

# Seeing Clearly: A Community-Based Inquiry Into Vision Care Access For a Rural Northern First Nation

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## Abstract

There are a variety of barriers to eye-care service access in rural Northern First Nations communities. Semi-structured, opened-ended key informant interviews were conducted on the topic of eye care, with eight First Nations individuals employed by the health office in a small Northern British Columbian First Nations community. Data analysis comprised identifying themes by analyzing similarities and dissimilarities in participants' narratives, including comparing and contrasting viewpoints of participants and placing themes within broader sociocultural and historic contexts. Themes identified in the data included the current state of community eye care, facilitators and barriers to accessing eye care, and community needs and preferences. The theme of "facilitators and barriers" was further analyzed, resulting in subthemes of awareness, attitudes, social, economic, and service related. Better understanding of the barriers and their interactions would provide a foundation upon which innovative eye-care programs might be developed.

**KEY WORDS:** First Nations, British Columbia, Aboriginal, eye care, access, barriers, social determinants

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## Résumé

Toutes sortes d'obstacles nuisent à l'accès aux services de soins ophtalmologiques dans les collectivités des Premières Nations du nord rural. On a procédé, auprès de personnes-ressources clés, à des entrevues semi structurées et ouvertes qui ont porté sur les soins ophtalmologiques et huit personnes des Premières Nations employées par le bureau de santé d'une petite communauté des Premières Nations du nord de la Colombie-Britannique y ont participé. L'analyse des données a consisté à dégager des thèmes en analysant les similitudes et les différences entre les exposés des participants, à comparer les points de vue des participants et à placer les thèmes dans leur contexte socioculturel et historique plus général. Les thèmes dégagés des données comprenaient l'état actuel des soins ophtalmologiques dans la communauté, les facteurs qui facilitent et entravent l'accès aux soins ophtalmologiques, ainsi que les besoins et les préférences de la communauté. On a analysé plus à fond le thème des « facteurs qui facilitent et entravent », ce qui a dégagé des sous-thèmes comme la sensibilisation, les attitudes, les facteurs sociaux, économiques et liés aux services. Une meilleure compréhension des obstacles et de leur interactions jetterait une assise sur laquelle on pourrait s'appuyer pour élaborer des programmes innovateurs de soins ophtalmologiques.

## INTRODUCTION

The vision health of Aboriginal peoples has gained increased attention over the past decade. This increased concern stems largely from alarmingly high rates of diabetes and the potential for eye-related complications in most Aboriginal communities, which include (as per constitutional recognition) Inuit, Metis, and First Nations peoples across Canada.<sup>1,2</sup> Although Aboriginal eye care and vision health is a growing concern for various organizations, including the Vision Institute of Canada, the National Collaborating Center for Aboriginal Health (NCCAHA), and the Canadian Association of Optometrists, little Canadian literature exists on the topic.<sup>3-5</sup> Even less community-based research exists.

Of the existing literature, much is either outdated or quantitative and biomedical in approach.<sup>6</sup> Furthermore, literature produced in the past decade often focuses on eye care in relation to diabetes and to the exclusion of other health realities. Few studies explore Aboriginal eye care as a social issue. Although it is increasingly common for health research, especially in Aboriginal communities, to acknowledge social and historical factors as key determinants of poor health, studies about Aboriginal eye care do not often explore contextual factors, such as the unique geographic, economic, and social landscape of each Aboriginal community.

Some concern is expressed in the literature about members of Aboriginal communities simply under-accessing eye-care services.<sup>1,6</sup> However, the level to which Aboriginal communities, especially northern and rural Aboriginal communities, are underserved remains unknown.<sup>7</sup> A qualitative, community- and research-based approach allows insight into what we suggest are more salient and nuanced factors affecting a community's ability to access eye care. Accessing care is highly influenced by various social determinants, which are recognized by the World Health Organization as the economic and social conditions that are largely responsible for health inequities.<sup>8</sup> Social determinants include factors like income, social support, education, employment conditions, social environments, physical environments, child development, access to health services, gender, culture, and physical health and coping skills.<sup>9</sup> Broadly speaking, social determinants are “the causes of the causes” of poor health, or the factors that interact to influence health status. Income, for instance, affects (especially First Nations') ability to access health services, quality of housing, quality of food, and several other factors that can impact health. Colonialism is a well-evidenced and significant social determinant of Aboriginal peoples' health.<sup>9,10</sup> Historical policies that reach into today, including the Indian Act and “Indian” reserves, have had devastating effects on traditional economies and family systems. Residential schools, resulting in loss of language and loss of culture, are understood as having lasting negative multi-generational effects on the health of Aboriginal communities.

