

## **Comprehensive Primary Health Care in the Island Lake Communities: What does it mean and how does it look?**

### **Project Background**

#### **Introduction:**

In 2009, funding was secured by a group of MB-based Aboriginal health researchers to investigate the place of Comprehensive Primary Health Care (CPHC) in Manitoba's Island Lake communities. Comprehensive Primary Health Care is defined as an approach to health system organization and services that strives to<sup>1</sup>:

- Increase equity in access to health care and other services/resources essential to health
- Reduce vulnerabilities through changes in community empowerment (capacities)
- Reduce exposures to risk through changes in social and environmental determinants of health
- Improve participatory mechanisms and opportunities and political capabilities of marginalized population groups reached by comprehensive primary health care initiatives
- Increase community resilience to enable effective responses to promote and protect health
- Achieve an equitable increase in population health outcomes

Specifically, this project proposed to answer the question: "What CPHC governance structure and service model is most appropriate to the health beliefs and values of the residents of Garden Hill, Red Sucker Lake, Wasagamack and St. Theresa Point?" These four communities, which together make up the Island Lake communities, were appropriately selected to support the research for a variety of reasons:

- Current initiatives examining public health delivery and health care governance structure were already underway in the region.
- There was a willingness from both the public health programs and the more treatment-focused primary health care program to work together for improved health in the communities despite current fragmentation between these two bodies
- The approach to dealing with health-related challenges in the communities, where such challenges include the highest population rate of diabetes and second-highest premature mortality rate in the province, will benefit from community involvement and critical attention

The project is a 3-year project, part of a larger international network of researchers and people interested in building CPHC and is funded by the Canadian Global Health Research Initiative and its 'Teasdale-Corti' Research Program. The research team consists of Grace McDougall (Regional Public Health Coordinator for the FARHA, co-leader of the Public Health Improvement Pilot Project (PHIPP)) Alex McDougall (Executive Director, Neewin Health Care Inc.) and Dr. Marcia Anderson DeCoteau (Assistant Professor in the

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<sup>1</sup> Revitalizing Health for All: Call for Expressions of Interest, 2

Department of Community Health Sciences, University of Manitoba). Carly Scramstad is the student research assistant.

## **Project Objectives**

The international objectives describe the broader goals of the “Revitalizing Health for All” project of which “Comprehensive Health Care in the Island Lake Communities: What does it mean and how does it look?” is a part:

### *International Objectives*

1. Systematically review recent past experiences of comprehensive primary health care from different regions of the world to determine what we know about how it works, what it needs to work and what it has accomplished
2. Train up to 20 early career primary health care researchers in undertaking new or augmenting existing CPHC research studies, in teams with ‘research users’ (health policy or program planners) and research mentors (experienced CPHC researchers)
3. Provide financial support to these research teams to undertake their proposed studies
4. Support the building of regional networks of researchers and research users (including civil society groups) to advance comprehensive primary health care as the basis for health system reform in their own countries
5. Create a rigorously sound knowledge base on the role of comprehensive primary health care in improving health equity that can be used in the advocacy work of these regional networks
6. Strengthen the People’s Health Movement in being a global voice for comprehensive primary health care

The local objectives describe the specific goals of “Comprehensive Primary Health Care in the Island Lake Communities: What does it mean and how does it look?”

### *Island Lake Objectives*

1. Document the conceptualizations of health, health beliefs, and values of the Island Lake residents.
2. Define the type of health care system that will support these health beliefs and values, using the Teasdale Corti definition of Comprehensive Primary Health Care as a starting point.

## **Methods:**

In order to meet the Island Lake Objectives a mixed methods approach was used including:

1. Research Agreement
2. Literature Review
3. Focus groups/Community level data gathering

## **Research Agreement:**

A research agreement that appropriately recognized and respected the communities’ rights to own, control, access and possess the knowledge generated through the research was

negotiated and signed by the researchers and appropriate community representatives. Although early written support was provided by two organizations that had representatives from all four communities, only Garden Hill First Nation signed the research agreement, and therefore research activities only proceeded in Garden Hill.

**Literature Review:**

A literature review of peer-reviewed academic and grey literature was performed to answer the following questions: what is already written about First Nations’ conceptualizations of health and comprehensive primary health care? Has FARHA or any of the four Island Lake communities already agreed upon a definition of health and by what process? Are there already CPHC or Indigenous-controlled health service governance models with similar multi-jurisdictional contexts that can be used as a template? The literature review was used to formulate the questionnaire on health care delivery and governance structure that was distributed to relevant community and health care system leaders during the community level data gathering. The literature also provided relevant background for the project and instances of best practice in the literature were incorporated into the project when appropriate.

A second literature review that looked at Indigenous definitions of health was performed. The search strategy for the review used the following databases and combinations of the following search terms:

Database	Search terms		
SCOPUS	Indigenous First Nations Wellness	Aboriginal Inuit	Definition Health
PubMED	Indigenous First Nations Wellness	Aboriginal Inuit	Definition Health
Journal of Aboriginal Health	Indigenous First Nations Wellness	Aboriginal Inuit	Definition Health

In addition exclusion criteria was applied to each search result in order to refine the search results:

1. Must discuss health in an indigenous context with preference given to definitions arising from an indigenous perspective
2. Must have an abstract
3. Publication date no earlier than January 2000

**Focus Groups/Community Level Data Gathering:**

To begin the project of defining health in the Island Lake communities, community members were invited to participate in focus groups or research activities. These research

activities were split by age into the following groups: youth (ages 19-29), adults and elders. Participants were recruited through the use of informational posters in the health centers, grocery stores and band office; invitations on the community radio; invitations through the Elders and Youth Advisory Council to the Public Health Improvement Pilot Project; and invitations through Home and Community Care workers. Informed consent was obtained from all research activity participants.

The *adult group* was held like a conventional focus group. The following questions were asked:

1. What does health or being healthy mean to you?
2. How does somebody stay healthy or improve their health?
3. What conditions need to be present in the community for the community to be healthy?
4. Keeping in mind the ideas about being healthy that have been generated earlier in the focus group, now think about what the health care system should do to support health. Consider the criteria on this poster that have been taken from a research project<sup>2</sup>. Are these important? Are some more important than others? Are there things missing that the health care system should do?
5. How could these criteria operate in the community? For example, how could the health care system lower environmental risks to health, or how can it increase the involvement of community members in making decisions about health programs or policies?

