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RESEARCH ARTICLE

A field-test of Not Deciding Alone to support Inuit with health decision making: co-production of a mixed methods study guided by aajiiqatigiingniq

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ABSTRACT
Shared decision-making supports person-centred care. Our team of Inuit-led and/or -focused organizations and researchers field-tested a strategy called Not Deciding Alone to support health decision-making. Guided by aajiiqatigiingniq, a principle of collective decision-making and consensus-building, we co-produced a mixed-methods study to: (1) train Qikiqtani region community health representatives (CHRs) with a workshop, (2) develop a radio show and survey, and (3) assess the radio show with Inuit community members in the health system. We evaluated participant experiences using forms, case studies, and an online survey. The workshop was delivered to 13 CHRs; seven (54%) provided evaluation data. All (100%) reported positive experiences with the content, activities, and facilitation. One (14%) said the workshop was too short; four (57%) agreed there was enough discussion time. Six (86%) reported new learning. Three radio show events were held with 33 survey respondents, the majority women (*n* = 25, 76%). Most found the show informative (*n* = 29, 88%) and helpful for future decision-making (*n* = 27, 82%), and said it would improve their confidence (*n* = 27, 82%). Not Deciding Alone was found to be an acceptable, useful, and relevant strategy for supporting health decision-making among Inuit community members.

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Introduction

Person-centred care involves treating people who face health issues as valued partners in health and social care systems. It is an approach in which people are encouraged to contribute their needs, values, and perspectives to manage and improve their health [1]. A person-centred care approach promotes autonomy and offers significant benefits such as enhanced quality of care and well-being for both those receiving and providing care [2,3]. Additionally, person-centred care has the potential to improve patient safety [4]. To make person-centred care effective, people must have opportunities to gain the knowledge, skills, and confidence to actively participate in their care decisions, within environments that foster shared decision-making between individuals and their care providers [5].

Studies show that many people lack opportunities to engage in informed decision-making with their care providers [6,7], for reasons related to organisational, care provider and recipient-perceived barriers [8]. For example, poor cultural awareness in organisations and by care providers discourages Indigenous people from seeking and engaging with services and increases the risks of

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harms from racism [9,10]. Structural inequities within care systems reflect power imbalances and oppression and leads to medical mistrust [11]. People depend on care systems during their most vulnerable moments. It is crucial for individuals to have the opportunity to work collaboratively with trusted care providers to make informed decisions for themselves and their families.

In an approach called "shared decision-making", people who are receiving care collaborate with their care providers to make health-related decisions. This process integrates peoples' informed preferences, values, and beliefs with clinical evidence from care providers to reach decisions [12,13]. Shared decision-making has been shown to improve patient outcomes and experiences [14], enhance the effectiveness of communication between health professionals and patients [15], and to present no associated harms [16]. Tools and approaches to support decisions about health are essential for encouraging engagement of people in their care and with their care providers.

The Not Deciding Alone project is an example of a shared decision-making strategy that reflects the interests of Inuit and service provider organisations. It originated in Ottawa, Ontario, when Inuit service providers raised concerns about experiences of Inuit within health systems. Not Deciding Alone has been developed as a strategy to support shared decision making processes by an interdisciplinary team based in Ontario, Nunavut and Northwest Territories, and includes a shared decision making workshop and materials. It centres on a shared decision making approach called decision coaching [16], a non-directive form of support delivered by care providers to people who face health decisions, to prepare to actively participate in making health decisions (www.notdecidingalone.com). Not Deciding Alone has been found to be useful and feasible for use by urban-based Inuit and service providers in an urban cancer care centre [17].

The field-test presented here began with the direction of community members from the Qikiqtani region of Inuit Nunangat, who encouraged the team to share Not Deciding Alone within the Qikiqtani communities. Previous research to explore the use of shared decision making with Indigenous populations has identified the importance of care providers who provide peer support, as they hold experiential knowledge similar to that of the group being supported [18]. Within the Nunavut care system, Community Health Representatives (CHRs) provide peer support within Inuit communities [19]. To prepare for this study the team engaged in consultations with CHRs and their networks, community members, policymakers, and others who provide care in Ontario and Nunavut. They agreed upon and developed a multi-phase study proposal to field-test Not Deciding Alone in the Qikiqtani region. The results of the initial research phases have been published elsewhere [20–25].

