An integrated knowledge translation approach to develop a shared decision-making strategy for use by Inuit in cancer care: a qualitative study

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ABSTRACT

Background In relation to the general Canadian population, Inuit face increased cancer risks and barriers to health services use. In shared decision-making (SDM), health care providers and patients make health care decisions together. Enhanced participation in cancer care decisions is a need for Inuit. Integrated knowledge translation (KT) supports the development of research evidence that is likely to be patient-centred and applied in practice.

Objective Using an integrated KT approach, we set out to promote the use of SDM by Inuit in cancer care.

Methods An integrated KT study involving researchers with a Steering Committee of cancer care system partners who support Inuit in cancer care (“the team”) consisted of 2 theory-driven phases:

- using consensus-building methods to tailor a previously developed SDM strategy and developing training in the SDM strategy; and
- training community support workers (CSWs) in the SDM strategy and testing the SDM strategy with community members.

Results The team developed a SDM strategy that included a workshop and a booklet with 6 questions for use by CSWs with patients. The SDM strategy (training and booklet) was finalized based on feedback from 5 urban-based Inuit CSWs who were recruited and trained in using the strategy. Trained CSWs were matched with 8 community members, and use of the SDM strategy was assessed during interviews, reported as 6 themes. Participants found the SDM strategy to be useful and feasible for use.

Conclusions An integrated KT approach of structured research processes with partners developed a SDM strategy for use by Inuit in cancer care. Further work is needed to test the SDM strategy.

Key Words Inuit, shared decision-making, integrated knowledge translation, co-creation, decision coaching, field tests


BACKGROUND

Inuit are inventive and resourceful and are dedicated to supporting the well-being of their community and loved ones. They are self-reliant, and they work together for a common goal, which is evident in activities of self-governance and decision-making. For thousands of years, Inuit have adapted to the changes in their environment, and they continue to find new and innovative ways to survive. Nevertheless, Inuit populations face, on average, a 10-year reduction in life expectancy in relation to the general Canadian population. The Inuit are inventive and resourceful and are dedicated to supporting the well-being of their community and loved ones. They are self-reliant, and they work together for a common goal, which is evident in activities of self-governance and decision-making. For thousands of years, Inuit have adapted to the changes in their environment, and they continue to find new and innovative ways to survive. Nevertheless, Inuit populations face, on average, a 10-year reduction in life expectancy in relation to the general Canadian population.

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Cancer is identified as the leading cause of differences in life expectancy between Inuit Nunangat (the traditional territory of Inuit in Canada) and the rest of Canada. Inuit Nunangat consists of the western edge of the Northwest Territories (the Inuvialuit Settlement Region), the territory of Nunavut, northern Quebec (Nunavik), and northeastern Labrador (Nunatsiavut). Inuit experience the highest mortality rate from lung cancer in the world. Although the rates of some cancers are decreasing or leveling off among Inuit compared with the general Canadian population, the rates of some other cancers continue to increase disproportionately. A contributing factor to that phenomenon is found in health care settings themselves. In mainstream Western-oriented health care settings, a lack of cultural awareness has been shown to have a deleterious effect on the health services participation rates of Inuit, First Nations, and Métis (Indigenous) peoples, increasing the risk that Indigenous people will encounter racism when seeking care. There can also be physical barriers to care, given that accessing key health services (for example, oncology specialists or treatment, or both) also involves decisions about travelling thousands of kilometres from rural and remote communities to major urban centres in southern regions of Canada (Figure 1). Finally, Inuit must overcome intimidating and unfamiliar bureaucratic barriers to obtain cancer care. All of those conditions might undermine opportunities for health and wellness. For example, it has been shown that Inuit who must travel for prenatal care are made vulnerable to harms, Inuit must navigate the complexities of an unfamiliar health care system, often while facing significant language barriers.

Research has also identified logistic complexities in access to health care across jurisdictions for First Nations populations who live in rural and remote areas and who must travel for health care. Access to health care systems for Inuit—and other Indigenous groups in Canada—is further complicated by a sociohistorical context in which Indigenous peoples have experienced a long history of negative health care experiences. Given the very poor health outcomes of Inuit, eliminating barriers and ensuring that Inuit can access and receive appropriate health care is an urgent need (Figure 1).

Shared decision-making (SDM) is an important evidence-informed strategy that holds the potential to promote patient participation in health decisions and that is considered a high standard of care in health systems internationally. In the SDM process, health care providers and patients work together to select diagnostic tests, treatments, management, and psychosocial support packages. Decisions are based on clinical evidence and the patient’s informed preferences. Health care delivery approaches and support tools, such as decision coaching and decision aids, are used to promote SDM. Use of SDM has also been found to benefit people who experience disadvantage in health and social systems. Such an approach has considerable potential to engage Inuit with health care providers in decision-making.

