Surveying Indigenous Cancer Support Needs
Survey Design and Development

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By

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ABSTRACT

Cancer survival rates are currently lower amongst Indigenous Peoples in Canada than non-Indigenous Peoples in Canada (1). Health professionals speculate that late cancer diagnosis and limited access to screening and support services are some of the main factors contributing to lower survival rate among Indigenous cancer patients (2). Fortunately, social supports have been found to improve cancer survival rates (3,4). Yet, there is little known about whether cancer support services meet the needs of Indigenous peoples. The purpose of this research was to create two survey tools that could evaluate the cancer support needs of Indigenous patients in Saskatchewan from both patient and health care provider perspectives. Surveys were created using existing cancer support surveys as reference, though none previously existed specific to Indigenous cancer patients. In addition, current literature surrounding Indigenous cancer supports was used to create the surveys along with informant input. Both surveys were created by matching survey content to themes to those found in an environmental scan and those in interviews from a study also evaluating cancer support needs for Indigenous patients. Surveys were validated using respondent validation and informant feedback. The result of this research was two survey tools; one to evaluate patient perspectives and another to evaluate health care provider or facilitator views on cancer support needs for Indigenous patients. The results of this study will benefit Indigenous cancer patients, their families, and their communities. The two surveys created in this study could help to inform health professionals and policy makers on the needs of Indigenous cancer supports in future research.

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DEDICATION

This research is dedicated to Indigenous cancer patients and their families. This is inclusive of anyone that has had, currently has, or has passed on from cancer. It is also dedicated to health care providers or facilitators working with Indigenous patients or their families.

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CHAPTER 1: REFLEXIVITY

1.1 Reflexivity & Researcher Background

Reflexivity in research is a necessary qualitative research process requiring self-reflection that allows the researcher to locate themselves in terms of the research context (6). Reflexivity and self-location are important to research in order for the researcher to acknowledge their research bias and to promote research validity (7). As such, I will share a little about myself, my interest in cancer research, and my interest in Indigenous research.

With regards to cancer, I have little professional experience aside from minor education in the medical and biological processes of cancer. Personally, I have never had cancer myself. I have however, experienced it as a friend, student, and family member of people that have had or currently have cancer. Through these experiences I know how hard this illness can be to fight and can attest to the importance of support to the battle against cancer. My professional and personal experiences with cancer have influenced this research study by promoting my passion for Indigenous health and by constructing the outsiders experience that I have with cancer.

In relation to the population of this research study I am a non-Indigenous white female with settler roots. I am from the small-town of Wolseley, Saskatchewan. I grew up in rural Saskatchewan and spent the formative years of my life on the Saskatchewan prairies.
I completed my Bachelors of Kinesiology and Health Studies at the University of Regina. My Bachelors education fostered a passion for public health which drove me to pursue a master's degree in Community Health and Epidemiology at the University of Saskatchewan. Throughout my undergraduate education I was allotted the privilege of studying Indigenous health through both a traditional and public health point of view. This interest has led me to pursue research with an Indigenous health focus. I became interested in Indigenous culture and health throughout my undergraduate education. To further this interest, I enrolled in various Indigenous studies, and Indigenous health studies classes. These classes helped foster my knowledge of Indigenous

issues, Indigenous culture, and Indigenous ways of knowing. In regard to current research I am excited for the opportunity that this project will give me to pursue Indigenous research.

1.2 Approaching Indigenous Research

One of my first classes in university was introductory Indigenous Studies, which opened my mind to the horrors of racism and cultural genocide that ravaged the communities of Indigenous Peoples of Canada on behalf of the government. Craving to learn more I took other classes in Indigenous studies and Indigenous health. My studies taught me more about the beauties of spirituality, and the Indigenous belief of holistic health; further fostering my interest in Indigenous health that continued to develop throughout my undergraduate education (6).

My interest for Indigenous research stems from the interest that I acquired in Indigenous history and health in my undergraduate education. It is also driven by a general interest in well-being, equality, and equity for all people. As a non-Indigenous researcher doing Indigenous research, I believe that respect for Indigenous culture, education on Indigenous history, and collaboration with Indigenous people are essential to any research conducted with Indigenous people. I think that it is important that research be fostered by aligned interests, working together, promoting co-learning, and that it is focused on strengthening Indigenous capacity for Indigenous research. My goal is not to conduct research on Indigenous people, but instead to use my skills and efforts to help lessen the health gap between Indigenous and non-Indigenous people by working with Indigenous people on issues that matter to them.

CHAPTER 2: INTRODUCTION

2.1 Introduction

Rates of cancer in Indigenous people are higher now than they have ever been in Canadian history (1). Cancer survival rates are also lower amongst Indigenous Peoples in Canada than non-Indigenous Peoples in Canada (1). In Saskatchewan First Nations cancer incidence increased four-fold from the years between 1967-1986, while cancer incidence for non-First Nation Saskatchewan citizens had only doubled (2). By 2001, cancer was identified as the second leading cause of death for First Nations females in Canada and the third leading cause of death for First Nations males (8). This upward trend of cancer incidence is continuing within the population of Indigenous Peoples in Canada (1, 2).

Compounded with the growing rates of cancer incidence within Indigenous Canadian populations, cancer survival rates are also lower amongst Indigenous Peoples in Canada than non-Indigenous Peoples in Canada (9). Health professionals speculate that late cancer diagnosis, less participation in cancer treatment, and lower cancer screening participation are some of the main factors contributing to lower survival rate among Indigenous cancer patients (9,10). In addition, cancer is typically feared in many Indigenous cultures, therefore experiences with cancer diagnosis and treatment may be especially difficult for Indigenous patients (8).

Further contributing to the problem of higher cancer incidence and mortality for Indigenous people is the complex and multi-jurisdictional organization of the health care system (10). First Nations, Métis, and Inuit health care policies in Canada are complex. Health care coverage for each group in Canada weaves between federal and provincial coverage, differs for Indigenous peoples living on or off reserve (though Métis people have the same coverage as non-Indigenous Canadians, on or off reserve), and changes between provinces leading to even more issues for Indigenous patients (10). Limitation of health services for specific Indigenous groups, as well as discrepancies in coverage dependant on status are examples of such issues; these issues further inhibit access to health care services and support services for Indigenous people in Canada (10).

In addition to the inconsistencies faced in the health coverage, different groups of Indigenous peoples commonly hold varied beliefs, worldviews, and languages (6). Unique Indigenous perspectives on life and health justify the need for health services and supports exclusive to Indigenous people (6). Ultimately, cancer is a frightening diagnosis for anyone but when compounded with issues already facing Indigenous peoples exploring cancer care for this population is especially unique.

2.2 The Problem

The health care system for Indigenous people is fragmented, complex, and multijurisdictional, therefore experiences with cancer diagnosis and treatment may be especially difficult for Indigenous patients (10). Fortunately, social supports and positive social relations have been found to improve cancer survival rates (3,4). Positive correlations have been found between informal and formal cancer supports and quality of life throughout treatment rates (3,4).

Yet, there is little information regarding how the cancer journey is understood by Indigenous cancer patients, their families, and their communities (9). There is also little known about the cancer care supports available to Indigenous cancer patients in Saskatchewan (11). Saskatchewan is currently the only province in Canada outside of the maritime provinces that does not have cancer support services or materials unique to Indigenous patients despite 16.3% of the population in Saskatchewan being of Indigenous identity (11,12). In Saskatchewan, there are seventy First Nations, and nine Tribal Councils (13). Indigenous people in Saskatchewan identify predominantly as First Nations or Métis (12).

This project focuses on cancer supports for Indigenous cancer patients and their families throughout their cancer journey. This encompassed gathering knowledge on different supports already available to Indigenous cancer patients throughout their care and using that information to identify how to make these supports more accessible to patients, and in addition to identify gaps in the supports for Indigenous cancer patients.

Cancer care supports are defined as programs, services, and groups that help cancer patients and their families cope with the physical and psychological stresses of cancer as a disease (4). The supports of interest will be those utilized throughout the entire cancer experience from cancer care to returning home. This project will create two survey tools designed to evaluate cancer supports and services for Indigenous cancer patients. Creating survey tools that can identify support gaps for the population will allow for targeted interventions, improved cancer care experiences, and may possibly result in better outcomes for Indigenous cancer patients.

It is important to know how Indigenous people in Saskatchewan understand cancer, to identify the cancer care supports available to Indigenous people in Saskatchewan, and to assess cancer care priorities of Indigenous people. **To help gather this information this study yielded two survey tools that can be utilized to explore the needs for cancer care supports specifically for Indigenous cancer patients, their communities, their families, and health care providers in Saskatchewan**. This information is vital to inform health policy, and to ensure that the necessary cancer care supports are available to Indigenous cancer patients, their families, and their communities in Saskatchewan.

2.3 Study Purpose

The purpose of this study was to design and validate two survey tools that will accurately explore First Nations and Métis cancer support needs in Saskatchewan. Feedback from an initial patient-focused survey lead to the creation of an additional survey targeted towards health care providers that provide or facilitate care for Indigenous cancer patients. The creation of a second survey was deemed necessary to further explore the barriers to accessing Indigenous cancer care supports. This study, therefore, will yield two survey instruments focused on improving access and availability of cancer care supports for First Nations and Métis people in Saskatchewan.

The primary objective of this research is to develop two survey tools that accurately explore the research question from two perspectives. One survey tool will be directed towards Indigenous cancer patients, survivors, and their family members. The second survey tool is targeted towards health care providers or facilitators working with Indigenous cancer patients.

Both surveys were created by matching survey content and themes to those from an environmental scan and key informant interviews obtained from the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* (11,14,15). Both surveys were validated using feedback from health care, patient, and research advisors to help improve survey accuracy.

This study could impact future research through the utilization of the patient and health care provider survey. These surveys could potentially be used in further studies to explore the needs, gaps, and prioritization of cancer care supports for Indigenous communities in places other than Saskatchewan, and potentially in other marginalized groups of people. The development of these two survey tools offers health systems and communities themselves with a blueprint of how to develop survey tools that are relevant for Indigenous communities.

The two survey tools yielded from this project will be available for use in other research or evaluation regarding support needs of Indigenous cancer patients. These surveys were designed to gather quantifiable information that could inform health planning and policy and support the need for Indigenous cancer care supports. The most immediate application of the surveys created as a result of this project work will be the use of one or more of the surveys in a mixed methods study designed to discover the support needs and priorities for Indigenous cancer patients and their families in Saskatchewan that my supervisor is conducting (hereafter referred to as the *Sakipakâwin project*).

2.4 Research Objectives and Question

The primary objective of this research is to develop two valid and rigorous survey tools. Both surveys will be validated using pilot respondent feedback to help improve survey accuracy.

The surveys will be designed and used primarily to answer the following question:

What cancer care supports, or qualities of cancer care supports are of priority to Indigenous people and Indigenous communities in Saskatchewan?

2.5 Definition of Terms

In this study cancer care supports will include supports available to Indigenous patients and their families from cancer diagnosis and throughout treatment, as well as supports available when patients return to their homes. For the purpose of this study cancer care supports will be defined in terms of both informal and formal supports. The terms formal and informal supports are used to fully encompass the supports available to Indigenous cancer patients, their families, and their communities (16).

Formal cancer supports will be defined as supports within the framework of paid professional work. Examples of formal cancer supports include services such as stress or pain management at a hospital. Informal supports on the other hand are supports outside of the paid professional framework. Examples of informal supports include the availability of family, relatives, and Elders (16). The following table summarizes and defines important terms used throughout this project.

Definition of Terms Table:

Term	Definition
Formal cancer supports:	supports within the framework of paid professional work (16).
Informal cancer supports:	are supports outside of the paid professional framework (16).
Indigenous :	Collective term referring to the original people of North America and their descendants (First Nations, Métis, and Inuit) (17).
non-Indigenous:	individuals with no Indigenous identity (17).
Aboriginal:	used if the referencing document used the term Aboriginal and/or if referencing Indigenous populations outside of North America.
Indigenous people(s):	used to be reflective of different Indigenous cultures and peoples. This term may be used to refer to groups or Indigenous people individually.

CHAPTER 3: LITERATURE REVIEW

3.1 Introduction

The goal of both surveys is to explore the needs for cancer support services for Indigenous people in Saskatchewan while prioritizing the needs of the people. In addition, to identify cancer care priorities of Indigenous communities and to discover cancer support needs for Indigenous patients and their families in Saskatchewan. The purpose of this literature review is to provide background and rationale for the study objective. Specifically, this review will contrast Indigenous views on cancer with Western views, explore the burden of cancer in Indigenous populations, discuss the importance of cancer supports, explore cancer supports available to Indigenous patients, and identify service gaps that may be contributing to increased cancer morbidity amongst Indigenous patients.

3.2 Cancer in Indigenous Populations

A study focusing on cancer screening and prevention in Indigenous populations states that prior to colonization cancer in Canadian Indigenous communities was rare (2). However, the incidence of several types of cancer (i.e. breast cancer, cervical cancer, lung cancer) in Indigenous populations is now higher compared with non-Indigenous cancer populations (1,18). In addition, this study shows that incidence of cancer in Indigenous populations is growing (2).

There are likely many causes for the increase in cancer incidence amongst Indigenous Peoples in Canada. One study attributes the difference in cancer incidence between the Indigenous and non-Indigenous populations to delayed detection of cancer in Indigenous communities (18). Ahmed, Sahid, and Episkenew also identify that Indigenous people often have limited awareness of cancer prevention and restricted access to prevention programs (2). According to the researchers, culturally relevant cancer materials, supports and services are also limited (2). These studies suggest that the spike in cancer incidence amongst Indigenous Peoples in Canada may be attributable to lack of cancer awareness amongst Indigenous people compounded with limited access to cancer screening and diagnostic services for Indigenous people (2).

Another study states that by 2001 cancer was named the third leading cause of death for First Nations males. Mortality rates increased, on average, 1.7 % per year from 1979 to 2001 (8). By 2001, cancer was also the second leading cause of death in females. Rosenberg and Martel, also reported that between 1972 and 1991 the cancer standard mortality ratio amongst Manitoba First Nations had increased 50% and 45% amongst males and females respectively (19). Likewise, another study cited that Indigenous people of Canada historically had much lower rates of cancer incidence, and lower mortality rates for all types of cancers (8).

A study on cancer in Indigenous populations in Ontario, compared the Indigenous cancer survivors in Ontario to the remainder of the Ontario population (18). This study found that cancer survival rates were lower in the Indigenous Ontario population in comparison to non-Indigenous populations (18). This study also found that the rate for cancer from 1968-2001 in Ontario Indigenous populations had nearly doubled from earlier rates (18). From these studies it is evident that cancer incidence in Indigenous Canadian populations is rising and that mortality rates for Indigenous Peoples in Canada are currently lower than for non-Indigenous Peoples in Canada (1,2,8,17).

As suggested in the literature, higher cancer mortality rates in Indigenous Canadian populations can likely be attributed to less cancer knowledge, delayed detection in Indigenous communities, and lesser compliance to treatment, however it can also be speculated that all of these issues are linked to colonization and its aftermath. Some of the effects of colonization include a lack of trust within systems and institutions (such as health care), as well as racism faced during care (20). This could contribute to fewer people seeking out preventative therapies or opportunities and lesser compliance with treatment amongst Indigenous patients. The worldview and view on health is also often different amongst Indigenous people as opposed to non-Indigenous people (21). These factors all support the need for Indigenous specific health care approaches and place value on Indigenous specific cancer supports.

3.3 Indigenous Views on Cancer

McCormick suggests that Western views of medicine greatly contrast Aboriginal holistic views on health (21). Contrary to Aboriginal customs that focus on all aspects of health, Conventional or Western medicine focuses predominantly on physical medicine. Conventional medicine also tends to rely on prescription drugs and other medicines to treat symptoms, and often do not treat the root of problems. In Conventional medicine there is little connection between spiritual, mental, emotional, and physical aspects. This is the importance of holistic medicine that most Aboriginal cultures teach. Aboriginal people believe that health is all inclusive and recognize the connection between the people, the food they eat, and their environment (21). Aboriginal people believe that the health of a person is all encompassing in terms of their mental, physical, emotional, and spiritual state (21).

In addition to contrasting views on health and wellness the literature suggests that Indigenous people may also have different views on cancer than those most predominantly present in Western culture (9, 19). The literature suggests that Indigenous people globally are generally more fearful of cancer than non-Indigenous people. Some state that Indigenous cultures in North America and Australia typically stigmatise cancer and people with cancer (9, 19). Rose Roberts states that in comparison to Western culture, cancer is often stigmatised more in Indigenous cultures (22). In addition, her Saskatchewan based research suggests that views on cancer vary amongst Indigenous Nations. From her research she mentions that the Woodland Cree, for example, saw cancer as a curse (22). Similarly, Shahid and Thompson, also found that fear of cancer and shame associated to cancer are common in Indigenous culture.

Shahid and Thompson, performed a secondary analysis on cancer articles to examine cancer and the cancer beliefs of Indigenous people of Australia. Shahid and Thompson, state that in their knowledge there is no word for cancer in any Indigenous language (9). Similar to Roberts, this study found that Indigenous views of cancer vary by Indigenous culture and by location as also mentioned by Roberts (22). However, all communities in Australia and North America generally viewed cancer as a death sentence and feared the disease (9). Shahid and

Thompson, also found that fear of cancer and shame associated to cancer are common in Indigenous culture (9).

Several articles suggest that fear of cancer may be contributing to the gaps in cancer and cancer supports experienced in Indigenous communities (9,19). Shahid and Thompson, suggest that fear and lack of cancer awareness may be contributing to an increase in cancer support gaps and a decrease in accessing support services amongst Indigenous people (9). This literature highlights the importance of contrasting views on cancer and wellness to overall health and promotes the need for cancer services exclusively catered to Indigenous people.

3.4 Importance of Cancer Supports

Cancer services that improve education and provide support for cancer prevention, diagnosis, and treatment could help improve cancer outcomes. Shahid and Thompson discovered that a lack of cancer knowledge and symptoms in Indigenous patients impeded them from pursuing medical attention, resulting in delayed diagnosis and treatment (9). The Canadian Partnership Against Cancer also indicate that an improvement in cancer awareness and cancer supports for Indigenous Peoples in Canada could potentially increase cancer prevention amongst the Indigenous Canadian population (23). Other studies, not specific to cancer, state that limited health literacy and a lack of knowledge or understanding result in poor compliance to treatment (24).

Another study suggests that utilization and availability of cancer supports may improve compliance with cancer treatments amongst patients. This study discovered that participating in a multidisciplinary intervention could be correlated to the likelihood of patients completing their prescribed chemotherapy regimen (25). The multidisciplinary intervention described in the study was the incorporation of support services such as exercise, education, and relaxation sessions into the patient's treatment plan. The likelihood of participants finishing prescribed regimens and hospitalization over the course of treatment was compared amongst patients with multidisciplinary interventions to other participants that received typical medical care. It was found that more members of the intervention group completed their planned regime than those in the control and in addition fewer of the intervention patients required hospitalization over care duration (25).

The majority of literature on informal and formal supports suggests that supports are important for cancer patients throughout treatment. Guidry, mentions that both informal and formal supports are important for patients with cancer, stating that these supports assist patients with continuing their treatment (4). Guidry also reports that most patients feel that medical professionals do not provide enough support information during diagnosis (4). The study also found that minorities (those of Black and Hispanic descent) reported benefits from formal and informal supports most often, finding particular benefit from social support or peer groups (4).

A large number of studies on supports, especially those involving peer or social support were conducted with breast cancer patients. Dunn and colleagues, suggested that peer supports were important for providing emotional supports to breast cancer patients (26). These studies and others generally agree that supports available to cancer patients influence quality of life throughout treatment (3,4,26). According to Ashbury and colleagues, supports available to cancer patients can be linked to quality of life after care and recovery from cancer. This study was done specifically on the effectiveness of one-on-one peer support for breast cancer patients and found that participants reported increased quality of life (27).

Similarly, Rodriguez and colleagues, found that the most important factor related to quality of life in advanced cancer patients was social support. This study documented that cancer patients reported increased quality of life with access to various social and peer supports (28). A study on social support and cancer survival found that social support and social relationships contributed to survival in cancer patients (3). This study found a positive correlation between social support and diminished psychological distress among patients (3). The study contributes this improvement to an increased feeling of hope and diminished sense of loneliness in those with access to more support (3).

One study found that peer supports increased favorable outcomes amongst cancer patients (29). Allicock established that peer support was important to patients, and family provide emotional and mental support during treatment. The authors claim that in this way social supports help individuals cope with their diagnosis and the stress of treatment (29). In addition, peer support programs such as those explored by Allicock, were found to improve the mood, improve care satisfaction overall, and provide hope for patients. Communication skills can be taught to counselors, peers, and family members to encourage support focused on the patient (29).

Allicock indicates that 60% of study participants felt more optimistic and 40% had increased confidence in health care autonomy with implementation of motivational interviewing techniques (29). This research indicates that support strategies can be taught to both professionals and non-professionals to support cancer patients and their caregivers (29). Similarly, another study found that support services psychosocial or otherwise, relieve emotional distress experienced by patients (30). In addition, this study found evidence to support that utilizing support services and tools has the potential to improve the overall health of patients (30). It is evident from these studies that cancer care supports can improve patient wellness, treatment compliance, and overall health outcomes (3,4,21,22,24,25,26).

3.5 Gaps in Cancer Supports

The literature suggests that there are many things contributing to the gaps in cancer supports in general, as well as supports specific to Indigenous people. Harris discusses that barriers to knowledge and barriers to care are evident in American cancer care. One of the most mentioned barriers to access to cancer care and services was distance travelled. The impact of this burden increases when compounded with travel time and the expense of travel. The remoteness and rurality of communities was also cited as a major concern for patients (31). It was also stated that there was no local screening available in these areas (31).

There is also evidence to suggest that the availability of supports to cancer patients are lacking especially for those in rural or remote areas (29,32). One study documented that people from rural locations face challenges such as access to health care and access to health services. This study found that people in rural areas of Northern British Columbia experienced increased levels of anxiety and stress due to limited access to care (32).

Access to cancer services from remote and rural communities was also a common concern in the literature regarding services in Saskatchewan (33). In northern Saskatchewan specifically, access to cancer services, care, and cancer related information is limited. Notably, 85% of the population in northern Saskatchewan is Indigenous (33). However, the Saskatchewan Cancer agency does provide screening programs for breast, cervical and colorectal cancers along with a mobile bus that travels to rural and Northern Saskatchewan providing mammograms for breast cancer screening (34). The Northern Mobile Health Bus also provides education on cancer prevention and screening however, it is only in commission from May to November, thus, limiting services available to Northern Saskatchewan residents from December to May (34).

The Canadian Partnership Against Cancer, highlights the impact of jurisdictional issues on cancer treatment for Indigenous people. Their report indicates that there are problems in care and follow-up between community-based health care and provincial cancer centers (23). Another issue mentioned by The Canadian Partnership Against Cancer, was that most reserve hospitals are staffed by nurses, thus, access to physicians for Indigenous patients is usually limited (23).

Medical coverage was also stated as an issue in the report as only status “Indians” which excludes Métis people and non-status First Nations, are covered by the Non-Insured Health Benefits program (23). The Non-Insured Health Benefits program provides First Nations and Inuit clients with health benefits covering a range of services including but not limited to vision care, dental care, access to mental health services, transportation services, and prescription medications (35). Other significant risk factors to Indigenous cancer control were stated as low socioeconomic status, poor diet, lack of exercise, and a lack of cancer prevention and screening (23).

Some articles also highlight gaps in access to service for Indigenous peoples specifically. One participant in Rose Robert's research mentions how they felt as if they were alone throughout their treatment and stated that they felt as if they had no formal support. Another participant mentioned that support during treatment especially in regard to housing was limited (22). Other participants point to significant gaps in the Northern healthcare system regarding cancer services (22). Many participants stated that they had experienced problems with finding help during treatment in Saskatoon; language barriers for example, were cited as an issue when seeking help from others (22). These findings suggest that Indigenous people face more barriers to care than non-Indigenous people in Canada, therefore also justifying the need for Indigenous specific health care supports (22).

