td>
<td>• Access to family doctors, specialists, walk in clinics</td>
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<td></td>
<td>• Transportation - long distances to travel for services</td>
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<td></td>
<td>• Over use of emergency room because lack of GPs in area</td>
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<td></td>
<td>• Need for pediatric and psychiatry services access</td>
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<td></td>
<td>• Continuity of care – high turnover of staff</td>
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<td>• The role of nurses in the community</td>
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<td></td>
<td>• Immunizations access</td>
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<td></td>
<td>• Hearing and foot clinics</td>
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<td>• Quality of care from physicians</td>
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<td>• Doctor-patient communication</td>
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<td></td>
<td>• Need for First Nations doctors or naturopaths</td>
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<td></td>
<td>• Cancer screening</td>
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<td></td>
<td>• Access to emergency services – police and ambulance</td>
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<td></td>
<td>• Coordination between different levels of primary care – physician and hospital</td>
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</tbody>
</table>
3. Public Health/Prevention

- Traditional medicine – use of plants
- Education for children about traditional medicine
- Nutrition
- Vitamins and supplements coverage
- Services coverage – chiropractic and optical
- Housing – adequacy and quality
- Environmental toxic hazards
- Access to quality drinking water
- Prescription and pharmaceutical policy
- Heart disease & stroke
- Cancer Prevention and Care
- Bronchitis and Asthma
- Ear infections
- Smoking
- Nutrition
- Dental Care
- Pre/post natal care – access to labor and delivery services
- Physical health promotion
- Diabetes – Type I and Type II
- Lupus
- Fibromyalgia
- Parenting education
- Elder care and health
- Thyroid conditions
- Brain aneurisms
- Allergies
- Arthritis
- Sexual health and education
- Smoking and obesity
- Celiac disease
- Auto-immune disease
- Alzheimer’s & dementia
- Early childhood development
- Brain injuries
- Teen pregnancy prevention and support

4. HR/Indigenous Cultural Competency Training

- Retaining health care workers (NPs) – high staff turnover
- Teaching workers how to work with community members in cultural appropriate ways
- Train medical staff on historical impacts of colonization
- Building community capacity for health
- E-Health or solutions for access
- Discrimination from physicians
Mental Health & Substance Use

Mental Health and Substance Use was a key theme discussed in community discussions. Some key gaps and priorities mentioned by participants are outlined in Figure 3. Suicide prevention among children and youth and a focus on early intervention for mental wellness in communities was a key theme. Peer support models of mental health and substance use programming offered within community settings can be a way to ensure that care is more culturally safe. A key gap is offering avenues for community members to access mental health and substance use support 24 hours a day and 7 days a week. Often on weekends or evenings is when people need additional support. A collaborative team approach to mental health and substance use treatment and support was mentioned as a way to better meet the needs of those with concurrent disorders or more complex issues. Incorporating trauma care into treatment models was mentioned as a key gap within communities and primary care.

Figure 3: Word cloud representing Mental Health and Substance Use themes from Fraser Health Region community meetings

Primary Health Care

Primary Health Care was a key theme discussed in community discussions. Some key gaps and priorities mentioned by participants are outlined in Figure 4. Participants mentioned the need for holistic models of primary care with coordination between the different levels of care and different service providers. Community members often find it difficult to advocate for themselves when communicating with their primary health care providers; resources that teach community members self-advocacy skills would be a great asset. Furthermore, workshops that bring community members and primary health care providers together to discuss communication issues and strategies for positive communication would be beneficial. A wellness focus and the use of a holistic wellness model to plan primary health care in Aboriginal communities was a priority. Access to all types of primary health care was mentioned as a gap, including dental
care. Participants mentioned barriers to accessing dental care including transportation, getting a dentist that would take them on as a patient and a lack of culturally competent dental care providers. With the high turnover of providers in some of these communities continuity of care is an issue. Community members hope to build trust with a provider and continue seeing this provider for care rather than having to create new relationships with new providers often. This was an issue mentioned for physicians, nurses, community health workers, and mental health and addictions specialists.