Research to explore the use of SDM with Indigenous populations has identified peer support as an important feature in the take-up of SDM and has also highlighted the importance of interpersonal relationships in SDM. Peer support workers are individuals with personal knowledge of the community similar to the group being supported, and the use of peer support has been found to extend the reach of health systems. Within the cancer care system, community-based peers who provide support to Indigenous communities are known by many names, but in the present study report, they are referred to as community support workers (CSWs). The CSWs and their community health care networks are well positioned to provide the critical support that is needed by Inuit who must travel far from their family and community to access health care.

Research Approach
Complex social and historical features of the mainstream Western-oriented health care system affect opportunities for the health and well-being of Inuit. It is therefore imperative that research be conducted in full collaboration with Inuit and their health system partners. The research reported here contributes new knowledge about an intervention to foster an approach to SDM with Inuit. Our work builds on a previous series of studies that were conducted in full partnership with an Indigenous community and that used a process of cultural adaptation and usability testing, resulting in a peer-support SDM strategy. All of those studies strictly adhered to a mutually agreed partnership and ethics framework, and used processes aligned with the sociocultural values of the people participating in the partnership. The study reported here was planned and conducted in full collaboration with an interdisciplinary team that is active in Inuit cancer care systems in Nunavut and Ontario.

The partnership was guided by mutually agreed-upon ethics guidance, including the Tri-Council Policy Statement 2, Chapter 9, and Guidelines for Health Research Involving Aboriginal People (2007–2010) from the Canadian Institutes of Health Research. It was important that Inuit worldviews were respected and promoted both in the research processes and in the development and use of the
research principles (the sdm strategy). In our research, the guiding principles of Inuit Qaujimajatuqangit (traditional knowledge) added a strengths-based approach to promote Inuit self-determination and self-reliance. Inuit Qaujimajatuqangit is a belief system that seeks to serve the common good through collaborative decision-making. Its principles have been passed down from one generation to the next and are firmly grounded in the act of caring for and respecting others. Inuit Qaujimajatuqangit guiding principles have been successfully used in other studies that incorporate Inuit with Western-oriented approaches.

The Ottawa Decision Support Framework was used to structure the study design. The Framework, which aims to address decisional needs, has been used with a range of populations. It consists of 3 key elements that guide people through health and social decisions: decisional needs, decision support, and decision quality. The Ottawa Decision Support Framework is used to describe the assumption that unresolved and, for the population in the present study, possibly unconsidered decisional needs could affect decision quality.

The overarching objective of the present study was to use an integrated knowledge translation (kt) approach to tailor and field-test a sdm strategy for use by Inuit in cancer care. Our specific study objectives were to:

- develop study partnerships between community, organizational, and researcher members;
- tailor a previously developed peer support sdm strategy to enhance participation by Inuit in decisions about their cancer care;
- develop training for the use of the sdm strategy;
- train csws in the use of the sdm strategy; and finally,
- conduct a field test of the sdm strategy with csws and community member volunteers who are patients in the cancer care system.

METHODS

Integrated KT Approach

Our research design was developed to ensure that knowledge shared by community partners would be included in the work. For that reason, community consultations and partnerships were a key part of the research relationship. That requirement was structured in an integrated kt approach. "Integrated kt" is an approach to research that involves the engagement of knowledge users (members of groups who can act on or will be affected by the research, or both) in research processes. For example, knowledge users might be patients or members of the public, funders, health system and policy decision-makers, health care providers, or training institutions (among others), who are engaged in the entire research process. Outputs from integrated kt research are more likely to be used in practice and applied in policy and can create opportunities within institutional academic spaces for a variety of forms of knowledge to coexist. The use of integrated kt received the approval of Inuit community partners (co-authors or acknowledged here) as an approach for knowledge users and researchers to work in partnership and draw on the expertise that each brings to the relationship.

Design

Our integrated kt study used qualitative research methods and has been described in detail elsewhere. The study design had 2 theory-driven phases:

- Using consensus-building methods to tailor a previously developed sdm strategy with Inuit and developing training in that sdm strategy
- Training csws in the sdm strategy, and then matching the csws with community member volunteers to test the sdm strategy

The study was approved by the Ottawa Health Science Network Research Ethics Board in May 2017 (no. 20170150-01H).

Setting and Participants

In phase 1 of the study, academic researchers (JJ, IDG, AH) worked with a Steering Committee that consisted of members from Inuit-led or Inuit-specific (or both) health and related organizations that support Inuit in cancer care systems. Many of those individuals are co-authors of this paper or are identified in the Acknowledgments. The researchers and the Steering Committee are together referred to as “the team.” Advisory groups and members who are active in Inuit and Indigenous cancer care were also consulted throughout the entire study for feedback and are also mentioned in the Acknowledgments.

