

# What Changes Would Manitoba First Nations Like to See in the Primary Healthcare They Receive? A Qualitative Investigation

## Quels changements les Premières Nations du Manitoba souhaiteraient apporter aux soins de santé primaires? Une enquête qualitative



GRACE KYOON-ACHAN, PHD  
*Research Fellow, Departments of  
Community Health Sciences and Family Medicine  
Max Rady College of Medicine  
Rady Faculty of Health Sciences  
Ongomiizwiin Research – Institute of  
Indigenous Health and Healing  
Winnipeg, MB*

JOSÉE LAVOIE, PHD  
*Director, Manitoba First Nations Centre  
for Aboriginal Health Research  
Professor, Department of Community Health Science  
Rady Faculty of Health Sciences  
Winnipeg, MB*

WANDA PHILLIPS-BECK, RN, BN, MSC  
NANAANDAWEWIGAMIG  
*Nurse Manager  
First Nations Health and Social Secretariat of Manitoba  
Winnipeg, MB*

KATHI AVERY KINEW, PHD  
NANAANDAWEWIGAMIG  
*Research Manager  
First Nations Health and Social Secretariat of Manitoba  
Winnipeg, MB*

NASER IBRAHIM, MSC, PHD  
*Research Associate  
Ongomiizwin Research –  
Indigenous Institute of Health and Healing  
Department of Community Health Sciences  
College of Medicine  
University of Manitoba  
Winnipeg, MB*

STEPHANIE SINCLAIR, MA  
NANAANDAWEWIGAMIG  
*Research Coordinator  
First Nations Health and Social Secretariat of Manitoba  
Winnipeg, MB*

ALAN KATZ MBCHB, MSC  
*Director, Manitoba Centre for Health Policy (MCHP)  
Professor, Departments of Community Health Sciences  
and Family Medicine  
Max Rady College of Medicine  
Rady Faculty of Health Sciences  
Winnipeg, MB*

## Abstract

*Background:* First Nations (FN) have unique perspectives and experiences of health and healthcare services, which are critical to the provision of effective community-based primary healthcare (CBPHC).

*Objective:* This paper shares FN perspectives on primary healthcare (PHC), taking geographical, cultural and historical realities into account, to elucidate opportunities to improve current healthcare services.

*Methods:* Semi-structured in-depth qualitative interviews were completed with 183 residents of 8 Manitoba FN communities. Grounded theory-guided data analysis was conducted.

*Results:* Improving PHC performance requires delivering timely and holistic healthcare that integrates traditional health knowledge, comprehensive CBPHC increasing services such as healthcare and medical transportation, healthy food as an important preventative measure and a culturally informed workforce backed by local leadership and promoting cultural respect.

*Conclusion:* The relationship between self-determination and health is a critical factor in the implementation of CBPHC. FN must be respected to decide healthcare priorities that reflect the needs and visions of each community.

## Résumé

*Contexte :* Les Premières Nations (PN) ont un point de vue et une expérience uniques quant aux services de santé, dont la compréhension est essentielle pour offrir des soins de santé primaires communautaires (SSPC) efficaces.

*Objectif :* Cet article vise à mieux comprendre le point de vue des PN sur les soins de santé primaires (SSP) – en tenant compte des réalités géographiques, culturelles et historiques – afin de repérer les possibilités d'amélioration pour les services de santé actuellement en place.

*Méthode :* Des entrevues qualitatives semi-structurées approfondies ont été menées auprès de 183 résidents de communautés autochtones du Manitoba, suivi d'une analyse des données selon la théorie ancrée.

*Résultats :* L'amélioration du rendement des SSP demandera une prestation des services en temps opportun et une vision holistique des soins qui intègre les connaissances traditionnelles; plus de services complets pour les SSPC, comme les transports pour raison médicale; une saine alimentation comme mesure de prévention; et une main-d'œuvre sensibilisée au respect culturel avec l'aide d'intervenants locaux.

*Conclusion :* Le lien entre autodétermination et santé est un facteur clé de la mise en place des SSPC. Il est important de respecter les PN dans le choix de priorités en santé qui répondent aux besoins et à la vision de chacune des communautés.