3.6 Cancer Supports for Indigenous People

The literature on Indigenous exclusive cancer supports is limited. Some supports for Indigenous patients were mentioned particularly for Indigenous populations in British Columbia and Ontario, but information was very limited in regard to Indigenous people of Saskatchewan (10, 28). There was, however, literature suggesting that supports and programs needed to be culturally sensitive and inclusive (36).

In British Columbia the First Nations Health Authority has a strategy for creating culturally safe and inclusive cancer care. The emphasis of this strategy is to create a culturally safe and humble health care system (36). This publication highlights the importance of incorporating traditional health and wellness views into the healthcare system to approach cancer in Indigenous communities. Recognition of the role of colonialism on the health of Indigenous people is also mentioned as an important factor in British Columbia's cancer strategy (36).

Culture and tradition play an important role in the recovery of Indigenous cancer patients. Poudrier and Mac-Lean, mention that for most women in their study spiritual customs were very important to their breast cancer recovery (37). This article also mentions that several women placed spiritual values and ceremonies as central parts of their healing. In contrast, a minority of women in the study did not value culture and spiritual aspects as important to their recovery (37).

Rose Roberts, a researcher based in Saskatchewan mentions the role of Indigenous healers in cancer treatment and states the importance of holistic medicine that heals the spirit as well as the body. One participant from Roberts study states that they felt as if their family member had received adequate medical care at the Cancer Clinic in Saskatoon, however that this care was not culturally relevant (22). This participant went on to state that because their spirituality plays a key role in their health that the cultural aspect to cancer treatment would have been an asset. This study highlights the importance of cancer care inclusive of Indigenous culture (22).

An environmental scan, conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* explores gaps in Indigenous cancer supports and services available in Saskatchewan (11). This scan discusses possible barriers to accessing those supports such as accommodation, medical transportation, and language barriers. Alternatively, the scan also indicates possible solutions to these problems such as patient navigators. The role of patient navigators is to aid patients and their families through the cancer system (11).

The environmental scan also discusses several services currently available to Indigenous people in Saskatchewan. These supports include a mobile bus that provides mammography to Rural and Northern Saskatchewan areas (11). Other services include in-hospital translation provided by the Saskatchewan Health Authority however, these services are dependent upon the availability of translators (11). Another Saskatchewan support is the availability of Elder support at Royal University Hospital and St. Paul’s Hospital in Saskatoon (11). The majority of the supports offered to patients but are limited to hospital locations (11).

Other provinces offer cancer care supports specific to Indigenous Peoples in Canada. These supports include toolkits and educational cancer materials in Indigenous languages (11). British Columbia offers a cancer guide specific to Indigenous Peoples in Canada that helps them organize documents, questions, and cancer treatment plans (11). Alberta, Manitoba, and Ontario all offer Traditional Wellness clinics, lodges, or health care agencies that provide Traditional Healing to cancer patients (11). These are just some of the services available in other provinces not currently available in Saskatchewan.

The scan highlights that there are no exclusively Indigenous cancer supports available in Saskatchewan at this time. All other provinces in Canada (with the exception of the maritime provinces) have at least one exclusively Indigenous cancer support, which is arguably still not enough (11). The environmental scan suggests that gaps in Indigenous cancer cares supports available in Saskatchewan may be addressed using programs and services from other provinces as reference (11). It can be derived from these documents that cancer supports and services are limited for Indigenous patients, especially in Saskatchewan (10, 11, 29).

3.6.1 Indigenous Cancer Supports in Canada Diagram

Figure 1 (below) categorizes the availability of cancer supports in each Canadian province. This figure shows both Indigenous and non-Indigenous specific cancer supports. Figure 1 also highlights the lack of Indigenous specific cancer supports available to Saskatchewan patients (11).

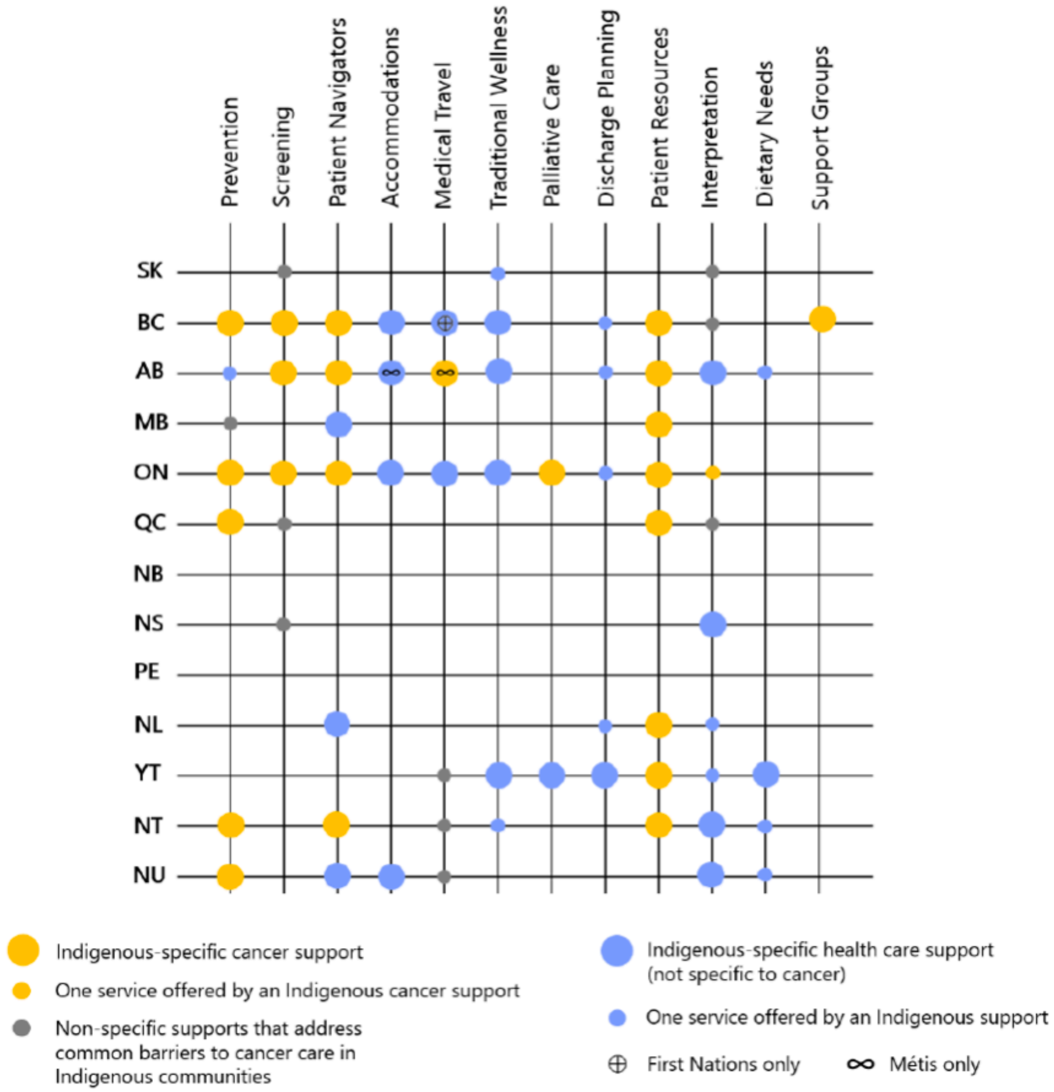


Figure 1. Cancer and General Health Care Supports for Indigenous Peoples by Province. *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families*. 2020.[11]

3.7 Indigenous Surveys & Non-Indigenous Survey Tools

Surveys are a well-established research method. However, the literature suggests that many surveys are not appropriately designed nor are they validated (38,39). Poorly designed surveys limit the validity of the instrument itself and diminish the reliability of the data collected from such tools (38). Panacek suggests that poorly designed surveys have given survey research a questionable reputation. However, Panacek also argues that if done well, survey research is a credible and legitimate research method (38).

Panacek describes the means of creating a reliable and credible research tool. These steps include having a clear purpose for the survey, focusing the survey on a research question designed to address that overall purpose, and to use prior surveys or survey techniques if possible (38). Panacek also mentions various methods of survey validation (38).

Similar to Panacek, Sonja et al, states that surveys need to be created to match scientific rigor similar to other research instruments. Like other instruments surveys need to be designed with rigorous protocols that include exact specifications for reproducibility and should be piloted within a population similar to control groups in other research (39). Panacek and Sonja et al., describe the need for creating a valid and reliable survey (38,39). Both emphasizing the need for a survey to measure what it is designed to and to yield consistent results over time (38,39).

Panacek describes validity as the degree to which a tool measures what it is designed to (38). In terms of survey research validity is often established by using or adapting another already validated survey. Once a survey has been previously published or utilized in a published study it is generally considered to be valid (38). In the absence of previous survey methods other forms of validity can be assessed. Content validity, for example, is described in the literature as validity assessed by a panel of experts revised for relevant content (38).

The literature was explored for current cancer support surveys in efforts to mirror or adapt current surveys for the purpose of this project. However, limited resources were found that explored cancer care supports explicitly, though there was some information or survey tools available that explored cancer care. These tools, however, were not specific to Indigenous people.

One survey, on patient experiences with cancer, focused more on the patients journey through treatment and surgery (40). This survey did however pose some great questions on patient understanding of cancer. This survey seems to do an excellent job of evaluating patient experience navigating the health care system during treatment but is not very specific to cancer care supports themselves (40). Another survey evaluated the psychosocial elements of support. This survey asked respondents if they did receive psychosocial support then who from (41). This survey also asks respondents reasons that they did not access support services (41).

Little literature was found on creating surveys for health care providers caring for Indigenous patients. Limited literature was also found regarding creating survey tools for Indigenous populations specifically, especially for those in Saskatchewan. The majority of survey tools found in the literature were government surveys collecting social and economic information from Indigenous people (12,42). Only a few studies were found with surveys unique to the Saskatchewan Indigenous population. These surveys include one by the Saskatchewan Health Authority focused on broader health issues (43). Though they did find some interesting information in regard to the need for a greater representation of Indigenous voices (43). Other studies such as one on renal disease in Indigenous populations used secondary analysis of other nation-wide surveys to complete their research (44).

There is also very little information on the process of developing survey tools specifically for Indigenous people. However, one document on adapting survey tools specifically for research involving Indigenous populations discusses the importance of community engagement, cultural safety, and reciprocity within the research 2020-08-26 9:15:00 AM(5). This document also outlines several useful steps for adapting surveys that emphasize engaging evaluation users, asking for their feedback and pilot testing in the community (5). These are useful steps for any project and not just for those looking to adapt pre-existing surveys for their own study. With the exception of the document the literature for creating surveys for Indigenous populations was very limited overall.

3.8 Gaps in the Literature

Though research has been conducted on the stigma and fear of cancer in Indigenous communities, little research has been conducted surrounding the communal understanding of cancer by Indigenous patients. In addition, there is little information surrounding what cancer supports are available for Indigenous cancer patients in Saskatchewan, nor is there any information on the ability of these services to meet the needs of Indigenous people (15). However, the literature that is present identifies a lack of Indigenous cancer support services in Saskatchewan (11).

The literature suggests that a lack of cancer awareness or knowledge diminishes the patient's likelihood to seek care and limits compliance with treatment protocols (24). In addition, some studies identify that cancer supports improve treatment compliance and overall outcomes (25). It is also evident in the literature that both formal and informal supports contribute to an increased quality of life in cancer patients (4). Most Indigenous research suggests a lack of support both formal and informal expressed by the community (22). The literature also indicates several barriers to care mentioned by the Indigenous community in regard to cancer care (22).

Limited literature is present on pre-existing surveys for Indigenous populations. This gap supports the need for creation of a survey tool unique to this study's objectives. This study seeks to create survey tools that can explore the needs for cancer care supports specifically for Indigenous cancer patients, their communities, and their families in Saskatchewan. This study will also be the first to create survey tools designed to help identify gaps in cancer care supports for Indigenous populations, and community prioritization of cancer care supports in Indigenous communities of Saskatchewan.

3.9 Summary of the Literature Review

The literature reveals that cancer cares supports are important to cancer treatment and recovery. However, the literature also indicates that there are limited support services available to Indigenous cancer patients exclusively. In summary, the literature suggests that the following things should be considered when creating a survey tool designed for an Indigenous population in Saskatchewan:

Cancer in Indigenous Populations:

a) The incidence of cancer in Canada's Indigenous population has grown (2).

b) The incidence of several types of cancer (i.e. breast cancer, cervical cancer, lung cancer) within Indigenous Canadian populations is higher in comparison to Canada's non-Indigenous population (16).

c) Mortality rates due to cancer are higher amongst Indigenous Peoples in Canada as opposed to non-Indigenous Peoples in Canada (16).

d) The discrepancy in cancer survival rates has been attributed to restricted access to preventative programs and limited cancer awareness. These differences are also thought to be the result of limited access to culturally relevant cancer supports (2).

Indigenous Views on Cancer:

a) Western views on medicine contrast Indigenous views (18).

b) Views on cancer vary depending on the Indigenous community and location (19).

c) Cancer is feared in many Indigenous communities (9).

Importance of Cancer Supports;

a) Lack of cancer awareness or knowledge diminishes the patient's likelihood to seek care and limits compliance with treatment protocols (9).

b) Cancer care supports improve compliance with treatment and improve patient outcomes (25).

c) Both formal and informal supports were found to be important to cancer recovery (7).

d) Peer supports were found to have a positive correlation with favorable cancer outcomes amongst patients (23,26).

e) Cancer supports are lacking or limited in rural and remote areas (23,26).

Gaps in Cancer Supports:

a) Distance was determined to be a major barrier to accessing cancer care and supports (26).

b) Access to cancer services and supports in remote and rural communities in Saskatchewan is limited (27).

c) Jurisdictional issues within the healthcare system were found to impact cancer treatment for Indigenous people (20).

d) Indigenous patients report feeling alone during treatment. Also reporting that they had no formal support and had a difficult time accessing accommodations and transportation (19).

Cancer Supports for Indigenous People:

a) Information on Indigenous cancer care supports in Saskatchewan is limited (28).

b) Indigenous cancer care support and programs need to be culturally sensitive and inclusive (28).

c) Traditional health practices, healers, and spirituality are important to Indigenous cancer treatment (19).

d) The discrepancy in cancer survival rates has been attributed to restricted access to preventative programs and limited cancer awareness. These differences are also thought to be the result of limited access to culturally relevant cancer supports (28).

e) There are no cancer support services exclusive to Indigenous people in Saskatchewan. All other provinces in Canada have at least one (11).

f) Most services available in Saskatchewan are limited to the hospital setting (11).

Indigenous Surveys and Survey Tools:

a) Many surveys are not appropriately designed (38).

b) Surveys instruments need to be created to match scientific rigor similar to other research instruments (39).

c) Survey tools specifically involving Indigenous people need to exhibit community engagement, reciprocity, and cultural safety (5).

CHAPTER 4: SURVEY RESEARCH AND DESIGN

4.1 Introduction

Surveys as a methodological tool are created to use questions to gather information (43). In addition, each survey needs to be designed to serve its individual research purpose. It is important that the survey reflects the research object and that it will gather information relevant to the research topic in a usable manner. Several components of survey design need to be considered when creating a survey. These components include role, validity, reliability, and survey topics. Components of survey format include question design, word choice, response choice, and question order. Additional steps should also be undertaken when creating surveys for Indigenous research.

4.2 Survey Role and Purpose

The survey process is systematically designed to gather information by asking respondents questions (45). Surveys are used to gather information from small or large samples of people. They are often created to understand human behaviours or an aspect of their life, to persuade an audience, or to address a need for modification or creation of a public service or program (45). In addition, surveys are designed to fill gaps in existing information or data. Surveys are also generally considered the best way to gather support or feedback on program planning (45).

The goal of writing a survey is that the survey reflects the survey topic or issue in a valid and accurate manner (46). This means that the questions are a representative of the overall survey topic and that they are presented to respondents in a way that will most accurately gather the information needed. Ideally the survey will be created in such a way that each participant will interpret the questions equally and that they will be able to answer them accurately with minimal error (46).

All survey questions should be created to be both valid and reliable. Valid questions are capable of gathering the information that they were intended to measure. Reliable questions provide consistently measures or results across similar situations (47).

The many benefits to survey research include the ability to collect data from a large representation of the population, the allotment for cross-sectional analysis of multiple variables, and the ability to measure a variety of personal opinions or attitudes (47). The survey method also has its weaknesses, however. The main weakness regarding survey design is the potential bias that can result due to survey design in terms of question wording or responses available, or due to lack of responses or missing information from respondent non-responses (45).

4.3 Surveying Other Populations

The purpose of surveying people is to gather knowledge about people and their lives. The information gathered from such surveys is typically used in decision making or to inform public action. For these types of surveys, it is important to identify study purpose (48). The study purpose will inform what information needs to be gathered from the survey. Once survey topic is determined, next the survey should be catered to the respective population. This information is important to creating a useful survey relevant to the study population (48).

4.4 Survey Format

Some of the ways in which surveys can be conducted are over the phone, electronically/online, or in a paper-based format (48). Telephone interviews are convenient in regard to location for both the researcher and the respondent. Contrarily, they are also very time consuming for the researcher to conduct (48).

One major advantage to a paper-based survey is that the researcher or researchers are often present to help respondents fill out questions, thus, limiting error or question misinterpretation. In addition, paper-based surveys are easier for use with populations that either have little familiarity or little access to the internet or technology (49).

Likewise, online surveys have many advantages. Online surveys are easier to distribute over large areas or to a wider demographic of people than paper-based surveys. Online surveys are also often more convenient for respondents as they can be filled out at any time from the comfort of home and can be sent to them via email. In addition, the data collected from online surveys is often less time consuming and easier to analyze as it is already in electronic format (49). Most survey software will allow for pre-set variables and conduct analysis right from the program. Some disadvantages to online surveys are the obvious technological issues, or issues with respondents not being as familiar with software. Another issue is that the researcher is often not present to help the respondents fill out the survey (49).

4.4.1 Survey Topics and Concepts

Surveys can be conducted on a wide variety of topics and concepts. These topics include demographics, lifestyles, needs, attitudes, decisions, and behaviour. Demographic questions seek to explore variables such as sex, age, family status, ethnicity, education, employment, and more (48). Demographic questions are often important as they can be analyzed to help correlate data to certain demographics. Lifestyle questions seek to identify patterns among participants. Lifestyle questions encompass the pattern of things people believe in or do. Lifestyle topics include the respondent’s interests, activities, and opinions (48).

Needs questions are often created to explore the participant desires or requirements from life. For these types of questions, it is often important to use a comparative ranking style to prevent all needs being ranked similarly. Though, several types of scales can be used for needs-based questions such as desirability scales (48). The participants attitude can also be evaluated. This involves exploring the participants feelings, knowledge, and actions towards a specific subject. Measuring knowledge of the subject is often done first. This can be done by asking the participant specific statements on the topic. Feelings are primarily evaluated using rating scales (48).

Questions based on decisions focus on the participants process of thought that lead them to an action. These questions could require a series of questions to evaluate various courses of action that could or were taken by respondents (48). It could also be important to evaluate the amount of outside influence such as by the media or from social factors that played a role in the decision-making process. Behaviour questions are related to the respondent's actions. This can involve determining why the person demonstrated that behaviour, as well as how often (48).

4.4.2 Creating Questions

Survey questions need to be carefully formulated so that they can gather accurate information while limiting bias (48). When drafting questions, it is advisable to avoid bias and to avoid objectionable questions as well as hypothetical questions (46). The questions should also not be too specific or vague. Survey questions should on the other hand use simple words and be kept short. It is also important that respondents are not treated in a condescending nature (46).

4.4.2.1 Question Wording

Wording in questions should avoid technical terms (unless well known in the field), jargon, or complex words. Simple questions should be used over specialized words. In addition, questions should be posed in as few words as possible with the question still making sense. Questions should also be formulated into complete sentences (46). Question structure should be simple and easy for respondents to comprehend. In addition, complex questions should be broken down into several smaller questions (50).

Another recommendation is to create questions that allow for comparisons with previously collected data (46). This could mean a comparison with census data for example. Double barreled questions should also be avoided. Double barreled questions are difficult to answer as they pose two questions in one (50). It is also advisable to avoid using double negative questions or leading questions (50).

4.4.2.2 Question Accuracy and Applicability

When formulating questions, it is important to make sure that questions are technically accurate. This means that the questions are free from spelling and grammatical errors. This also means that questions are free from punctuation or formatting errors (46).

It is important to consider whether a question is applicable to the applicant and to also allow them to opt out of the question if it is not (48). One should also consider whether respondents have enough information to accurately respond to the question. If not, it may be appropriate to provide them with more information such as a definition (46). In addition, it could be helpful to provide a "do not know option" to allow for respondents to use when they do not. This option or a "not applicable" option also allows researchers to distinguish between a non-response from a question that does not apply to them (50).

4.4.2.3 Question Structures

There are three different ways that survey questions can be structured. These include open-ended questions, partially closed-ended questions, and closed-ended questions. Open-ended questions allow respondents to provide their own answers. Whereas, close ended questions provide response options for respondents (48). Partially closed-ended questions provide respondents with response options while also allowing them to provide their own answer if needed (46). Close ended questions can also have ordered or unordered response categories (46).

4.4.2.4 Open vs. Closed Questions

Surveys can use open ended or close ended questions or a combination of both to ask respondents questions. Close ended questions limit the responses that can be gathered from participants and are therefore, easier for data analysis. Close ended questions are useful when the researcher would like information on specific topics or would like information on a specific scale. Open ended questions on the other hand allow for respondents to provide unique answers that are not limited by the survey. In this way open ended questions limit bias that can be inherently present in pre formulated close ended questions (48).

4.4.2.5 Response Options

Survey response options can be given in a variety of ways such as multiple choice and scales. It is important that response tasks are clear so that respondents understand how to answer the question appropriately (50). It is important that response categories are mutually exclusive to avoid confusing the respondent (46). In demographic questions asking about age for example, one should avoid ranges that overlap such as 20-30, 30-40, as the 30-year-old respondent would have trouble placing themselves on the scale. A more appropriate response option would be 20-29, 30-39,40-49, etc.

Response options given to respondents can inadvertently determine responses. Commonly when offered, the non-response option when given is typically chosen by respondents (51). When given, neutral options may be chosen so that respondents can avoid polarizing to harshly to one side of an issue. The non-response option may also discourage meaningful answers (51).

Contrarily, non-response options can reduce the magnitude of format driven effects. In addition, non-response options can also strengthen the correlation between opinion reports and other variables. This is because when a non-response option is present and not chosen it is more likely that the respondent is being truthful about their response than if a non-response option was given. However, non-response options may encourage a lowered response rate and may diminish the sample size of each individual question (51). In addition, check all that apply questions should not be used to avoid the primacy effect where respondents are likely to choose from the first few options (46).

When providing time frames in question response options it is important that the time frames are appropriate for the question (46). One potential problem is formulating questions with inappropriate time frames because they do not reflect well on the activity. For example, asking questions about weekly activity but giving responses in days or hours instead of weeks.

Another is that respondents may have difficulty recalling everyday tasks. In this case, time estimates are the best response options. In addition, cognitive recall is often a problem and in this case it may be best to ask questions in recent time frames. Vague quantifiers should be avoided if more precise time measurements can be used (46).

Response options given in scales should be provided with equal positive and negative options (46). Some scalar options to evaluate concepts include agreement scales, importance scales, frequency scales, satisfaction scales, and comparison scales (52). Some examples of these scales would include strongly agree to strongly disagree, extremely important to not very important, extremely satisfied to not at all satisfied, and one of the best to not as good (52). In these cases, it is recommended to put the lesser option such as not very important as a 1 and the greater option such as very important as a 5, for example, when quantifying responses as this is easier for the respondents to understand (46).