In phase 2 of the study, and after consultations and receipt of permissions from the leads of Inuit-specific health care provider and community partner organizations, csws were invited, through a purposive sampling approach, to participate in the study (to be trained and then matched with a community member volunteer to test the sdm strategy). Inuit community members who volunteered and became participants in the study were invited, through posters, by community partner contacts to engage in the study testing the sdm strategy. Expressions of interest by potential community member participants were followed by discussions with the first author (JJ) about the study to determine whether the community members wished to participate. Inclusion criteria for community member participants were adults who had received a diagnosis of cancer within the past 2 years and who were able to participate in an interview in English or Inuktitut. Interviews were considered an acceptable format in which to engage with participants (csws, community members) and to learn from their experience in the cancer care system. The participant sample size was determined by theoretical saturation, defined as the point at which subsequent interviews contributed no new concepts. That point was estimated to be fewer than 16 interviews. Interviews were conducted from January to March 2018.

The research took place in Ottawa, Ontario, and with residents of Nunavut in Inuit Nunangat, specifically the Qikiqtaaluk (Baffin) region. When travelling for medical care outside of Nunavut, Inuit community members stay at local medical boarding homes. The Ottawa home is Larga Baffin. Inuit community members who travelled to Ottawa from the Qikiqtaaluk region were engaged to participate in the study and were interviewed while in Ottawa.
Procedure
The procedure for conducting the study was based on a process of adaptation used in a previous SDM strategy\textsuperscript{24}. Written informed consent was sought and obtained from all participants (the team members, csws, community member volunteers). The first author (JJ) and a research assistant (AH) worked to facilitate the 2-phase study in a series of steps. The intervention to be adapted was a previously developed SDM strategy that consisted of a patient decision aid (the Adapted Ottawa Personal Decision Guide) designed to be used with decision coaching\textsuperscript{24} (Figure 2).

After a process of informed consent, focus groups and individual interviews were conducted using interview guides. The semi-structured interview guides for the focus groups and individual interviews supported a process of cultural adaptation\textsuperscript{24}. In addition, the interview guides were pilot-tested before use to ensure that they were tailored to meet the needs of the various groups (that is, for team members during focus groups, for csws during post-training interviews, and for csws and community member volunteers during field testing). The questions in the interview guides aimed to assess the usability of the SDM strategy, meaning the content (relevance of the ideas and concepts in the SDM strategy to the people, context), the process (appropriateness of the delivery format for the people, context), and the feasibility of use in cancer care settings. Upon completion of the team focus group, csw post-training, and usability interviews, member checking was conducted\textsuperscript{44}. Upon completion of the interviews with the community member volunteers, post-interview consultations with the community member participants was not possible because of medical travel schedules.

Data Collection and Analysis
To analyze participant (team) responses during the development of the SDM strategy and the training objectives and processes, data (notes and meeting documents) were synthesized in an iterative process during and upon completion of the focus groups\textsuperscript{44}.

During training of the csws in the SDM strategy, information about the acceptability, usefulness, and relevance of the training were gathered through written field notes and in the csw post-training interviews. Descriptive analysis was used to make iterative adjustments to the strategy training. Interviews were analyzed to seek demonstration of self-efficacy and learning objectives in the training. Findings were reviewed with the team, and the SDM strategy training was agreed on and finalized.

To analyze participant (csw, community member) interview data assessing the SDM strategy, a 6-phase process of thematic analysis\textsuperscript{43} was used:

- Familiarization with data
- Generation of initial codes within each transcript (for example, “support is important”)
- Search for themes (for example, “people face challenges in the cancer care system”)
- Review of themes
- Definition and naming of themes, which were further confirmed or adjusted by an independent second reviewer (AH, LM)
- Reporting themes

One person (JJ) was central to the process; other team members had the process described to them and were engaged for feedback. Data saturation was assessed by 2 independent reviewers (AH, LM), who found that the collection of new data confirmed already identified issues.

Throughout the entire analysis process, findings were considered in relation to the strengths of Inuit society that were described and confirmed by Inuit community members of the team. The final findings were reviewed, shared with advisory groups for confirmation of population relevance and appropriate interpretation, and then confirmed with the team.