The *youth* were invited to an activity night. They were asked to do art projects that reflect their ideas on what makes them healthy, what makes their community healthy, and how youth can be involved in making sure the health system responds to their needs. They were then asked to describe their pictures, and did so verbally and in writing.

The *elders* were invited to a breakfast, and a focus group designed to be more like a sharing circle was held. The following questions were used as guides

1. What does it mean to be healthy?
2. How would you like to be involved in making sure the health system responds to your health needs and the needs of the community?

At times throughout the elder focus group participants spoke in Oji-Cree, which was translated at the meeting into English.

In addition to the focus groups, questionnaires developed based on the literature review, current governance structures for public health and primary care and proposed governance models for the Public Health Improvement Pilot Project and the Island Lake Primary Care centre were given to key individuals involved in health care or community governance (health directors, health portfolio councilors, Chiefs). Informed consent was obtained prior to administering the questionnaire from all participants.

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<sup>2</sup> The criteria on the poster were plain language interpretations of the components of Comprehensive Primary Health Care, and are included in Appendix 1.

### *Garden Hill:*

The research agreement with Garden Hill was signed on June 3, 2010 by Chief Dino Flett. The research activities were held on July 8 and 9, 2010, with five participants attending the adult focus group, and seven at the elder breakfast. The youth activity night was not completed as there were no participants. A second visit was arranged to Garden Hill on November 9 and 10, 2010, with 6 participants attending the elder sharing circle and five participants attending the youth activity night. The adult focus group was not completed as there were no participants.

### *Red Sucker Lake, St. Theresa Point and Wasagamack:*

No research agreement was signed with these communities and so no research activities were held.

### **Data Analysis:**

The interviews were recorded and transcribed and the transcriptions distributed to each of the researchers. Each researcher was responsible for reading and reviewing the transcripts and identifying the major themes. One member of the research team took the lead role in developing a written draft of major themes. All three of the researchers then read and reviewed this draft, with continued analysis of the transcripts until consensus was reached as to the major themes. The group thematic analysis resulted in a narrative report of the major themes with supporting quotes from the interviews included.

The written description of the art projects were included in the thematic analysis, and also digital images taken of the projects will be inserted in reports to highlight the major themes.

### **Results:**

Community members who attended focus groups were asked a variety of questions regarding health and Comprehensive Primary Healthcare. The responses are divided into two major thematic areas: The first area looks at how participants defined health and the conditions necessary to be healthy. The second area groups participant responses as they relate to the major concerns of CPHC, this includes participant identification of barriers that exist to being healthy and living in a healthy community, as well as participant suggestions for how to deal with specific community health issues.

#### **Objective 1:**

**Document the conceptualizations of health, health beliefs, and values of the Island Lake residents.**

Participants identified a comprehensive list of features that helped to define a local conception of health as well as outline the conditions necessary to be healthy. These are outlined below and are accompanied by supporting quotes from the transcripts:

## **Food**

Food was identified as a major contributor to health in a variety of different ways, including healthy eating and food security. In addition, a significant amount of discussion was focused on traditional food, which will be discussed in a separate section to follow. In terms of healthy eating participants identified that eating healthy is a key component of being healthy:

“Being healthy is having proper diet.”

Participants identify that reading labels so they know what they are eating is important:

“Another thing that I always think about is food – that food you eat. Like, people buy food. They don’t watch out what they’re buying. Like, there’s labels on everything, eh? They have to read – how many calories each, and if they’re fatty.”

Concerns about the price of food were significantly emphasized:

“One of the things that our community are affected is by the high cost of food. And it’s – we have only one grocery store in our community and they’re really expensive. Like, the price of milk: at one time, it was over, about, close to \$15.”

“If we only had the low prices of healthy foods, it would benefit us more”.

## **Physical Activity**

Notions of being active were important in community definitions of health. Community members recognized that part of being healthy is:

“being very active, not just laying around, watching TV.”

In the art projects, one participant describes this very explicitly:

“The story of my picture is about being active because being healthy is about being active. One of the pictures I put is a girl jumping in the lake. Another is the lady jogging because it is a good way to stay healthy and fit. An old lady is laughing because she enjoys living. We really need to get the young youth really active there is too much time using the computer, watching tv and playing video games.”

Barriers to living an active lifestyle were identified as well:

“Walking typically was our main activity that we do around here – is walking. But the conditions of our roads is really bad. Like, if it’s raining, it’s too muddy to walk or ... Especially when it’s bad is when it’s – when it’s dry, it’s too dusty, too. So it’s pretty – pretty bad.”

In addition to the dusty or muddy conditions of the roads, the presence of garbage, dead dogs and old cars were mentioned as deterrents to exercise as well:

“When you go for a walk, you can see the old cars that are left on the road, too, eh? The old cars: they never pick up.”

Traditional lifestyles, as mentioned above, were recognized by participants as being more healthy in terms of food, but also in terms of activity:

“We have to move. We can’t just sit around and expect somebody to do those things for us. We gotta learn; it’s up to – really up to us to teach our young people to use – how to use those things. Same thing as when we – when we used ... trap-lines.”

One suggestion for improving physical activity in the community was to have one day a month or every two weeks where everyone walked to work. Participants expressed that this would “help with the environment” and “help with exercise”.

### **Healthy Body Weights**

Combining concerns about food and physical activity, many participants identified healthy body weights as important in defining health:

“Too many people are – are too overweight. Because by just sitting, you get fat.”

One art project shows a woman doing pushups alongside a picture of fruits and vegetables and is described as follows:

“My picture represents dieting, obesity and a peace of mind, body and soul. Garden Hill Community needs more nutritional foods. The main concern is the high cost of foods such as fruits and vegetables in our stores. We need to replenish our bodies with lots of water and healthy food. Garden Hill has the highest risk of diabetes and we need to help these people and educate the community by promoting exercise and eating healthy foods.”