We contend the most appropriate way to study Indigenous use of and access to eye care is by employing a qualitative research approach that accounts for social, cultural, and historical contexts surrounding choices about eye health. A qualitative community-based project was thus designed to explore access to eye care for a rural Northern First Nation in British Columbia. The purpose of this community-based project was to open new spaces for key informants to express thoughts and feelings about access to eye-care services in their communities.

## METHODS

The Lake Babine Nation is a First Nation located in Northern British Columbia. It is the third largest First Nation band in British Columbia with a population of over 2,300 people.<sup>11</sup> The nation consists of five communities, three of which are inhabited year round.<sup>12</sup> Each community is uniquely situated in its ability to access care. Woyenne is located adjacent to the Village of Burns Lake and has access to a local optometry clinic. Tachet and Fort Babine are smaller and more remote communities and require an hour or two of travel to access the nearest clinics.

This study was conducted in Woyenne, the largest of the Lake Babine Nation communities. Woyenne is the administrative centre for the Lake Babine Nation and houses both the band office and the health office.

**PARTICIPANTS**

Aboriginal employees at the Woyenne health office were invited to share their unique perspectives on the provision and access of eye care in their communities. Employees at the health office are originally from various Lake Babine communities and were thus able to offer first-hand knowledge about the communities throughout the Lake Babine Nation. We believed these people might have insight into the challenges faced by the health office and community members, in considering eye-care services. Potential key informants were identified and invited to participate predominantly because a community knowledge holder identified them as playing a role in eye care within the community. The involvement of community knowledge holders is in-line with best practices for conducting community-based research with Indigenous communities.<sup>13</sup> In total, eight individuals expressed interest in participating. We also used some snowball sampling techniques to identify other people who would have relevant experience within the office. The participant sample represented a variety of demographics; six women and two men aged between 20 and 60 years participated. All participants were of Aboriginal descent.

**PROCEDURES**

Undertaking research with First Nations requires adhering to specific and culturally appropriate protocols, including receiving support from the local band and council government and developing personal relationships to ensure appropriate ethical behaviour. We spent most of our lives in Northern BC, working with and in northern communities, including many First Nations communities and organizations, which ensured many pre-existing connections and relationships. We also received clearance from the institutional research ethics board at the University of Northern BC. After obtaining written consent from the participants, we conducted face-to-face qualitative interviews and audiotaped participants in a location of their choosing in their community of Woyenne. The interview consisted of 13 semi-structured, open-ended questions (Appendix A). The interviews were then transcribed and analyzed for themes. Data analysis consisted of close critical readings of the work. Thematic analysis emphasized discursive systems of power that might be present in the narratives, which allowed us to explore similarities and dissimilarities in the participants’ narratives—especially regarding how eye health was socially determined. We also accounted for decolonizing perspectives in order to ensure a privileging of Indigenous storytelling traditions, traditions that often prompt participants to respond to questions from a community perspective and with a more open-ended, sometimes even metaphorical, response to direct questions. Finally, we approached the participants’ words as narratives and tried not to extract components of a story told without recognizing the story’s social and historical context. Critical race theory informed our approach to the narratives, meaning that narratives were understood to stand on their own, as opposed to being questioned or scrutinized for some objective content of “truth” or “fact.”

**RESULTS**

The key informant interviews yielded three categories of qualitative information (data sets). We categorized the first data set as information pertaining to the current state of eye-care services. The second data set can be summarized as “facilitators and barriers to accessing care.” In this second data set, participants’ statements were further analyzed to reveal five subthemes: awareness, attitudes, social factors, economic, and service related. We categorized the third data set as that which identified community-specific needs and preferences (Figure 1).

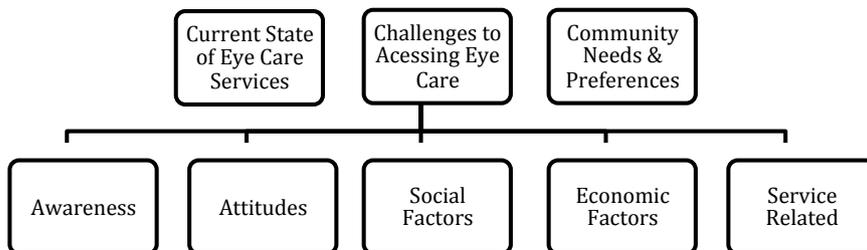


Figure 1. Themes and sub-themes identified by key informant interviews.