When giving the respondents attitude scales where they are asked to agree with a statement for example it is important to give the respondent the both sides of the attitude in the question. Respondents, therefore, should be asked whether they agree or disagree. This also helps to eliminate bias within questions based on wording (46). Another way to avoid bias is to avoid unequal comparisons in response options (46).

4.4.3 Context Effects

Context effects in survey design is the question order and the effect that order has on the survey itself. The context of the survey is varied by changing question order. In addition, question content overlap leads to an increase in perceived correlation between the two questions. For these reasons it is best to organize a survey for this reason as proceeding questions may influence questions later on (48).

A directional context effect is the shift between question interpretation of two or more questions as a function of their question order. Correlational context effects are the effect that the relation between two or more questions have in terms of context. Unconditional context effects refer to when context have little impact on subsequent question answers (48).

4.5 Establishing Survey Validity

Validity is the degree to which a tool measures what it is designed to (38). In terms of survey research validity is often established by using or adapting another already validated survey tool which has been utilized in a published study. Once a survey has been published or has been used in a published study it is generally considered to be valid (38). In the absence of previous survey methods other forms of validity can be assessed.

Survey researchers can assess face validity, content validity, criterion validity, predictive validity, and construct validity (38). Face validity is usually established by the investigator or co-investigator in the project and is generally considered a weak assessment of validity. Face validity is simply whether the survey instrument seems to make sense at face value by simply looking at the survey. Content validity is assessed by a panel of experts that review and revise the survey for relevancy (38). Criterion validity is established by matching the survey instrument to other “gold standard” instruments in the field. Predictive validity is the ability of the instrument to predict scores similar to that of “gold standard” assessment. Construct validity is assessed by correlating data patterns of data collected from utilizing the survey instrument to other measures of a similar kind (38).

4.5.1 Piloting Surveys

A pilot study is a small study conducted to test research protocols and instruments prior to implementing them on a larger scale (53). Therefore, a survey pilot is when a small sample of the intended research population tests out the survey tool in preparation for a larger population (53). This allows for a preliminary test of the survey tool, its contents and questions before it is applied to a larger population. Piloting a survey can help determine if there are any issues with the survey that require refinement prior to full implementation of the tool (53). These problems may include the participant's difficulty understanding or interpreting the questions, technical difficulties, formatting issues, and time of completion (53).

A pilot survey will also ensure that questions are being asked in a way that gather the most relevant and meaningful data (53). There is no set sample required for pilot studies it is suggested for a survey to be piloted with numbers ranging from 10 to 40 participants (54). A maximum of 10% of the overall study size is recommended for a pilot sample size (54).

Survey pilots are conducted to minimize errors in research instruments and protocol problems prior to mass implementation. Pilots also help to identify whether a survey will accurately answer research questions and objectives (53). Other steps of survey piloting in addition to questionnaire development include critiquing questions, informal survey testing, and systemic review of the questionnaire (55).

4.6 Survey Limitations

Like all methods surveys have their own limitations. Such limitations include assessment of causality, sensitive questions, distribution, cost, and expertise. In terms of sensitive questions, it is common for respondents not to answer such questions because they feel threatened by the question. This limitation to the survey method may result in missing data if the respondent may choose not to answer the question or it can also contribute to the desirability bias where clients select answers that are more socially desirable rather than being honest (48).

The limitation assessment causality refers to the inability to assess causality based on survey data. This comes in effect in several ways. Surveys are always based off personal opinion, reporting, and response. A person may not respond accurately or honestly, therefore, causality cannot be inferred. A person may respond honestly but may be limited by their own perception of themselves, events, or otherwise and therefore causality can also not be inferred (48).

Distribution may be a huge limitation to a survey. This comes into effect based on the distribution method. In some cases, it may be difficult to access the study population. In other cases, the survey may be limited to a specific format i.e. paper or internet which both pose their own issues. Paper surveys are harder to distribute and make data analysis more difficult as all responses have to be entered manually. The information from internet-based surveys on the other hand can be easier to compile as it is all digital. However, the internet format is not always user friendly and can be difficult for less tech savvy participants (48).

It can be costly to distribute surveys especially large surveys. This is due to the material and time to implement surveys in a proper manner. In addition, surveys specifically, good surveys can be difficult to create. Therefore, survey expertise is vital. It is important that a survey is created in such a way that the research question will adequately be addressed, that the respondents can easily fill out the questionnaire, and the information is gathered in a usable format (48).

4.7 The Researcher's Role

It is the responsibility of the researcher to familiarize themselves with the survey method and its limitations. The researcher should also research the subject that they are surveying on so that they can answer any questions if need be. Gathering information on the survey topic is also important to survey generation and design (48).

In addition, when doing researcher in collaboration with other people it is also the researcher's responsibility to respect their vested interests. The researcher needs to ensure that the survey will assess what the other party needs or desires from the survey tool. In such a case, it is also important to note that the other party often owns the survey and all survey data (48). This is especially true when conducting research with Indigenous populations and is to be respected by the researcher at all times (56).

4.8 Professional Ethics

Researchers should not conduct any research that will seek to skew or bias survey results. Researchers should always protect the identity of survey participants, keeping them anonymous unless the participants desire to be identified. Researchers should inform respondents of survey sponsors if appropriate or relevant to the survey topic (48).

When working with a sponsor or other party the researcher should always protect the interests of those parties. Thus, the researcher should also treat all data as the property of the sponsor or third party. This may vary based on research agreement (48).

4.9 Adapting or Creating Surveys for Indigenous Research

Some guidelines can be followed when adapting surveys for research with Indigenous communities. These steps include planning. This involves determining whose interests are best served by the research, who benefits from the research, and who designs its questions (5). These steps highlight the need for collaborative and inclusive research.

Other steps include community engagement and respect, cultural safety, respect for different ways of knowing, relevance, and reciprocity (5). Community engagement involves learning from the community or communities and being inclusive and respectful of their culture.

Participatory research also has its place in this step. Participatory research also means building relationships with the community (5). Cultural safety and respect for different ways of knowing is also important. This involves considering how research can bring of traumas that Indigenous people have experienced in the health care system (5). This also means recognizing different point of views and the experiences of others (5).

Ensuring relevance comes from community involvement and creating a community driven survey or research tool (5). When adapting the survey, it is important that the audience is kept in mind. Communities differ, specifically Indigenous communities may have different beliefs or practices and the adaptive survey needs to be respectful of that (5). The researcher may also want to ask themselves if the questions will make sense to the community, and whether they will gather meaningful information with the use of the question (5).

Reciprocity involves sharing the information gathered or in the case of this project the survey tool created. Reciprocity also involves building relationships and trust with the community. This step may also involve feedback from the community or participants (5). In this project feedback was a very important process of survey design.

Finally, responsibility describes the responsibility of the researcher to follow the aforementioned steps to research or survey adaptation. This means that the research is being carried out in a respectful and culturally safe manner. Responsibility in Indigenous research also means that the community will have access to the survey tool to review (5).

Specific steps for adapting surveys include engaging evaluation users. The following framework created by the *Canadian Partnership Against Cancer,* depicts the balance between responsibility, respect, relevance, and reciprocity and the research design. This diagram illustrates the steps that can be used to conduct culturally safe research during survey adaptation and design (5).

A vast majority of surveys are created by non-Indigenous researchers for non-Indigenous research. Therefore, it is important to adapt surveys to reflect community desires and needs. This point further emphasizes the need for community participation in research. It also makes a case for creating survey tools specifically for Indigenous people similar to those created in this project.

4.9.1 Survey Adaptation for Indigenous Research Framework:

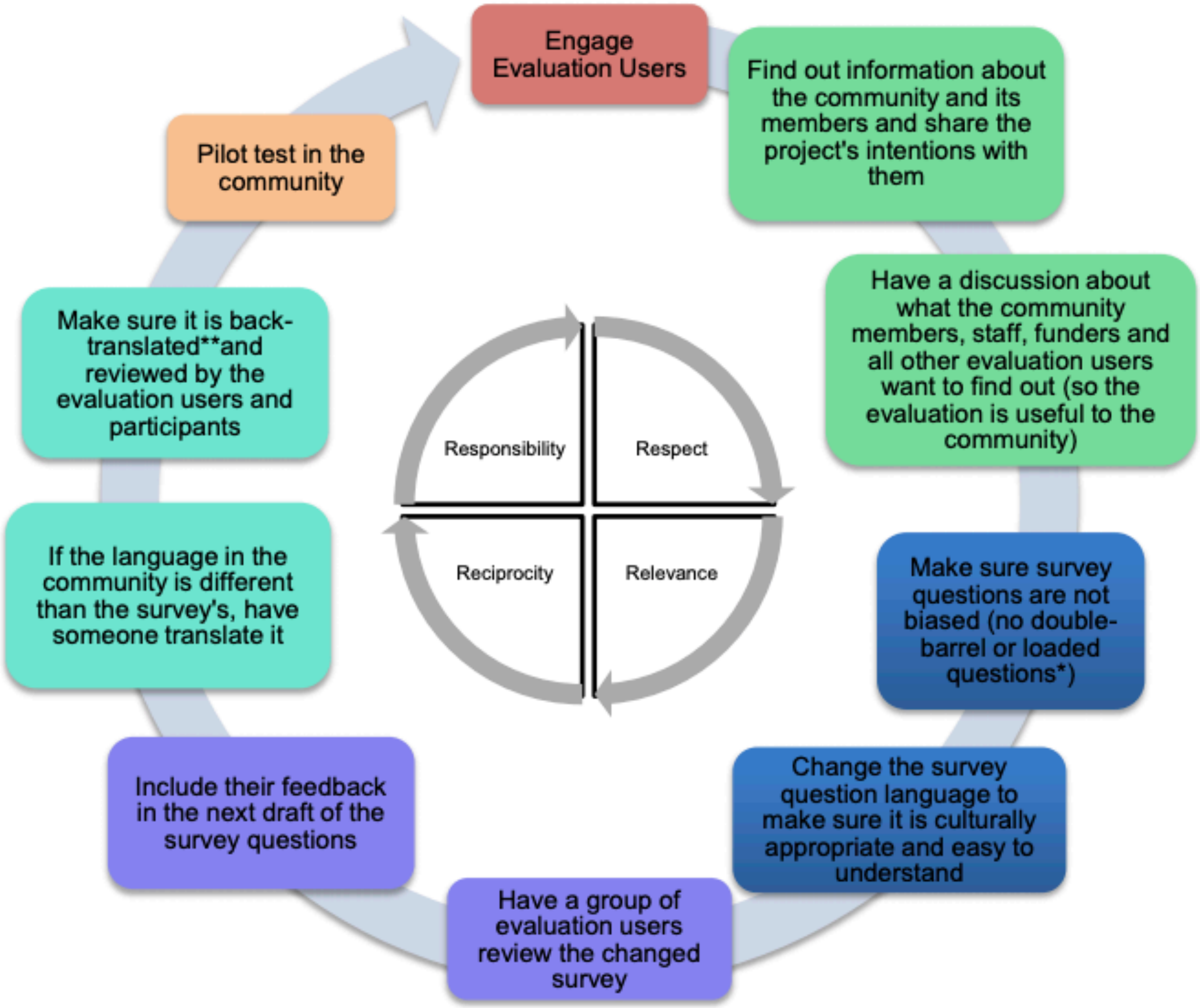


Figure 2. Adaptation Framework**:** A guide for adapting existing survey tools for use in northern, rural and Aboriginal communities. *Canadian Partnership Against Cancer.* 2011.[5]

CHAPTER 5: METHODOLOGY

5.1 Methodology Introduction

The purpose of this project was to create valid and accurate survey tools to explore and evaluate Indigenous cancer care supports and services in Saskatchewan. Both surveys are rooted in quantitative research and are reflective of quantitative approaches, while being respectful to Indigenous people and inclusive of their voices. Both surveys were created to gather quantifiable information.

This study yielded two survey tools that explore the separate perspectives of Indigenous cancer patient or family members and health care providers. The two survey questionnaires are the result of various sources of input and methods of validation. Both surveys were created with the involvement of Indigenous and health care informants at various stages of the project.

5.2 Paradigm and Theory

A paradigm is the lens through which research aspects are examined. Paradigms have their own perceptual orientations and assumptions. These unique assumptions allow the researcher to frame their research in terms of worldview and beliefs (57).

Both surveys are quantitative tools rooted in the postpositivist paradigm. Assumptions of the postpositivist worldview are that that data collection is objective, quantifiable, and that researchers test a theory (58). Another assumption of the postpositivist world view is that reality is subjective, however individual realities can only be known imperfectly (57).

The postpositivist worldview also allows for the recognition of potential researcher bias and its influence on quantitative research (58). My motivation as a researcher is based on the knowledge that Indigenous cancer patients face higher mortality rates than non-Indigenous patients and that Indigenous specific cancer supports are limited (1,9). As such, my bias is towards compelling the Saskatchewan Cancer Agency to improve upon Indigenous cancer support services by creating surveys that could potentially gather information that can quantify the need for said services.

The surveys will be rooted in a postpositivist paradigm that aligns with the scientific approach to the survey design with an emphasis on empirical collection of data (58). The surveys resulting from this study were designed to gather quantifiable information that could inform health planning and policy. Therefore, it is appropriate that the surveys be rooted in a quantitative paradigm that can attempt to quantify support needs for Indigenous cancer patients.

An Indigenous research framework was not employed in this study because the objective nature of this research does not align well with Indigenous paradigms. Indigenous research methods value life, community, and the interconnectivity of all things (7). Indigenous methodology as described by Kovach, is a relational approach to research that encompasses Indigenous culture and values such as narratives into research for Indigenous people by Indigenous people (7). However, this study will be inclusive of input from Indigenous informants.

In addition, Kovach, states that that non-Indigenous people should only be conducting research with Indigenous people when Indigenous methodologies are not being used, or when the research is done in collaboration with Indigenous people (7). Therefore, as I am not an Indigenous researcher, I felt that it may be inappropriate to utilize Indigenous frameworks and methodologies. Instead this study engages in participatory research aligned with Indigenous patients, leaders, and Elders to ensure respect and inclusivity of the research, its contents, and products.

5.2.1 Study Paradigm and Methodology Summary Table (57–59)

The following table summarizes the paradigm, theoretical perspective, methodology, and method utilized in this study.

Study Paradigm and Methodology Summary Table:

Paradigm	Post-positivist
Ontology	Reality is subjective (More than one reality exists), but these separate realities can only be known imperfectly. Potential researcher bias
Epistemology	Reality can be measured
Theoretical Perspective	Post-positivism
Methodology	Survey Research
Method	Questionnaire

5.3 Methodology and Method

Surveys are a type of research method used to gather data in social research methods (60). There are two categories of surveys; the interview and the questionnaire. Focus groups are a type of survey group interview. Questionnaires are typically used in research to get information from a large group of people, to test a new idea, and to understand what happened or to what extent did something occur (60). Questionnaires are the survey type utilized in this study.

The surveys in this project were created by reviewing the questions of two other surveys on cancer support needs and using them as reference for question content. One of the reference surveys focused on patient understanding of cancer diagnosis (40). The other reference survey focused on psychosocial supports as well as their availability and use to patients (41). Neither of these surveys are specific to Indigenous cancer support needs.

In order to customize survey content to the Indigenous community patient informants were consulted. Several patient informants and health care informants were recruited to provide feedback and input on this project. These informants were identified due to their involvement in a project similar in nature to this one (also on Indigenous cancer support needs), titled the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Familie*.

The involvement of said informants in the *Sâkipakâwin project* was known to the researcher. Informants were recruited for inclusion in this project at an advisory meeting for the *Sâkipakâwin project* that the researcher attended. At this meeting the informants also agreed to provide feedback for this project and aid in questionnaire development. The purpose of this process is to ensure that this study is culturally respectful and relevant to the needs of Indigenous people of Saskatchewan.

Other steps in addition to questionnaire development included critiquing questions, informal survey testing or feedback, and systemic review of the questionnaire (61). Survey questions were evaluated for use of double-barreled questions, overly long questions, and question flow. Survey experts were consulted to help with both survey development and critique. Expert consultation is also recommended for survey creation, this was done in collaboration with Indigenous health providers and researchers to gather initial feedback on a primary survey draft (51).

In addition, the surveys were created and adapted using qualitative key informant interviews and an environmental scan on Indigenous caner support needs. These documents will be evaluated for common themes and content and then matched to existing survey design. Adapting the surveys with consideration of qualitative interviews and the environmental scan will help to ensure that the survey questions are congruent to the research objective. Themes found in these documents will inform survey design and content; this ensures that survey questions are relevant to the study population. The purpose of both surveys is that they will allow for individuals of Indigenous communities and their health care providers to identify Indigenous cancer support needs and priorities.

5.4 Target Populations

This patient survey was designed to be filled out by Saskatchewan Indigenous cancer patients, survivors, or their family members. The target population is patients and family members 18 years of age and older. Eighteen was chosen as the minimum respondent age as it is the age of majority or maturity. This survey is also targeted towards First Nation and Métis people as they are the Indigenous groups represented within Saskatchewan. For this reason, the patient survey may need to be adapted for future research with other Indigenous populations.

The health care provider survey was targeted towards Health Directors of Saskatchewan First Nation and Metis communities. Health Directors in Saskatchewan are Indigenous and provide or facilitate Indigenous cancer care and supports. Future research targeting other HCPs who may or may not be Indigenous may need to consider including one or more questions to address the potential for bias or racial discrimination of respondents. This survey was developed with the help of current Health Directors and health care providers. No minimum age was set for respondents in this survey as that was not deemed relevant to analysis. In addition, asking age was not necessary as all health care providers or facilitators are likely over the age of 18.

5.5 Study Design

Two new instruments were designed as a part of this research that can be used to survey Indigenous communities. The patient survey asks Indigenous people about their views on cancer, experience with accessing cancer supports in Saskatchewan, and needs for cancer care supports in communities and throughout treatment. An additional survey targeted towards Indigenous cancer care providers and facilitators evaluates perceived barriers to support access. These surveys could be instrumental in exploring the priorities of Indigenous communities in regard to their views on cancer supports and services.

The surveys were designed to be conducted in a web-based format so that they are more easily distributable over larger distances and in order to streamline both data collection and analysis. Both surveys include open-ended questions and cover subjects on cancer care service gaps, and cancer care support priorities. This will allow for unique responses to fit community needs. The surveys also include closed-ended questions that rank cancer care supports and cancer care support gaps based on priority or need by the population. Response scales are representative of importance scales that evaluate the importance of cancer supports to respondents. Others also explore satisfaction with current services by utilizing competence scales, and agreement scales to assess overall agreement for cancer support needs.

The survey was created by generating an item pool and by determining the scale of measurement from current literature. Most questions utilize Likert scales to quantify results, the size of the Likert scale is dependent upon the nature of the questions. Respondents are also given examples of cancer care barriers to rank in priority. This offers a quantifiable measure for needs assessment and will result in the creation of new tools for evaluation (59). Demographic questions were included in the beginning of the surveys to obtain information that could be pertinent to data analysis and results.

To ensure relevance to the population the qualitative interviews and environmental scan from another project will inform the content of the survey. The qualitative interview and environmental scan information allow for a survey that will yield information pertinent to the study and its population. They also allowed for the evaluation of study content. Content will also be matched to information derived from key informant interviews and an environmental scan conducted by the *Sâkipakâwin project*.

Five standard categories of survey validation currently exist in addition to the use of previously validated surveys; these categories include, face validity, content validity, criterion validity, predictive validity, and construct validity (38). Face validity was established by the investigator along with informants and researchers working on the *Sâkipakâwin project*. Content validity was assessed through feedback from patient informants and provider informants, and researchers. Other forms of validity such as criterion validity will not be assessed as no gold standard measurement instrument for this type of research currently exists. Predictive validity will also not be assessed as there are no patient outcomes to compare the survey instruments to. Lastly, construct validity, will also not be addressed as the survey will not be piloted in this study, thus, there will be no pilot answers to allow for analysis of answer patterns (38).

5.6 Possible Future Analysis

The two surveys were designed in a way to allow for quantitative analysis based on descriptive statistics. Descriptive analysis is one analysis method that future researchers could use to analyse the data gathered from this study (14). Descriptive analysis can be used to determine the most important and least important cancer support needs for Indigenous cancer patients, needs averaged to each community, as well as the range of needs.

In addition, descriptive analysis could be performed to identify trends in the data. Data could then be analyzed based on the research question in terms of coding data into similar cancer support needs or themes together or barriers to accessing treatment (14). Response scales will likely be representative of importance scales that evaluate support or support character importance. Others will explore satisfaction with current services or agreement scales to assess overall agreement for cancer support needs. The data set can be summarized via measures of central tendency such as mean, median, and mode responses to survey questions (58).

5.7 Conducting Indigenous Research

It is important to have unique protocols with regards to Indigenous research because the factors that influence Indigenous communities are different from non-Indigenous communities (6). Those factors could potentially change research outcomes and therefore, they need to be considered (6). It is no secret that colonialism and its aftermath have greatly impacted Indigenous communities and Indigenous people in various ways (20). From a health focused perspective, this is revealed through an increased prevalence of diseases in Indigenous populations such as cancer, diabetes, obesity, HIV, substance abuse, etc. since colonization began (52). Therefore, it is important to consider the effects of colonialism while respecting Indigenous culture in research involving Indigenous populations.

OCAP® which stands for Ownership, Control, Access, and Possession, is based on the premise of applying self determination to research (56). Methods for OCAP® involve participatory research, culturally appropriate research, and increased community involvement with regards to research methods and outcomes. The idea is to increase respectful and relevant information for First Nations people and minimize colonial research (56).

Through OCAP® Indigenous people will have access to their research, they will also have the right to manage this research (56). This unique form of research forces colonialist researchers to reevaluate their knowledge and to reform colonial research views to better depict the truth behind the research. This can be achieved by increasing education of researchers and increasing the participation of the community in the research so that the research and researchers understand the significance of the data being collected (56). Indigenous research protocols can be used to ensure that research is done with Indigenous people for Indigenous people. Thus, meaning that the people are more than research subjects but also research participants developing research that respectful and meaningful to their people (62).

This study was designed to serve the purpose of the community, give voice to the community, involve reciprocity, and to be collaborative with the help of Indigenous patient informants. As suggested by *The Canadian Partnership Against Cancer*, Indigenous patient advisors provided survey questions, language, and to assessment as to whether the survey draft will gather appropriate information (23). These methods also align with standards and OCAP® principles for Indigenous research where the research needs to be done with and for Indigenous people, the research needs to be useful to the people, and the research also needs to be disseminated in ways useful to the community (63).

5.8 Patient Oriented Research

Patient oriented research is the involvement of or partnering with patients and their families in the research process (64). There are several levels of patient oriented research whether it be to inform, consult, involve, collaborate, or empower patients in the process (64). The involvement of patients in this development of this study was by definition consultation in which feedback on research products, analysis, and decisions was sought (64).

5.9 Patient Involvement in this Study

An advisory team of First Nation and Métis patient informants and community officials were consulted in the making of both surveys. These informants include Indigenous Elders, Indigenous community leaders, and Indigenous cancer patients. The purpose of this advisory team was to ensure that this study was culturally respectful and relevant to the needs of Indigenous people of Saskatchewan. The patient informants were consulted at quarterly meetings and by email on study design and progress. This involved gathering input on the survey and drafts of the survey at several meetings between the researcher and the patient informants. The patient informants also reviewed the final draft of both surveys.

The involvement of First Nations and Métis people in this research was important to ensure respect for First Nations and Métis people within Saskatchewan. In addition, consulting with the patient informants helped to evaluate whether the survey would not only be relevant to the population but also usable and feasible for research with said population. These measures also helped to ensure cultural respect and relevancy.