## Introduction

The importance of primary healthcare (PHC) in improving overall health outcomes and healthcare experience cannot be overstated. Its capacity to support people in preventing illness and managing various conditions, thereby reducing pressure on hospitals, is well known (Beaglehole et al. 2008; Starfield et al. 2005; World Health Organization [WHO] 2008). Its usefulness, is, however contingent upon the ability to provide comprehensive and relevant preventative and disease management healthcare to individuals and communities (WHO 2008). Building on a broader understanding of the health disparities and ongoing challenges faced by First Nations (FN) communities (Freemantle et al. 2015; Martens et al. 2005; Shen et al. 2016; Smylie 2012), this article aims to (1) illuminate community-based primary healthcare (CBPHC) experiences and perspectives of FN communities in Manitoba, (2) highlight potential ways to build on existing strengths in addressing health gaps, and (3) outline key areas to collaboratively optimize culturally informed PHC based on unique models of healthcare that are influenced by the context of FN communities in Canada.

## Background

Health inequities experienced by FN communities contribute to higher rates of chronic conditions. Poor quality of life and outcomes are also reflected in the continued inability to meet specific health needs due to ongoing colonization and ill-fitting policies and legislation (Alfred 2009; Allan and Smylie 2015; Brondolo et al. 2009; Browne et al. 2016; Lavallee and Poole 2010; Lavoie et al. 2010). FN access health services through a complex jurisdictional maze of federal, provincial and FN community-based services. This maze is informed by a policy and legislative patchwork that has to date failed to clarify what services FN are entitled to and from whom (Lavoie 2013; Lavoie et al. 2012, 2016). Even where there is some clarity as to what is available and who should be providing services, policies and funding do not support the effective provision of those services. To illustrate, the federal government funds, and to a limited extent delivers, a complement of CBPHC services on FN reserves. Since 1989, FN communities may have been exercising some control over their community-based health services, but this control is limited by paucity of funds (Lavoie et al. 2007). Local service delivery also faces a number of structural and personnel challenges. To begin, PHC nurses remain employed by the First Nations and Inuit Health Branch of Health Canada (FNIHB). This appears to be true for all FN communities where PHC nurses practise, with the exception of 33 FN communities in northern Saskatchewan, one community in Manitoba and, since 2013, FN communities in British Columbia who are not working with the First Nations Health Authority. For various reasons, nursing vacancy has been a long-standing problem for FNIHB, and communities depend on contracted “agency” nurses to fill in temporarily. Agency nurses, however qualified, have a limited relationship with the communities they serve and little time to develop necessary relationships (two weeks to a few months), and this way of working does not promote continuity of healthcare (Minore et al. 2001; Tarlier et al. 2007).

## Methods

### *Study design*

A community-based participatory research framework was implemented from the conception of the study, data gathering, analysis and interpretation to knowledge dissemination (Kyoan-Achan et al. 2018). The study was guided by grounded theory (Charmaz 2006; Engward 2013). Qualitative and Indigenous methods were appropriate, in that these adopt a decolonizing approach, are storied and are collaborative. Semi-structured and open-ended interviews encouraged expanded responses to questions (Chatwood et al. 2015; Chilisa 2012; Flicker et al. 2015; Kite and Davy 2015; Smith 1999). Interviews were completed between April 2014 and December 2015.

### *Ethics*

Ethics approvals were granted by the University of Manitoba Research Ethics Board and First Nations Health Information Research Governance Committee (HIRGC). HIRGC oversees ethics processes on behalf of Manitoba FN. Data collectors obtained written informed consent from respective communities and individuals prior to conducting interviews. In keeping with FN research ethics principles, agreements signed between the communities and researchers outlined community protocols within the parameters of ownership, control, access and possession of data. These principles are intended to regulate and guide research involving FN peoples, to ensure research is conducted respectfully and meaningfully for and with FN (National Aboriginal Health Organization First Nations Centre 2007).