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## CURRENT STATE OF EYE-CARE SERVICES

Participants shared their knowledge and opinions about the current state of eye-care services in their communities. Both on-reserve and off-reserve services are available to Lake Babine communities. The health office in Woyenne plans and organizes the on-reserve services for all of the communities. Different participants identified different services, indicating a lack of fully cohesive and centralized knowledge about the services available. Some knew of an optometrist who had recently provided on-reserve eye-care services and others discussed a mobile diabetes clinic that also provided some eye-screening services. Although there are some on-reserve services, they are available at a very low frequency. Local off-reserve clinics are also available, although some travel is required for people living in Tachet and Fort Babine. If secondary care is required from an ophthalmologist, a significant amount of travel is required of members from all communities. Participants expressed varying degrees of knowledge about the services available to the community. They were aware of the off-reserve services available; however, some of the on-reserve initiatives were less well known.

Participants emphasized the distinctness of each of the communities in their nation. Consequently, geography, economic, and social factors uniquely shaped each community's ability to access care. Several participants expressed concern about people's ability from the two more remote communities of Tachet and Fort Babine to access care because of increased challenges around isolation. In particular, barriers such as vehicle access, cost of fuel, leaving family, dangerous roads, and winter driving conditions were all identified as much larger and more pressing considerations for those in the more remote communities. Also, a commonly expressed feeling was that, although residents were aware of services available off-reserve, they tended to wait until such services were offered on-reserve due to travel costs and the stress of leaving their family and community for a potentially long period of time. One participant suggested that community members were specifically waiting for on-reserve care because the health office covers the exam fee. The participant noted that, "right now people are waiting [for a time when] we bring someone [on-reserve]. [They're] waiting so they don't have to pay the exam fee" (Participant 1: Personal communication; interview). Developing an understanding about the current state of eye-care services would allow a deeper understanding about strengths and weaknesses of the current standard, thereby providing an evidence base for improvement.

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## FACILITATORS AND BARRIERS

We analyzed and categorized the barriers thematically to provide a summary of specific challenges faced by the communities. Further exploration of each theme, based on statements made by the participants, provides unique insights both into individual beliefs and more generalizable opinions. The details provided from the interviews helped to identify specific issues that might be addressed in order to improve access to care. We identified the following five types of barriers: awareness, attitudes, social factors, economics, and service-related barriers. We explore these in depth, here.

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## AWARENESS

Awareness is a major determinant in accessing care. In short, one has to be aware of a service in order to access it. Service awareness, eye-care insurance awareness, and awareness about the importance of eye care can influence if and how a person accesses care. Participants generally felt there was some awareness about the services available. However, the question surrounding the frequency and location of services elicited significantly varied responses, suggesting that awareness might not be as high as the participants perceived. Another awareness barrier was lack of knowledge about how non-insured health benefits (NIHB) function. The significant gap in awareness regarding NIHB may deter access to service. Because many on-reserve First Nations people live with elevated rates of poverty, fear of incurring costs may prohibit even preliminary inquiries about eye-care services. Within the payment structure for eye care in British Columbia, there are three potential payers for Status Indians. The three sources of payment are the provincial medical services plan, NIHB, and the patient. Occasionally, individual reserves may decide to cover or help cover the patient's portion of the exam fee. Awareness about available services was also identified as a barrier for some people living on the reserve. Participants expressed concern about whether individuals were fully aware of the importance of eye care. As health care workers,

the participants were acutely aware of the importance of eye care for vulnerable populations, such as children, diabetics, and seniors; however, they were unsure if this awareness extended to the general community. Although there was a generalized awareness about eye care health services, a significant amount of confusion and concern among participants remained.