In addition to the patient informants, several health care advisors were consulted in survey development. Feedback on finalized drafts of the health care provider survey was gathered from said health care advisors that work closely with the First Nation and Métis communities within Saskatchewan. This feedback was important to determine the usability of the survey amongst health care providers working with First Nation and Métis populations.

This study benefited from Patient oriented research in a way that meant the survey could be used to more accurately assess First Nation and Métis cancer care support needs as respectfully and as relevantly as possible. The process of seeking patient input is especially important when working with a population to which you are an outsider or with which you are less familiar.

CHAPTER 6: SURVEY TOOL CREATION

6.1 Survey Creation Introduction

Initial survey content was created using themes and gaps as identified in the literature review. The patient survey was created to explore gaps and needs of Indigenous cancer patients and much of the survey content was informed by present literature. In addition, pre-existing surveys on cancer care support needs were used to create survey content. Though those surveys were not focused on Indigenous populations. Content and themes suggested by patient informants was also taken into consideration when formulating survey questions.

The survey was created following formatting recommendations of several established articles and texts on survey format and design. Formatting became an important part of survey design as the surveys needed to be short while covering a breadth of issues. It was also important for the validity of the surveys that the questions be asked and formatted properly. In addition, surveys were created to be easy to follow and user-friendly.

Finally, feedback from the patient informants, and other researchers was elicited to help finalize the survey. This feedback was essential to ensuring the appropriateness of the survey for the use in First Nation and Métis research. The resulting drafts of both the initial patient survey and the sub-sequential health care provider survey were finalized using additional feedback and by using qualitative interviews to legitimize survey content. It is also important to note that the health care provider survey was a product of the feedback given on the patient survey.

6.2 Creating the Health Care Provider Survey

The health care provider survey was created as a by-product of the patient survey. During a feedback session on the patient survey it was indicated that distribution issues such availability of Indigenous cancer patient information within Saskatchewan and patient privacy would limit the ease with which the patient survey could be distributed in the future. Thus, also limiting the amount or quality of vital data that could be collected from the population in regard to

Indigenous cancer care supports. As a result, it was suggested that a subsequent survey be created that was more easily distributable.

During the feedback session it was suggested that a more easily accessible population should be used for a survey in substitute. This population however, still needed to have knowledge on Indigenous cancer care and supports and still needed to representative of the population. It was determined that a population that would still allow for exploration on Indigenous patient cancer support needs would be the health care providers and managers responsible for Indigenous cancer care in Saskatchewan. This would include both Indigenous and non-Indigenous health care providers or facilitators.

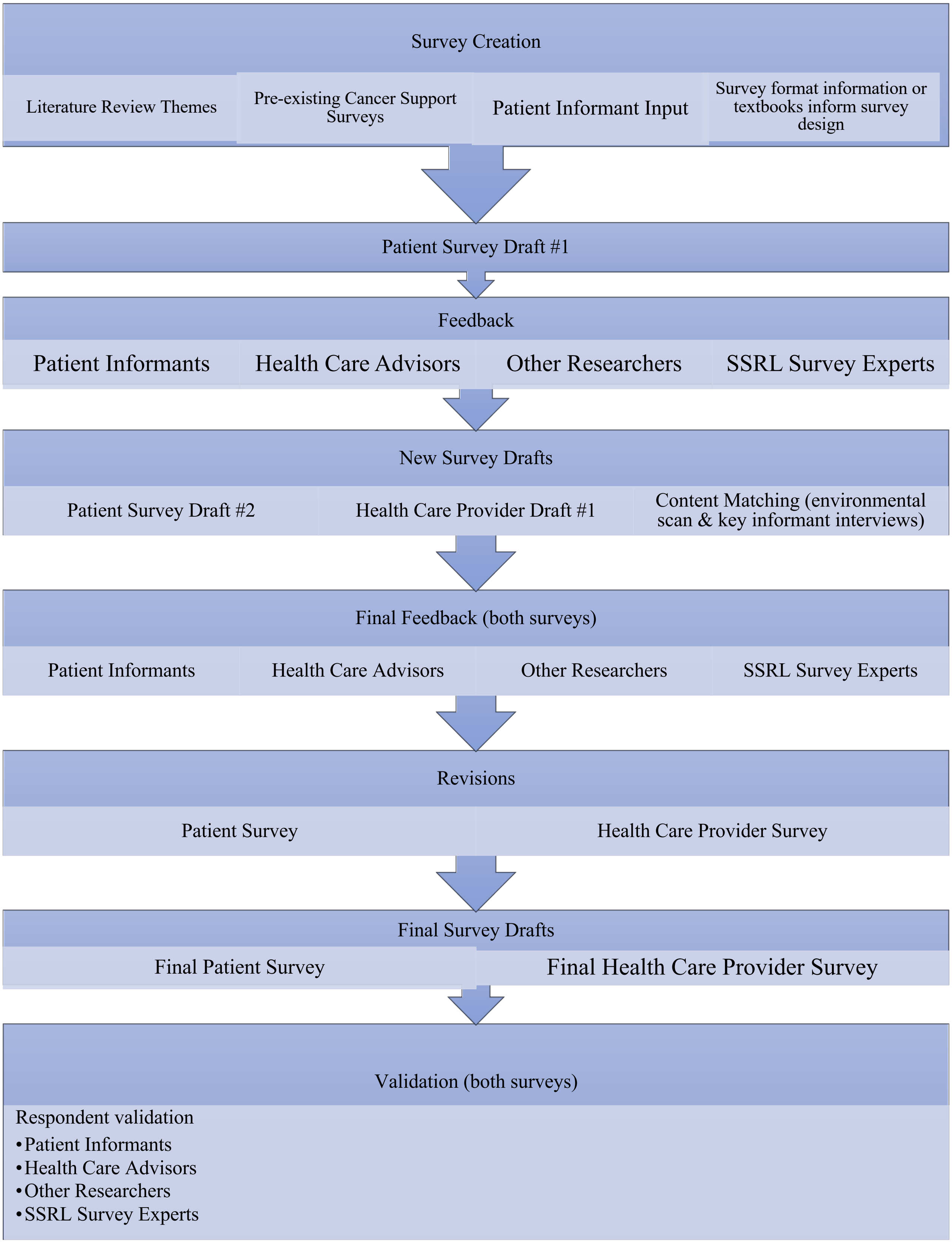
Health care providers and managers are easier to identify, contact, and distribute the survey to than individual patients. In addition, health care providers and managers can still disclose important information in regard to First Nation and Métis cancer support needs as well as barriers to accessing these services in Saskatchewan. Due to this feedback from the patient informants on the patient survey a survey targeting health care providers was created.

Content from the patient survey was altered to create the healthcare provider survey. Questions were altered to be directed towards healthcare providers and facilitators as opposed to patients and family members. The majority of questions were transferable from the patient survey to the health care provider survey. Remaining questions were designed or generated from healthcare provider and researcher feedback. Both the patient and the health care provider surveys were still seen as potentially important tools for future research and therefore both surveys were finalized.

6.3 Survey Creation Method Framework

The following framework outlines the process used to create and finalize both survey drafts. The framework depicts all sources used to create the initial patient survey and how feedback from that initial survey lead to the creation of the health care provider survey. The framework also shows the different methods of survey validation and forms of feedback utilized in design.

Figure 3. Survey Creation Method Framework:



6.3.1 Survey Comparison Table

The following table compares the Patient and Health Care Provider surveys in terms of survey creation, content and design. The purpose of this chart is to make the differences between the two surveys and therefore the purpose of two individual surveys apparent. Important differences between the two surveys will be bolded and marked with an asterisk for distinction.

Survey Comparison Table:

	Patient Survey	**Health Care Provider Survey**
Survey Creation	**Initial Survey Created from: ● Literature review themes and gaps ● Patient informant input ● Other cancer support surveys not specific to Indigenous peoples ● Survey design textbooks and information inform design	By-product of patient survey due to feedback
Survey Content	● Close and open-ended questions ● Several demographic questions ● *Patient and family member perspective ● *Focuses on patient journey and patient access ● *Focuses on the desires and wishes of patients or their family members and the barriers that they personally face	● Close and open-ended questions ● Few demographic questions ● *Health care provider perspective ● *Focuses on barriers to patient support access ● *Focus on health care solutions and training
Survey Design	● Web-based but also usable on paper ● Written for a literacy level of grade 9-10 ● Limited jargon	● Web-based but also usable on paper ● Written for a literacy level of grade 12 ● Some common terms that would be known to health care providers

6.4 Creating Survey Content

Content of the patient survey was generated using several sources. The literature review and patient informant requests were taken into consideration when drafting the initial patient survey. Other cancer support surveys not exclusive to Indigenous populations were consulted to format questions surrounding general supports. The finalized versions of the patient survey and health care provider survey, however, implement feedback and input from a variety of other sources.

6.4.1 Using the Literature Review

Themes derived from the literature review were used in the creation of the initial survey. The literature review identifies the disparities between Indigenous and non-Indigenous cancer patients. The literature also identifies many barriers or aspects of supports that could be helpful in improving access and utilization of cancer care supports and services by Indigenous cancer patients. Both the patient and health care provider surveys were created to evaluate the importance of barriers and to identify what changes could be made to improve access to Indigenous cancer care supports.

The literature review discussing limited understanding of cancer also revealing that it is often feared in Indigenous cultures (9). The literature review also suggests that Western views on medicine and health often contrast Indigenous views (6). Both of these themes lead to questions surrounding cancer patient understanding within the patient survey.

These questions seek to identify aspects of the cancer journey that Indigenous patients may be struggling with whether that’s promotion, diagnosis, treatment, or post-treatment supports. The survey also seeks to understand what barriers may be contributing to the lesser understanding. In addition, several questions were created that cater to Traditional Healing and Wellness. These questions stem from the difference between Indigenous and Western views on medicine and care as depicted in the literature review (6).

Evidence in the literature review reflect the importance of both informal and formal cancer care supports (4). This information led to questions created within the surveys that seek out information on both formal and informal supports. Informal support questions ask the patients whether they find value in informal supports such as discussion groups. Another question asks respondents whether they use the supports or whether they are available.

Questions on formal supports explore the value or use of supports within hospital and care. This includes questions on nurse navigators, translators, pamphlets etc. These types of questions are present in both the patient and health care provider survey. Patients and health care providers are also asked if they felt that patients were given enough information on supports prior to and after treatment.

Particular barriers are also mentioned within the literature review to be a hindrance to cancer care services and support access. These barriers include distance, rural or remote locations, and jurisdictional issues (20, 26, 27). There are questions on both surveys asking patients to identify if they perceive distance, rural or remote locations, jurisdictional issues, or accommodations as barriers. Respondents are also asked to rank these barriers based on the participants view on how much they deter support or service access.

The literature review also points out the importance of culturally respectful and appropriate services or supports (28). Both the patient and health care provider survey access whether respondents feel as if current supports or services are culturally inclusive and respectful. Respondents are also asked to identify to which degree if any they feel that racism plays a role in access to supports.

The health care provider survey also includes a question that seeks to explore whether respondents feel as if there are an appropriate amount of cancer support services available to both First Nations and Métis patients. Health care providers are also asked if they felt that increasing cultural competency training would improve access or utilization of services by Indigenous cancer patients.

6.4.2 Patient Informant Requests

Seven patient informants of Indigenous identity (both First Nations and Métis) including three Elders, two cancer patients, and two Indigenous community leaders were consulted in survey creation. At an initial meeting with patient informants involved in the study prior to survey collection several recommendations were made for the patient survey.

First, it was recommended that the survey inquire about the desire for Indigenous navigators or translators. Another request was for the survey to explore traditional health requests or that some questions explore the desire for culturally inclusive supports. Other suggestions included a focus on cancer and the understanding of cancer for one or more questions. These recommendations were used for the initial survey design.

6.4.3 Using Other Surveys as Reference

Two surveys were used to gauge for survey content surrounding cancer supports. These support surveys were not specific to Indigenous populations and were therefore only used to guide creation of questions surrounding support content and question formatting. The content derived specific to these surveys were more focused on cancer as a diagnosis.

One survey specifically was conducted on experiences of cancer care (40). This survey first asks respondents to identify as a cancer patient or a family member. The patient survey tool imposes a similar question asking if respondents are a cancer patient, survivor, or a family member.

The survey then goes on to assess types of cancer diagnosed and referral to a specialist which were questions deemed not to be necessary for this survey. The survey asks respondents to indicate if they understood the explanations given to them. They were also asked whether they were happy with the way that they were told (40). The patient survey was formulated to include similar questions trying to distinguish both if Indigenous cancer patients understood their diagnosis and if they were given information in a satisfactory way.

Another survey that focused on psychosocial aspects of cancer evaluated the use of psychosocial supports for cancer patients (41). Two survey questions for the patient survey were formulated in reference to this survey. Those questions involve whether survey supports were available to patients. The reference survey asks patients which support services they use and if not then why they do not use them (41). The patient survey also includes a question asking patients barriers to cancer support access. Again, these surveys are not specific to Indigenous people and therefore, their use for survey design was limited.

6.4.4 Summary of Survey Content

From the above sources it was evident that the patient survey needed to explore the cancer journey. This also meant that it would be evident to try and evaluate what aspects respondents understood about their journey and what information was provided to them throughout their journey. These questions would help determine if Indigenous cancer patients are provided with adequate information to understand their cancer journey throughout treatment.

It is also evident that the patient survey should have questions that reflect the need or desire for Traditional treatments and supports. Next the importance of supports and Indigenous specific supports would need to be evaluated. This includes the need for Indigenous navigators or translators. The survey would need to assess potential barriers to accessing treatment or supports specific to Indigenous cancer patients as well as utilization of services by patients and their family members.

The health care provider survey would be designed to evaluate similar themes but from a different perspective. This survey would be focused less on understanding the cancer journey and more so on the ability of the health care system to provide support and services to Indigenous cancer patients and their families. This includes potential issues with current services and supports and possible ways to improve upon them.

6.4.5 Survey Topics or Concepts

Several survey topics will be utilized to cover the desired content. Demographic questions will be asked to gather information on both the patient and health care provider populations. Other survey topics such as respondent attitude, need, and lifestyle type questions will be used to assess other information.

Attitude-based questions will be used to evaluate respondent attitudes on current cancer support or services and their qualities. This includes asking respondents the extent to which they agree and disagree with statements on cancer support services and supports for Indigenous people. Lifestyle questions will be used to assess current patterns in service or support usage. Lifestyle questions will also be used to assess barriers to accessing supports and services. Needs-based questions will be used to determine potential desires of respondents. This includes evaluating the need for more traditional support or service options or the desire for Indigenous navigators or translators.

6.4.6 Survey Formatting

Survey format consists of question typing, individualized question format, word choice, and question order (48). Several different aspects of survey design such as context effects, variables, positioning, and response options change how a survey is understood and how it can be utilized (48). Survey format and design help to ensure that the survey can be followed in a logical manner and that the questions are designed in ways that are both user friendly and appropriate for data collection (48).

6.4.7 Question Types

Both open and closed-ended questions are used in the questionnaires. Open-ended questions are used in both surveys to establish concerns regarding the surveys and their contents. Both surveys also allow for additional comments on the survey topic to allow the respondents to include additional information they would like to include not already posed in the surveys.

The majority of both surveys utilize closed-ended questions. Closed-ended questions were chosen as they allow the survey to gather information with minimal burden to respondents (44). Closed-ended questions were also important to evaluate specific qualities of cancer care supports and services.

Both the patient survey and healthcare provider survey were created to be web-based while, still being easily adaptable to paper format. To accommodate this the questions needed to be usable in either format. Therefore, using closed-ended questions with multiple choice or scaled response options is necessary to ensure that the survey format is easily translatable from web-based to paper.

6.4.7.1 Question Word Choice

Both the patient survey and the health care provider survey will be formulated to use as simple of words as possible. Both surveys will also aim to be free of jargon with the exception of some health care jargon present in the health care provider survey. The survey questions will also be formulated into full sentences and will use as few words as possible.

6.4.7.2 Creating Questions for Low Literacy

When writing for low literacy participants it is important to ensure that the questions will be understandable and easily readable for participants. Some recommendations for writing low literacy materials include keeping writing and wording simple, sequence questions in themes or a logical order. It could also be useful to use short words and sentences, use the same words consistently, or enlarge words or font. It may also be helpful to test the reading level of the survey or document (65).

Both the patient and health care provider surveys were created with low literacy levels in mind. This is to help ensure that the surveys could be distributed to a larger population of people. Both surveys were formulated with themes together so that the question flow was easy to follow. The patient survey in particular, was formulated using words consistently throughout and with similar question types to make it easier to follow. The patient survey registered at a reading level of grade 10, while the health care provider survey registered with a reading level of grade 12 on the Flesch-Kincaid grade scale.

6.4.8 Question and Response Typing

Response options in both the patient survey and health care provider survey employ mutually exclusive scales. Both surveys use scaled response options to determine respondent opinions or views on various themes. The scale types used in these surveys include agreement, satisfaction, and importance scales. All scaled options include equal positive and negative options, usually with the inclusion of a neutral option. Scalar options were also formulated to give both sides of the argument to avoid biasing respondents. In addition, close ended questions in both surveys include both ordered and non-ordered response options where applicable.

6.4.8.1 Patient Survey and Response Types

As mentioned earlier the non-response option or “no opinion” option is typically chosen when offered. To mitigate this effect the “no opinion” option was limited only to “not applicable” in this survey. The “not applicable” option was important as this survey is designed for current cancer patients, cancer survivors, and family members. For example, certain questions such as those inquiring about ease navigating the hospital during treatment may not apply to family members.

6.4.8.2 Health Care Provider Survey and Response Types

Unlike the patient survey this survey employs no "no opinion" or "not applicable" options. This was done to avoid the respondents choosing these options by default. There is, however, several neutral options. It was deemed necessary to allow for a neutral option in the chance that respondents did not feel strongly in either direction of the spectrum.

6.5 Context Effects and Order

The context of a survey is varied by changing the order of questions. When designing a survey, it is important to consider that proceeding questions may have important information for following questions or they may change the need or consideration of following questions. In addition, survey context or the context of individual questions may be changed by proceeding questions (48).

The context of the survey can also affect what respondents consider as they answer the questions. This means that survey context and ordering can contribute to how survey respondents evaluate questions and can alter how the respondents perceive the questions as they answer. Survey context can compensate for bias (48).

6.5.1 Patient Survey and Order

Demographic questions were positioned last next to open-ended questions and included questions that could be useful for data analysis in the future. Demographic questions included questions such as age, cancer relation, and Indigenous identity. These questions could be used to correlate age, cancer relation, and Indigenous identity to overall opinion if found to be significant.

This survey sequenced in terms of information more relevant to cancer supports during treatment or at the hospital followed by supports available after treatment and in the community. This order was used to make the survey both easier to follow and more logical for survey respondents. The survey ends with an open-ended question asking for additional information about the cancer journey. This was intentional as this question would likely take more time and may elicit an emotional response. Therefore, by leaving it at the end the respondents are less likely to be drained while answering the proceeding questions.

6.5.2 Health Care Provider Survey and Order

This survey contains few demographic questions as aspects such as those included in the patient survey (i.e. age, gender, and Indigenous identity). These types of questions were not deemed to be appropriate or necessary for this survey. Time spent facilitating cancer care for Indigenous patients was the only demographic question asked as time spent could potentially be relevant to cancer care support needs and perspectives.

Similarly, to the patient survey a chronological design was followed in this survey design starting with information during cancer diagnosis, supports during treatment, supports following treatment, and supports available in recovery. Questions were also grouped together based on their content information to maintain a logical flow. Once again, this survey ended with open-ended questions. These questions inquire about opinions on survey content and additional comments. These questions allow researchers to gather further information that may not come from the survey. In addition, the open-ended questions were included at the end of the survey to lessen the burden on respondents and to maximize feedback on the entirety of the survey.

6.6 Survey Length

Survey length needs to be catered to survey population and survey purpose. It is essential to both gather enough information while not overwhelming the test population. Both the resulting patient and health care provider surveys created in this research questions were kept to the minimum needed to gather sufficient information on Indigenous cancer care support needs.

A short survey is both a benefit and a limitation to the survey design. The benefit to a shorter survey is that it ensures better question response. However, a shorter survey may limit the amount of data that can be collected from a survey. Therefore, a shorter survey requires that the questions used be designed in a way that will maximize data and information collection with fewer questions. A short survey will also increase response rates (50).

To maximize on survey length, most questions include several sub parts. This means that several questions are strung together using one leading statement that can be used followed by several combined statements. This is one way that the survey was created to limit the amount of questions while still ensuring that the appropriate amount of information could be gathered.

6.6.1 Patient Survey Length

The patient survey is eleven questions long. The survey was created to be short in nature to maximize response rates. In order to maximize on survey length several questions are multi-faceted and cover several topics or question under one heading. In this way it was possible to cover all desired survey content without a lengthy survey design.

6.6.2 Health Care Provider Survey Length

This survey was limited to ten questions. The health care provider survey was designed to be relatively short to cater to the busy lives of most health care professionals. This was important to ensure that future respondents will not be daunted or deterred to participate in the survey based on length alone.

6.7 Survey Design Comparison Table

The following table compares the patient survey and health care provider survey in terms of survey and question design.

Survey Design Comparison Table:

	Patient Survey	Health Care Provider Survey
Survey Topics	● Demographic questions: gather information on respondents age and relation to cancer ● Attitude questions: evaluate attitudes on current cancer supports ● Lifestyle questions: gather information on respondent lifestyle and barriers ● Needs questions: evaluate respondents needs and desires	● Demographic questions to gather information on respondent experience providing care ● Attitude questions: evaluate attitudes on current cancer supports ● Needs questions: evaluate gaps in current supports and services provided
Question Types	● Open and closed-ended ● Open ended give option for further information on patient experience	● Open and closed-ended ● Open-ended evaluate the survey
Word Choice	● Written for low literacy at a grade level of 9-10	● Written with limited medical jargon ● Written to a literacy level of grade 12
Response Typing	● Limited no option or not applicable options ● Several neutral options ● Likert scales	● No not applicable options given ● Several neutral options ● Likert scales
Context Effects and Order	● Designed to follow patients or family members journey from cancer diagnosis to recovery	● Questions grouped to flow logically ● Supports available from diagnosis to recovery

CHAPTER 7: SURVEY CONTENT

7.1 Survey Content Introduction

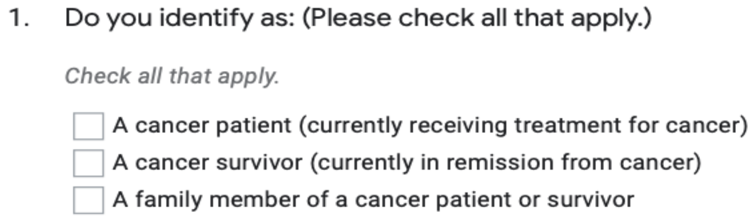
The content of both the patient and health care provider surveys result from informant feedback, other surveys, and the literature review. The following chapter will go into depth on the questions and contents of both surveys. Question appropriateness and reasoning will also be explored.

7.2 Patient Survey Content

The purpose of this survey was to explore the cancer care support needs and priorities of First Nation and Métis people in Saskatchewan. This survey was also designed with the possibility in mind for the survey to be generalized to a larger Indigenous population. The body of the survey explores cancer support needs from diagnosis, through treatment, and into recovery (See Appendix A).

7.2.1 Demographic Questions

The first question on this survey asks the respondent to identify as a cancer patient, cancer survivor, and/or a family member of a cancer patient or survivor. This is important information as several questions within the survey may not be applicable to families for example and so this question may help to explain the responses on certain questions. Demographic questions also include one asking for indication of Indigenous identity and status.



1. Do you identify as: (Please check all that apply.)

Check all that apply.