RESULTS

Phase 1

Developing Partnerships: Research Participants
We convened a Steering Committee, which was a subset of the 13-member team (\(n = 10\)). Steering Committee members reported holding a role within an organization that provided health care or other forms of support (or both) to Inuit. Some members reported having a role within an Inuit-led organization (\(n = 5\)). Those organizations included Larga Baffin (an urban medical residence for Inuit), Tungasuvvingat Inuit (an urban organization supporting Inuit primarily based in Ottawa), Ottawa Health Services Network Inc. (a nonprofit organization that coordinates health care for residents of the Qikiqtaaluk region of Nunavut referred to Ottawa for health care), The Ottawa Hospital Aboriginal Cancer Program (a program with special focus on Inuit and other Indigenous groups), and the Indigenous Cancer Control Unit of Cancer Care Ontario. Steering Committee members reported a range of ages (20–70 years) and genders (Table i).

The team used consensus-building methods and, with feedback from advisory groups, collaboratively developed a SDM strategy tailored to meet the needs of Inuit cancer system users. During the study, advisory groups were consulted, including the Joint Ontario Indigenous Cancer...
Committee, the Cancer Care Ontario Indigenous Navigator team, the Regional Indigenous Cancer Leads, and the Ottawa Health Services Network Inc.’s Inuit medical interpreter team. We also maintained an active and collaborative relationship with the Indigenous Cancer Control Unit of Cancer Care Ontario.

Participating csws (n = 5) reported a range of 1–29 years of experience and provided support to approximately 2–5 (or more) patients in the cancer system each week. We engaged with community member volunteers (n = 8) who were residents of Nunavut, who indicated receiving cancer care in Ottawa, and who interacted with a range of 1–5 (or more) health care providers. Community participants ranged in age from 40 to more than 80, with a mix of self-reported genders, some having dependents, and education ranging from elementary to university level. To preserve the anonymity of all participants, limited demographic data are presented (Table i).

### Tailoring the SDM Strategy

In a series of 3 focus groups, a previously developed sdm strategy was discussed in the cultural context of Inuit experience in the cancer care system. The team explored stages in the cancer care journey of Inuit and identified missed opportunities for them to participate in decisions about their health. For example, people often do not understand why they are travelling to Ottawa, Ontario, from Nunavut. The team identified 3 sdm stages that were affirmed by the advisory groups: preparation for sdm, engagement in the sdm event with the health care provider, and follow-up for sdm plans.

The team chose to adapt the previously developed sdm strategy to focus on the first stage of the sdm process (preparation for sdm) as appropriate for the cultural context of Inuit and the cancer care system. Discussion centred on the role of Inuit community and relational approaches to health and wellness in decision-making about cancer care. Another

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**TABLE 1**  Demographic data for the study participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Steering committee members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In Inuit-led organization</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>In health care delivery or support organization</td>
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<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–30 Years</td>
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<td></td>
</tr>
<tr>
<td>31–40 Years</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>41–50 Years</td>
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<tr>
<td>51–60 Years</td>
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<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Sex or gender</td>
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</tr>
<tr>
<td>Self-identify as woman</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Self-identify as man</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Self-identify as other</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Prefer not to self-identify</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Community support workers</td>
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</tr>
<tr>
<td>Participants</td>
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</tr>
<tr>
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<td>0</td>
<td></td>
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<tr>
<td>2–5</td>
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<tr>
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<tr>
<td>Sex or gender</td>
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<td></td>
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<tr>
<td>Self-identify as woman</td>
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<td></td>
</tr>
<tr>
<td>Self-identify as man</td>
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<td></td>
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<tr>
<td>Self-identify as other</td>
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<td></td>
</tr>
<tr>
<td>Prefer not to self-identify</td>
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<td></td>
</tr>
<tr>
<td>Provide care for dependents</td>
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</tr>
<tr>
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</tr>
<tr>
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</tr>
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</tr>
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<td></td>
</tr>
<tr>
<td>University</td>
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<td></td>
</tr>
</tbody>
</table>

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a  Could belong to more than one category.
b  With cancer; approximate number.
c  With whom they are currently interacting.
identified factor in cancer care was that many Inuit must make a long journey from the Qikiqtaaluk region to Ottawa. Using an iterative and consensus-building approach, the team proposed a 6-question tool for use by trained csws with Inuit patients to prepare for sdm with health care providers. The team and advisory group members who are Inuit translated sdm as “Not Deciding Alone,” and that name was used to explain sdm and to label the sdm strategy in the context of Inuit and their experience in the cancer care system (Figure 3). In a series of 2 focus groups—and based on a previously developed workshop—training in the sdm strategy and training objectives and processes were developed in relation to the role of csws and the context of Inuit experience in the cancer care system.

In summary, the revisions to the sdm strategy (the booklet and training) occurred in a series of consultations with team members using an interview guide and with feedback from advisory groups. Over the course of the study, a total of 8 consultations (5 focus groups and 3 e-mail consultations) were held with the team members, and 10 consultations (4 presentations and 6 face-to-face meetings) were held with advisory groups, at which point no further changes were required by the team or advisory group members. Screening and testing by translators fluent in multiple dialects of Inuktitut were conducted to ensure that the final versions of the translated sdm strategy booklet retained the original intent. After all team members came to agreement, the revised sdm strategy titled “Not Deciding Alone” was prepared for field tests with csws who had completed training in how to use the sdm strategy (outlined in the next subsection).