### **Being Clean**

Being clean was a theme that came up several times throughout the discussion groups and was mentioned in relation to a variety of areas including personal hygiene, houses, yards and the community in general. As regards personal hygiene, participants identified being clean as one of the main ways of being healthy:

“Being healthy means being – trying to be more – like, more hygiene or more clean way of skin and how to clean your hands and everything.”

Keeping your house clean, “being very clean in your house and everywhere”, was also mentioned as an important way of staying healthy. In addition, many of the art projects included pictures of cleaning products.

Barriers to keeping clean were mentioned as well. The issue of running water and the high cost of cleaning products were identified as barriers:

“The community needs better housing with plumbing.”

“Javex costs ..about \$21.99.”

Beyond issues of personal hygiene and clean homes, participants spoke about the need for clean yards and a clean community environment:

“To be healthy, here’s another thing: clean environment.”

Despite knowing that a clean yard is important, participants describe that this is not always an easy thing to accomplish.

“... the people – the health – the people would say, “Try and keep your – keep your – your yard clean,” you know? What can **you** do? Heh! ... but what can we do if the garbage man doesn’t show up? Clean up – pick up your garbage. You know, you have no choice; just leave it outside. And if you leave it inside, it’s gonna get smelly. You can’t leave – leave ...garbage in your inside. You got no choice but to take it outside.”

Participants discussed that without garbage pick-up it is very difficult to keep their yards clean:

“So it’s – it’s pretty bad when you get – you have to wait to get your garbage picked up or something like that. So it’s really difficult. So it’s really difficult to live in a clean environment when you don’t pick up your stuff right away. You know?”

In addition to garbage polluting the community, the number of abandoned vehicles was raised repeatedly.

“There’s also a need to keep the community in general clean. The removal of derelict vehicles from the homes would help the residents. ‘Cuz they don’t have the resources to do that themselves. So the community needs to help in that aspect – where these old vehicles lying around need to be gathered and disposed of elsewhere, and not left in front yards like they are now.”

Suggestions were provided that community members could initiate a community clean-up or get the high school students “to make big signs like this – this big that said ‘No Litter in Our Community’. Or you can say ‘Keep Our Community Clean.’”

## **Mental Health**

The notion of mental health was mentioned, especially with respect to healthy pregnancies:

“I think your mind is important, too ... to have a clean mind ... to have a healthy mind ... and I believe that affects the baby they’re carrying”.

It was also important for youth:

“We’re trying to teach our children to have healthy minds. All they see is death”.

The discussion on mental health was tied to the need for community leadership and the need for positive programming.

### **Substance Abuse**

Substance abuse was discussed with regards to health of the community. This has already been mentioned with regard to unhealthy pregnancies, but participants also expressed concern about substance abuse in youth:

“I think we need the Chief and Council to encourage more young people, you know, to try and – even they did something bad: they need more encouragement. Don’t need to make them – you know, make them feel they wanna do something else, instead of getting drunk with super-juice, you know?”

Participants discussed negative strategies for dealing with substance abuse that were not helpful to the community such as the “Monday Night Report’ or the weekend – from the previous weekend – how many people that were arrested for drunkenness.” They discussed that community members caught drinking lose their jobs and have money taken off of their welfare cheques, and that this has a negative impact on their families because in the end “they don’t have enough food to eat for their kids”.

### **Prenatal Health**

Prenatal health was discussed extensively by the elders. Concerns raised involved the diets of pregnant women in the community:

“...you know, in regarding to young girls that are pregnant. I’ve noticed that, you know, they’re not eating the food they’re supposed to be eating. They’re eating chips or all this junk food, eh? And sometimes I wonder, you know, when the baby’s born, it’s not healthy at all. ‘Cuz I think they’re eating the wrong foods. And they should be eating – what they should be eating is the – you know, like, wild food, eh?”

Another concern was substance abuse. One speaker pointed out:

“that one of the probable causes of miscarriages would probably be linked to alcohol- and drug-abuse.”

Discussion on prenatal health also led to discussion of traditional methods of assisting in childbearing. This was spoken of with much respect:

“But my grandmother, who delivered many, many babies, told me when I started to have my first – maybe first month or 1<sup>st</sup>, 2<sup>nd</sup> month: she told me there’s a certain

way I have to turn around. I have to turn over on my stomach for the first four months – this way and that way. And then, after that, for me to turn around, I have to turn over. I have to get up, sit up and then turn this way. That’s what she told me. Because there were professionals – those ladies – midwives. They were professionals. They delivered many babies, you know? A long time ago, if a lady is expecting, they have to move – they always used to move around, eh? And then, they take one of the midwives to the trap-line. They know when they’re due. They take their midwives to the trap-line. That’s what they used to do. Not many babies died.”

A final observation about motherhood was that:

“women in [the] past breast-fed their children. They were not brought up with the bottle. And in those days, the women and children were more healthy. And I guess her observation would be that the change in the way that the children are brought up today may be a contributing factor to why children are sick. Their immune system may be low because of that.”

Overall, participants identified that sharing traditional knowledge about eating and moving was an important way to help young mothers and improve the health of the next generation.

## **Parenting**

Along with the discussion on prenatal health, parenting was mentioned as an important part of a healthy community. One concern was that currently:

“parents: they don’t have anything to teach. They don’t know what to teach their children today. Because, I think, they’ve lost that.”

Some of the participants provided the following explanation for the difficulties in parenting:

“we lost all those – our values, learning from our parents who were teaching their children. ‘Cuz they weren’t there. They were in either residential school or away from home. But, like, for us: I didn’t go to school; I think it was just a little bit. But our parents managed to - taught us some of those things – some of those things. ‘Cuz we weren’t taken away. Or we weren’t sent away. But some of those people that were out: they had no way of learning those things.”

The concern was expressed that much of the traditional knowledge important for raising healthy children was lost.

Several suggestions were provided to help young parents and included the suggestion that there be trained workers who could

“have those workshops with these young mothers ... I think home visits are important – for them to go to their homes and to teach the young mothers, as they look around in the kitchen area, in the living room area, how they can utilize the things that they have there to improve the lives of their young ones. And as these

young mothers are also carrying, they can – these workers can teach the young mothers at home, not just workshops – the hands-on teaching, I think.”