### *Participants*

Participants included 8 of 63 FN communities in Manitoba, representing four of five local languages – Dakota, Dene, Cree and Ojibwe. Each community indicated interest to participate through a written Band Council Resolution. Selection was based on tribal origin, geography, size, governance and health delivery model, that is, nursing stations and health centres. Access to PHC varies with each model. Nursing stations are nurse-managed and provide limited PHC services. Health centres generally provide health promotional information and minimal public health services.

### *Data collection and analysis*

Purposive sampling targeted male and female community members, FN and non-FN healthcare workers, health services users and elders. In all, 183 key informant interviews and three focus groups were completed across all communities. A small community of about 800 people conducted 10 interviews, and four other small and medium communities of fewer than 3,000 people conducted about 20 key informant interviews. Further, three larger

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communities of up to 5,000 people each had 30 interviews and focus groups, and the largest community of 8,000 people had over 50 interviews. Local research assistants were trained to collect data and translated questions and responses into respective local languages or English as necessary. Interviews were audio-recorded, transcribed verbatim and sent back to communities for validation. (For research questions, see Appendix A at the end of this document). Preliminary analysis was completed manually by two university-based researchers, a nurse research manager and a policy analyst at First Nations Health and Social Secretariat of Manitoba (FNHSSM) using an open coding system to identify key ideas and themes. Preliminary results were presented to respondents and community members at community data presentation sessions in each participating community. In this way, all communities co-interpreted and validated their data, highlighting key ideas and messages. In so doing, we significantly reduced the “researcher effect” on the analysis (Miles and Huberman 1994). Data were organized by participating communities and by interview questions, then uploaded. Results were developed from both interview data and discussions that had taken place during community data presentation and validation sessions.

## Results

### *Elements to improve quality primary healthcare for FN*

The following themes represent common and majority views of all eight participating communities. They sum up the stated CBPHC needs of the respondents.

### *Redefining quality healthcare*

Timely access to whole person healthcare was said to be crucial. Respondents maintained that in accordance with traditional teachings, health results from a balance of the physical, spiritual, emotional and mental aspects of a person, and healthcare needs to recognize and take that approach in providing healthcare to FN patients.

Quality healthcare means that we are meeting the needs of the community; individuals, families and community in a holistic way. So, we are meeting not just their physical health, but their emotional and their spiritual health ... because there is such a history of colonization, the residential schools, all of that soul sickness. We need to address all that. (A001)

It’s just being timely [care]. As long as you know you can get in and within a reasonable amount of time. (E004)

Respondents considered quality healthcare to be how quickly they could access needed care within or outside their communities, and whether the care given took a holistic rather than fragmented approach.

### *Inequity in resources and equipment*

Respondents worried that they may not currently have access to qualified healthcare providers or updated technologies. Thus, they feared possible inaccurate diagnosis and erroneous treatments as a result. One respondent said,

The X-ray machine is so old that they can't even get an accurate picture sometimes ... they send first-year students to use our community as guinea pigs and that's not right. That was my only beef with our nursing station here; they send first-year student to diagnose our people and all the equipment here is old. They need to update them. (GFG004-1)

Respondents expressed the need for better technology, advanced equipment and qualified providers to support diagnosis and treatments as part of improving CBPHC. Many were concerned they might continue to receive substandard PHC unless qualified providers were retained and equipment frequently updated.

### *Community-based healthcare*

Respondents wanted care brought closer to their communities, so members did not have to leave their communities and families for extended periods to access healthcare in towns and cities. They described quality healthcare as "... getting the services that we require and not having to relocate" (B006). Personal difficulties were reported when accessing healthcare off-reserve, which include leaving young children, spouses and aged parents behind; not having family members or friends to accompany patients; feeling lonely and confused in urban centres; and managing illnesses while struggling to navigate larger, unfamiliar health centres and hospital environments.