**The SDM Strategy: Not Deciding Alone**

The team developed materials to train and support Inuit community csws to prepare community members for sdm with health care providers. The final product—the sdm strategy called “Not Deciding Alone”—takes the form of 4 learning modules for health care provider learners (for example, csws who provide peer support) and a booklet to guide conversations with community members who are preparing to meet and engage in sdm with health care providers. The booklet consists of 6 questions in both the Inuktitut and English languages. The sdm strategy was tested in phase 2 of the study.

**Phase 2**

**Training in the Use of the SDM Strategy**

Leaders at 3 urban organizations (Larga Baffin, Tungavnguat Inuit, Ottawa Health Services Network Inc.) that provide support or health care to Inuit who travel to Ottawa for their cancer care expressed interest in the sdm strategy training and were identified as recruitment sites for csws and community members. Five csws who provide support to patients in cancer care systems volunteered and were trained to use the sdm strategy. At the completion of training, the csw trainees were able to demonstrate the predetermined objectives to the training facilitators (JJ, AH). That is, the csws demonstrated—through discussion, use of examples, and role play—that they were able to define basic concepts of sdm, discuss the relevance of sdm with Inuit patients in the cancer care system, and demonstrate the use of the sdm strategy.

**Field Test of the SDM Strategy**

The 5 csws were matched to 8 community member volunteers to form csw–community member pairs (n = 8). Each csw–community member pair was provided with the sdm strategy booklet, comprising 6 questions to aid people in their preparation for engagement in the sdm process (Table II, Figure 4). Each csw–community member pair was observed to read and understand the booklet; to engage in discussion prompted by the booklet; to use the booklet in both Inuktitut and English, with some pairs (n = 3) using the booklet exclusively in Inuktitut; and to have sufficient space to make notes in the booklet. The initial csw–community member pairs (n = 2) provided feedback about the accuracy of translation and recommended placement of the Inuktitut language first, followed by the English language. That adjustment was made before further testing with the remaining csw–community member pairs (n = 5).

The researcher (JJ) conducted interviews with the csw–community member pairs. All (n = 8) csw–community

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**FIGURE 3** Shared decision-making infographic.

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TABLE II  Booklet questions, rationale, and fit with shared decision-making (SDM)

<table>
<thead>
<tr>
<th>Question</th>
<th>Rationale and fit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you understand why you are going to see your health care provider?</td>
<td>People might not understand why they have been asked to meet with one or more health care providers. They might have travelled a long distance without having anyone inform them about why they are going to see the health care providers. For SDM to occur, the patient and the health care provider must be clear about the decision that they are meeting to discuss.</td>
</tr>
<tr>
<td>What do you want help for? How does this affect you?</td>
<td>People might not be confident to share information about their health concerns with health care providers. As well, people value the expertise of health care providers to help with their health. With SDM, patients bring expertise about their health concern or concerns to health care decisions with their health care provider or providers.</td>
</tr>
<tr>
<td>What are your worries?</td>
<td>People might not be confident to share information about their lives that affects decisions about their health care. For example, Inuit might consider health care decisions from the perspective of how having a contributing community member absent (for example, hunter, caregiver to dependents) affects their family and community, rather than from an individual perspective. Inuit also have recent experiences with residential schools, medical ships that removed family members, and other events that have created distrust of Western-oriented health care systems. With SDM, patient views and values are considered in weighing health care options and the risks and benefits of those options, while health care decisions are made together with health care providers. SDM has been found to promote culturally safe care.</td>
</tr>
<tr>
<td>What are you hoping will be better after seeing your health care provider?</td>
<td>People might not be confident to share information about their lives that might be very different from lives lived in an urban setting. For example, people might want help to be able to resume activities that are not familiar to urban-based health care providers. With SDM, patient views and values are considered in weighing health care options and the risks and benefits of those options, while health care decisions are made with health care providers.</td>
</tr>
<tr>
<td>Are there traditional or cultural ways to heal that you use or want to know more about?</td>
<td>People might not be confident to share information about what could support them in participating in their health care. For example, Inuit might derive comfort from familiar food (such as country food) or from community resources to support them during their care. With SDM, patient views and values are important both for making and for following through on decision-making with health care providers.</td>
</tr>
<tr>
<td>What information do you need and who can support you to make good health decisions for you?</td>
<td>People might not have the resources or supports to follow through on a decision for a plan of care. The final step in the SDM process is agreement between the health care provider and the patient for a feasible plan of care.</td>
</tr>
</tbody>
</table>

member pairs expressed positive views about the use of the booklet and said that they would both use it again and recommend that a friend or family member use it. The qualitative interviews with the community members and csws identified 6 themes. The first 2 themes were shared by the community members and the csws (“The SDM strategy has to be used by Inuit early in the cancer care journey,” “This booklet makes it easy to talk about what is important”). The next 2 themes were unique to the community members (“It is good to talk about what is important to me,” “People with cancer face challenges in the system”). Finally, 2 themes were unique to the csws (“This SDM strategy helps me to engage with a patient,” “The booklet helps us to talk about what is important”).