Research approach

Our team, called the Not Deciding Alone team, engages in collaborative research to promote self-determination and Inuit sovereignty in research processes and care systems [26]. We promote the idea that people have the right to have their say in their health decisions, and we develop and assess interventions to enhance participation of people in their health decision making.

Our team consists of two key groups comprised of Inuit, Indigenous, and Euro-Canadian members: 1) a Steering Committee, including an Elder, who guide the project; and 2) academic researchers who operationalise the research tasks (JJ, KF, BH), all authors on this paper. We share concerns about Inuit experiences with, and access to, care services. Together, we bring expertise in: Inuit societal values, Inuit and Indigenous health issues; policy development and decision making, service delivery; shared decision-making, collaborative research approaches; and Indigenous and Western academic research methodologies and methods. We promote Inuit worldviews in research processes and in the development and application of shared decision-making tools and strategies. We use the term research "co-production" to describe a collaborative approach across the research lifecycle that considers the needs of partners and supports their engagement [27–29]. We view research engagement to reflect research governance processes, where those who administer, deliver, and/or use care systems partner as members of the team as equals to co-produce knowledge [30,31]. Co-production is likely to generate knowledge that is useful and used in practice and in policy. Furthermore, as co-production is recognised to support action on the equitable conduct of science [32], it is an important approach for our work as we strive to uphold Indigenous sovereignty in research practices and outputs.

The work we report on here is premised on Inuit Societal Values, Inuit Qaujimajatuqangit (IQ), to guide a strengths-based approach that promotes self-determination and Inuit sovereignty in research and emphasises collaborative decision-making for the common good [33,34]. Our work is aligned with the National Inuit Strategy on Research (NISR) [26] and adheres to a mutually agreed upon ethical framework and research partnership [35,36]. Our research approach is described elsewhere [20,24], and emphasizes action and reflections on principles agreed upon by all research partners [37,38]. We prioritise Inuit knowledge systems and experiences, and work to ensure that Inuit and Inuit communities are the primary benefactors of our work. The Not Deciding Alone project is guided by ongoing consultations, reflects community priorities, and incorporates understanding of shared decision-making principles developed from learning with Inuit community partners.

To guide our thinking about Not Deciding Alone, we use a framework that depicts shared decision making processes as highly relational called the Shared Decision Making Process Framework (version 2). It is based on our learning about shared decision making in collaboration with Inuit community partners and incorporates concepts from Indigenous and non-Indigenous shared decision making frameworks and models (Figure 1) [20]. The purpose of the framework is to structure reflection on concepts important to shared decision making processes that include the context and people involved, and their influence on shared decision making processes and practice.

We wanted to field-test Not Deciding Alone as a strategy to support health decision-making in the Qikiqtani region of Nunavut. Our goal was to co-produce knowledge that could be applied in policy and practice, especially for team members and their broader networks interested in shared decision-making interventions. We determined that a mixed methods study was most appropriate to determine if Not Deciding Alone might be considered acceptable, useful, and relevant. Our study objectives were as follows:

(1) train Qikiqtani CHRs with a Not Deciding Alone workshop;
(2) develop a radio show about shared decision making with trained CHRs and an accompanying evaluation strategy;

Diagram from Jull, J., Fairman, K., Oliver, S., Hesmer B, Pullattayil AK, Not Deciding Alone Team. Archives of Public Health: https://doi.org/10.1186/s13690-023-01177-1