Again, the role of experiential learning, ‘hands-on teaching’, was emphasized as opposed simply telling young mothers what to do.

### **Link to the Land**

Many participants identified a link with the land as an important part of being healthy, though this was emphasized more in the elder group than in the adult group. One participant remarked:

“You know, you don’t think about your pain or anything, just think about what you see out there – you see – watching eagles or something like that. You know, just to be out there is good”.

Another participant connected health and the wilderness through the notion of creation and healing:

“When we go in the wilderness, we are healed... Because we see the creation, we hear the creation. We see creation moving, clouds moving. And we think; it makes us think. And we are healed.”

In the art projects, pictures of nature including animals, water and land were prominent. One participant explains:

“The picture of the lake looks beautiful we need to keep our land clean, and the way the water looks we need to stay calm”.

Reliance on the environment for resources such as clean water and traditional food were discussed along with statements about the spiritual connection to the land.

### **Traditional Food**

Several aspects of traditional food were mentioned with regards to health. First, it was widely acknowledged that eating traditional food was a healthy way of eating both because of the food and the activity required to obtain food:

“Back in the past how our elders lived and ate it never gave them diabetes, where they lived active life.”

One elder described that she

“was raised on a traditional diet of moose, fish. And the food was plentiful at that time. She recalls the preparation of the food to be mostly dried, smoked and boiled. It wasn’t rarely ever fried. And she attributes her health to this diet that she was brought up on.”

In addition to the understanding of traditional eating as healthy eating, community members also expressed the need for teachings about traditional food to be passed on. This was expressed by both the young adults and the elders. In one of the art projects there was a:

“picture of the elders to babies represent the teaching of living and eating healthy”

Elders expressed the need to start teaching the younger generations. One elder described teaching his own family:

“So what I’m trying to do now is trying to teach ‘em how to clean fish, how to, you know, clean the wild games – like the birds and the ducks and stuff like that. You know – how to prepare them properly. That’s what she’s teaching them – to try and get them to eat the proper stuff they were taught to eat, that we were taught to eat. You know? And I think – you know, like, their kids want to eat fish and they want to eat lots of moose meat. Wild meat: they love eating that. And every time I get fish, one of my grandsons – great-grandsons says: “You got jackfish?” Heh! Heh! He loves seeing that, eh?”

Another elder described the differences between the older and younger generations regarding traditional food:

“Even – when I go over on, say, a fishing trip – one-day fishing trip, I probably take bannock and tea – things like that. But if I take one of my young grandsons: chips, soft drinks – you know, things like that.”

While the focus group participants identified the health benefits of traditional eating and the desire to pass on teachings about traditional food they also identified the barriers to traditional eating. One participant explains

“... if we need to go out and... go out in the bush, it is – the fuel: it costs high. So it’s – even if you eat traditionally, it – the food is high, as well.”

Another participant expresses that:

“we’re losing the freedom to do that by having our guns licensed, by having our boats also getting licensed. Not everybody’s gonna be able to – to get that done.”

Finally, if the barriers of fuel costs and licensing can be overcome, participants also described barriers to traditional eating imposed by a lack of physical ability:

“We gather – we do the harvest in the fall and quite a bit of wild stuff, like fish and other things. So this is what we use. That’s – it ... good to be healthy, be able to do things. ‘Cuz I know – another thing I know: I know how it feels when you can’t do anything, when you’re bound to a bed or a chair.”

## **Traditional Medicine**

Traditional medicine was a very important theme that came up in the elder focus groups but was not mentioned in the adult focus group. There were many facets of traditional medicine that were discussed, the first of which was the need to learn about and use traditional medicines:

“There’s so much medicine out there that – which we have to find out. But it’s up to us to find them. And this is what we want to see – is the community to get involved in these things by finding out – to teach our kids.”

An important aspect of this teaching is that it could not be accessed in a textbook, but that rather there is an emphasis on experiential learning:

“...that’s the same thing as those Indian medicine. There’s no books. There’s no way you pass. You know, you don’t graduate. You know, it’s – it’s just your understanding and knowledge that you – that counts in Native traditional teachings.”

In addition, one elder brought up the idea of life-long learning and learning from each other:

“You’re always learning. There’s always somebody who’s – who knows a little bit, something else, not better but there’s always somebody who knows different ways. So that’s how people learn that way”.

The elders talked about the networks available to support learning about traditional medicines, including international meetings and cooperation:

“...we have people that used to come to our meetings from Hawaii, Chile, Japan, you know, and different countries, and trying to find information – what they are using and trying to combine everything that – what we have in our country in different places. ‘Cuz everybody uses whatever’s available in their – in their own back yard or something, in their own homes... And we were told that we should be able to find a way to cure Diabetes if we all combine everything together, as the years go by.”

One key point was that:

“It’s what we have in our mind, in our knowledge that should – that should be put together – what we have learned from our area and what we’ve learned from different other countries and communities.”

Another important point about traditional medicine is that it is not practiced for profit:

“...there’s always talk about money whenever we do something. But money doesn’t cure anything.”

“No, we don’t do that. We don’t charge anything.’ But even here, sometimes people come and ask for weekends and they wanna pay. And I said, ‘We don’t charge anything.’ But again, sometimes we told them, what they do is: sometimes they give ‘em either tea or tobacco, you know? That’s just to show you appreciation”.

The use of traditional medicines was also coupled with maintaining traditional values, including respect for all things:

“respect the plants and stuff like that, stuff that we use off the Mother Earth”.

Furthermore, this respect is accompanied by humility:

“You have to respect – respect the medicine that you give to people... Like, we’re medicine – medicine people, medicine man. You can’t go around and say, “This is what I did,” you know, ‘cuz you have to respect – very humble and respect what you did to other people. You just pray for them – your medicine to work.”

The mention of prayer also highlights the spiritual aspects of using traditional medicines. Elders discussed that:

“we can’t go around and say, “This is what helped her,” like, you know? You know, sometimes we – we believe that they’re also giving – we believe it’s all those prayers that was done for her, you know? That’s what helped her.”