Theme 1 – The SDM Strategy Has to Be Used by Inuit Early in the Cancer Care Journey

The csws and community members both stated that the SDM strategy should be used as early as possible in the cancer care journey and gave examples of when and how such use could be achieved. For example, one csw explained, “Using it earlier can help us to keep track of new patients; [the] booklet can help someone to have a conversation or to give information to health care providers that is important to the patient.” A patient expressed views about the use of the SDM strategy as a support: “Good, very helpful—both here, but I think also in the community.” Another patient explained that the use of the SDM strategy would be helpful because “there is a need for meetings in the communities so that people can understand.... There is a need in small communities to talk about this information.”

The csws reported that the use of the SDM strategy booklet as a communication device could alleviate a common and upsetting experience of community members who do not understand the complex health care processes:

[It is] very, very upsetting to not know what is going on, and the worst is thinking that they [Inuit patients] are coming here for a short time and then finding out that they have to stay longer away from their home, their family. Sometimes the health care provider says, “Okay, you can go home now,” and the patient thinks it means home—not back to the medical residence to wait for more appointments. That is a terrible disappointment.
Theme 2 – This Booklet Makes It Easy to Talk About What Is Important

Community members and csWs both expressed the importance of having a way to communicate with health care providers. The csWs talked about how useful it is to have an opportunity to talk with a patient in a conversation that is guided by the booklet and that creates a helpful timeout to focus on what is happening:

There are so many health care providers—such as the nurse, case manager—to keep track of. So new patients can get information on who they are going to see. The booklet can help someone to have a conversation about what matters to them with each health care provider.

That view was reinforced by other community members, one of whom said, “It [the sdM strategy] is comfortable. With someone else, it’s good to talk about what is going on... A good way to get to know someone.”

During interviews, the csWs explained how common misunderstandings of cancer can be further complicated by health systems processes:

Sometimes [community members] call [cancer] the “no cure disease” or “dying.” Health care providers often rush. People have questions, need time to sit down. Often health care providers just think of the illness—not that it’s body, mind, and soul [for Inuit who receive a cancer diagnosis]. It’s not just about the self... it’s about the community.
All community members expressed their approval of the sdm strategy: “I am happy to use this, [because] something is needed.”

**Theme 3 – It is Good to Talk About What Is Important to Me**

Many community members talked about how the sdm strategy facilitated an opportunity to talk about their experience. As one person said, “Only cancer patients can know how it is—and there is a need to have a say in what is going on.” Others explained how talking about health care can be a challenge for members of the community and the importance of finding ways to communicate as a way to share information and to get support:

> Others need to try [the sdm strategy]. [I have] no fear of talking about health. I have a daughter who is younger and who encourages me to talk and to be positive. I like to use something like [this booklet, this conversation with the csw].

All community members expressed the importance of finding ways to help people talk with someone about their health, as one community member said, “It’s helpful to talk with someone.”

**Theme 4 – People with Cancer Face Challenges in the System**

Some community members shared stories about challenges in the cancer care system that make it hard to navigate. One person said, “[I am] afraid to approach, afraid to expose self, had a bad experience when trying to figure out health issues. [I was] not treated well. This tool is a good idea and would help us.” Others identified how use of the sdm strategy could help to negotiate the health care system: “I like [the booklet]. It is visual, showing, so I can see what is written. [It is] helpful too, as sometimes people give false information, and so this is a way to help with that, writing things down can help.”

Community members also expressed a wish to share information about the use of the sdm strategy with other patients who have cancer:

> I am willing to help people know about the experience of having cancer and to share [the questions in booklet] with other cancer patients. It was overwhelming to hear of my diagnosis with cancer, and I want to help others to know what they can do.

**Theme 5 – The SDM Strategy Helps Me to Engage with a Patient**

All of the csws talked about how colonial history and ongoing negative experiences create challenges and anxiety for Inuit and undermine opportunities for engagement with their health care providers:

> There is a history for why people are not good at talking with their health care providers. The government controlled them [such as with residential schools, ships that removed community members during tuberculosis outbreaks and other significant events] and that is how they are used to living. Then to come here and to hear “you know best” is scary.