☐ A cancer patient (currently receiving treatment for cancer)
☐ A cancer survivor (currently in remission from cancer)
☐ A family member of a cancer patient or survivor

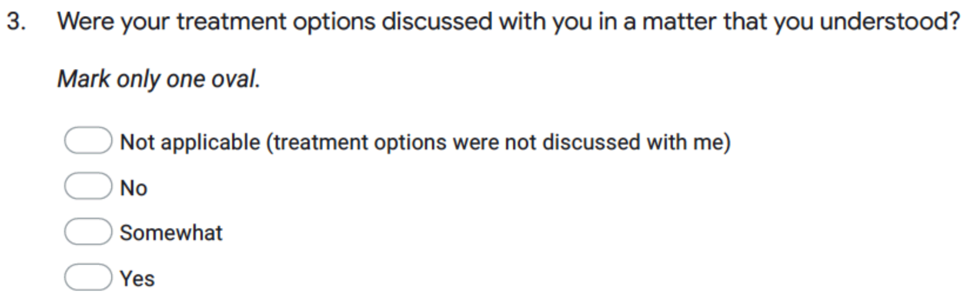
This survey also, asks several identifying questions such as age range and gender. Gender may be relevant to gather information on specific cancer services needed or desired unique to a certain gender. Age may be relevant information if commonalities are found in future research between certain needs and certain age demographics. This question would also be important for implementing policy as it allows for age specific targeted intervention.

The final identifying question is for the respondent to indicate their Indigenous identity with the option not to disclose. This question asks specifically about First Nation or Métis status in concordance to the Indigenous population in Saskatchewan. Again, this information may be used to ascertain if specific cancer needs are needed or of priority to specific populations.

7.2.2 Diagnosis Questions

Questions on cancer diagnosis focus in on the quality of information given to patients on diagnosis, treatments and cancer supports at the time of diagnosis. This section also assesses whether patients understood the information that they were given. Information on traditional treatments and whether these were given to patients is also assessed.

Responses to these questions could potentially be used to change protocols health care providers use with Indigenous cancer patients, or more specifically First Nations and Métis patients in Saskatchewan. Data from these questions could also help to determine whether patients are understanding the information given to them on diagnosis, treatment, and supports from care providers. This information could also be vital to cancer diagnosis protocols or rapport between health care providers and patients.



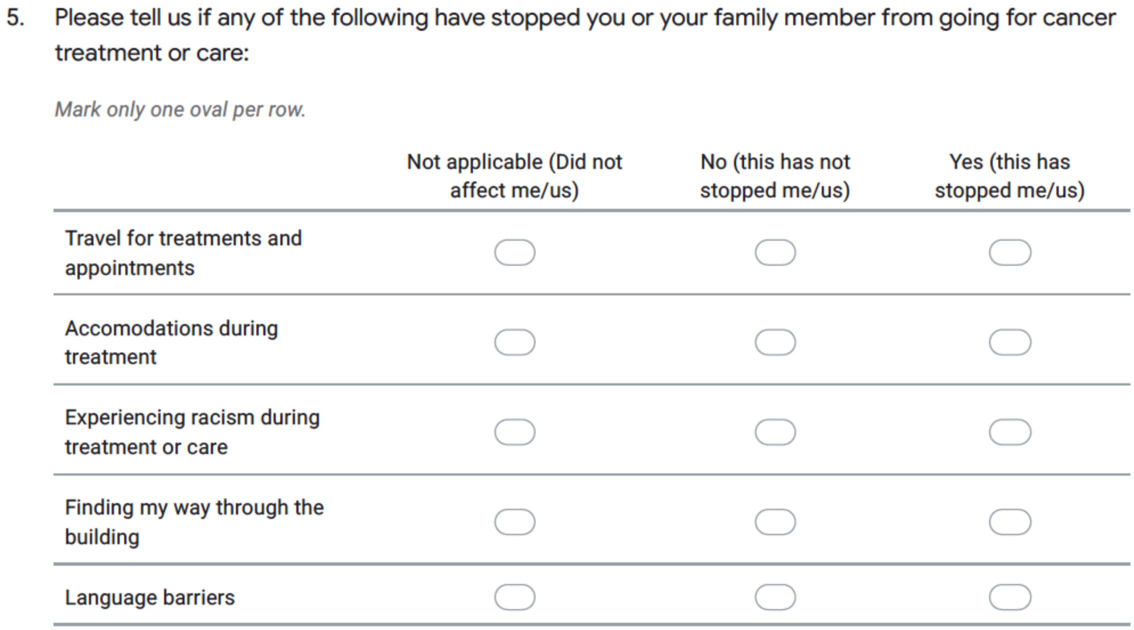
3. Were your treatment options discussed with you in a matter that you understood?

Mark only one oval.

○ Not applicable (treatment options were not discussed with me)
○ No
○ Somewhat
○ Yes

7.2.3 Treatment Questions

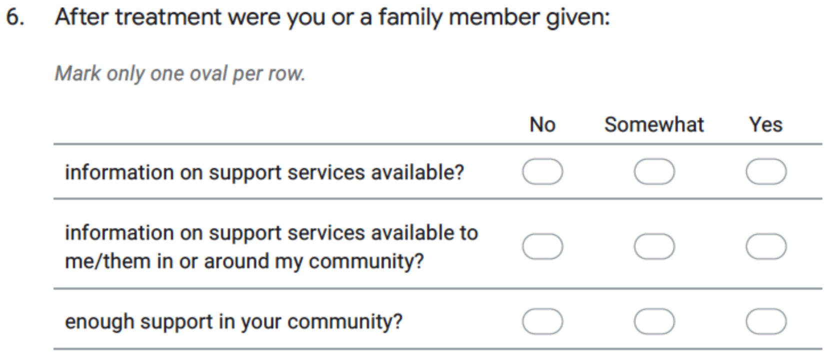
These questions discuss information on traditional treatment options and whether they were discussed with the patient. This question would help explore both whether patients feel traditional treatments are discussed, and if they would like them discussed at all. Other treatment questions focus hospital navigation. These questions reference Indigenous translators, and patient navigators. These questions could help determine whether these services should be or if they are available to respondents. In addition, these questions assess whether these services if available are helpful or how they could be improved.



5. Please tell us if any of the following have stopped you or your family member from going for cancer treatment or care:

Mark only one oval per row.

	Not applicable (Did not affect me/us)	No (this has not stopped me/us)	Yes (this has stopped me/us)
Travel for treatments and appointments	○	○	○
Accomodations during treatment	○	○	○
Experiencing racism during treatment or care	○	○	○
Finding my way through the building	○	○	○
Language barriers	○	○	○



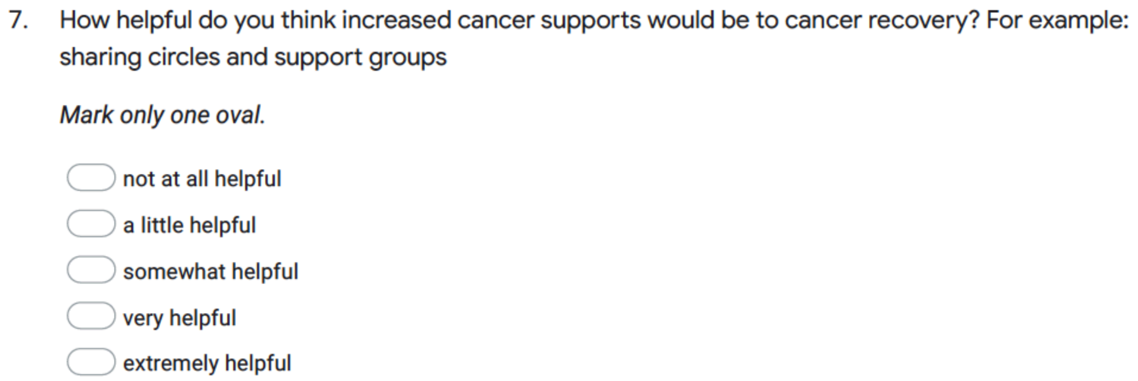
6. After treatment were you or a family member given:

Mark only one oval per row.

	No	Somewhat	Yes
information on support services available?	○	○	○
information on support services available to me/them in or around my community?	○	○	○
enough support in your community?	○	○	○

7.2.4 Recovery Questions

These questions involve gathering data regarding information on supports given to patients after treatment. These questions also explore whether the respondents feel as if increased cancer supports would help cancer recovery. Such data could help improve cancer recovery by improving cancer supports available to patients in the future.



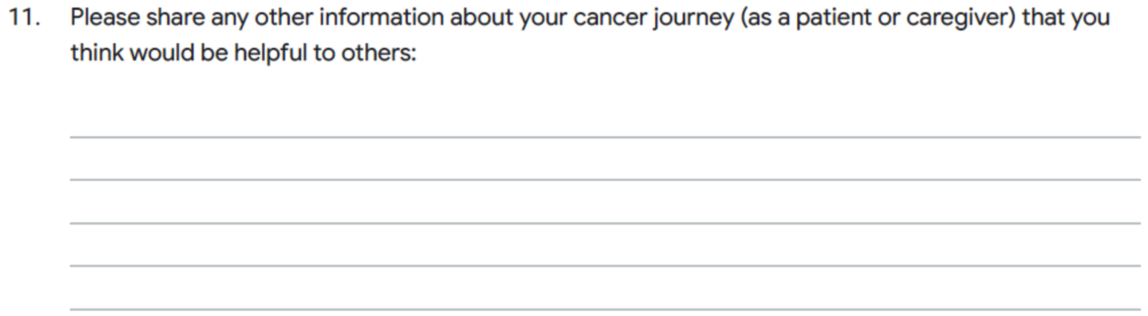
7. How helpful do you think increased cancer supports would be to cancer recovery? For example: sharing circles and support groups

Mark only one oval.

○ not at all helpful
○ a little helpful
○ somewhat helpful
○ very helpful
○ extremely helpful

7.2.5 Open-ended Questions.

The final question asks the respondent if they would like to share any further information on their cancer journey. This question is optional as it is expected that respondents may not want to disclose any further information. The purpose of this question is to allow for variability in the survey and to allow for respondents to share unique individualized answers.



11. Please share any other information about your cancer journey (as a patient or caregiver) that you think would be helpful to others:

7.3 Health Care Provider Survey Content

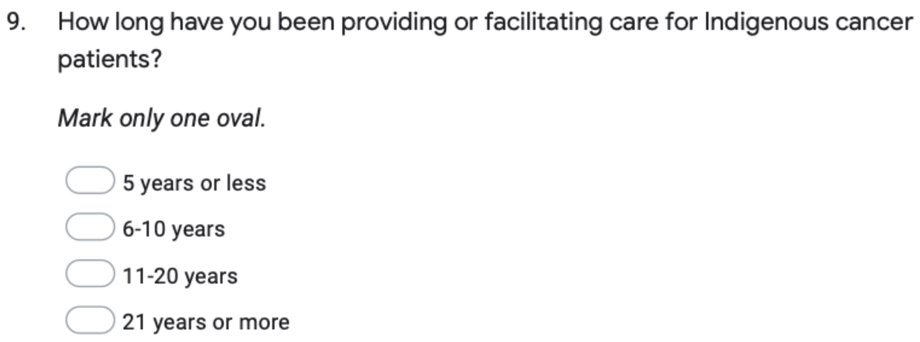
The health care provider survey was created as a by-product of the patient survey. Therefore, the content of both are similar. The patient survey was adapted to target health care providers and was formulated with questions more appropriate to providers. The health care provider survey was developed after feedback from the patient survey indicated that the patient survey may be hard to distribute in Saskatchewan.

It was suggested by the patient informants that a survey targeting health care providers working with Indigenous patients be formulated as well. This survey would be easier to distribute and could possibly more easily asses some of the gaps present in current health and support services available to First Nations and Métis cancer patients in Saskatchewan.

The purpose of this survey is to explore the gaps or limits to cancer care supports as seen by health care providers in First Nation and Métis cancer care in Saskatchewan. The questions focus in on barriers present for First Nations and Métis patients. Other questions asses what qualities of cancer care supports health care providers deem to be relevant or as potentially helpful to Indigenous cancer patients (See Appendix B).

7.3.1 Demographic Questions

The only demographic question in this survey asks respondents how long they have been providing or facilitating care for Indigenous cancer patients. This question was asked to explore whether time providing care or experience with providing care is linked to certain priorities for Indigenous cancer care as seen by respondents. No other demographic questions were included in the survey as they were not deemed as necessary for data analysis. For example, asking age or gender is not expected to correlate to specific answers from respondents.



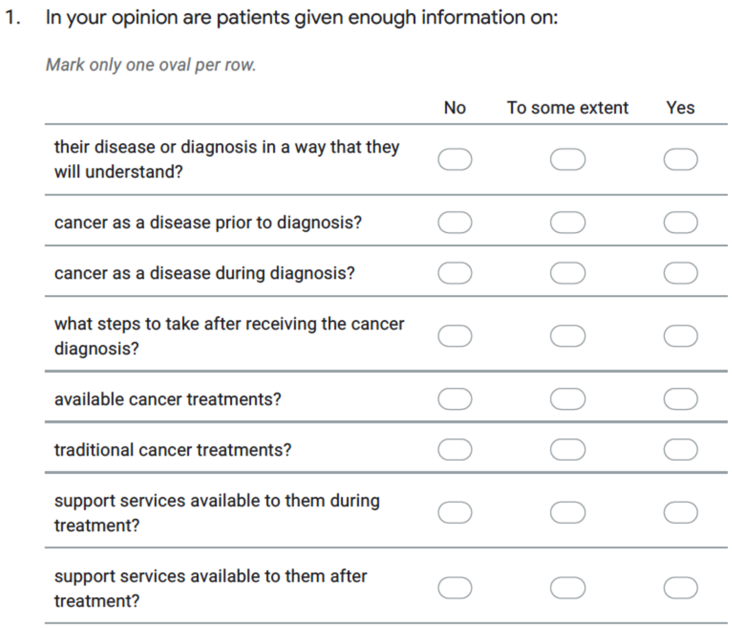
9. How long have you been providing or facilitating care for Indigenous cancer patients?

Mark only one oval.

○ 5 years or less
○ 6-10 years
○ 11-20 years
○ 21 years or more

7.3.2 Diagnosis Questions

These questions seek to evaluate whether health care providers believe that Indigenous cancer patients are given enough information on cancer treatments and services at the time of diagnosis. These questions also explore information divulged in regard to specific cancer support services at the time of diagnosis. The data from these questions could potentially be used to improve upon the information given to Indigenous patients at diagnosis.



1. In your opinion are patients given enough information on:

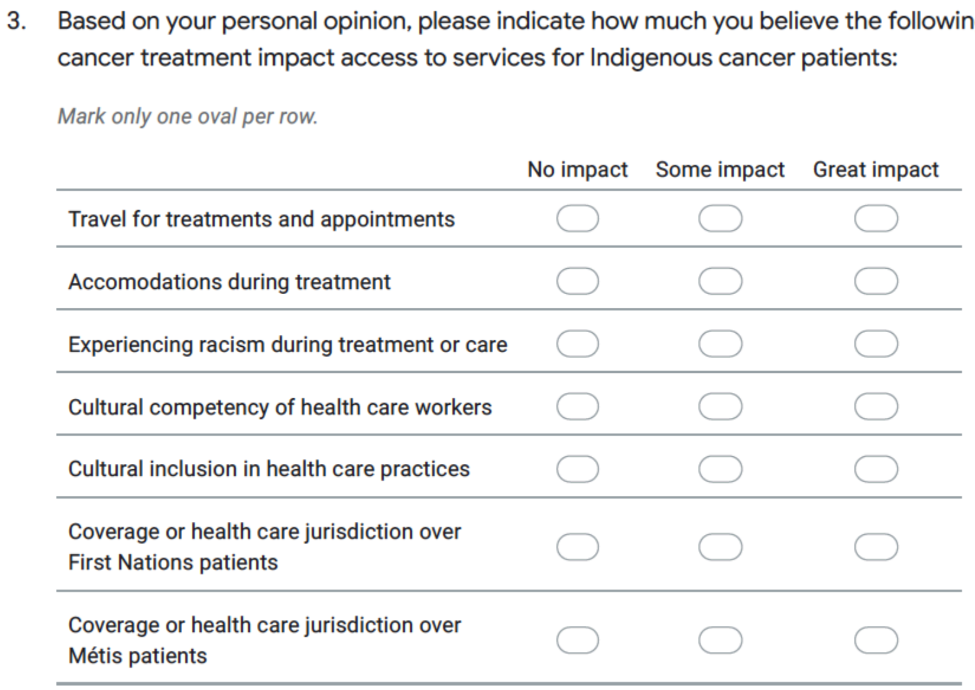
Mark only one oval per row.

	No	To some extent	Yes
their disease or diagnosis in a way that they will understand?	○	○	○
cancer as a disease prior to diagnosis?	○	○	○
cancer as a disease during diagnosis?	○	○	○
what steps to take after receiving the cancer diagnosis?	○	○	○
available cancer treatments?	○	○	○
traditional cancer treatments?	○	○	○
support services available to them during treatment?	○	○	○
support services available to them after treatment?	○	○	○

7.3.3 Treatment Questions

Treatment questions in the survey explore health care provider views on providing traditional treatment options. This data could be linked to potential barriers with providing traditional treatment options. In addition, treatment questions assess health care provider opinions on Indigenous navigators, and translators. These questions also explore the importance of language barriers during treatment. Data from these questions could be used to help improve and ease treatment for Indigenous cancer patients.

Other treatment questions ask respondents to rank potential barriers to treatment for Indigenous cancer patients based on the affect they perceive these barriers have on their patients receiving treatment. Barriers mentioned include; travel, accommodations, cultural inclusion of services, and medical coverage. This data will provide information on the most important barriers affecting Indigenous cancer care.



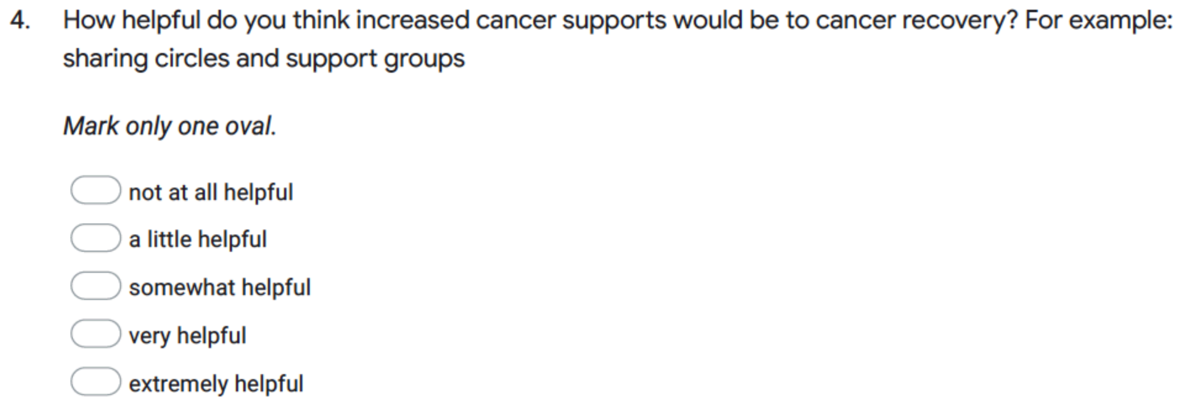
3. Based on your personal opinion, please indicate how much you believe the following barriers to cancer treatment impact access to services for Indigenous cancer patients:

Mark only one oval per row.

	No impact	Some impact	Great impact
Travel for treatments and appointments	○	○	○
Accomodations during treatment	○	○	○
Experiencing racism during treatment or care	○	○	○
Cultural competency of health care workers	○	○	○
Cultural inclusion in health care practices	○	○	○
Coverage or health care jurisdiction over First Nations patients	○	○	○
Coverage or health care jurisdiction over Métis patients	○	○	○

7.3.4 Recovery Questions

Questions focused on patient recovery inquire whether health care providers believe that increased cancer supports would benefit cancer recovery. Recovery questions also ask respondents to evaluate the adequacy, availability, cultural competency, and cultural inclusivity of the services currently available. Data from these questions could be used to improve current cancer support services currently available to Indigenous cancer patients. These questions could also help to support increasing cancer care supports available to patients and could influence them to be more culturally inclusive or competent.



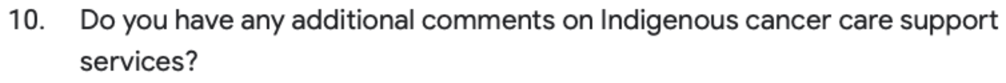
4. How helpful do you think increased cancer supports would be to cancer recovery? For example: sharing circles and support groups

Mark only one oval.

○ not at all helpful
○ a little helpful
○ somewhat helpful
○ very helpful
○ extremely helpful

7.3.5 Open-ended Questions

This survey ends with two open-ended questions. The first question asks for any additional comments on Indigenous cancer care support services. The second question asks for comments of concerns on the survey and its questions. These open-ended questions allow respondents to include additional information that they see as relevant to the survey topic. These questions also allow for data variability and for the survey to go beyond the formal close ended questions asked.



10. Do you have any additional comments on Indigenous cancer care support services?

7.4 Survey Content Comparison Table

The following table compares the patient survey and health care provider survey in terms of survey content and question types.

Survey Content Comparison Table:

	Patient Survey	**Health Care Provider Survey**
Demographic Questions	• Cancer relation or experience • Age • Gender • Indigenous identity	• Experience providing care or facilitating Indigenous cancer care
Diagnosis Questions	• Explore information on diagnosis • Explore information on supports given at diagnosis	• Explore the adequacy of information given to patients on supports and disease at diagnosis • Explore the quality of information given to patients on cancer supports
Treatment Questions	• Explore the need for Traditional treatment options • Experience with barriers during treatment • Hospital navigation • Importance of Indigenous navigators and translators	• Explore the need for Traditional treatment options • Explore opinions on current health care system in terms of cancer support services and care • Evaluate need or presence of Indigenous translators • Evaluate barriers to treatment
Recovery Questions	• Explore information given on supports available to patients • Explore use of supports by patients • Explores significance or importance of specific supports	• Perceived support benefits to cancer recovery • Evaluate cultural competency and inclusivity of programs
Open-ended Questions	• Allows for respondents to elaborate further on their cancer journey	• Additional comments on the survey • Concerns regarding the survey

CHAPTER 8: ADAPTING SURVEY CONTENT AND QUESTIONS

8.1 Introduction

Survey questions and content were adapted using informant feedback, triangulation, and content matching. Feedback from seven patient informants, two health care advisors, two researchers, and one survey expert were cultivated to adapt survey content or format. In addition, an environmental scan and key informant interviews conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* were utilized in this study to evaluate the appropriateness of survey questions and to identify gaps in survey content (11, 13).

8.2 Survey Feedback

Survey feedback was gathered on several occasions during survey development. Survey feedback was gathered at meetings, in focus groups, by open discussion, or by email. This included feedback from two other researchers (both involved in the *Sâkipakâwin project* and familiar with Indigenous research), one professional very experienced in survey design and implementation, as well as seven patient informants and two health care providers. Meetings and emails involved an open discussion between patient informants and the researcher on the content of the survey and the survey design. The aforementioned individuals were also provided with focus group like questions to help guide the discussion on survey content and format (See Appendix C).

8.2.1 Feedback for the Patient Survey

The following is a summary of the feedback for the patient survey from seven patient informants. All seven informants were of Indigenous identity (both First Nations and Métis) including three Elders, two cancer patients, and two Indigenous community leaders. Feedback was summarized into various categories including wording, content, format, and distribution. The feedback section will then proceed to discuss feedback from health advisors, other researchers and survey experts.

8.2.1.1 Wording Feedback

It was determined during one feedback session that the language used in the patient survey may not be appropriate for the target population. Several members indicated that the patient survey would need to be adapted to be more reader friendly. A significant amount of people mentioned that some of the words may be hard to understand. Overall, it was recommended that a majority of the survey be rewritten with a lower level vocabulary to appeal to a larger audience.