Finally, the elders discussed that traditional medicine and western medicine could be used in concert:

“...this is what we’ve been taught. “There’s no way they’re gonna interfere with each other...” And this is what we’ve been doing all the time. Even I’m using medicine, what I get from nursing station – about 5 different kinds for my Diabetes. And I’m still using the Native medicine. It even helps a lot, you know? It doesn’t interfere.”

## **Water**

Water was a very important theme that arose in the focus groups and it has already been mentioned, above, in relation to being clean. Plumbing was a major issue that was discussed and was also represented in the art projects with pictures of sinks and toilets. One participant offered the following description of their art project that showed a tap with running water, a composting toilet and a polluted lake:

“The middle part deals with how we need water or could have toilets that are waterless composting and that we need education on how to dispose of bodily fluids safe.”

There was concern about the disposal of bodily fluids, and families whose washrooms consist of pails that get dumped in the bush, which then goes into the lake:

“That’s why, when you do – it will - always contaminates our fresh water. And when kids go swimming out in the lake, they get e-coli. So it’s not safe to go swimming

out in the lake no more. We used to drink right outta the lake before, not too long ago.”

The need for running water and plumbing was expressed alongside the need to maintain services that were currently in place. This included cleaning of the water tanks:

“They’re supposed to clean them at least twice a year with bleach – whatever they use to clean those tanks. And they – ever since they installed those containers, they haven’t been cleaned at all – not once.”

Beyond cleaning, participants also identified water delivery as a problem:

“But it’s very hard to get water and stuff in our reserve, eh, in some parts. They really have to really conserve their water.”

The need to conserve water arises because, as one participant explained:

“Sometimes people wait a week or – for them to get the water. ‘Cuz the water boy doesn’t take the water where the – when they want it, eh? I don’t know why – what’s keeping them? Maybe there’s too many people that are lined up for water”.

## **Housing**

Housing was an area of major concern for study participants, with one of the primary issues being overcrowding:

“...I was watching the news; it was last week. And they were talking about these inmates in the penitentiary. They said they were overcrowded. Like, there’s two of them in one cell and they called it overcrowded. And I said, ‘What about our people? You got about 3 or 4 families living in a 3-bedroom house. Aren’t we overcrowded? How can we be healthy?’ And they’re worried about inmates; there’s two inmates in one cell.”

The concern about overcrowding led to major health concerns:

“Like, overcrowding of our homes: like, one gets sick, everybody gets sick.”

As mentioned previously, barriers to keeping one’s self and one’s home clean are compounded with the problems of overcrowding and illness.

In addition to overcrowding, the other major housing concern was the quality of the houses:

“Some of these houses: they’re very old and they’re not insulated or they don’t have windows; they just use plastic.”

One participant describes living “in a house without no doors, just boards, no insulation, all cold.”

Finally with many houses being overcrowded and structurally unsound, participants discussed the need for new housing. Here, participants expressed concern about communication regarding new housing and distribution of new housing:

“We don’t know what’s going on with the housing. All – all we heard was just there’d be no houses this year. That’s what I heard – the Chief. That’s what they said, eh? – no houses this year. So we don’t really know what’s going on with the houses. Only the Chief and Council knows.”

Participants expressed concerns about the distribution of housing, Housing was understood to be preferentially available to councilors or those related to Chief and Council.

“they only give them – the family – to ‘em. Like, they only give them the new houses”.

### **Expense of Basic Necessities**

In the above categories many participants identified high costs associated with basic necessities. These included the high cost of healthy food; the high cost of fuel and gun or boat licensing for obtaining traditional foods; the high cost of cleaning products to keep houses clean; and the high cost of housing. The high cost of basic necessities, previously mentioned with regard to different areas concerning health, was an important condition affecting health in the community.

### **Community Perspective**

Community was a central concept in the discussions about health and often when a definition of health was given it was inclusive:

“Overall, just being active and mentally healthy, too, as well, for the – not for myself but our family, our family’s community – community as a whole, I guess.”

In addition, participants identified that poor health could be a feature of the community and not just of the individual. As regards the high price of groceries one participant explained:

“it really affects the community’s overall health, maintaining or preventing any sickness...”

### **Community Participation/ Engagement**

Despite a community-oriented understanding of health, focus group participants mentioned that not all community members were ready to get involved in keeping the community healthy:

“We need – we need help from our community. We have different issues. We have different conditions. We have different situations. But when we asked our community, they have – they don’t have time.”

Some participants mentioned being generally discouraged by the turnout of community members to meetings, although there was also mention of several events where the community did work together including a community clean-up, prayer walk and diabetes walk:

“And we can still do it. When we want to get together and do something – like, for instance, we have a Diabetes walk once a year. People do it. They don’t ask questions; they just go. They walk all the way from one end of the reserve, you know, just – and also we have a prayer walk once a year. That, too: you know, people just get up and go. No questions asked. You know? But if we wanna do something, you know, people seem to say, ‘Am I gonna get something out of it? Or what do I get – T-shirt or something like that?’”

Participants expressed the belief that if they worked together the community could become stronger:

“...we can fight the way – how to help each other, help the whole community”.

### **Community Independence**

In addition to approaching health with a community perspective, another important aspect in defining health was community independence. One participant remarked:

“You gotta do it yourself. You gotta keep – you know, you gotta keep working. You don’t expect people to come and do for you. That’s another thing ...we’re dependent, instead of independent. You know, it’s just the way we were brought up by the Government.”

Another participant attributes a lack of community initiative to government involvement as well:

“And that’s just the way we are - really dependent. And that’s the way the Government is making us to be. You know? Okay, the Chief and Council are really trying to get things going. And they can only go so far; they don’t get results if they don’t get funds. You know, they – they run into a brick wall so many times, and no matter how much they try”.

Participants identified a need for change to come from within the community, for example in cleaning the community:

“what we need is a clean environment. And how are we gonna do that? We have to do it the way it was done years ago. The people did that themselves. They didn’t have to get paid when they do something. They get together. And we can still do it. When we want to get together and do something”

### **Community Leadership Responsibilities**

The role of community leadership in improving the health of the community was discussed. In one instance, participants discussed the role of community leaders as people who needed be able to make changes:

“And sometimes we have leaders that are afraid... But if you wanna be a leader, you have to be very forceful. You gotta do it; you gotta tell us what you have to do to make the people realize, particular realize what they – what’s supposed to be done.”