The csws talked about how the booklet made conversations straightforward and described it as simple, not something that people can “shut down.” Many csws also said that they liked to use the booklet because it prompts conversation and helps with what are sometimes difficult conversations for the csws:

> People come with no idea of why, and we are having to bridge two worlds for them. Often patients have no idea why health care providers tell them to get on a plane, and then they think they are coming for treatment for three days and then it becomes two weeks. It is a tough situation—as often people have no money, no support. People need to be able to explain their situation and how it is for them. People need to know that they are not alone.

The csws also liked the potential for the sdm strategy to change the way in which community members view themselves as active in their health care because “it gets them thinking.”

**Theme 6 – The Booklet Helps Us to Talk About What Is Important**

Most of the csws shared their concerns about patient safety and a role for the sdm strategy:

> Communication is a real challenge. Sometimes there is confusion among health care providers about who is coming to clinic, and if the patient does not know why they are going and feels that they cannot talk to the health care provider to understand why they are going for health care, that is a problem.

All of the csws talked about how the booklet was “very easy, straightforward … to the point. What people want help for … might be other things. And health care providers always ask about medicines.”

During the interviews, many csws explained how important it is to have conversations with people about their well-being and how csws are often alone to support patients—a fact that csws identified their patients as also recognizing:

> [Patients] really understand how hard this is on us as peer supports. It’s hard to tell bad news and to see what people go through. I was humbled when there was a patient who had cancer and who wanted to pray for the [csws] because it was hard news for us to tell his family.

The csws viewed the sdm strategy as having potential to engage other cancer care providers in a network of support around the patient.
**Health Systems Factors**

The researchers (JJ, AH, IDG) gathered data related to health system factors and the use of the SDM strategy (the training and field testing). Analysis of field notes collected by the researchers during multiple (>10) consultations with the csws and their management team revealed

- the importance of flexibility in when and how the SDM training occurred, to accommodate complicated and changing csw schedules. For example, some training took place in office settings, and other sessions occurred in clinical care settings in a quiet room when the csws had a few hours between patients, but had to remain on site ready for other calls.
- the importance of building on the expertise that csws bring to the SDM strategy training. For example, during the training, the csws discussed the relevance of SDM concepts to the patients they supported and explained how the SDM strategy might be used to support patient participation in cancer care.

Members of the csw management team (n = 2) indicated that the SDM strategy training aligns with the role of the csws to support Inuit patients negotiating the cancer care system.

The use of the SDM strategy was enhanced by recognition on the part of csws and their health systems supports (managers, nurses, schedulers, and so on) of the value of the SDM strategy for community members in cancer care, and by the time and opportunity for csws to use the SDM strategy within a complex schedule.

**DISCUSSION**

We used an integrated KT approach to engage patients and other knowledge users in a research study to develop a SDM strategy. After the field test of the SDM strategy, interviews with csws and community members identified 6 themes. The concepts identified in the interviews added to the evidence about SDM and the potential utility of a SDM strategy (training and a booklet) to enhance participation of Inuit in decisions about their cancer care. Our work contributes knowledge about the use of an integrated KT approach to research as a way to engage patients and other knowledge users in research. Our work also emphasizes the relational features of SDM for use in cancer care and contributes to a growing body of literature about Indigenous people and the use of SDM in health care settings.

**Integrated KT to Engage Patients and Other Knowledge Users in Research**

The use of an integrated KT approach created opportunities for knowledge users (including patients) to engage in the development of an intervention to facilitate SDM. Patient engagement to develop tools that promote SDM might lead to decisions that are more patient-oriented. International work is under way to promote knowledge user engagement in health research. For example, the U.S. Patient-Centered Outcomes Research Institute has identified the involvement of patients, caregivers, clinicians, and other health care stakeholders throughout the research process with potential to influence research to be more patient-centred, useful, and trustworthy, and ultimately to lead to greater use and uptake of research results by patients and the broader health care community. In Canada, recent similar initiatives such as the national Strategy for Patient-Oriented Research have fostered evidence-informed health care through innovation to improve quality, accountability, and accessibility. Like the U.S. Patient-Centered Outcomes Research Institute, the Strategy for Patient-Oriented Research aims to integrate the views and values of patients into health systems. Engagement of patients and other knowledge users in research disrupts the notion of research as the domain of academic researchers alone and expands research to include many forms of expertise. In the present study, such engagement led to the development of a SDM strategy.