## ATTITUDES

Participants spoke broadly about feelings of apprehension towards eye care, which may result in people being less likely to seek out or access services; conversely, if there is a comfortable and positive attitude about eye care, people may be more likely to access it.<sup>14</sup> The three main attitudes expressed by participants were inconvenience of seeking care; a sense of eye care as wellness; and feelings of mistreatment by the government, who they linked to eye care. Many participants said that accessing off-reserve services is a major inconvenience, particularly for people living in the Lake Babine communities. One participant thought community members were pursuing alternatives to accessing care, including buying and using cheap department store reading glasses. This participant believed the convenience and wide availability of department store reading glasses made them an attractive alternative for community members, despite these glasses perhaps having deleterious impacts on overall vision health. The participant stated, “I think that it’s more convenient for them to just go downtown and just buy a set of reading glasses for twenty bucks” (Participant 2: personal communication; interview). Participants also linked eye health to overall health status, acknowledging that it does impact quality of life. One participant discussed how altered vision, due to dilated fundus examination, and the inability to drive immediately after an appointment, affects people’s ability to access resources outside rural communities and, consequently, their quality of life. Many Indigenous people in Canada have remarkable strengths and resiliency. Equally true, as Elder Willie Ermine once noted, is the tendency of settler researchers to “pathologize” Indigenous peoples – arguably an extension of ongoing colonial violence.<sup>15</sup> Nevertheless, especially in isolated Northern First Nations communities, there are often elevated rates of poverty; having a car, or the money to buy gas for it, must be accounted for when considering issues around eye care and health.

Feelings of mistreatment toward the government were also expressed in the interviews. Several participants voiced their concern about budget cuts, changes to NIHB, and the quality of government-funded eyewear available to First Nations people. Participants associated lower-quality government-funded glasses with outcomes like social exclusion, stigmatization, and racism. In other words, participants felt that governments might, within a context of vision health and care, be perpetuating ongoing social and historical colonial narratives in which First Nations are “second-class” citizens. One participant discussed an experience of being made fun of because of their “funny glasses” while growing up. This was a hurtful experience that might have impacted not only the participants decision to access eye care, but also the kind of advice the participant offered to other community members. Based on our personal connections with optometrists in the north, we validated the participants’ concerns about the quality of government-funded eyewear. One optometrist noted that, “The funding model does not allow higher-quality frames that would be more durable to be purchased. They do fund lenses reasonably, but those patients requiring a progressive lens must pay the out-of-pocket difference from a bifocal. With the common use of computers, a bifocal lens is inappropriate but likely the only option available if the patient was poor. Most first nations are getting a budget frame and basic lenses compared to other patients”(personal communication with a Northern BC optometrist, email; March 17, 2015).

The aforementioned attitudes can directly shape access of eye-care services by either encouraging care (link between eye care and wellness) or discouraging care (feelings of marginalization by the government). If First Nations vision health is to be improved, it is necessary to consider how experiences and understandings about government or professional attitudes towards First Nations people influence and shape their access to and choices about care.

## SOCIAL

Identified social factors included lack of translators for Elders, feelings of discomfort in clinical settings, and conflicting community events—many of which were culturally imperative. The availability of translators for Elders is incredibly important for improved communication between

the patient and their doctor. The challenge of finding translators to attend appointments was one of the main reasons cited for preferring on-reserve care: within their home communities, Elders and others for whom English is not their first language were more likely to find translators. Away from home, such informal translation was more challenging. The interviews also made apparent that community members sometimes feel misunderstood by health care practitioners. One participant recommended practitioners travel to reserves to see how the communities live. This might result in greater cross-cultural understanding, something participants clearly voiced as a potentially positive factor in increasing First Nation buy-in to vision care. In addition, increasing levels of trust between practitioners and patients could prove to be valuable in encouraging community members to access care and developing continuity of care.

Another culturally specific aspect that needs to be better understood by vision care practitioners is the relatively transient nature of members of First Nations reserve communities: many people travel to attend important community events, such as funerals, marriages, potlatches, naming ceremonies, and educational milestones. Many members also move back and forth between communities or back and forth between their reserve communities and urban centres.<sup>16</sup> Thus intermittent or travelling vision health care clinics may not reach intended populations simply because of scheduling.

### ECONOMIC

The most frequently discussed barrier explored by participants concerned the expenses associated with seeking care. Indeed, all participants identified expense as a major barrier. Participants discussed how costs associated with exams, travel, and eyeglasses affected their community members' ability to access care. The majority of individuals in many First Nations communities are from low-income backgrounds, so expenses such as eye exams are a lower priority than, for instance, food and shelter expenses. Some participants stated that community members are simply waiting until eye-care services are available on the reserve in order to save on expenses.