**Figure 4: Word cloud representing Primary Health Care themes from Fraser Health Region community meetings**

### Public Health

Public Health was a key theme discussed in community discussions. Some key gaps and priorities mentioned by participants are outlined in Figure 5. Participants mentioned the need for more support for incorporating traditional medicine into primary health care services or creating models of care that can work collaboratively with traditional approaches. Creating more culturally safe services was also mentioned specifically in the area of pharmacy services, dental care, sexual health interventions and pre and postnatal care. Parenting education and support and pre and postnatal care within communities is a key priority. A number of gaps were mentioned with regards to care for Elders within communities including access to: specialist care, transportation for health care, accessible housing options, emergency or ambulance services, prevention, culturally appropriate services, pharmacy and pharmaceutical management, chronic disease management and prevention. Water quality and environmental toxins that can impact health are a concern in several communities. With increased industrial activity in the surrounding areas some community members are concerned about the potential health impacts this might have. Some participants mentioned that future environmental health research could look at the impact of industrial activity on surrounding communities’ health and access to healthy water.
Prevention

Prevention was a key theme discussed in community discussions. Some key gaps and priorities mentioned by participants are outlined in Figure 6. A number of health issues were mentioned that were in need of prevention initiatives including: youth health, heart disease, stroke, obesity, diabetes, nutrition, smoking, injury, cancer and teen pregnancy. Physical health promotion is a key area of prevention that was mentioned as a gap that needs to be addressed. Community members hope for more initiatives that will promote physical health and in turn prevent chronic disease for community members of all ages with a focus on children and youth wellness.
Indigenous Cultural Competency and Human Resources

Indigenous Cultural Competency and Human Resources was an overarching theme discussed in community discussions and included as a theme almost all discussions. Some key gaps and priorities mentioned by participants are outlined in Figure 7. Indigenous cultural competency has been part of the Indigenous health discussion across BC for the past few years as a major gap that must be addressed. Aboriginal community members described feeling discrimination from physicians and other health care providers and feeling the effects of power dynamics when seeking health care. It was suggested that medical staff must be trained to understand the impact of colonization and how this affects health and that medical staff be trained to use culturally appropriate ways to deliver care. High staff turnover in communities can lead to a lack of culturally competent care. Service providers come to work in communities for short periods of time and after they have gained trust and begin to understand the culture of the community they are then transferred somewhere else leaving community members to work to create relationships with new providers. Participants mentioned the importance of continuity of care and building the capacity to provide health care within the community to prevent this high turnover. Creating capacity within communities was mentioned as a way to address some of the barriers to accessing services that community members often face. E-Health was also suggested as a way to provide better access to some specialized services that may not need to be provided within the community.

What is working in Communities

Although community conversations were largely focused on the topic of identifying gaps and barriers to accessing primary health care services and programming in the Fraser region communities, there are also a number of community services that are working well. Some services that were mentioned as working well are not present or funded within all communities in the region and therefore may serve as recommendations for what to implement in communities that do not currently have these programs offered. Figure 8 summarizes services or programs that have been working well in Fraser Health Aboriginal communities.
<table>
<thead>
<tr>
<th>Mental Health &amp; Substance Abuse</th>
<th>Primary Health Care</th>
<th>Public Health &amp; Prevention</th>
<th>Human Resources &amp; Indigenous Cultural Competency</th>
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<tr>
<td>• Pilot Programs with Cultural Approaches</td>
<td>• Fraser Health Client and Staff Safety Policies</td>
<td>• Seabird Health Promotion Workshops</td>
<td>• Seabird School in Traditional Medicine</td>
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<td>• Mental Health Case Worker that travels up the Canyon</td>
<td>• Within Community Health Services</td>
<td>• Youth Workshops</td>
<td>• Training people within community in Crisis and Critical Incident Management</td>
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<td>• Have Alcohol and Drug workers in some communities</td>
<td>• Working to merge traditional medical model with cultural approaches</td>
<td>• Recreation Worker</td>
<td>• Van and driver to take community members to their appointments</td>
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<td>• Concurrent Disorder Clinician</td>
<td>• Stó:lō Health</td>
<td>• Dental Health Prevention - all ages</td>
<td>• Community members supporting one another in their work</td>
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<td>• Youth worker in some communities</td>
<td>• Dentist in Stó:lō Nation</td>
<td>• Recreation and Sports</td>
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<td></td>
<td>• Dental programs that travel to communities</td>
<td>• Cultural Activities</td>
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<td></td>
<td>• Massage Therapy and Traditional Healing</td>
<td>• Diabetes and Arthritis Services for Elders</td>
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<td></td>
<td>• Health Workshops</td>
<td>• Fraser Health diabetes resources</td>
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<td>• Home Nurse</td>
<td>• Falls Prevention</td>
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<td>• Midwifery Programs</td>
<td>• Mobile Cancer Screening</td>
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<td></td>
<td>• Primary Health Centres in some communities with doctors and nurses</td>
<td>• Mobile Diabetes Programming</td>
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<td>• Nurse Practitioners</td>
<td>• Eye Clinics</td>
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<td>• Foot Clinic</td>
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<td>• Nurses &amp; CHRs</td>
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<td>• Home Care and Community Care</td>
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<td>• Hearth Health Clinic</td>
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Figure 8: Table representing what services or programs are working well in Fraser Health Aboriginal communities
Conclusions & Discussion

The current study achieved the key objectives of identifying community research priorities for primary health care in the Fraser region Aboriginal communities and developing sustainable research partnerships. The study results have been presented back to community groups and will continue to be disseminated with the goal of pursuing future research projects based on the identified priorities by community participants. Fraser region communities call for applied community based research with the focus on affecting change in health policy to improve access to primary care and improve existing services. The research team will continue to pursue funding opportunities to conduct projects based on the identified community goals for primary health care improvement.