In addition, community members recognized that community leaders had a role to play in growing pride in the community and therefore making the community more healthy:

“That’s been one of our problems within our community – is: there’s a lack of encouragement, empowerment from the Chief and Council.”

Here community members provided a suggestion for the role of community leaders:

“I think we need to – we need to – the elders or the Chief and Council: we need – they need – the young people need to hear from the Chief and Council and the elders that they have something good to go on all their life, eh?, that they maybe feel good, take pride on themselves, you know?”

In addition to encouraging youth, community members also suggested that there was a role for positive programming in growing the health of the community. Currently participants expressed:

“I think that’s one of the main problems that we have. There’s no – there’s nothing else to do in our community. You know, it’s basically wait for Welfare. You know? There’s nothing else happening within our community.”

“The community should motivate our community by, you know, starting up some kind of a program, like have, say, hockey. You know? At least they’ll have a goal set for them. You know, motivate students – talking about joining their – you know, looking at playing in the NHL.”

This, one participant suggested, would also lead to “Reducing drop-outs” and more kids staying in school.

## **Advocacy**

As participants discussed the issue of community dependence on government they also discussed the need to advocate on behalf of the community, for example, as regards the overcrowding of houses:

“‘They’re worried about 2 inmates in one cell? And they call it overcrowded.’ I said, ‘Let’s get something on a Facebook and see how much feedback we get from that.’”

The idea in this case was to publicize the issues of the community and “see how much help we can get from the outside”, speaking out on behalf of the community, rather than depending on government action.

## **Equity**

The issue of equity arose as a concern at a variety of levels. The first was with regard to the federal government and government priorities as reflected by where money is spent:

“...now Government is talking about all-weather road. You know, where are they gonna get all that money? Every time we ask for it, they say, “No money.” Like when he said Hydro: where do they get all that money? It’s so easy for them to get money to – and what – what are we gonna benefit outta that?” ... “You know, it’s just that – they don’t have any money to help the communities. But they have money to do a lot of things outside.”

Participants expressed concern that government spending failed to take into account the needs of their community.

Equity was also a concern within the community. As previously mentioned, community members identified the distribution of housing to family of chief and council as an area of concern. Furthermore, one participant identified questions about equity as regards single mothers:

“Here you gotta – I don’t know – live with your husband in order to get a new house. Heh! Heh! And they give – it’s not fair, too - what they’re doing – fair – like, you’re a single mom trying to make it. So you live anywhere you can.”

Finally, issues with community services were also brought up, specifically issues within the nursing station. This will be discussed further below, however, one of the art projects points to this in some detail with the following description:

“The bottom part deals with Health Care. How we the people don’t get Respect from certain Health staff and that it needs to be change. ie. Feel like they just want us in and out right away or they make us feel awful. The blindfolded part means how some of them don’t diagnose correctly just to get us out right away.”

## **Safe and Accessible Health Care**

Participants discussed safe and accessible health care as an important condition for health. An idea that emerged several times over was that community members did not feel they were getting adequate treatment at the nursing station. In one example:

“one mother said in there she was really given heck by the nurse – for trying to bring her child in. And that shouldn’t be. It shouldn’t happen. Now those young parents – they start being afraid to bring the children”.

One of the art projects shows a drawing of a “1-minute doctor” moving patients through the line as quickly as possible.

Another concern about the delivery of health care was that people were being turned away over the phone without a proper in-person assessment:

“...a lotta times, when you phone in, they’ll tell you, ‘Don’t come in. It’s not an emergency,’ like you said. But then, you still bring a child in and the nurse – when was it? Was it 2 days ago? Anyway, I heard... that the nurse had refused to see one of the children that were sick. And apparently that child was sent home. And the parents know when their child is sick. So another nurse came on duty and she sent that child out. And I think she’s just barely making it in Winnipeg.”

Other participants described similar circumstances of being turned away or being intimidated by the front-line staff at the nursing station and receiving inadequate care.

Suggestions provided in relation to the nursing station included that:

“I think the most important thing in that is how you’re being received by the front desk and by the screening nurse and the nurse-in-charge. And I think that’s – a lotta young people run into that and they’re afraid. They’re afraid for that. And that’s the reason they – they need to be respected. And there needs to be education for the receiving end.”

### **Objective 2:**

**Define the type of health care system that will support these health beliefs and values, using the Teasdale Corti definition of Comprehensive Primary Health Care as a starting point.**

### **Local reflections on CPHC:**

The adult focus group was asked to discuss the five tenets of the definition of CPHC:

1. Everyone has fair access to healthcare and other services or resources that they need to be healthy.
2. The community can work together more, with more knowledge and skills, and in a stronger way to promote and protect the health of community members.
3. The social and environmental factors that impact on health – for example, housing and water supply – are improved so people are less likely to get sick from these factors.
4. Community members are more active in decisions about the healthcare system and other policies affecting them and their health. And –
5. Everyone in the community gets healthier.

With regards to the first tenet, the adults discussed fair access to housing as described above. One participant explains that:

“I have lived in [Garden Hill] for – for 25 – over 25 years; I haven’t got a new house. So I’ve been living in all these old houses, renovating them.”

In addition, concerns about housing programs and costs were discussed.

“I mean, the people should have a say – a say in – a say before they can do that. They – the Chief should have told what – the community they’re gonna [let ‘em ?] in the community so the people will know and say - the people will say, [“I’m dissatisfied for them to do that”], you know? I don’t think it’s fair for them. Like, I don’t think it’s fair for them to pay for the HMC Housing ‘cuz it’s on the community and isn’t working”.

Beyond housing, the adults identified the cleaning of water tanks as another area where access to services required for health was not available.

“And the Band receives money to hire somebody to take care of that – cleaning all the tanks. But they haven’t spent a penny on it yet.”

Discussion about the second tenet, regarding the community working together to promote and protect health led to discussion about prevention and suggestions for promoting health through presentations and involvement of health care workers:

“We need to – they need – the workers need to do more presentations on a public place so we can be aware – what’s happening, you know?”

“...they need do more – do more presentations on local, not only – not just to sit in their office and say – expect babies to come and – mothers to come over and to ask him questions. They need to get more – go out more, do presentations like that.”