That's scary for a lot of people ... especially elderly persons, they don't even know how to speak the language, English or whatever they speak, they don't know. And then they don't know where they're going. It's hard for us. Especially when you get shoved out alone, by yourself. A lot of times I was taken out by myself, nobody was with me. I didn't know the city, nothing, I was just there. And then we didn't get to my room until 2 o'clock in the morning ... it's hard. (G002)

This situation was said to be even more difficult for elderly persons travelling alone, some of whom do not speak English and may feel disoriented just by leaving familiar environments.

### *Homecare*

Elders relocating for long-term and/or palliative care were said to leave a vacuum in the community. Echoing others, one respondent emphatically stated, "We don't want to leave;

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we don't want our Elders to leave" (C006). Another expressed being disheartened when elders have to be transported out of their homes for healthcare in facilities far away from their families.

There's a lot of our Elders that are in personal healthcare homes far from the reserve whereas a lot of family members have a hard time getting to them even just to visit on a daily visit. If we had a personal care home here it would be more access to not only immediate family but like grandchildren, friends and relatives to visit on a daily basis. (H002)

Conversely, many expressed concern that elders who remain in communities often do not have adequate care when they have to be confined to their homes because of illness, suggesting that an investment in homecare presents a real opportunity to improve CBPHC. All communities wanted "Elders' lodges" with more healthcare aides in each FN community, so elders could be at home, closer to family and friends, to be cared for within an appropriate cultural context.

### *Medical transportation*

Respondents said getting to and from healthcare facilities off-reserve or even within the community can be difficult for those without a means of transportation. Most communities do not have taxis, public transportation system or ambulance services. Many respondents wanted medical transportation service or, where it already existed, more and better vehicles with drivers.

Well to me, why I find it [medical transportation] a big part of our First Nations, just helping with transportation to and from your medical appointments ... to many resources that are off-reserve. (B017)

[W]hy don't [this community] have their own ambulance ... ? They should have somebody there all the time on call. (D002)

Some communities had one van to service the entire population, ranging from fewer than 1,000 in small communities to over 8,000 people in larger ones. Some did not have drivers around the clock to transport patients in emergencies. It was suggested that increasing the number of vehicles and drivers per community could ensure timely transportation to health facilities on- and off-reserves for more people, potentially improving access to healthcare and reducing cost of medical evacuations otherwise.

### *Supports when accessing healthcare off-reserves*

Respondents pointed to the need for better accommodations and adequate emotional

supports when leaving for healthcare outside FN communities. They reported difficulties associated with leaving to receive care in provincial facilities located off-reserve.

Better accommodations, not just Third World conditions when we have to go to a hotel and it's full of bugs or something like that, where we're treated like third-class citizens ... The whole thing of going out of town on day [medical] trips, needs to be examined and things have to change. People have to be dealt with fairly. (A009)

I was very very upset. Where was I going to go? I had no money, I had no room. Where was I supposed to go? I had eye patches on my eyes and I couldn't take care of myself. I couldn't. Someone had to lead me around. I couldn't take care of myself. That was very very upsetting to know that there was no room available for me. And then they try and shove you in a place that nobody would want to sleep at. (B009)

Others mentioned not having adequate food allowances while receiving treatment off-reserve and going hungry. Respondents continued to be upset long after returning to their home communities and remained fearful of leaving again for healthcare or trusting arrangements made on their behalf.

### *Healthy food*

Access to affordable healthy food was reported to be of high priority for FN health improvement. Respondents reported either not being able to afford healthy food options or nutritious food simply not being available for purchase in community grocery stores. One respondent lamented the state of food in his community:

I do have access of course to the grocery stores and what's provided is what people buy. I understand that and that's the way the system works. It upsets me that there is not more healthy food provided. It upsets me that food is not subsidised in northern communities, that food security is such an issue, that the food that's available is garbage, it's not food. Its food-like products. I feel incredibly strongly about that. Also, when you're unhappy you're going to eat food that makes you feel better, so those are the foods that are high in sugar, high in salt, high in fat and that's what people go for, right. It's cause they're self-medicating. I think that [healthy food] is a huge contribution to the health and well-being of the community. (A001)

A clear association is made between food and health. It was suggested that people will purchase healthy food when those options are available and affordable. They will otherwise rely on unhealthy alternatives, which may also be used to soothe negative emotions when facing difficult life circumstances.