When eye care has been offered on the reserve, the nation's health office has funded the portion of the eye exam fee that would not ordinarily be covered through government funding. Thus, one of the reasons residents prefer to wait for on-reserve eye care is the decrease in personal out-of-pocket expenses. Financially, the expense of subsidizing eye exams affects the health office by consuming resources that might have otherwise been directed towards other health initiatives within the community. The low-income nature of these communities greatly affects the individual's ability to access care as well as the expense incurred by the health office in providing eye care for their communities.

### SERVICE RELATED

Service-related barriers included a lack of availability of on-reserve care. The lack of services and the difficulty of getting practitioners to travel to the reserves have created a deficiency of culturally safe and easily accessible on-reserve services. These challenges are exacerbated in remote communities, highlighting the multiple challenges faced especially by residents of small and isolated First Nations. Insurance eligibility coupled with the low frequency of on-reserve care is an additional challenge. If the period for renewed eligibility has not elapsed, the individual may need to wait a long time before services are offered on the reserve again. For instance, if a patient received an eye exam on July 20, 2013, they would not be eligible for another exam until July 20, 2015. So, if eye-care services were offered on-reserve July 15, 2015, they would not be eligible to receive a funded eye exam and may have to wait another year or more until on-reserve care was offered again. This scenario is particularly concerning due to the lower health status of First Nations communities and the role eye exams play in early identification of various systemic diseases, such as diabetes.

Off-reserve services and secondary levels of care require travel, which is a major deterrent to seeking care. In particular, the large geographical distance between the reserve communities and secondary eye-care services such as ophthalmologists is a substantial barrier due to the increased distance of travel.

## COMMUNITY NEEDS AND PREFERENCES

The interviews yielded information about community needs and preferences. All of the participants expressed a strong preference for on-reserve care for the community. On-reserve care reduces cost to the individual, travel expenses, and language-related barriers. Participants felt on-reserve care was more customized to the unique needs of their First Nations community. There was such a strong preference for on-reserve care that we questioned whether community members would access off-reserve care, even if barriers were addressed. On-reserve vision care might ultimately be the best solution to poor eye health in First Nations communities. Participants also felt the frequency of service was too low and that there was a lack of follow-up. One participant discussed an experience where some individuals from the community had asked the office workers questions about the on-reserve care they had recently received. The office worker did not know where to direct the questions because the optometrist had already left. This illustrates the need for greater continuity of care and the development of lasting relationships between practitioners and the community. It also demonstrates the need for long-term relationships and a commitment to continuing clinical knowledge among First Nations communities.

Participants expressed a desire for more community education about the importance of eye care. Education through workshops, accessibly worded and culturally specific pamphlets, in addition to more education during appointments, were all suggested. Participants thought that these initiatives would be well received by community members.

The qualitative community-based interviews produced a wealth of information surrounding community access to eye care. The value of this study is in the specific comments nuanced in the context of the participants' conversations with the researcher. Many of the issues are intimately linked and can only be briefly examined here.

## DISCUSSION

Key informant interviews as an instrument for qualitative inquiry empowers participants in a way that values their views and perspectives.<sup>17</sup> By listening to the participants' viewpoints it is possible to both deepen our understanding about the functioning of the community more broadly and about the specific challenges they face. This in turn yields valuable information about ways to cultivate lasting and meaningful relationships between practitioners and communities. Upon analysis of both the interviews and existing literature, a number of important points surfaced.

The findings of this research affirm the importance of a social determinants framework when exploring eye-care accessibility, particularly in First Nations contexts. Reading and Wein suggest there is a relationship between health inequities and "the degree to which inequalities in the social determinants of health act as barriers to addressing health disparities."<sup>10</sup> Many of the barriers discussed by participants can be traced to social roots. Consequently, ocular health should be considered in relation to social determinants of health. Furthermore, as some literature emphasizes how different communities have been differently impacted by history and colonialism, it is important to understand the unique and particular ways that social determinants, including colonialism, manifest in relation to eye and vision health.<sup>18</sup> The importance of community differences was reflected upon by participants who emphasized the uniqueness of each of the three communities, underscoring the importance of health research using a historical lens to develop a greater and more specific understanding about First Nations communities.<sup>19,20</sup> Due to the uniqueness of the communities, each one should be considered individually when addressing the challenges they face in accessing care.