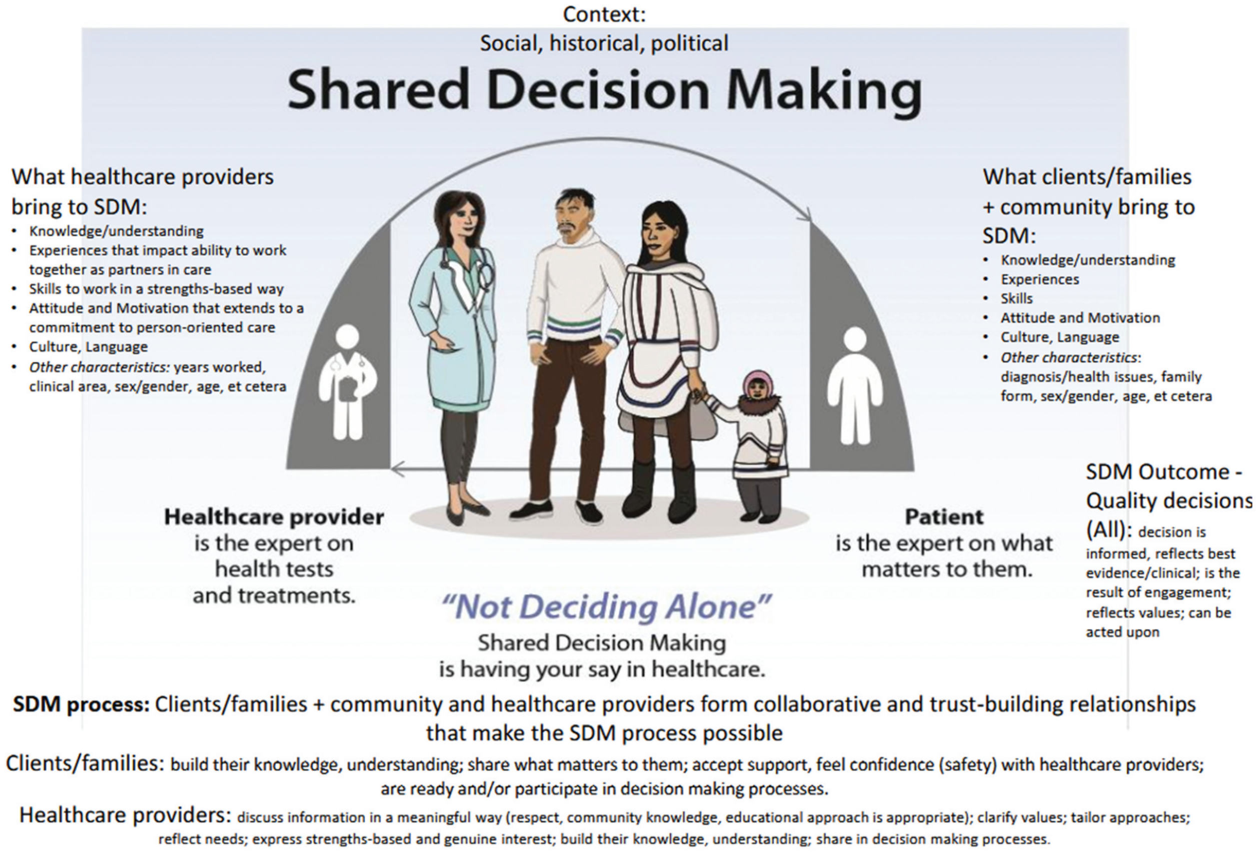


Figure 1. Shared decision making process framework (version 2).

(3) assess the radio show with community members.

The study was approved by the Nunavut Research Institute and the Ittaq Heritage & Research Centre, Clyde River (#01 003 23 R-M), and Queen's University Research Ethics board (6034673–1172293).

Methods

Here we describe our three-stage study: the design, a description of the participants and setting, the procedure in the conduct of our study, followed by the data collection and analysis. The team participated in each stage of the study.

Design

Our mixed-methods study was designed to uphold collaborative research approaches and describe participant experiences with care systems. We combined quantitative data gathering with narrative methods to add depth to the description of opinions and healthcare experiences [39–41]. To structure our study for co-production, we used the Collaborative Research Framework that describes an integrated knowledge translation (KT) approach to co-production [42,43]. Integrated KT supports collaboration between team members, from defining the research question to applying the findings [44]. The Framework emphasizes iterative processes, including establishing governance structures to balance power among team members for research co-production. In research, consensus methods bring evidence and expert opinion together to address knowledge gaps and build agreements [45]. Our team prioritized Inuit approaches to build consensus and address Inuit-specific health issues, to ensure meaningful engagement, mutual respect and learning, and reconciliation [46,47].