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### *More and better prepared health workers*

Respondents called for additional health workers in their communities so as to reduce wait times and improve local access to care.

Having access to a doctor instead of having to wait four months, have a doctor here in the community. To have what the south has, dentist, doctors, and specialists in the community. Easy access to it at least and not wait, forever. When somebody is sick [in the community], they wait for five months. They could get more sick. In the four or five months the problem might be too late ... those kind of services would help. (F002)

More training and certification were also requested to increase the skills of community-based service providers.

### *Promoting continuity of care through cultural orientations*

Respondents also want all health workers to be adequately oriented to community-based contexts. This, they said, would facilitate communication and promote continuity of care. Respondents discussed the current state of affairs in some communities.

There's probably one full-time nurse that lives in the community ... to fill in the gaps are the agency nurses that come in from different places and there's just lack of consistency for clients. They [agency nurses] don't know the clients; they don't know the community, and then the clients or the patients have to tell their whole story again in a 15-minute span. So the consistency is not there when we have agency nurses coming in or when it's not fully staffed. (GFG004-1)

Agency nurses, because of their short stay, may not develop the relationships needed for continuity of care. Although perhaps an adequate stop-gap measure, the system's reliance on agency nurses is problematic for long-term, culturally safe healthcare delivery. Appropriate contextual understanding of the history, culture, language and ongoing experiences and maintenance of consistent provider–patient relationships were desired. In the absence of these, misunderstandings and missed information, which could prove costly to individuals' health, may result.

### *Local leadership*

The role of band council leadership in healthcare decision-making was also emphasized. One respondent echoed others in saying:

Our Chief and Council need to be more involved in the health services to make the health services delivery better. They need to be there to speak up for the community. (C007)

Community leadership is seen as advocating for and negotiating healthcare on behalf of communities. Respondents want their leaders to articulate needs and seek resources to support the health of the community by sitting at relevant policy and implementation tables within local, regional and national health authorities. This is not yet the case for many FN communities; therefore, their perspectives are often missed.

### *Jurisdictional cooperation*

Respondents argued that jurisdictional confusions create difficulties in collaboratively delivering health programs in FN communities.

For me, I would like to tap into the provincial services more where mental health is concerned. [However] in order for me to tap into provincial services, I would have to relocate my client [off-reserve] because we are federal here and we can't tap into provincial services because of where we are. That's why if I want to tap into provincial services, I would have to relocate my client. That is, it can't be done, especially for mental health. (B006)

Respondents suggested that fewer restrictions and more intentional cooperation policies from federal and provincial jurisdictions would allow for better resource sharing and access for patients.

### *Integrating traditional health knowledge*

Several respondents called for recognition and collaboration between conventional medicine and traditional health knowledge.

An integrated health centre ..., so you would have your doctors, you would have your nurses, you would have your diagnostic things, but you would also have your traditional people working alongside in the same building. And you have all of these things where you can have traditional healers coming in, you can have traditional work being done, ceremony being done, in the same building where you have your nurses and your doctors and your social workers and whatever, an integrated approach where you can have both working alongside ... That collaboration is essential. I don't think you can have two separate organizations working towards the health of the community independently. I think they need to come together and be integrated. (A001)

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Endorsement of this collaborative system will mean that communities are equally supported to access both options seamlessly as needed without associated discouragements, guilt or shame as currently tends to be the case.

### *Focus on the community*

Respondents also envisioned a PHC system that places community at the centre of healthcare, “a system that’s responsive to those served” (C008). It was said that all PHC providers within this system would make an effort to understand the histories, experiences, geographical limitations and opportunities of the people they serve. An absence of such understanding is seen as leaving room for harmful assumptions and stereotypes leading to discrimination and poorly delivered healthcare.