In addition, concern was expressed about the youth in the community not having anything to do or anything to look forward to. One participant suggested that:

“they need more, something to do. Need more – more people or young people so they can – something to do. More – create more awareness – something like that.”

Prevention was noted as an important and realistic way of improving community health;

“...everybody will get running water – sewage and water: that will never happen. But something we have to do – we have to look at prevention.”

The third tenet of the definition of CPHC was the most significantly emphasized. Participants were keenly aware of the social and environmental factors that impact on health. These included the high cost of food, and the fact that “we can’t afford them”; housing conditions including lack of plumbing, and the economy.

“Cuz some of these houses: they’re very old and they’re not insulated or they don’t have windows; they just use plastic. And these kids: they have to go in the pail in order to go to the washroom.”

“Unemployment rates are really, really high.”

One suggestion to help improve the social and environmental factors impacting on health was to have:

“...community resources workers in our community – like, providing some kind of housing – more housing, proper housing, houses being built properly, maybe more like liaison workers for the community members.”

These workers could help to advocate for better housing on behalf of the community members.

In terms of the fourth tenet of the definition of CPHC, participants remarked on barriers to involvement in health and suggested ways to create more awareness and involvement in health. One of the main concerns was the lack of motivation from community members to get involved:

“When we – we’re trying to do something now for the community, sometimes people don’t show up so we can do – give ‘em information – what they need to learn. That’s the problem. People don’t show up for the – say, if we have a workshop.” When community members do show up “they won’t show up for the activities. That’s – they only show up for the food - if they have something to eat or something for themselves to – to get something.”

Providing food was therefore a suggestion for how to motivate more community participation, as was providing transportation:

“...you can tell them rides will be provided. Maybe they’ll come.”

The aforementioned lack of communication between Chief and Council and the community is also considered in this category: without open communication it is difficult for community members to become involved in decisions about their health.

### **Objective 3:**

#### **Propose a governance structure and service model for this Comprehensive Primary Health Care System.**

#### **Literature Review**

A literature review of CPHC in First Nations communities in Canada was performed and highlighted some key areas of interest for future CPHC projects and planning. Specifically seven themes emerged as particularly significant points of discussion to be considered in planning of a governance structure. These were:

1. Political tradition and trends: Issues relating to First Nations’ health and health policy are subject to the changes and trends inherent in the political arena. The review mentions the protection of treaty rights and the identification of “Treaty Indians’ as political issue that affect health care provision, but are not clearly emphasized in the regional, provincial and federal politics.<sup>18,24</sup>

2. Structural barriers: A history of jurisdictional issues and continuing instability in this regard have a significant effect on the health care service delivery and consequently health outcomes.<sup>2, 6, 7, 9, 11, 16, 23</sup>
3. Reciprocal responsibility/Accountability: Both the Government and First Nations peoples are responsible for improving health outcomes of their people. Specifically, both parties need to accept this responsibility, a component of which includes increased First Nations participation in health care policy-making and implementation.<sup>3, 6, 7, 16, 19</sup>
4. Accessibility/Geography: Many variables contribute to access to health care (or the lack thereof) for First Nations peoples, however geography is particularly important considering the Northern and remote location of many of Canada's First Nation communities.<sup>1, 2, 6, 7, 16, 23</sup>
5. Social determinants of health: Of the social determinants of health culture was revealed in the literature as being the most profound and warranting a category of its own. Other important determinants included gender and mental health barriers.<sup>2, 6, 7, 16, 23</sup>
6. Culture: The limited availability of culturally safe health care, including services with culturally-based programs and awareness of local cultural and linguistic practices was a significant theme in the literature review indicative of unmet needs in the First Nations health care delivery.<sup>1, 2, 14, 24, 25</sup>

Additionally this review highlighted the need for a clearer definition of CPHC and its goal in projects that were attempting to improve primary health care in First Nations communities.

A second literature review on Indigenous definitions of health was also performed. The conclusion of this review emphasized the need for local definitions of health, the need to look carefully at the meaning of holistic health care in different communities<sup>28</sup> and found several overlapping themes in Indigenous definitions of health, particularly social determinants of health, culture and land<sup>28, 33, 36</sup>. The key point of this review was that focus on community self-determination and respectful, open-ended, dialogical processes were of critical importance in determining community definitions of health<sup>28, 29, 32, 36</sup>.

Currently in the Island Lake Region there is a public health project operating that is examining ways to improve public health program and service delivery. The project is governed by an Oversight Body that includes organization/ government representatives from all involved parties. A governance model for the new public health program and service delivery model has been agreed to, and is composed of the following:

1. Board of the Four Arrows Regional Health Authority (composed of two members, one political and one with health knowledge, from each of the four Island Lake communities).
2. Executive Director, Four Arrows Regional Health Authority.
3. Senior Public Health Lead, Manitoba Health and relevant Manitoba Health regional health authority(ies).
4. Senior Public Health Lead, First Nations Inuit Health-Health Canada, Manitoba Region
5. Senior Public Health Lead, partner provincial Regional Health Authority
6. Director of the Northern Medical Unit, University of Manitoba.

In addition to the Joint Governance Committee described above, there is an Elders and Youth Advisory Council composed of one elder and one youth member from each community. This committee has the role of being available to advise the governance committee or any of the public health units/ programs to ensure local and cultural relevance.

### **Discussion:**

The purpose of the current study was to document the conceptualizations of health, health beliefs, and values of the Island Lake residents and to define the type of health care system that will support these health beliefs and values, using the Teasdale Corti definition of Comprehensive Primary Health Care as a starting point. Repeated attempts were made to engage all Island Lake communities in the study, however, only Garden Hill First Nation was able to sign the research agreement in time therefore all data pertains only to Garden Hill. A third objective of the study was to propose the most appropriate governance structure and service model for this Comprehensive Primary Health Care System based on questionnaire results. As only one questionnaire was returned, suggestions regarding governance structure and health care service models are provided but the proposed analysis of questionnaires is not included.