The Inuit societal value of aajiiqatigiingniq emphasises cultural knowledge and consensus decision-making and guided our team's actions. Aajiiqatigiingniq involves collective, iterative processes for building consensus and seeking solutions [47,48], central to Inuit notions of wellness and community harmony [49]. This value supported our team across the research lifecycle in the following activities [48]:

(1) **Relationship-building**: Establish and maintain trusted relationships.
(2) **Research preparation**: Develop shared understandings of the research approach, priorities of partners, and contextual considerations.
(3) **Research conduct**: Ensure the research methods reflect shared understandings and experiences of those in the research relationship.
(4) **Relational consensus and application**: Collectively interpret and confirm the results and create agreed-upon plans for sharing and applying findings.

We report on our work to ensure transparency and completeness to meet expectations defined by Inuit Tapiriit Kanatami for the role of research in regions and communities and used the National Inuit Strategy on Research [26]. (Additional Files 1.)

Participants and setting

Our team members were co-facilitators and interpreters for both the workshop and radio show events. Participants were purposively sampled [50] from the Qikiqtani region of Nunavut and included CHRs (for a workshop) and community members staying at a medical boarding home (for radio show events). We recruited Nunavut community members, meaning those who are travelling for care or are in the role of medical escort for someone who must obtain their care outside of Nunavut. Community members stay at regionally designated medical boarding homes when travelling for care outside of Nunavut. For our study we engaged with community members staying at a medical boarding home from the Qikiqtani region.

All potential participants were informed about the study through posters and invited to discuss the study with the co-facilitators. Inclusion criteria required participants to be able to engage in study activities in either Inuktitut or English and to meet the following roles: a CHR (workshop), or a community member who is a care recipient or medical escort (radio shows). All study materials were available in both Inuktitut and English.

Before the start of the study, there were consultations and permissions from the CHR program leaders and CHRs for the study topic (shared decision making, Not Deciding Alone) and proposed plans for research with the integration of local knowledge and experiences. For example, recognising radio as a widely used form of community engagement in Nunavut, the team confirmed the plan to develop and assess a radio show as a strategy to share Not Deciding Alone, explain its importance, and prepare community members for health decision-making.

In the first stage of the study at the CHR annual territorial meeting, the CHRs were invited to participate in a workshop with the option to join as a research participant. In the second stage of the study, participating CHRs and team members developed a radio show about Not Deciding Alone, an accompanying survey for use by community members, as well as case studies. In the third stage of the study, community members staying at a medical boarding home were invited to listen to the radio show and then invited to complete a survey to share their views on the radio show.

Procedure

First, we outline the process to plan and prepare the study and the events that shaped the conduct of the study. Next, we describe the three-stage study involving 1) the training of CHRs, 2) the development of a radio show and survey, and 3) the assessment of the radio show with community members (Figure 2).