It was mentioned that it may be more appropriate to use First Nations and Métis as opposed to Indigenous throughout the survey as those are the Indigenous populations represented within Saskatchewan. If this survey was meant to be distributed throughout Saskatchewan than using First Nations and Métis would be more appropriate. A demographic question asking people to disclose their Indigenous identity or rather to indicate, if they so wish to, whether they are First Nation, Métis, status, non-status, etc. was also suggested.

8.2.1.2 Content Feedback

Demographic questions were assessed, and a question asking for identification of the respondent's specific Indigenos band or Nation was deemed to be unnecessary. The first question evaluating cancer status was asked to be reworded to be more inclusive of cancer family members. As mentioned previously, it was recommended that a demographic question regarding Indigenous identity specific to First Nation and Métis to represent the Saskatchewan population be included in the demographic section of the survey.

It was mentioned that the patient survey needed to assess cancer patient understanding in a more direct manor. Recommendations were to adapt questions regarding information on cancer and cancer supports from providers to questions that directly ask the patient if they were not only given such information but if they understood it as well. Many individuals emphasized the importance of understanding as this aspect is crucial to support throughout cancer treatment.

Other comments indicate that the journey of cancer and seeking cancer support needed to be more prevalent in the survey. It was mentioned that it was important to understand the journey throughout cancer treatment and recovery and the barriers faced along this journey to best address those barriers. These comments inspired the chronological flow of the survey. From this suggestion the survey was formatted into a format that followed patient diagnosis, to treatment, through to recovery.

Input suggested that questions be adapted to better explore how cancer patients understand the medical system. It was recommended that more questions be included that assess how patients view cancer is handled in the healthcare system. In addition, questions should explicitly ask how the patients are challenged by the healthcare system throughout their journey.

In addition, many felt as if the survey lacked questions in regard to traditional views and traditional treatments or supports. It was suggested that these components should make up a larger part of the survey and be better represented within the questions. It was also mentioned that the current question asking patients if they wished traditional treatment and support options be given to them in addition to Western treatment options was both strong and important. Questions on Traditional medicine and treatment options were thought to be crucial to the survey and its contents.

Another well liked question was one regarding the evaluation of Indigenous navigators and translators in the hospital. However, it was also recommended that the questions assess how important it was for the respondent that these individuals speak their language or be of Indigenous identity themselves. The patient informants also recommended that the two; navigators and translators be assessed individually rather than as a combined item.

8.2.1.3 Format Feedback

Early on a common remark was that the survey consisted of too many questions. It is important to note that at this point the survey was designed with an over-abundance of questions of questions to give evaluators more questions to critique. This also allowed for gathering more information on what sort of content would be preferred for the study.

Several similar questions were combined to minimize survey length. In addition, several questions were deemed not to be necessary or thought not to gather useful information. For example, one question requested respondents to indicate the distance they travelled for care or services. This information was not thought to be as relevant as whether distance travelled was perceived as a barrier to care by participants.

After a more finalized version of the study was created it was still found that the survey contained to many questions. Certain questions were recommended to be combined and streamlined into formats that allow for asking several questions from one stem. Other questions were recommended to be left out or eliminated from the survey, especially if they were similar to other questions already included in the survey.

The overall format of the survey was deemed to be representative of study purpose. Survey feedback unanimously stated that they felt the survey did an adequate job of assessing cancer care supports and cancer care support qualities available to Indigenous cancer patients. With the adaptation of a few questions and format it was believed that the survey could be a useful and accurate tool.

8.2.1.4 Distribution Feedback

Feedback from the patient survey brought to question how the survey tool would be distributed to First Nation and Métis cancer patients or families. How to distribute the survey respectfully, appropriately, and logistically was questioned by patient informants. The lack of information on Indigenous cancer patients or family members and the limited disclosure of their information was mentioned by several people. Some questioned whether enough participants could be identified with or without the availability of this information. It was also, indicated that seeking out individual patients may infringe on patient privacy.

The logistics of distributing a survey to individuals was thought to be daunting by most patient informants. No good method for distributing the survey to individual patients and family members could be determined. At this point is was determined that it would be more appropriate to create a survey tool targeting healthcare providers that work closely with First Nation and Métis people in Saskatchewan.

8.2.2 Health Care Provider Feedback

Health care provider feedback included the feedback from several health care providers or managers currently providing care for First Nations or Métis cancer patients within Saskatchewan. Their feedback was sought through email correspondence. The health care provider or manager was provided with a current copy of the survey as well as with several questions regarding the survey to help provide feedback (See Appendix C).

8.2.2.1 Demographic Feedback

Health care provider feedback included comments on demographic survey components. Demographic questions were assessed, and it was deemed unnecessary to ask gender on the healthcare provider survey. It was felt as if gender would likely not contribute to the survey in a meaningful way nor would it be significant to data analysis. The need for questions on age were also brought into question. In discussion it was determined that these variables would have little to no effect on survey outcome and that they were not significant to data results or analysis.

The only demographic question deemed to be important was time providing or facilitating care for Indigenous patients. This question could be relevant because experience could possibly be correlated to particular responses. Time spent working with or for the population could also be linked to views on certain barriers to treatment or to specific views on cancer supports.

8.2.2.2 Format Feedback

Some of the questions that ask about patient’s knowledge were indicated as hard to read or follow and were recommended to be reformatted. It was also, suggested that some questions be removed or formatted in a way to make them more applicable to health care providers or health managers. Most recommended formatting changes focused on improving the flow of the survey.

Questions on translators and navigators was suggested to be separated. This change would allow for better analysis of the two aspects and their importance separately. It would also allow for further questions centralized around each individual aspect or program rather than having them lumped together.

One specific question regarding an opinion on the helpfulness of cancer care supports was flagged as to having too many options grouped together. Instead, an alternative question that asks respondents to rank supports such as support groups, navigators, and translators separately based on personal opinion. This question adaptation would again allow for better data on individual interventions or supports and which ones are deemed to be the most helpful.

This survey was also regarded as to have an excess of questions. Feedback unanimously inundated that the survey would likely not be filled out properly if it was time consuming and difficult for respondents to fill out. It was recommended to mitigate this by combining questions together to still adequately gather information without creating a lengthy survey. This could be done in a way that took for example a question on ranking the effect of a barrier to treatment to then list several barriers and have them ranked one after the other. By altering the survey in this way, it becomes both faster and easier for the respondent to fill out.

8.2.2.3 Content Feedback

It was mentioned for this survey that it may be more appropriate for the survey to be more directed towards Indigenous populations in Saskatchewan or more specifically to First Nations and Métis people of Saskatchewan. The informants did not feel that anything needed to be added to the survey. They did indicate however that several questions could be removed or adapted. As mentioned, before it was suggested that certain demographic questions be removed. It was also indicated that certain survey questions on Indigenous cancer supports be altered to evaluate individual aspects of the supports such as cultural competency.

8.2.3 Researcher Feedback

Feedback from researchers working on the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families,* were consulted in survey design and content of both surveys. These researchers were recruited based on their involvement in a study of similar nature. Correspondence occurred via email. These researchers were consulted at all stages of survey design and provided feedback throughout the design process. The majority of suggestions were format based including rearranging questions for easier question flow. Other suggestions were on question wording and format so that they were easy to both understand and answer for respondents.

A question involving barriers in both surveys was also recommended. This question was included to rank possible barriers to accessing care or supports based on their importance as seen by respondents. It was also, suggested that a sex demographic question be added to the patient survey as it this information could be used to support policy decisions for increasing cancer care support services. It was indicated that gender could influence targeted services available or could allow policy makers to implement changes specific to a certain gender if the data revealed a difference in cancer support needs between genders.

8.2.4 Survey Expert Feedback

Feedback from individuals experienced in survey design and creation was important to develop a survey that was functionally sound. This step was important to ensure that the surveys were formatted in a way that would make sense for data analysis and for the participants. This step was also vital to designing well-designed survey tools.

Feedback from one survey expert was sought by email. The expert was identified due to their involvement in survey research at the Social Science Research Laboratories at the University of Saskatchewan. The expert was informed on the study purpose and project design of both surveys. The expert was contacted by email and was requested to provide input on survey design. This occurred with every draft of the survey(s) created.

The majority of recommendations involved the appropriate common suggestions to improve question format were made. These included changing question design and selection choice. These recommendations would make the survey easier to use and survey data easier to analyze.

8.2.5 Survey Feedback Summary Table

The following table outlines the most important or relevant feedback to survey design and finalization.

Survey Feedback Table:

	Patient Survey	Health Care Provider Survey
Patient Informant feedback for first draft	• Identifying participants would be difficult • Distribution will be difficult due to the limited knowledge on Indigenous health and Indigenous cancer patients • *Targeting Health Care Providers could solve this problem	N/A
Patient Informant feedback on new drafts	• Survey is too lengthy • Need to have more focus on patient experience • Language is inappropriate • Too much jargon • May be difficult to understand • Needs to elaborate more on patient understanding • Need more questions on Traditional treatments	• Survey is too lengthy • Should focus more on barriers • Slightly too much medical or health jargon • Needs to incorporate Traditional treatment methods
Health Care Provider Feedback	N/A	• Should focus on solutions • Gender was not a necessary demographic question
SSRL Feedback	• Mostly on format • Question design • Word choice	• Mostly on format • Question design • Word choice
Researcher Feedback	• Should evaluate barriers • Sex demographic question	• Should focus on barriers
Final Feedback	• Mostly on format and word choice	Mostly on format and word choice

8.3 Deciding on Questions

After questions were drafted initially using the literature review, patient informant requests, and other surveys as reference questions were evaluated using informant feedback. The initial patient survey consisted of twenty-eight questions. It was decided that final versions of both surveys would only contain approximately ten questions. This decision was made based on informant and expert recommendation that the surveys should only take approximately ten minutes of the respondent's time.

Questions were eliminated or adapted according to informant and expert feedback as described above. Feedback from respondents of the intended survey populations ensure that the survey questions are appropriate and relevant to the survey population. Questions were also combined whenever necessary to limit survey length.

In addition, question content was adapted to be inclusive of the themes identified in the environmental scan and key informant interviews conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* (11, 13). This further guarantees that the surveys cover all appropriate themes and content needed to support policy change. In addition, it will secure that both surveys were created to gather information that they need to fulfill the intended survey purpose.

8.4 Triangulation

Triangulation is the use of various methods or data sources to create well rounded results and to establish credibility of the findings (66). Triangulation will be performed by matching survey content and themes to those found in an environmental scan and key informant interviews conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* (11, 13). The idea is that if the different sources discover similar evidence then the data sets corroborate each other. Therefore, if similar evidence or themes are retrieved from the interviews and environmental scan as present in the surveys and their contents then there is a good chance that the survey questions are valid and credible (66). Triangulation was used to identify gaps in survey content and to assess question relevance by matching survey contents and themes of the survey to those in an environmental scan and key informant interviews conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* (11, 13).

8.4.1 Environmental Scan

An environmental scan conducted as a part of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families,* was used in this project to validate survey content (11). This scan dives into cancer supports available all over Canada with a focus on Indigenous cancer supports. The scan also explores Indigenous cancer supports provided in Saskatchewan (11).

The scan begins by discussing differences in care such as Indigenous Traditional medicines as opposed to formal cancer treatments such as chemotherapy. The scan also highlights some possible barriers to treatment such as medical transportation, accommodation, and language barriers. These suggests are congruent with the barriers evaluated within both the patient and health care provider surveys formulated in this study.

The scan also describes several service and support suggestions that could improve access to care such as interpretation services and cancer patient navigators. The importance of patient navigators is mentioned in the scan as Indigenous patients have different world views. The scan also suggests that cancer patient navigators be Indigenous as they would understand the needs of Indigenous patients in a way that non-Indigenous navigators could not. This is congruent with survey content that asks about the importance of Indigenous patient navigators. Other questions ask survey respondents whether they feel it is important for Indigenous translators and navigators to be Indigenous themselves. Another question asks about the importance of these people speaking Indigenous languages whether or not they are Indigenous people.

The scan goes on to describe several supports available to Indigenous people outside of Saskatchewan. These supports include toolkits and educational cancer materials in Indigenous languages (11). British Columbia offers a cancer guide specific to Indigenous Peoples in Canada that helps them organize documents, questions, and cancer treatment plans (11). Both the patient and health care provider survey evaluate the need for Indigenous cancer support materials for a possible solution or aid to limited cancer understanding and limited access to care.

Throughout feedback and input sessions it was made evident that Traditional Healing and medicinal practices were an important quality of Indigenous cancer care supports. The survey seeks to evaluate this by asking respondents whether they want Traditional Healing methods to be discussed with them throughout treatment, or whether any Traditional Healing methods were discussed with them throughout treatment. The environmental scan describes that other provinces offer Traditional Wellness clinics, lodges, or health care agencies that provide Traditional Healing to cancer patients (11).

According to the scan other provinces also have access to other supports such as support groups and discharge planning. British Columbia offers talking circles for patients and family members (11). Manitoba has a series that coordinates discharge plans for Indigenous cancer patients that involve community health and support facilities (11). Both of the services depict the importance of continued care from hospital to home. The patient survey explores community-based supports and whether they were discussed during treatment. The patient survey also asks respondents whether they have any support groups available to Indigenous cancer patients and/or their families in their communities.

There were many themes included in the environmental scan also reflected within both the patient and health care provider surveys created from this study. These congruencies help to establish content validity amongst the surveys. There was, however, not any information included in the scan that was both missing from the surveys and deemed to be important to survey content. Therefore, the surveys were not altered due to environmental scan material.

8.4.2 Key-informant Interview Analysis

Analysis of key-informant interviews with healthcare professionals that work with Indigenous cancer patients in Saskatchewan made available to the researcher was used to check survey content and question relevance. These key-informant interviews were also obtained from the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families*, with permission from the research team (13). Participants of these interviews included two physicians (one Indigenous and one non-Indigenous), two health care authorities, one Indigenous political leader, and a health care management worker.

The information contained in this analysis was gathered in six interviews. Interview participants were asked open ended questions over the telephone. Interview questions inquired about cancer supports were available to Indigenous cancer patients and their families specifically.

The key themes of informant interviews were used to content check and ensure that the survey covered the main concerns or information of Saskatchewan health care professionals working with Indigenous cancer patients. Likewise, key themes could also be adapted for the patient survey by focusing on patient experience.

Upon review of the interview analysis and when comparing said analysis to survey content it became apparent that some key themes were missed in survey development. Key themes or concerns brought up in the interviews that were not already included in the surveys up until this point were then added to the surveys. This process helped to ensure that the surveys asked questions that were relevant to the study population and that pressing issues were not missed in survey content.

8.5 Key-informant Interview Themes

The following are common themes derived from the *Sâkipakâwin project* key-informant interviews. These themes were derived from key-informant interview analysis done by other researchers. These themes are thought to be important to survey content as they further its relevance and relatability to the research populations.

8.5.1 Diagnosis and Follow-up Support Needed

The most frequently mentioned supports recommended by interviewees was patient navigators and translators. The importance of having patient navigators both in hospitals, cancer centers, and Indigenous communities was mentioned by interview participants. The goal is that these people would be able to ease the stress of Indigenous cancer patients and could help ease their journey throughout care by offering support.

Interview participants stated that navigators could help patients as soon as they arrive to cities or hospitals for treatment. Navigator roles would include things such as arranging transportation, accommodation, and potentially navigating throughout the hospitals. Patient navigators would also be responsible for cross-communication between physicians and patients, potentially helping to explain treatments and medication to patients.

Interview participants stated that they did not think that Indigenous patient navigators needed to be Indigenous themselves. It was mentioned however, that being able to speak Indigenous languages would be a tremendous asset and may be necessary. Cultural competency and knowledge are mentioned as a necessary skill. Interview participants also state that training patient navigators should be a priority for the healthcare system.

8.5.2 Barriers to Treatment

Interview participants mentioned some possible barriers to treatment specific to Indigenous cancer patients. These barriers may include the contrast between Western and traditional Indigenous worldviews. The difference between Western and traditional views on health may create an interesting divide between patients and their treatment plans.

The two views on health are not very well integrated into the current health care system in Canada. Evidently, patients wishing to pursue traditional treatment options will have difficulty accessing those services throughout their treatment. In addition, there is a rise of Indigenous cancer patients and the health care system is not prepared to appropriately to help treat those patients.

Another barrier to treatment mentioned that may be unique to Indigenous patients is the lack of knowledge on the health care system according to interview participants. Respondents mention that Indigenous patients also tend to have less confidence in the health care system itself which also creates problems when accessing treatment or carrying out a treatment plan. This compounded with a potential language barrier could really limit the availability of services to patients.

8.5.3 Barriers to Support Systems

Barriers to implement support systems were a common theme amongst the key-informant interviews. Barriers mentioned by participants include the complicated relationship between provincial and federal health care systems. This is elevated for Indigenous cancer patients. A lack of data about Indigenous cancer patients was mentioned as significant barrier.

Many barriers mentioned by key-informants centered on respect and trust. Participants mentioned barriers such as a lack of trust between Indigenous peoples and the healthcare system. Consequently, cultural differences and a lack of respect for traditional practices was also mentioned as a barrier to care. Likewise lack of cultural competency amongst health care practitioners was mentioned as another barrier.

Racism and judgement based on socio-economic factors was mentioned in the analysis as a potential barrier to access support services. In addition, the lack of Indigenous representation among medical staff and at cancer treatment centers was identified as limitation to current health care procedures. Interview participants state that an increase of Indigenous medical staff could possibly help patients feel welcome and safe during treatment. This would also help to reduce the impact of racism another potential barrier to treatment. Again, it was mentioned that navigators could help to reduce this gap and improve patient relations.

Interview participants also mention specific barriers to remote cancer patients. Problems with access to transportation and accommodation are exacerbated for these patients. Remoteness in itself is also its own barrier as patients need to travel long ways for treatment and often have to travel alone.

8.5.4 Proposed Solutions

To bridge the gap between health service and support access interview participants recommended increasing incentives for bettering patient care in remote communities. This would involve incentives to increase access and utilization of services and supports. Another recommendation was to create plans or procedures that could increase patient compliance to care plans in home communities. Notably, this could also be addressed by increasing access to health care services and supports in communities.

Making translational cancer care materials such as pamphlets available in several Indigenous languages was recommended as a possible solution to improve access and understanding of cancer care. This could also improve access and adherence to care plans or supports. Indigenous lodges were proposed as culturally respectful and understanding places that could potentially address travel and accommodation issues.

8.5.5 Commonalities with Survey Content

The key-informant interviews echo the content of the patient and health care practitioner surveys in many ways. The need for patient navigators and translators is common amongst all three documents. The surveys also evaluate the need for these individuals to be Indigenous themselves, speak an Indigenous language, or both. A common theme throughout the key-informant interviews was the desire and importance of traditional practices. Both surveys evaluate the need or desire for traditional services.

The key-informant interviews mention several barriers to treatment and services access such as transportation and accommodation. The health care provider survey asks respondents to rank these barriers as to how they view their impact on patients accessing services. The patient survey currently did not contain a question addressing these barriers.

8.5.6 Differences with Survey Content

There are a few main differences that will be included in the final versions of the surveys. The patient survey lacks questions regarding the difference between Western and Traditional worldviews and their influence on treatment. In addition, the survey could include a question surrounding trust for the health care system and feeling safe and respected during care. The patient survey could also include a question surrounding the importance or desire for Indigenous health care staff. Another common theme that is missing from the patient survey is the evaluation of racism experienced throughout care.

The health care provider survey should include questions about whether participants feel as if the current health care system can adequately provide services and support for the influx of Indigenous cancer patients. More importantly, can the system provide these services in a culturally inclusive and respectful way? Other potential questions may include, whether respondents feel the need for Indigenous staff members to be present at hospitals and care facilities. Evidently, the health care provider survey also had limited content on proposed solutions to problems.

8.6 Triangulation and Survey Comparison Table

The following table outlines the comparison between the key informant interviews, environmental scan, and the survey content. This table will depict the commonalities and differences between the environmental scan and key informant interviews to the survey drafts. These commonalities will be broken down into themes or similar messages found between the four documents. Differences between the documents will be presented if found to be necessary for survey inclusion.

Triangulation and Survey Comparison Table:

	Environmental Scan	Key informant Interviews
Themes similar to those in surveys	• Differences in Traditional and Western medicine • Barriers to treatment such as transportation • Support suggestions such as a presence of patient navigators and translators	• Diagnosis and follow-up support needed (Patient navigators and translators are needed) • Barriers to treatment such as transportation • Barriers to accessing support systems such as racist and lack of trust • Importance of Traditional practices
Differences to surveys	• Supports currently available outside of Saskatchewan	• Proposed solutions such as increased cultural respect training • **Patient survey** lacks questions regarding differences in Western and Traditional views • **Patient survey** could include questions on desires of having Indigenous health care staff • Health care provider survey
To include in surveys	• Nothing	• **Patient survey** could include questions on desires of having Indigenous health care staff • **Health care provider survey** should include questions to explore solutions and to assess the adequacy of system to provide support to Indigenous patients

8.7 Survey Adaptation Conclusion

Themes identified from the key informant interviews and environmental scan to be missing from the surveys were assessed by the researcher for relevance and need for survey inclusion. Those deemed to potentially gather information pertinent to the study goals or survey design were included in the surveys. In addition, all feedback was considered for survey inclusion or adaptation.

CHAPTER 9: SURVEY FINALIZATION

9.1 Introduction

The final survey products are the results of survey feedback, respondent validation, and content matching. Both surveys were adapted according to the feedback given and themes found within the key informant interviews and an environmental scan. Both final surveys are inclusive of all final feedback and were sent to all informants prior to finalization.

9.2 Revisions

All revisions from the meetings, feedback sessions, and emails were considered for the final survey drafts. This process was integral to final survey design and content. Final survey feedback from patient informants, health advisors, and researchers was sought after matching survey content to interviews on Saskatchewan Indigenous cancer support needs and an environmental scan.

9.3 Adapting the Surveys

Both surveys were altered to be inclusive of the missing content expressed by the key-informant interviews. One question was adapted to be inclusive of traditional health practices and to address personal feelings on the health care system. Another question was created to address potential barriers or the importance of these barriers to patients in regard to whether they hinder access to care.

The health care provider survey was missing content on the readiness of the health care system and the availability of Indigenous staff. Two questions were modified to be inclusive of this information. A new question was developed in the health care provider survey evaluating the effectiveness of solutions proposed in the interviews.

9.4 Final Review

Final drafts of the surveys were sent out for feedback. This final draft was inclusive of the changes made due to data from the key-informant interview analysis. The final review feedback consisted only of minor format and wording changes.

Final review suggestions included adding prefer not to say options for several demographic questions. Other suggestions include merging two similar questions into one question. In addition, a suggestion was made that one of the patient questions be changed to more user-friendly or lower literacy language. There were few other changes proposed at this time. All feedback respondents agreed that both surveys were inclusive of main issues facing Indigenous cancer patients. In addition, it was agreed that both surveys contained appropriate questions that would fulfill the survey purpose.

Surveys were finalized including all initial feedback, key-informant interview analysis information, and final feedback. The surveys were once again sent out for approval with no further feedback or suggestions made. At this stage is was determined that the surveys were valid tools capable of addressing the study purpose and answering the research question.

9.5 Finalized Surveys

Survey content, format, and design was finalized following a final review from researchers, survey experts, and patient informants (See appendix A and B). This finalized format was inclusive of the feedback gathered throughout the process of survey development. It was also inclusive of themes and information in the key-informant interviews and environmental scan of the *Sâkipakâwin project: Assessing the Support Needs for Saskatchewan Indigenous Cancer Patients and their Families* (11, 13).