Through thematic analysis of the focus groups a range of characteristics, ideas and conditions important necessary for health were outlined. These were food, physical activity, health body weights, being clean, mental health, substance abuse, prenatal health, parenting, link to the land, traditional food, traditional medicine, water, housing, expense of basic necessities, community perspective, community participation/ engagement, community independence, community leadership responsibilities, advocacy, equity, and safe and accessible health care. The results are indicative of the breadth of meaning involved in the concept of health as understood by the community and they direct further development of health care systems toward understanding and incorporating this wide definition of health.

As regards the Teasdale Corti definition of health, participants identified each of the tenets to be important with regards to the health of the community. However, because of the significant emphasis on and discussion of traditional lifestyles including food and medicines, addition of a clause considering the role of traditional health systems is recommended to complete the Teasdale Corti definition of CPHC. The association between traditional ways of life and health was commonly identified and the potential for community empowerment through the passing on of traditional knowledge was recognized as an area for community development and capacity building.

Discussion surrounding safe and accessible health care revealed concerns about front-line screening. The disparity from urban health care, where all patients *must* be seen and medically assessed, is alarming. Results from this study may be used to further investigate potentially unsafe health care practices, such as denying patients care over the telephone and may prompt re-evaluation of such practices.

Notable differences between adult and elder research activities included the language used in discussion and focus on traditional medicines. The elder participants spent much of the discussion using local dialects to communicate, where the adults spoke almost exclusively in English. Discussion of language as important in defining health did not arise in the adult or the elder focus group. In addition, the elder sharing circles identified traditional medicines as an important in defining health, whereas this topic did not arise in the adult focus group. The adult participants did not neglect to point out the significance of traditional lifestyles and of the handing down of traditional knowledge, however traditional medicine was not explicitly mentioned as being a part of health and/or traditional lifestyles. One possible explanation for this difference can be inferred from the elder discussion on residential schools: the elders identify that many traditional teachings were not passed on as a result of children being sent or taken away from their parents. Therefore, the younger generation of adults may not have been taught about these medicines, or may not have grown up using them given the political climate when they were children and youths.

The results from the literature reviews as well as the narrative report of community responses in focus groups has led to the development of the following suggestions for proposing a governance structure and service model for a CPHC system:

1. Incorporation of traditional healing systems into the definition of a CPHC system. This should be developed with the full engagement of traditional healers and knowledge keepers in the communities. Key aspects of this should focus on recreating the roles of traditional midwives as critical players in improving prenatal health, and teaching and enabling community members of all ages to hunt, gather, and prepare traditional foods.
2. Acknowledgement of and action on social and environmental barriers to health through modalities such as community resource workers or community advocates working within the health care system. Specific positions like housing liaison officers that bridge between the health and social systems should be created. Teaching advocacy skills to both health workers and community members would empower them to act on issues of food security, housing, and accessibility to other basic necessities.
3. Development of community capacities through hands-on teaching and home visits to help community members develop skills, such as parenting or home maintenance skills. In this way, health care that happens outside of the health center/ nursing station needs to receive greater emphasis and support with strong leadership within the community and regional government and health care systems.
4. The community's confidence that they will receive safe and accessible health care needs to be increased. This will include taking action to reduce unsafe practices in healthcare so that all patients must be seen and medically assessed at presentation to the nursing station (like at a triage desk in an urban emergency room) and also increasing community control over primary health care. Involving health leaders in the community (who could be health center staff or elders, for example) in training front-line workers in respectful and culturally safe care is needed.
5. These measures need to be adopted through practices consistent with community self-determination, and with attention to details such as transportation that will increase community participation and engagement.

There were several limitations to the study, the most prominent of which was the engagement with only one of the four Island Lake communities. Further, while two visits were arranged to the Garden Hill community, only one youth art activity and one adult focus group were held due to lack of participation. Questionnaires were another area in which desired participation was not achieved, and therefore a governance system has not been proposed as that would have been based on questionnaire results. Researchers anticipate increased participation in their future work after having learned from the experience and having developed an awareness of the barriers that exist to participation. Transcription of the elder sharing circle conversations placed a limitation on the interpretation of data, due to significant use of the local language and the lack of transcriptionists with background in the local language. This limitation was managed as two of the researchers did have language capacity in Oji-Cree and were able to translate directly both during the focus groups and later from the focus group recordings.

An element of the global CPHC project that has not yet been discussed in this report is the triad aspect of the research team. Initially our research mentor was Dr. Turnbull, with Dr. Anderson as the junior researcher and Grace McDougall and Alex McDougall as research users. However, after the initial study design period we did not often engage our research mentor as he also has a very busy schedule and is based in Ottawa. We also were able to hire a student research assistant, and Alex McDougall was elected as Chief of his community limiting his availability to continue on with this project. Therefore, our roles shifted through the project with Dr. Anderson being more of the mentor to Grace McDougall and the student. All members felt they learned a lot through this process not just about the topic but also in designing and carrying out community based research in First Nations communities.

It was unfortunate that we were not able to hold the second in-person meeting with the other Indigenous teams as our first meeting was very productive in terms of sharing knowledge, planning for future collaborations in this project, discussing ethical issues of global Indigenous research and relationship building.

### **Conclusion and Implications:**

Overall, after learning about local conceptualizations of health from the members of Garden Hill First Nation, a health system modeled after the definition of Comprehensive Primary Health Care is anticipated to better meet the needs of this community. One key addition to the proposed definition is to incorporate traditional healing systems in a way that is respectful and appropriate as determined by local traditional healers and knowledge keepers.

The results of the study will be delivered to the community in the summer of 2011. Community based research team members anticipate this will be very helpful to the community in the further development of healthcare system governance and healthcare delivery. Additionally, results will be disseminated in the peer-reviewed literature as there is little currently written about CPHC in Indigenous contexts.

## **Appendix 1: Plain Language Interpretation of Criteria of Comprehensive Primary Health Care**

1. Everyone has fair access to health care and other services/ resources that they need to be healthy;
2. The community can work together more, with more knowledge and skills, and in a stronger way to promote and protect the health of community members;
3. The social and environmental factors that impact on health (e.g. housing, water supply) are improved so people are less likely to get sick from these factors;
4. Community members are more active in decisions about the health care system and other policies affecting them and their health; and,
5. Everyone in the community gets healthier.

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