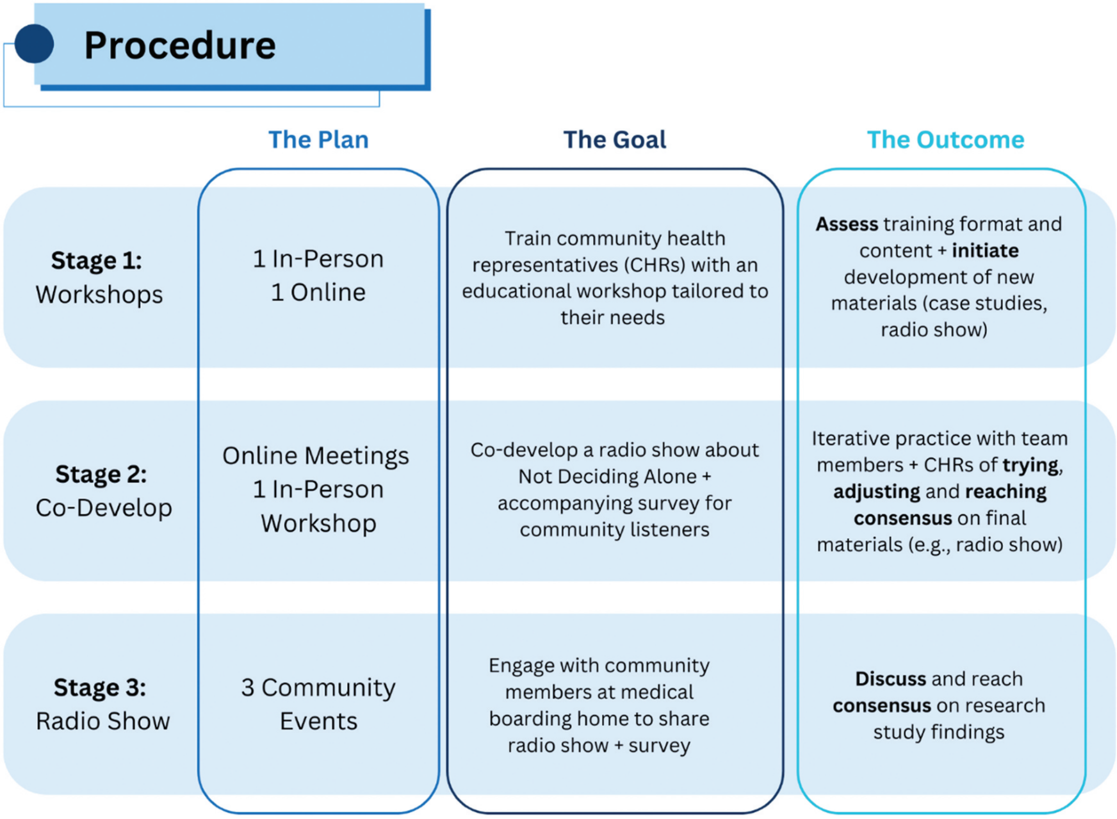
Plan and prepare

The study plans were confirmed through in-person and online meetings with the team, CHRs, and network members who are care systems supports and would need to know about our work (for example, managers, policy makers, schedulers). These consultations showed that shared decision-making and the proposed field-testing of the Not Deciding Alone workshop were perceived as acceptable to CHRs and those who support care system networks in Nunavut. Agreements were reached on the format, timelines, and focus for the proposed work, and described in a research proposal.

Events

Following funding success, the study's timeline was influenced by several events. The workshop was originally planned for a launch in November 2019 at the CHR annual territorial training in Iqaluit; however, due to a cyberattack in Nunavut the workshop was rescheduled to March 2020 and then cancelled because of the pandemic. Pandemic restrictions and the CHR role reallocation within the care system further delayed the workshop. The team and CHRs maintained contact through emails and online discussions to share knowledge about Not Deciding Alone.

- Stage 1: In November 2022, territorial pandemic restrictions eased. A team member was invited with a local co-facilitator to deliver a one-day in-person Not Deciding Alone workshop at the CHR annual training in Iqaluit. The workshop was also provided online for remote participants.



	The Plan	The Goal	The Outcome
Stage 1: Workshops	1 In-Person 1 Online	Train community health representatives (CHRs) with an educational workshop tailored to their needs	**Assess** training format and content + **initiate** development of new materials (case studies, radio show)
Stage 2: Co-Develop	Online Meetings 1 In-Person Workshop	Co-develop a radio show about Not Deciding Alone + accompanying survey for community listeners	Iterative practice with team members + CHRs of **trying**, **adjusting** and **reaching consensus** on final materials (e.g., radio show)
Stage 3: Radio Show	3 Community Events	Engage with community members at medical boarding home to share radio show + survey	**Discuss** and reach **consensus** on research study findings

Figure 2. Study procedure.

- Stage 2: The Not Deciding Alone workshop initiated the development of a radio show and accompanying survey. At the February 2023 CHR annual training, two team members delivered a second in-person workshop to review, edit and confirm the radio show and survey.
- Stage 3: Team members hosted events at an urban medical boarding home, where the radio show was presented to community members.

Stage 1: The Not Deciding Alone Workshop. Leading up to the workshop, the CHRs were informed about the workshop and the proposed study through emailed posters and online meetings with team members (TK, JJ). These activities allowed CHRs to contribute to the workshop objectives and strategies (for example, the use of learning theory, approaches to meet CHR learning needs), and assessment approaches including methods to evaluate their experiences. While all CHRs from Nunavut were welcome to participate in the workshop, only the Qikiqtani CHRs were invited to join the research study and provided written informed consent for data collection through evaluation forms and facilitator notes. The workshop (one in-person, one online) focused on training CHRs in shared decision making and decision coaching, structured with facilitated discussions of case studies.