The goal of SDM is ultimately to benefit patients. The development of SDM programs in ways that include patients is therefore important and emerging. Given that health care decisions are influenced by family and community traditions, it is important to explore a variety of cultural interpretations of SDM. Our use of interviews with csws and community members who are active participants in cancer care systems brings real-world experience and expertise into research processes. The inclusion of csws and community members in the research contributes to knowledge about a SDM strategy and demonstrates that knowledge users, including patients, have an important role in the development of SDM tools and approaches.

The knowledge that was developed by the partners in the present study has been defined as culturally appropriate and relevant by community- and organization-based knowledge users. The result is products that are immediately useful to those delivering care in the cancer care system (Figure 4). It is critical to learn how to use integrated KT with Indigenous research partners in ways that contribute to the respectful inclusion of Indigenous knowledge within Western-oriented research and health systems. The use of an integrated KT approach in our study has provided a valuable opportunity to learn about how to do research in partnership with knowledge users who are members of the community (including patients), health care providers, and organizational leaders in cancer care systems.

**Relational Features of SDM in Cancer Care**

Our study also contributes to a growing body of literature about SDM to support Indigenous patients in health care settings. Previous work conducted with First Nations, Inuit, and Métis women has shown that SDM is viewed as including relational features that are also identified as core competencies in the conduct of SDM. Relational competencies in SDM are defined as those necessary to create an environment for communication and interaction in clinical settings, and includes listening to and involving patients to the degree that patients wish to be involved. The study reported here contributes evidence in support of the enactment of relational core competencies in the conduct of SDM. Specifically, we report on the development of a SDM strategy for use by peer support workers to prepare patients to engage in SDM with cancer care providers.
Our findings reinforce the importance of preparation for making decisions with a health care provider. An approach in SDM called “decision coaching” occurs when trained health care providers provide nondirective support to people, preparing them to make health care decisions consistent with their own values and beliefs. Decision coaching also tailors decision support to be relevant to each situation and aims to build decision-making skills so that people can apply those skills in other settings. Decision coaching has been identified as an essential feature of SDM with Inuit, First Nations, and Métis patients in the provision of culturally safe care. Our findings support the importance of a SDM strategy that includes decision coaching for potential use in cancer care settings.

Limitations and Strengths
One limitation of our study is that we engaged with a small group of CSWs and patients who are from a particular region of Nunavut and who were based at the time of the study in an urban setting (Ottawa). Depending on their region in Nunavut, Inuit might travel to very different urban settings for health care—each with unique provincial health care delivery systems and supports (Figure 1). As well, the sample of CSW participants were individuals who were particularly interested in the use of SDM and were seeking ways to enhance their support of patients in cancer care systems. Many community members met with the researchers to learn about and discuss the study, but were reluctant to sign consent forms or to engage formally in the research. For that reason, our study possibly included participants who were more used to the Western-oriented approach to research.

The strengths of the present study start with the involvement—from design, to conduct, to interpretation and dissemination—of an interdisciplinary team and advisory groups who are active members of cancer care systems that provide service to Inuit. Another strength is that the study included members of the Inuit community. The work used an integrated KT approach that facilitated the building of relationships that have been sustained and are continuing now in a longer-term study. As well, purposeful engagement of CSWs and community members as participants in the research ensured consideration and incorporation of the views of those individuals in the use of a SDM strategy, and so was more likely to create knowledge that is useful and usable. Our study used processes similar to those previously developed to adapt a SDM strategy in collaboration with an Indigenous community. Those processes previously used to adapt a SDM strategy were validated in a synthesis of approaches for adapting or validating SDM tools.

- Explore the original SDM tool and the new cultural context
- Adapt the original SDM tool to the new cultural context
- Pre-test the preliminary version of the adapted SDM tool
- Field-test the adapted SDM tool in a real-use context

The conduct of our study has provided a valuable opportunity to learn about how to do research in partnership with an interdisciplinary team and with advisory groups who are active members of cancer care systems that provide service to Inuit and that include members of the Inuit community.

Reflections on the Value of Funding
The objective of our study was to use an integrated KT approach to promote the use of SDM by Inuit in cancer care. To foster patient-oriented care practices, there is a need to learn about how to do research in partnership with those who are knowledge users in cancer care systems. The funding obtained for this study supported research processes that engaged an interdisciplinary team with advisory groups and Inuit community members.

Conclusions
In an integrated KT approach, structured collaborative research processes involving researchers and cancer care system partners were used to develop a SDM strategy for use by Inuit. The SDM strategy was developed to enhance participation by Inuit in decisions about their cancer care. The CSWs and community member volunteers who were patients in the cancer care system found the SDM strategy to be useful and feasible in cancer care. Further evaluation of the use of integrated KT in the development of SDM tools and approaches is needed to promote patient-centred cancer care.

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Conflict of Interest Disclosures
We have read and understood Current Oncology’s policy on disclosing conflicts of interest, and we declare that we have none.

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