It is believed that the final surveys titled the *Patient: Indigenous Cancer Care Supports Survey and Health Care Provider: Indigenous Cancer Care Supports Survey* will accurately evaluate cancer care support needs of First Nations and Métis people in Saskatchewan. Both surveys were created in collaboration with other Indigenous researchers, survey experts, and Indigenous health professionals. Due to the involvement of Indigenous health care workers, facilitators, community members, and patients in Saskatchewan both surveys were created to reflect the needs of Indigenous cancer patients in Saskatchewan to the best of their ability.

CHAPTER 10: SURVEY VALIDATION

10.1 Validity Introduction

Survey validity is the ability of the survey to gather the information that it is intended to measure (47). The purpose of this study was to gather information on cancer support needs for Indigenous cancer patients, their families, and communities. The perspectives and opinions of Indigenous cancer patients, their families, and health care providers are extremely important to this research. Therefore, the methods of validity utilized in this study are face and content validity.

10.2 Methods of Validity

The study is patient oriented and proposes positive change for the Indigenous community. Therefore, respondent validation fits with the logistics of the study. Respondent validation was used to check the themes of the study. Indigenous patient informants also had the opportunity to examine the final survey content (66). This allowed them to validate or discredit the themes and interpretations that have been created from the data.

Face validity was established by the investigator along with informants and researchers working on the *Sâkipakâwin project*. To ensure survey content validity the project's seven patient informants were consulted on survey development and reviewed the finalized survey. These patient informants included three Indigenous Elders, two Indigenous cancer patients, and two Indigenous community leaders. Another way in which this survey was validated is through review of the questions and feedback from patient informants. Survey follow-up will be essential to gather this information.

Survey follow-up was conducted via group debriefing after reviewing survey drafts. This review process allowed for exploration into how respondents may have interpreted the questions and thus, limiting misinterpretation by other respondents in the future. Several steps will be followed during the feedback process including establishing question meaning, judging question appropriateness, and reviewing questions for exclusion or revision. Semi-structured questions were used to evaluate question appropriateness and understanding (See Appendix D). This process will also allow the research team to ascertain whether the survey will gather the information that it is intended to in a way that the respondents will understand.

Two health directors were also consulted on survey format and question appropriateness over email. Their input will be utilized to help finalize the pilot version of the survey questions. Content and face validity will be sought at this stage. Face validity will be sought through personal opinion on the surveys by the health leaders and patient informants (67). Content validity will be explored through feedback and through content matching (67).

Other forms of validity such as criterion or predictive validity were not conducted as there are no gold standard tools with which to compare the newly created tool (67). Test retest reliability will also not be assessed as the survey tool will not be piloted in this study and therefore responses cannot be compared (67). Construct validity is also usually assessed by correlating pilot data to other measures of another kind (67). Again, this study was not piloted and so there is no ability to compare pilot data, nor is there any gold standard to compare the pilot data against. Other documents or measures of a similar kind, such as the environmental scan and key informant interviews of the *Sâkipakâwin project*, could also be compared to pilot survey data in the absence of a gold standard, however these instruments were used to create the two tools and therefore cannot also be used for validation (14,67).

10.3 Face Validity

Face validity is the degree to which the survey instrument makes sense at face value. Face validity is determined merely by looking at the survey (38). Face validity was gathered via email correspondence. Face validity was first determined by the researcher and two other researchers of the *Sâkipakâwin project*.

Face validity was then assessed by both patient informants and health care providers. Both groups determined that both the patient and health care provider surveys questions appeared to make sense. This was determined based on the personal opinion of informants on survey questions. It was determined by all parties that both the patient survey and health care provider surveys made sense at face value.

10.4 Content Validity and Respondent Validation

Content validity was established via respondent validation. Respondent validation is the process of using respondents to check for survey accuracy and resonance with personal experience (68). Respondent validation fits with the logistics of my proposed study as it is patient centered. Experts and respondents were sent the surveys via email to assess survey format, question interpretation, design and relevancy. Respondent validation will be used to check the themes and content of surveys for relevance to the population. This will allow informants to validate or discredit the themes, interpretations, and format of survey questions.

10.4.1 Format Validation and Interpretation

The overall format of both the patient and health care provider survey were deemed to be representative of study purpose. Survey feedback unanimously stated that they felt the survey did an adequate job of assessing cancer care supports and cancer care support qualities available to Indigenous cancer patients. With the adaptation of a few questions and format it was believed that the survey could be a useful and accurate tool.

Question interpretation was determined by assessing what each party thought each question meant after reading them without any outside context or information. The intention of each question was then shared with respondents. At this point it was determined whether each question was indeed interpreted by respondents relative to its intended interpretation.

10.4.2 Patient Survey Feedback and Validation

Patient informant feedback of the final surveys was used to determine survey validation. Final patient informant feedback determined that questions were indeed appropriate to the population. The survey was thought to be easy to understand and complete.

The survey also was determined to be relevant to study purpose at this point. Patient informants felt that the survey, its questions, and contents could be used to adequately gather information that could better highlight the need for Indigenous cancer support needs in Saskatchewan. It was also determined that the patient survey was respectful and inclusive of Indigenous people(s) and traditional aspects to cancer care.

10.4.3 Health Care Provider Survey Validation

Health care provider feedback included the feedback from several health care providers or managers currently providing care for First Nations or Métis cancer patients within Saskatchewan. Their feedback was sought through email correspondence. The health care provider or manager was provided with a final copy of the survey.

It was found that the survey did adequately assess cancer care supports and qualities of those supports for Indigenous cancer patients in Saskatchewan. Content was determined to be appropriate for health care providers and respectful of their experiences. The informants did not feel that anything needed to be added to the survey at this point.

10.4.4 Researcher Feedback and Validation

Two researchers involved in Indigenous research such as the *Sâkipakâwin project* were consulted for content validation. These researchers assessed survey questions for relevancy to the study design, purpose, and appropriateness to study design. It was determined that both the patient survey and health care provider survey reflected themes congruent with those identified in the *Sâkipakâwin project* as discussed earlier.

It was determined that the surveys were formulated in ways that were both respectful to Indigenous people(s) and appropriate to the respondent targets that they were created for. It was determined that both surveys should be interpreted by the respective parties as intended by study design. These researchers also determined that the survey, its questions, and its contents were both relevant to the population and appropriate for the study purpose.

10.4.5 Survey Expert Feedback and Validation

Feedback from an individual experienced in survey design and creation was important to develop a survey that was functionally sound. This step was important to ensure that the surveys were formatted in a way that would make sense for data analysis and for the participants. This step was also vital to designing well-designed survey tools.

Feedback from one survey expert was sought by email. Final survey expert feedback determined that the survey was formatted according to survey creation recommendations. Survey expert feedback also determined that questions were formatted as to gather appropriate information without bias. The questions were also thought to be appropriately interpreted by respondents.

10.5 Validation Conclusion

Both face and content validity were explored. Face validity was assessed by the researcher and other experts. Both surveys were determined to make sense at face value by looking at the surveys, thus, establishing face validity.

Content validity was determined via respondent feedback. Respondent feedback was sought from both patient informants, health care provider informants, researchers, and survey experts. All parties determined that both of the surveys were created to reflect the study purpose and were designed in such a way that would fulfil said purpose. It was also determined that both the patient and health care provider surveys were appropriate for the intended populations and reflective of their experiences with Indigenous cancer support needs in Saskatchewan. It was determined that both surveys were designed to be relevant to the study purpose and populations, thus, content validity is also assumed.

10.6 Survey Validation Summary Table

The following table outlines the most important or relevant feedback to survey validation.

Survey Validation Summary Table:

	Patient Survey	**Health Care Provider Survey**
Face validity	Makes sense at face value	Makes sense at face value
Format Validation and Interpretation	• Representative of study purpose • Survey adequately assesses cancer support needs for Indigenous patients	• Representative of study purpose • Survey adequately assesses cancer support needs for Indigenous patients
Patient Survey Feedback and Validation	• Relevant to study purpose • Respectful to population • Easy to understand and complete	N/A
Health Care Provider Survey Validation	N/A	• Survey adequately assesses cancer support needs • Respectful to Indigenous patients • Relevant to health care providers
Researcher Feedback and Validation	• Survey adequately assesses cancer support needs • Respectful to Indigenous patients • Relevant to patients • Similar themes to other research	• Survey adequately assesses cancer support needs • Respectful to Indigenous patients • Relevant to patients • Similar themes to other research
Survey Expert Feedback and Validation	• Limits bias • Questions formatted appropriately • Formatted to gather adequate information	• Limits bias • Questions formatted appropriately • Formatted to gather adequate information

CHAPTER 11: FINAL CONSIDERATIONS

11.1 Introduction

This project and its products were created with careful consideration of several factors. These factors include working with Indigenous communities, distribution difficulty, language considerations, and cultural appropriateness. The survey products and this thesis are also the result of several unforeseen barriers that altered both project and survey design. Despite these barriers however, this research has yielded two reliable survey tools that could potentially be used in future research to improve cancer support needs for Indigenous cancer patients.

11.1.1 Working with Indigenous Communities

This project was originally designed to pilot the patient survey within a First Nations community in Saskatchewan. Timeline and accessibility of the community however, made this process unfeasible for a master's thesis. In addition, it was noted that Indigenous cancer patients and their family members would be extremely difficult to access to pilot the study. Therefore, by nature of this topic and of the population that this study engages with, navigating survey creation was less than straightforward. As a result, survey validation was determined via informant and expert feedback as well as in congruence with the data analysis of qualitative key-informant interviews from another project. In efforts to still be reflective of Indigenous voices the survey creation was inclusive of Indigenous patient informant feedback and recommendations. This feedback was highly regarded and was always included in survey formulation or design.

11.1.2 Distribution

The inability to easily identify Indigenous cancer patients due to the lack of Indigenous patient information and infringement on privacy limits the ease of patient survey distribution. It was made apparent in feedback sessions and meetings with patient informants that sending the patient survey to individual patients and family members would be very difficult. It was evident that survey distribution would be difficult to control. This is an important consideration for future studies either using the patient survey created from this study or in research of similar nature. These factors provide additional reasons that the survey was not piloted within the population.

In response to feedback a secondary survey was created that covered similar content and aimed to answer similar questions as the patient survey but was targeted towards health care providers. This additional survey was created to resolve distribution issues as health care providers or administrators are easier to contact and will be more easily available for survey participation. For this reason, use of the health care provider survey may be more advisable than the patient survey for future research.

11.1.3 Language Used

Both surveys were created with the target population in mind. This included formulating surveys and wording the questions to be inclusive of lower literacy levels. However, the surveys were created in English. It may be advisable to have the surveys translated to other languages if found to be appropriate for the study population in the future.

11.1.4 Cultural Inclusivity

Another important consideration for future research using the survey tools resulting from this research is that the questions are designed for research in Saskatchewan. The patient survey only inquiries about First Nations or Métis status as those are the most prominent Indigenous populations in Saskatchewan. Future researchers may need to adapt the surveys to other populations or to be inclusive of other Indigenous groups.

11.1.5 Cultural Appropriateness

As a non-Indigenous researcher, it was very important for me to be respectful of Indigenous cultures and people. I acknowledge that as I am neither Indigenous, nor a cancer patient that I cannot fully relate to the subject matter of this survey and therefore, needed help creating and designing the survey.

Indigenous patient informants and health care advisors were instrumental in closing this relational gap and were fundamental to the research process. In this way, the Indigenous patient informants played a key role in survey development. With their guidance both survey tools were created with the help of Indigenous voices and perspectives.

11.2 Barriers

Throughout this project several barriers were faced and addressed. These barriers affected the overall nature of the project and altered the final product of the master's thesis. Other barriers affected development of the initial survey tool and lead to the creation of an additional tool.

11.2.1 Lack of community access

Limited community access was a huge barrier for this study. In addition, the scarceness of information on Indigenous cancer patients hindered participant identification and may be a problem for researchers in the future. This resulted in the inability to pilot the study within the community.

11.2.2 Limited Information Indigenous Survey Development

There is limited information on creating Indigenous surveys published in academia. There is little information on creating content and many studies are not inclusive of the survey design process. This is even more true in regard to creating surveys for vulnerable populations or for Indigenous populations. In this way, this project is unique as it can provide some insight into what this process could look like for other researchers.

This study made use of materials on survey formatting to design survey tools. It is also important to note that Indigenous patient informants and health care advisors played a vital role in the development of the surveys. Much of the survey content came from informant feedback or suggestions and their comments on the survey were always taken into consideration for survey revision. The participation and guidance of Indigenous patient informants helped to lessen the burden of limited information on creating surveys for Indigenous peoples.

11.3 Knowledge Translation

The project employed an Integrated Knowledge Translation Plan where patients, families, Elders, Indigenous community leaders, health care providers, and decision makers were involved at key stages of the research process. This is congruent with Indigenous research protocols where the communities have access to and possession of results (56). In Indigenous research, communities should be consulted as to which ways research dissemination would be the most useful to them (56). For this reason, both surveys will be presented to the Indigenous patient advisors. In addition, the final copies of surveys will be available to all respondents, patient informants, healthcare advisors, and feedback participants involved in survey development.

Research knowledge and results will also be disseminated in a variety of ways as chosen by the research team to be appropriate for the study population. Knowledge will be mobilized both to academic and general audiences. Academically the knowledge will be published as articles in peer-reviewed journals. In addition, the findings of this study will be presented at the Indigenous Health Summit as well as at other Indigenous gatherings.

11.4 Ethical Considerations

This study gained university ethics approval on September 12, 2019. Ethical approval was sought from the University of Saskatchewan ethics board (69). CIHR and OCAP® protocols for ethics approval were followed for research with Indigenous populations (56). One ethical issue was the dissemination of results in a way that will be the most helpful to participants, this was addressed by consulting the research advisory council on what they believe are the most useful ways of sharing knowledge.

Ensuring respect for Indigenous culture was also important to consider. This was fostered with the help of community leaders, patient informants, and health care providers. Other ethical issues involved collecting data working with a vulnerable population. These challenges were navigated using the OCAP® principles and Tri-Council research policies (39). OCAP® addresses typical ethical issues common in Indigenous research and provide guidelines for the most ethical ways to do research with Indigenous populations (39).

11.5 Limitations

One major limitation in creating the original survey was the inability to distribute the survey efficiently. It was discovered at one of the meetings with the advisory team that a survey targeting patient experience would be hard to distribute on a mass scale. Patient privacy and lack of Indigenous health information would make it hard to identify individuals to participate in the survey. This limitation fostered a second survey targeted towards Indigenous Health Care providers.

One of the most significant limitations to the patient survey is that surveys will be conducted in English. This is a significant limitation as many Indigenous languages hold important aspects of Indigenous worldviews (70). To lessen the effects of the survey being conducted in English open-ended questions have been included in the survey to ensure that different outlooks can be represented. In addition, questions that ask the respondent to include any concerns or further information they would like to add have been included to mitigate the impact of language barriers. Language should not be a limitation to the health care provider survey.

In addition, the web-based design of the survey may be limiting for some participants. The web-based design of the study may be challenging for participants that are not well-versed with technology. To mitigate this problem both surveys have also been drafted to paper format and are easily usable in either web or paper designs.

11.6 Significance of Study

The surveys created from this study can be utilized in further research to benefit Indigenous cancer patients, their families, and their communities. These surveys explore the understanding of the cancer journey and barriers experienced while accessing care for Indigenous people of Saskatchewan. In addition, these surveys were created to evaluate support services available to Indigenous cancer patients as well as the limitations to these services. This information could allow for the de-stigmatization of cancer in the communities and identify cancer care barriers in Saskatchewan Indigenous communities.

These surveys could be used in the future to help inform health professionals and policy makers on the needs of Indigenous cancer supports. In addition, the surveys can be used to identify gaps in cancer care supports available to Indigenous cancer patients and assess cancer care priorities in Saskatchewan Indigenous communities. This knowledge could help to optimize cancer care support utilization in Indigenous populations, and ultimately reduce cancer-related deaths in Indigenous cancer patients in Saskatchewan.

These surveys could foster future research on cancer in Indigenous patients or communities, and research involving supports for Indigenous cancer patients in other parts of the world. This study could also impact future research through the utilization of the patient and health care provider surveys created. These surveys could potentially be used in further studies to explore the needs, gaps, and prioritization of cancer care supports for Indigenous communities in places other than Saskatchewan, and potentially in other marginalized groups of people.

11.7 Suggestions for the Future

When using the survey tools created from this research project researchers should be aware of their target audience adjusting the survey accordingly. In addition, this research should be conducted in concordance with OCAP® principles (56). These principles ensure the reciprocity and inclusiveness of research (56).

Both surveys created in this project can be used as a template for future research whether that be for exploring Indigenous cancer support needs or other Indigenous health support needs. The *Sâkipakâwin project,* however, plans to send the health care provider survey to Health Directors, as such the health care provider survey was created and targeted towards Saskatchewan Health Directors (14). Health Directors in Saskatchewan are Indigenous and therefore future researchers sending the health care provider survey to non-Indigenous health care providers may need to create a question asking respondents to disclose their Indigenous identity. This question would make the health care provider survey considerate of the probability of bias when including non-Indigenous health care providers as participants.

In my opinion as became evident when designing both survey tools, several steps need to be taken to improve cancer care supports for Indigenous cancer patients not only in Saskatchewan but in all of Canada. The introduction of patient navigators and translators, culturally inclusive and respectful treatment or services, and traditional ways of healing into the system could potentially be some key factors in improving these services.

In addition, reducing the burden of potential barriers to care such as racism, transportation, and accommodation could help increase access to supports and services for Indigenous populations. The question is; which of these barriers most greatly limit Indigenous cancer patients and their families from getting the cancer treatment and support that they deserve during care? In addition; which of these steps will help improve cancer outcomes for Indigenous patients and increase supports success the most?

My hope is that the survey tools derived from this research can be implemented and utilized to help answer some of these questions. The result of research utilizing the surveys created in this project could help influence change in cancer supports available to Indigenous peoples. Such research also has the potential to improve cancer supports or services, increase access to those supports and services, and ultimately lead to better outcomes for Indigenous cancer patients and their families.

11.8 Conclusion

The aim of this project was to develop a reliable and valid survey that will help to identify the supports available to Indigenous cancer patients and their families in Saskatchewan, and to discover the gaps or limitations in these services. As a result, this project has fostered two survey tools. One, directed towards patients to explore individual barriers and support needs for patients. The other, targets health providers working with Indigenous cancer patients to explore their view on cancer care barriers and to gather information on institutional supports available to patients. The goal for the surveys created as a result of this project is that they will improve support for Indigenous cancer patients and inform cancer supports that are catered to cancer patients with Indigenous backgrounds. Both surveys could also inform policy and planning that could improve cancer care and ultimately outcomes for Indigenous cancer patients.

REFERENCES

1. Bramley D, Hebert P, Jackson R, Chassin M. Indigenous disparities in disease-specific mortality, a cross-country comparison: New Zealand, Australia, Canada, and the United States. N Z Med J. 2004 Dec 17;117(1207):U1215.

2. Ahmed S, Shahid RK, Episkenew JA. Disparity in cancer prevention and screening in aboriginal populations: recommendations for action. Curr Oncol. 2015 Sep 11;22(6):417.

3. Ell K, Nishimoto R, Mediansky L, Mantell J, Hamovitch M. Social relations, social support and survival among patients with cancer. J Psychosom Res. 1992 Sep;36(6):531–41.

4. Guidry JJ, Aday LA, Zhang D, Winn RJ. The role of informal and formal social support networks for patients with cancer. Cancer Pract. 1997 Aug;5(4):241–6.

5. Canadian Partnership Against Cancer. Adapting Framework: A Guide For Adapting Existing Survey Tools For Use in Northern, Rural, and Aborignal Communities. [Internet]. 2011. Available from: https://static1.squarespace.com/static/5763a7c5893fc07fb7f03a38/t/57717343d482e9a7c3b85e8d/1467052879724/3+-+adaptation+framework+CAPTURE+objective+3.pdf

6. Chilisa B. Indigenous research methodologies. Thousand Oaks, Calif: SAGE Publications; 2012. 343 p.

7. Kovach M. Indigenous methodologies: characteristics, conversations and contexts. Toronto ; Buffalo: University of Toronto Press; 2009. 201 p.

8. Elias B, Kliewer EV, Hall M, Demers AA, Turner D, Martens P, et al. The burden of cancer risk in Canada's indigenous population: a comparative study of known risks in a Canadian region. Int J Gen Med. 2011;4:699–709.

9. Shahid S, Thompson SC. An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US. Aust N Z J Public Health. 2009 Apr;33(2):109–18.

10. Aboriginal Cancer Care Unit Cancer Care Ontario. Aboriginal Cancer Care Needs Assessment "It's Our Responsibility" …Cancer Care Ontario, 2002. Retrieved from: https://www.ptcc-cfc.on.ca/common/pages/UserFile.aspx?fileId=13686.

11. Groot, et al. Sâkipakâwin An Environmental Scan of Provincial Cancer Supports for Indigenous Patients and their Families in Saskatchewan. 2020. Prepared for the Sâkipakâwin project in partnership with the Saskatchewan Centre for Patient Oriented Research, the University of Saskatchewan, and the Sask Health Research Foundation.

12. Canada G of CI and NA. Surveys on Aboriginal Peoples [Internet]. 2011 [cited 2019 Feb 20]. Available from: https://www.aadnc-aandc.gc.ca/eng/1321384019753/1322059098232

13. Branch G of CAA and NDCC. First Nations Map of Saskatchewan [Internet]. 2008 [cited 2020 Aug 23]. Available from: https://www.aadnc-aandc.gc.ca/eng/1100100020616/1100100020653

14. Groot, et al. Sprout Grant Relevancy Review Intake Form and Patient Engagement Application Development Award Request. 2017. Prepared for the SCPOR Sprout Grant in partnership with the Saskatchewan Centre for Patient Oriented Research.

15. Groot, et al. Key Informant Interview Analysis. 2019. Prepared for the Sâkipakâwin project in partnership with the Saskatchewan Centre for Patient Oriented Research, the University of Saskatchewan, and the Sask Health Research Foundation.

16. Formal caregivers, informal caregivers, and carers [Internet]. [cited 2019 Feb 20]. Available from: https://www.reflectionsonnursingleadership.org/features/more-features/Vol39_3_formal-caregivers-informal-caregivers-and-carers

17. Branch G of CI and NACC. Indigenous peoples and communities [Internet]. 2009 [cited 2020 Aug 23]. Available from: https://www.rcaanc-cirnac.gc.ca/eng/1100100013785/1529102490303

18. Nishri ED, Sheppard AJ, Withrow DR, Marrett LD. Cancer survival among First Nations people of Ontario, Canada (1968-2007): Cancer survival among Ontario First Nations. Int J Cancer. 2014 Jul;n/a-n/a.

19. Rosenberg T, Martel S. Cancer trends from 1972-1991 for Registered Indians living on Manitoba Reserves. Int J Circumpolar Health. 1998;57 Suppl 1:391–8.

20. Wesley-Esquimaux CC, Smolewski M, Aboriginal Healing Foundation (Canada). Historic trauma and aboriginal healing. Ottawa: Aboriginal Healing Foundation; 2004.

21. McCormick RM. The facilitation of healing for the First Nations people of British Columbia. Univ Br Columbia [Internet]. 1994 [cited 2019 Jan 11]; Available from: https://doi.library.ubc.ca/10.14288/1.0053949

22. Roberts, Rose. Roberts, Rose. Stories about cancer among the Woodland Cree in Northern Saskatchewan, Canada. 2005. Psycho-Oncology. 17. S5-S6.

23. Canadian Partnership Against Cancer. First Nations Cancer Control in Canada Baseline Report. Canadian Partnership Against Cancer. 2013. Retrieved from: https://www.partnershipagainstcancer.ca/wp-content/uploads/2017/12/fnim-action-plan-cancer-control.pdf.

24. Nichols-English G, Poirier S. Optimizing adherence to pharmaceutical care plans. J Am Pharm Assoc (Wash). 2000;40(4):475-485.