Stage 2: Development of radio show, survey, community materials. After the workshop, the team, including participating CHRs, collaborated in online meetings to further develop the radio show and a survey. Through an iterative process of feedback, pilot testing, and backward and forward translation, they ensured the radio show and survey were aligned with local contexts (the Qikiqtani region of Nunavut).

An in-person one day workshop was co-led by CHRs and team members (JJ, TK) to share updates, and review concepts and materials. This session included facilitated discussions integrated into group sewing activities. CHR feedback was used to refine the radio show content and survey, with a focus on confirming their relevance for community use. Following the workshop, the team finalised the radio show script and survey. The radio show was recorded by team members (MZ, JJ) and produced. by a sound engineer (SA). The survey was posted to a separate webpage by the team's multi-media support (RA).

Based on CHR feedback, the team also confirmed and developed additional community materials from the case studies used in the Not Deciding Alone workshop. The team and CHRs followed a process similar to the radio show and survey (iterative processes of feedback, pilot testing, translations, alignment with local contexts). They decided to develop the case studies into comics, to be accessible and shared widely with community members. This process involved the researcher team members (BH, JJ, KF) working with the team members and a graphic design company to produce the case studies as comics. The team, CHRs, and network members were consulted to develop a range of formats for the comic that included posters, handouts, and folded informational cards ("k-cards") that CHRs indicated are preferred by community members. All materials were iteratively refined until team members and CHRs agreed on the final content, translation, visuals, and format. The evaluations of these materials are ongoing and will be reported elsewhere.

Stage 3: Radio show. The team and team members (MZ, JJ, OHSNI Inuit Interpreter Team) prepared for and hosted three events at an urban-based medical boarding home. Community members who were residents of the medical boarding home were informed about the study in advance through posters and given opportunities to ask questions. All community members were invited to three events held between May 15 and 1 June 2024, that involved games, food, and presentation of the radio show. After listening, community members could choose to review the informed consent form with an Inuktitut- or English-speaking team member and complete an online survey. Data on their views of the radio show were collected, and the survey was closed following the third event.

Data collection

Stage 1

Workshop evaluation. The workshop was evaluated based on its acceptability (suitability for its intended purpose), usefulness (practicality and helpfulness of the training), and relevance (importance and significance to participants and their situations). Acceptability was assessed through CHR agreement to participate, workshop attendance, and evaluation reports. Usefulness and relevance were measured using responses from a post-workshop evaluation form, including open-ended comments, and by observing participants' application of learning objectives during discussions, and case study activities. Facilitators also collected notes on participant feedback regarding the workshop's delivery and content.

Evaluation form (workshop). The team adapted a set of standard post-workshop evaluation questions [51], previously used to assess shared decision-making workshops for healthcare professionals and the public [52]. Adaptations included questions about whether participants found the workshop activities supportive, the facilitation engaging and respectful, and the workshop aligned with Inuit societal values. The evaluation form consisted of closed-ended questions on a four-point Likert scale (Totally Disagree, Disagree, Agree, Totally Agree) across four categories: content, activities, facilitation, and general feedback. Each section included space for open-ended comments, along with an additional question about whether participants learned something new about shared decision-making. The tool was translated and back-translated, pilot-tested, and validated by the team [53] as culturally and linguistically appropriate for participants.

The evaluation was administered at the end of the workshop, using a retrospective method to reduce participant burden and minimise response shift bias – when participants' understanding of questions changes over time, potentially masking program effectiveness [54,55]. Researchers (JJ, TK), who also facilitated the workshop, delivered the evaluation as participants in previous studies indicated a preference for assistance with paper-based tools [17].

Stage 2

Development of radio show materials. To generate content for the radio show, the team and CHRs first identified the need for case studies to explore shared decision-making concepts, and to collect and present locally relevant information about shared decision-making. In a series of online meetings prior to the conduct of the Not Deciding Alone workshop, two case study topics were identified, drafted, and collaboratively revised by the team and CHRs until consensus was reached on the content and relevance. The case studies were designed to reflect community experiences and needs, and to engage workshop participants in discussions.

At the workshop, the CHRs participated in facilitated discussions with the case studies in relation to their communities and understandings of shared decision-making. They provided feedback on how the case studies could be improved to better align with their work and community needs [56]. The CHRs also provided guidance on the structure and content of a radio show and on designing an appropriate, accessible, and anonymous survey to assess community member views on the radio show. Following the workshop, the radio show and survey format and content were collaboratively developed in a series of online meetings by the team and CHRs, in addition to revised versions of the case studies. The radio show, survey and case studies were confirmed with the team and CHRs, and in a second in-person workshop with the CHRs.