A particularly interesting insight offered by participants concerned levels of community awareness surrounding on-reserve eye care services. Participants believed good community awareness existed about the on-reserve eye care services. However, responses about the frequency and location of these services varied. In a study by Palagyi and colleagues, awareness about services was found to be the greatest barrier to accessing eye care for a group of Indigenous people in Timor Leste.<sup>14</sup> Although the circumstances of the Indigenous people in Timor Leste may be radically different from peoples in Canada, this finding demonstrates the importance of service awareness. It is important not to overlook awareness as a barrier; further inquiry may be valuable.

The barriers cited most often in the interviews were economic and travel barriers. These seemed to be the major reasons for preference of on-reserve care. Participants felt that having on-reserve care helped eliminate many of the barriers to accessing care, including cost of exam, understanding of insurance, travel, and language barriers. Having exams on the reserve also helps the community's health office to ensure children in the community are in fact receiving eye care. However, drawbacks to on-reserve care do exist, including low frequency of service availability (e.g. clinics travel in intermittently) and the challenge of finding practitioners to travel to the rural communities.

Some participants expressed concerns and awareness about the relationship between diabetes and eye care. In the literature, significant concern is expressed about the elevated rates of diabetes in many First Nations communities and the potential for eye-related complications.<sup>1,2</sup> Some of the participants' statements suggest that greater education and diabetes-specific eye care initiatives might be valuable to these communities.

Another important aspect of providing care to First Nations communities is developing ongoing patient-doctor relationships. A significant amount of literature discusses the importance and continuity of such relationships, particularly within the context of Indigenous communities.<sup>21-23</sup> Based on participants' statements, their communities could greatly benefit from more follow-up and continuity of care. It takes time to earn a community's trust and truly understand their social, cultural, and historical circumstances. Understanding the community is important for providing culturally sensitive care and developing cross-cultural understanding. One limit of this study is that the results are specific to the communities investigated and should not be generalized to other settings and communities. Nevertheless, it might be surmised that creating semi-self-sustaining eye-care services would benefit these and other First Nations communities.

## CONCLUSION

The topics of access to eye care and social determinants are inseparable when considering a community's access to care. Research should go beyond acknowledging the existence of these determinants. An ideal approach should attempt to develop the understanding of these factors within the context of the research and to address the underlying issues. Community-based qualitative research as a method for inquiry provides a wealth of information that has enormous value both for the community and for practitioners. Identifying a community's understanding about issues affords professionals the foundation upon which to develop meaningful understandings about the communities they work in. Furthermore, discussing and acknowledging issues surrounding eye care promotes greater awareness and fosters discussion within the community. Many of the social, economic, and service-related barriers are easily addressed through a well-designed eye-care program. The barriers related to awareness and attitudes are more difficult to address and their effects are likely underestimated. Future eye-care initiatives should take a community-specific approach, be predictable and consistent, and incorporate features designed to address community awareness and attitudes, particularly, in addition to the other barriers. From here, it may be possible to see even more clearly a future of optimal optical health.

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## APPENDIX A

### 1. Participant profile:

- a. Age
  - b. Gender
  - c. Are you a member of the Lake Babine Nation?
  - d. How long have you been involved in Health Care with the Lake Babine Nation?
  - e. What is your role within Lake Babine Health?
2. In your view, what challenges do your communities face in accessing eye care?
  3. When Lake Babine Health introduces a new health program, what are the biggest factors that determine its success?
  4. What type of appointments are best for your communities? On-reserve versus off-reserve eye care? Scheduled appointments versus drop-in format?
  5. Has awareness or lack thereof about eye care services impacted your community in accessing services? For instance do your community members know of the services available to them?
  6. What are some prevalent attitudes in regards to eye care in your community? For instance, do people feel that there is no need, feel they can manage without or accept eye problems as a normal part of aging?
  7. What eye care services are available to your communities?
  8. Are the eye care services available to your community easily accessible? What would make them more easily accessible?
  9. Do you think the eye care services available to your community are adequate? How might they be improved?
  10. What do you think could/should be done to get more people from your community to use the services available?
  11. From a health organization perspective what are the biggest challenges that Lake Babine Health faces in securing eye care for its communities?
  12. Reflecting on the recent on-reserve eye care services that were provided, what went well and what do you think could have been done differently?
  13. Do you have anything else you'd like to tell me about on the topic of accessing eye-care?