Findings indicated that communities have the desire to create an active relationship with health professionals to better meet their health service needs and participate in the ‘coproduction of health’ (Chiarella, Salvage & McInnes, 2010). The Arnstein Model outlined by Chiarella, Salvage & McInnes (2010) asserts that community participation with the ultimate goal of community empowerment can begin with information, consultation and then partnership between communities, health care providers and policy makers. First Nations communities in the Fraser region struggle to access culturally appropriate and accessible primary health care, which was identified as one of their immediate priorities. Lomas et al (2003) distinguished between technical and interpretive assessments for setting primary health care priorities, technical assessments depend on population data and interpretive assessments depend on the stakeholder opinions involved. It is apparent that some of the primary health care needs of the communities who participated in the current study are not adequately captured in population data assessments to determine priorities for services; therefore stakeholder partnerships between these communities and policy makers are required to incorporate consumer input into health services. The model of partnership outlined by Brands and Gooda (2006), which involves cooperative relationships between universities, research institutions and users of the research, with extensive community involvement and partnership, provides a promising example to be used with Fraser region communities. This model would work to address power imbalances in setting the research agenda with Aboriginal communities and ensure that the research results target multiple levels within the health policy system. Furthermore, the health care providers themselves must be involved in this process in order to understand the needs of the communities they serve. A knowledge broker model proposed by Dobbins et al (2008) could also work to enhance collaboration and facilitate knowledge exchange between researchers, communities and the service providers themselves. Communities in the Fraser region identified that they are knowledgeable about what their communities need in terms of primary health care and service improvement and they are hopeful for lasting meaningful partnerships with researchers, health service providers and policy makers with the goal of improving the health of their people and communities.
Next Steps

Partnerships for Meaningful Research

The current study involved the creation of interdisciplinary partnerships for research including building upon existing partnerships between Fraser Health region First Nations communities and representatives, Fraser Health Aboriginal Health and Simon Fraser University, Faculty of Health Sciences. The Fraser region First Nations community and research partners will support the development of research teams to carry out research projects based upon one or more of the research priorities developed as a result of this project. One key next step identified as part of the current project is to seek out future partnerships between Fraser region First Nations communities and other primary health care research groups creating linkages that can facilitate research to be conducted that meets the communities’ identified priorities. This project facilitated the creation of a partnership between SFU researchers and Fraser Health Authority; it is anticipated that this is a long-term relationship that will continue with future research projects and research grants with the aim of improving primary health care for Aboriginal communities in the Fraser region. A database is to be created with the primary health care research priorities identified by the First Nations communities that participated in this project. This database will guide researchers to create partnerships for their projects with the communities who have already identified priorities in their research area. Other next steps involve exploring opportunities to apply for primary health research grants to investigate the gaps and barriers to primary health care services, which was identified as a major theme throughout the community discussions. With community-specific barriers to primary health care identified as part of this project it is increasingly important that communities drive the research agenda and that future research projects aim to build research capacity within communities. The partnerships developed as part of this project will seek to support and partner with communities to develop and carry out research projects that are of interest to them with a focus on creating change and addressing barriers that communities have identified. The community discussions held as part of this project identified that further work needs to be done to develop protocols for research and engagement with these communities and to ensure that future projects have guidelines in place to ensure that First Nations are empowered as the research leads for projects conducted with their communities.
Partnerships for Primary Health Care Improvement

One of the primary outcomes of this project was building partnerships for research with First Nations communities in the Fraser Health region. Further partnerships are to be developed between Fraser Health Aboriginal Health, Divisions of Family Practice, Fraser Health Primary Health Care, First Nations Communities and the First Nations Health Authority to work to address the gaps that were identified in community discussions.

Ensuring that First Nations in the Fraser region drive the future developments in primary health care is important to ensure that gaps and barriers identified are addressed and First Nations receive culturally relevant, culturally safe and appropriate access to primary health care services. Creating a process for compiling First Nations specific research in the region and facilitating access and sharing mechanisms for research can help prevent some of the research fatigue that exists in communities and lead to the creation of more research partnerships with the common goal of improving primary health care for Aboriginal people in the region.
References


Aboriginal Health Services