## Discussion

### *Creating a functional primary healthcare system for FN*

Primary healthcare principles advocate for individuals, communities and countries to define and create what health and well-being means for them (WHO 2008). The implicit position is that with the right supports in place, individuals and communities can chart appropriate courses of action toward attaining and sustaining optimal health (Browne et al. 2016; Eggington 2012; Greenwood et al. 2015). It is clear from the results in this study that FN communities know what factors would contribute toward their health. However, appropriate and adequate supports are required to improve CBPHC and the health of the communities. A recent report has again stated the need for supports, echoing others before it (Missing and Murdered Indigenous Women and Girls 2019). It emphasizes the need for timely access to comprehensive healthcare and adequate resources to support structures and initiatives aimed at prevention and public health. It also emphasizes the recognition and incorporation of traditional health knowledge (THK) as necessary in the pursuit of holistic health for FN people. THK is an existing and vibrant part of community-based PHC, with many turning to traditional medicines, practices and knowledge to prevent and/or treat diseases. However, this existing system is neither supported by nor integrated into the formal system (Letendre 2002). This gnawing gap still exists in the health and healthcare services of FN peoples and communities (Kyoon-Achan et al. 2019). It can be addressed by reviewing and updating relevant policies (Lavoie 2018).

Basically, the FN communities that participated in this study have made calls that align with the Truth and Reconciliation Call to Action #18 to “recognize and implement the healthcare rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties” (Truth and Reconciliation Commission of Canada [TRC] 2015). The recommendation to improve cultural orientations of healthcare workers in FN communities also addresses the TRC Call to Action #28, which recommends education for

professionals working with FN people to “... include the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, Indigenous law, and Aboriginal–Crown relations. This will require skills-based training in intercultural competency, conflict resolution, human rights, and antiracism” (TRC 2015). Although many of these recommendations have previously been made by others (Browne et al. 2016; Haggerty et al. 2018; Katz et al. 2017; Lavoie 2013; Lavoie et al. 2007), these do not appear to have been heeded considering the continued dismal health indices. The missing link appears to be a stark lack of policy action. The Manitoba FN who participated in this study have once again clearly identified areas of actionable change. A real opportunity lies in implementation. We therefore call on Indigenous and non-Indigenous healthcare policy experts to consider these viewpoints in planning a new direction for FN health.

### *Study limitations*

The study included 8 of 63 FN communities and does not claim to speak for all FN communities.

### **Future Research**

Jurisdictional cooperation between federal and provincial health systems and services, if done intentionally, can potentially transform CBPHC and significantly improve healthcare delivery to FN peoples and communities. This relationship as well as specific areas of active cooperation beyond funding agreements can and should be studied to provide evidence-based cooperative strategies to both jurisdictions.

### **Implications**

Acting on the findings of this study could significantly improve the current CBPHC landscape in FN communities. First, the federal and provincial jurisdictions should work collaboratively to address existing jurisdictional barriers to adequate healthcare delivery for FN patients. Removing confusing jurisdictional bureaucracy when navigating healthcare services, for both patients and healthcare providers, will increase access to relevant primary and specialized healthcare. Second, health human resource planning and development will ensure that current vacancies are filled with qualified workers in FN communities. A long-term strategy to eliminate this gap is to train FN people who will commit to long-term service in their own communities. This strategy, besides reducing attrition rates and promoting continuity of care, presents the additional benefit that FN health workers already know the contexts and can implement culturally safe healthcare delivery. Third, owing to the different models of healthcare in FN communities, ongoing collaboration with regional health authorities and other healthcare facilities is necessary to augment the services available in communities. These relationships can be negotiated and reviewed on a regular basis for

continued learning and improvement. Finally, FN leaders, chiefs and councils should be represented at all levels of healthcare planning and implementation, so as to provide context and articulate specific conditions and needs of the people.

*Correspondence may be directed to: Alan Katz, MBChB, MSc, CCFP, Director, Manitoba Centre for Health Policy (MCHP), Professor, Departments of Community Health Sciences and Family Medicine, Max Rady College of Medicine, Rady Faculty of Health Sciences, 408-727 McDermot Avenue, Winnipeg, MB R3E 3P5; tel.: 204-789-3442; fax: 204-789-3910; e-mail: Alan\_Katz@cpe.umanitoba.ca.*

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