Stage 3

Radio show survey. To conduct the field-test of the radio show, the team and CHRs developed and pilot-tested an online survey. A letter of information was made available on the survey site. Participants were asked for demographic information about their cultural background, gender, decade of birth, details on their trip to an urban setting for care. Participants were also asked questions to determine 1) their views on the radio show as a delivery method for shared decision making messages, 2) their learning about shared decision making from the radio show, and 3) whether the radio show would help prepare them to participate in health decisions in future meetings with care providers.

The survey included nine items, presented one per page, designed to take five minutes or less to complete on a participant's phone or a study iPad. Participants could skip any questions they preferred. The survey link was provided to all radio show participants and posted on a private page of the study website. At the end of the survey, participants were offered the option to provide contact information to receive a $40 e-transfer as a thank-you for their participation. To ensure anonymity, the survey did not collect IP addresses and restricted responses to one submission per participant.

Analysis

The researchers (JJ, BH, KF) engaged the team in collaborative data analysis for the Not Deciding Alone workshop and radio show evaluations. As our team used mixed methods to collect data findings, we integrated quantitative and qualitative findings to provide a comprehensive description of the results [57].

Workshop evaluation

Quantitative responses were counted, and qualitative data from open-ended questions were analysed using content analysis. Responses were organised into categories, with each question considered a topic and participant responses guiding the development of codes within each category [58]. Frequency counts were reported alongside illustrative quotes. Through an iterative process of discussion, feedback, and agreement, the team refined the narrative accounts of shared decision making presented in the form of a radio show script and two case studies, ensuring they were strengths-based, relevant, and useful for Inuit in care systems [39–41].

Radio show evaluation

Quantitative survey data and open-text responses were analysed by one researcher (JJ) using frequency counts and content analysis. Findings were reviewed and confirmed by the team through discussion, with a focus on concepts related to shared decision-making and Inuit experiences in care systems.

Results

We describe the results of the field-test of Not Deciding Alone as a strategy to support health decision-making. First, we provide the characteristics of participants (CHRs) and then describe the results of the evaluation of the Not Deciding Alone workshop. We include the radio show and case studies with these results. Then, we provide the characteristics of participants (community members) and the results of the radio show evaluation.

Characteristics of participants (workshop)

Of the 13 CHRs who participated in the Not Deciding Alone workshop (in person, online), seven (54%) signed consent forms and agreed to share their evaluation for use in the research study. The consenting participants reported a range of one to over 30 years of experience in supporting community health, and self-identified as Nunavummiat.

Results (workshop)

Workshop content

All participants (*n* = 7, 100%) reported that the workshop information was understandable, clear, and the content relevant to their work One participant commented that the facilitator was soft-spoken.

Workshop activities

All (*n* = 7, 100%) participants agreed the workshop length was appropriate, the stated goals were met, and their participation supported. Participants also agreed the information would be useful for others. There were slightly less positive responses regarding if there was enough time for the workshop, for while most (*n* = 6, 86%) were positive, one (14%) participant disagreed. Comments reflected positive responses to the content and ideas for shared decision making.

Facilitation

The participants (*n* = 7, 100%) agreed they could share their views and experiences, that facilitators were respectful of participant views, and that their views were respected. There were mixed responses for if facilitators left room for discussion with most agreeing (*n* = 4, 57%), two with no response (29%) and one disagreed (14%). A participant felt encouraged by the participation of others in the workshop, saying "the other CHRs have great input".

Overall workshop comments

All (*n* = 7, 100%) participants reported that the workshop met their expectations, and the workshop structure allowed for discussion. Participants agreed the workshop was guided by IQ principles. All (*n* = 7, 100%) participants indicated they would recommend the workshop to the people they support, friends, family and co-workers. Participants related comments to reflect their appreciation of the resources, the appropriateness of the workshop and the importance of the topic. Six (86%) reported new learning about shared decision making (Table 1).