25. Cheville AL, Alberts SR, Rummans TA, Basford JR, Lapid MI, Sloan JA, et al. Improving Adherence to Cancer Treatment by Addressing Quality of Life in Patients with Advanced Gastrointestinal Cancers. J Pain Symptom Manage. 2015 Sep;50(3):321–7.

26. Dunn J, Steginga SK, Rosoman N, Millichap D. A Review of Peer Support in the Context of Cancer. J Psychosoc Oncol. 2003 Dec 24;21(2):55–67.

27. Ashbury FD, Cameron C, Mercer SL, Fitch M, Nielsen E. One-on-one peer support and quality of life for breast cancer patients. Patient Educ Couns. 1998 Oct;35(2):89–100.

28. Rodríguez AM, Mayo NE, Gagnon B. Independent contributors to overall quality of life in people with advanced cancer. Br J Cancer. 2013 May 14;108(9):1790–800.

29. Allicock M, Carr C, Johnson L-S, Smith R, Lawrence M, Kaye L, et al. Implementing a One-on-One Peer Support Program for Cancer Survivors Using a Motivational Interviewing Approach: Results and Lessons Learned. J Cancer Educ. 2014 Mar;29(1):91–8.

30. Adler NE, Page A, Institute of Medicine (U.S.), Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs [Internet]. Washington, D.C.: National Academies Press; 2008 [cited 2020 Jul 4]. Available from: http://site.ebrary.com/id/10225184

31. Harris R, Van Dyke ER, Ton TGN, Nass CA, Buchwald D. Assessing Needs for Cancer Education and Support in American Indian and Alaska Native Communities in the Northwestern United States. Health Promot Pract. 2016 Nov;17(6):891–8.

32. Olson RA, Howard F, Turnbull K, Munroe D, Zirul C, Manji R, et al. Prospective evaluation of unmet needs of rural and aboriginal cancer survivors in Northern British Columbia. Curr Oncol Tor Ont. 2014 Apr;21(2):e179-185.

33. Irvine, L. Irvine L, Quinn B, Stockdale D. Northern Saskatchewan Health Indicators Report 2011. Athabasca Health Authority and Keewatin Yatthe and Mamawetan Churchill River Regional Health Authorities. Retrieved from: http://www.mcrhealth.ca/media/files/Northern%20Saskatchewan%20Health%20Indicators%20Report%202011.pdf.

34. Our Partnership with SCA ‹ Cancer Foundation of Saskatchewan [Internet]. Cancer Foundation of Saskatchewan. [cited 2020 Jul 4]. Available from: https://cancerfoundationsask.ca

35. Canada G of CIS. Non-insured health benefits for First Nations and Inuit [Internet]. 2019 [cited 2020 Jul 4]. Available from: https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517

36. First Nations Health Authority. Improving Indigenous Cancer Journeys in BC: A Road Map. First Nations Health Authority, Metis Nation BC, the BC Association of Aboriginal Friendship Centres, and BC Cancer. 2017. Retrieved from: http://www.fnha.ca/wellnessContent/Wellness/improving-indigenous-cancer-journeys-in-bc.pdf.

37. Poudrier J, Mac-Lean RT. "We've fallen into the cracks": Aboriginal women's experiences with breast cancer through photovoice. Nurs Inq. 2009 Dec;16(4):306–17.

38. Panacek EA. Survey-based research: General principles. Air Med J. 2008 Jan;27(1):14–6.

39. Ziniel SI, McDaniel CE, Beck J. Bringing Scientific Rigor to Survey Design in Health Care Research. Hosp Pediatr. 2019 Oct;9(10):743–8.

40. Christian T. Evensen, Kathleen J. Yost, San Keller, Neeraj K. Arora, Elizabeth Frentzel, Tamika Cowans, and Steven A. Garfinkel. Development and Testing of the CAHPS Cancer Care Survey. Journal of Oncology Practice 2019 15:11, e969-e978

41. Carlson LE, Angen M, Cullum J, Goodey E, Koopmans J, Lamont L, et al. High levels of untreated distress and fatigue in cancer patients. Br J Cancer. 2004 Jun;90(12):2297–304.

42. Government of Canada SC. Aboriginal Peoples Survey (APS) [Internet]. 2016 [cited 2019 Feb 20]. Available from: http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3250

43. Saskatchewan Health Authority (Indigenous Health Working Group). Indigenous Health in the new Saskatchewan Health Authority: Summary of Findings [Internet]. 2018 Jun. Available from: https://www.saskhealthauthority.ca/about/Documents/Indigenous-Health-Summary-Report.pdf

44. Dyck RF. Mechanisms of renal disease in indigenous populations: influences at work in Canadian indigenous peoples. Nephrology. 2001;6(1):3–7.

45. Nancy Thayer-Hart, Office of Quality Improvement, Jennifer Dykema, Kelly Elver, Nora Cate Schaeffer, John Stevenson, University of Wisconsin Survey Center. Survey Fundamentals: A Guide to Designing and Implementing Surveys. 2010.

46. Dillman DA, Smyth JD, Christian LM. Internet, phone, mail, and mixed-mode surveys: the tailored design method. 4th edition. Hoboken: Wiley; 2014. 509 p.

47. Priscilla A. Glasow. Fundamentals of Survey Methodology. 2005.

48. Alreck PL, Settle RB. The survey research handbook. 3rd ed. Boston: McGraw-Hill/Irwin; 2004. 463 p. (McGraw-Hill/Irwin series in marketing).

49. Ferligoj A, Mrvar A. Developments in applied statistics. Ljubljana: Fakulteta za družbene vede; 2003.

50. Franklin S, Walker C, Statistics Canada. Survey methods and practices. [Internet]. Ottawa: Statistics Canada; 2010 [cited 2020 Jun 4]. Available from: https://central.bac-lac.gc.ca/.item?id=12-587-x2003001-eng&op=pdf&app=Library

51. Krosnick JA, Holbrook AL, Berent MK, Carson RT, Hanemann WM, Kopp RJ, et al. The Impact of "No Opinion" Response Options on Data Quality. Public Opin Q. 2001;66(3):371–403.

52. Fowler FJ. Improving survey questions: design and evaluation. Thousand Oaks: Sage Publications; 1995. 191 p. (Applied social research methods series).

53. Hassan ZA, Schattner P, Mazza D. Doing A Pilot Study: Why Is It Essential? Malays Fam Physician Off J Acad Fam Physicians Malays. 2006;1(2–3):70–3.

54. Hertzog MA. Considerations in determining sample size for pilot studies. Res Nurs Health. 2008 Apr;31(2):180–91.

55. Chaudhary AK, Israel GD. The Savvy Survey #8: Pilot Testing and Pretesting Questionnaires. :6. University of Florida Institute of Food and Agricultural Sciences. Retrieved from: https://edis.ifas.ufl.edu/pdffiles/PD/PD07200.pdf

56. Schnarch B. Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research. 2004;16.

57. Kivunja C, Kuyini AB. Understanding and Applying Research Paradigms in Educational Contexts. Int J High Educ. 2017 Sep 5;6(5):26.

58. Creswell JW. Research design: qualitative, quantitative, and mixed methods approaches. 4th ed. Thousand Oaks: SAGE Publications; 2014. 273 p.

59. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Thousand Oaks, Calif: SAGE Publications; 2007. 275 p.

60. Kirby SL, Greaves L, Reid C. Experience, research, social change: critical methods. Third edition. North York, Ontario, Canada: University of Toronto Press; 2017. 373 p.

61. Government of Canada. TCPS 2 - Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada.2016. Retrieved from: http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/.

62. View of Ethics of Aboriginal Research | International Journal of Indigenous Health [Internet]. [cited 2020 Jun 5]. Available from: https://jps.library.utoronto.ca/index.php/ijih/article/view/28935/24063

63. Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance (Paper). [Internet]. 2014 [cited 2019 Jan 11]. Available from: https://ezproxy.kpu.ca:2443/login?url=http://www.deslibris.ca/ID/10095457

64. SPOR. SPOR: Strategy for Patient-Oriented Research. Putting Patients First. [Internet]. 2014. Available from: https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

65. How to Write Low Literacy Materials [Internet]. [cited 2020 Jun 4]. Available from: https://joe.org/joe/2001february/tt2.php

66. Creswell JW, Poth CN. Qualitative inquiry & research design: choosing among five approaches. Fourth edition. Los Angeles: SAGE; 2018. 459 p.

67. Bolarinwa. Principles and methods of validity and reliability testing of questionnaires used in social and health science researches [Internet]. [cited 2019 Apr 11]. Available from: http://www.npmj.org/article.asp?issn=1117-1936;year=2015;volume=22;issue=4;spage=195;epage=201;aulast=Bolarinwa

68. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? Qual Health Res [Internet]. 2016 Jun 22 [cited 2020 Aug 5]; Available from: https://journals.sagepub.com/doi/10.1177/1049732316654870

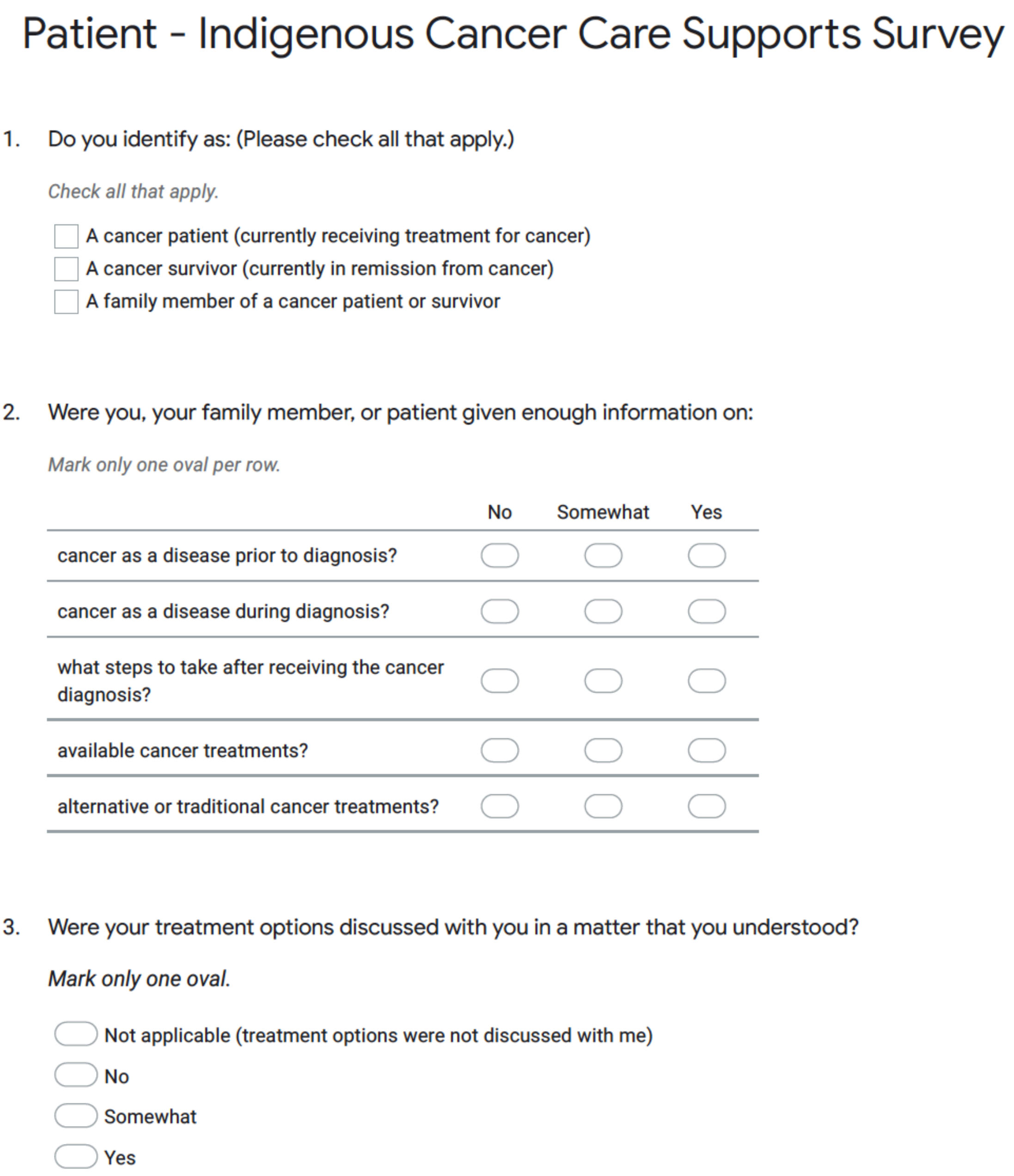
69. University of Saskatchewan. How do I get ethics approval? 2016. Retrieved from: https://vpresearch.usask.ca/researchers/ethics1.php.

70. Facing History and Ourselves. Stolen lives: the Indigenous peoples of Canada and the Indian residentials schools. Toronto, ON: Facing History and Ourselves; 2015.

APPENDICES

APPENDIX A

PATIENT SURVEY



Patient - Indigenous Cancer Care Supports Survey

1. Do you identify as: (Please check all that apply.)

Check all that apply.

☐ A cancer patient (currently receiving treatment for cancer)
☐ A cancer survivor (currently in remission from cancer)
☐ A family member of a cancer patient or survivor

2. Were you, your family member, or patient given enough information on:

Mark only one oval per row.

	No	Somewhat	Yes
cancer as a disease prior to diagnosis?	○	○	○
cancer as a disease during diagnosis?	○	○	○
what steps to take after receiving the cancer diagnosis?	○	○	○
available cancer treatments?	○	○	○
alternative or traditional cancer treatments?	○	○	○

3. Were your treatment options discussed with you in a matter that you understood?

Mark only one oval.

○ Not applicable (treatment options were not discussed with me)
○ No
○ Somewhat
○ Yes

4. Please agree or disagree with the following statements:

Mark only one oval per row.

	Does not apply to me	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
"I trust the health care system during cancer treatment."	○	○	○	○	○	○
"I/we experienced racism when going for cancer treatment."	○	○	○	○	○	○
"It was easy to find my way around the hospital when I arrived."	○	○	○	○	○	○
"There needs to be more Indigenous staff at hospitals or treatment centres."	○	○	○	○	○	○
"Indigenous translators should be available during hospital visits."	○	○	○	○	○	○
"Indigenous translators would be helpful for Indigenous cancer patients during treatment."	○	○	○	○	○	○
"It would have been helpful to have someone show me around the hospital."	○	○	○	○	○	○
"I/we were given information on support services to use throughout treatment from my health care provider."	○	○	○	○	○	○
"Traditional treatment options should be discussed along with other Western medical options."	○	○	○	○	○	○
"Traditional treatment or support options were mentioned to me/us."	○	○	○	○	○	○

5. Please tell us if any of the following have stopped you or your family member from going for cancer treatment or care:

Mark only one oval per row.

	Not applicable (Did not affect me/us)	No (this has not stopped me/us)	Yes (this has stopped me/us)
Travel for treatments and appointments	○	○	○
Accomodations during treatment	○	○	○
Experiencing racism during treatment or care	○	○	○
Finding my way through the building	○	○	○
Language barriers	○	○	○

6. After treatment were you or a family member given:

Mark only one oval per row.

	No	Somewhat	Yes
information on support services available?	○	○	○
information on support services available to me/them in or around my community?	○	○	○
enough support in your community?	○	○	○

7. How helpful do you think increased cancer supports would be to cancer recovery? For example: sharing circles and support groups

Mark only one oval.

○ not at all helpful
○ a little helpful
○ somewhat helpful
○ very helpful
○ extremely helpful

8. Aboriginal ancestry:

Mark only one oval.

○ Status/First Nations of Canada
○ Non Status/First Nations of Canada
○ Métis
○ Inuit
○ Prefer not to say

9. Please select your gender:

Mark only one oval.

○ Male
○ Female
○ Other
○ Prefer not to say

10. Please select your age range:

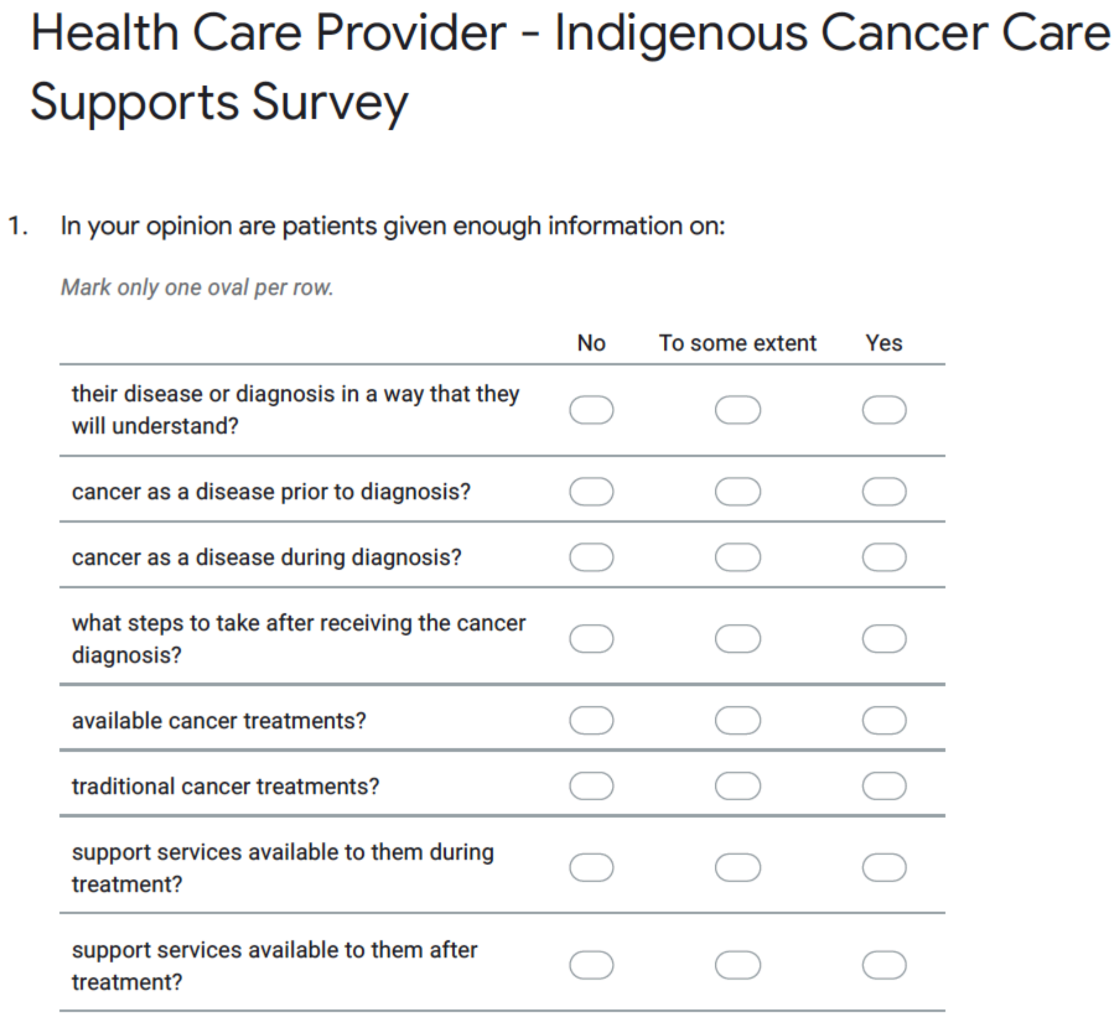
Mark only one oval.

○ 18-25
○ 26-40
○ 41-60
○ 61+
○ Prefer not to say

11. Please share any other information about your cancer journey (as a patient or caregiver) that you think would be helpful to others:

APPENDIX B

HEALTH CARE PROVIDER SURVEY



Health Care Provider - Indigenous Cancer Care Supports Survey

1. In your opinion are patients given enough information on:

Mark only one oval per row.

	No	To some extent	Yes
their disease or diagnosis in a way that they will understand?	○	○	○
cancer as a disease prior to diagnosis?	○	○	○
cancer as a disease during diagnosis?	○	○	○
what steps to take after receiving the cancer diagnosis?	○	○	○
available cancer treatments?	○	○	○
traditional cancer treatments?	○	○	○
support services available to them during treatment?	○	○	○
support services available to them after treatment?	○	○	○

2. Please indicate how much you agree or disagree with the following statements:

Mark only one oval per row.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
"Traditional treatment options should be discussed along with other medical options."	○	○	○	○	○
"Indigenous navigators would be helpful to Indigenous cancer patients."	○	○	○	○	○
"Indigenous navigators should be Indigenous."	○	○	○	○	○
"Indigenous navigators should speak Indigenous languages."	○	○	○	○	○
"Indigenous translators would be helpful to Indigenous cancer patients."	○	○	○	○	○
"Indigenous translators should be available during hospital visits."	○	○	○	○	○
“Indigenous translators would be beneficial for Indigenous cancer patients during treatment.”	○	○	○	○	○

3. Based on your personal opinion, please indicate how much you believe the following barriers to cancer treatment impact access to services for Indigenous cancer patients:

Mark only one oval per row.

	No impact	Some impact	Great impact
Travel for treatments and appointments	○	○	○
Accomodations during treatment	○	○	○
Experiencing racism during treatment or care	○	○	○
Cultural competency of health care workers	○	○	○
Cultural inclusion in health care practices	○	○	○
Coverage or health care jurisdiction over First Nations patients	○	○	○
Coverage or health care jurisdiction over Métis patients	○	○	○

4. How helpful do you think increased cancer supports would be to cancer recovery? For example: sharing circles and support groups

Mark only one oval.

○ not at all helpful
○ a little helpful
○ somewhat helpful
○ very helpful
○ extremely helpful

5. Based on your personal opinion please rank these supports based on their importance to indigenous cancer care (1 being least important and 4 being most important)

Mark only one oval per row.

	1 (least important)	2 (third most important)	3 (second most important)	4 (most important)
Sharing circles	○	○	○	○
Support groups	○	○	○	○
Indigenous patient navigators	○	○	○	○
Indigenous patient translators	○	○	○	○

6. Do you believe that there is an adequate amount of cancer support services...

Mark only one oval per row.

	No	To some extent	Yes
available to First Nations cancer patients?	○	○	○
available to Métis cancer patients?	○	○	○
available that will be able to meet the growing need for Indigenous cancer support services?	○	○	○

7. Of the support services available:

Mark only one oval per row.

	Not at all	To some extent	Very
How culturally competent do you believe the cancer support services are?	○	○	○
How culturally inclusive do you believe the cancer support services are?	○	○	○

8. “To what extent do you think that the following changes could improve access and utilization of services or supports by Indigenous cancer patients?”

Mark only one oval per row.

	Not at all	Little	Some	A lot
Increasing the amount of Indigenous staff at care facilities	○	○	○	○
Increasing cultural competency training amongst health care workers	○	○	○	○
Increasing the number of translators or health care providers that speak Indigenous languages	○	○	○	○
Increasing the number of patient navigators available to patients	○	○	○	○
Cancer care pamphlets and other materials available in multiple Indigenous languages	○	○	○	○
The development of plans or procedures that could increase patient compliance to care plans in home communities	○	○	○	○

9. How long have you been providing or facilitating care for Indigenous cancer patients?

Mark only one oval.

○ 5 years or less
○ 6-10 years
○ 11-20 years
○ 21 years or more

10. Do you have any additional comments on Indigenous cancer care support services?

11. Do you have any comments or concerns regarding this survey, its questions or contents?

APPENDIX C

FEEDBACK QUESTIONS

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Focus Group Guide

Surveying Cancer Support Needs for Indigenous People of Saskatchewan

1. Do you think that the survey adequately assesses cancer supports or cancer care support qualities available to Indigenous cancer patients in Saskatchewan?

2. Is there anything that you think should be added to the survey?

3. Do you have any suggestions to improve the survey questions or format?

4. Do you think anything should be changed about the survey?