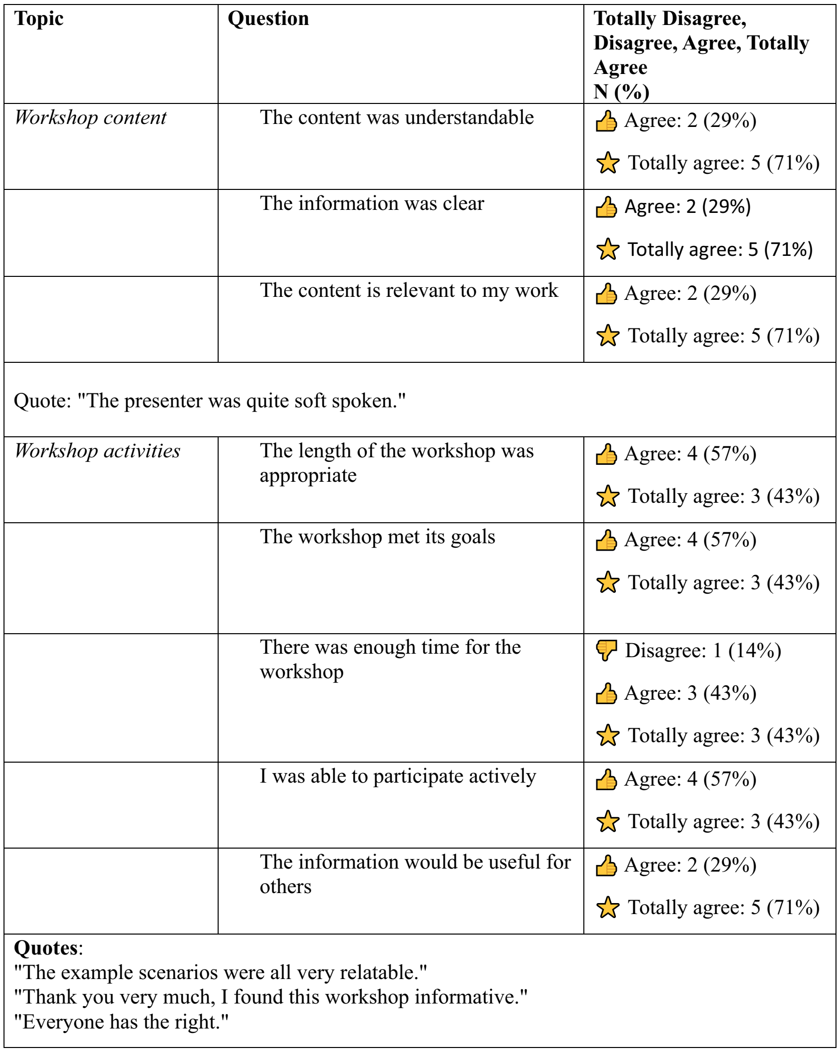
During and in online calls to follow up on the workshop, the facilitators (JJ, TK) and CHRs used consensus building methods to explore experiences of Inuit in their access and uptake of care. Discussion centred on missed opportunities and relational approaches to health and wellness in decision making, and the role of care providers who are trained to provide decision coaching (non-directive support). The team and CHRs developed a radio show to share important information with community members from these discussions (see www.notdecidingalone.com). They also developed two case studies to describe and apply shared decision making concepts in daily life. The final versions were agreed upon by all (the team, CHRs) as helpful additions to Not Deciding Alone resources, and a way to convey locally relevant knowledge about how to prepare for participation in health decision making (Figures 3,4,5,6).

Characteristics of participants (radio show)

Three community events to play the radio show were held, and for each of these there was an estimated attendance at between 15 and 40 people (a total between 45 and 120). Of these, 33 people chose to participate in the survey. Except for 2 participants who started but did not respond to questions, participants completed their surveys, and statistical correction was not used.

All participants self-identified as Inuk. Most respondents identified as women (*n* = 25, 76%), with some (*n* = 6, 18%) as men, and a few (*n* = 2, 3%) preferred not to say. Participants' ages spanned 19–72 years of age, and most participants (61%) had visited the local health centre in the past month. Of the 33 participants, five (15%) had never visited the local health centre. Some

Table 1. Workshop evaluation ($N = 7$).



Topic	Question	Totally Disagree, Disagree, Agree, Totally Agree N (%)
Workshop content	The content was understandable	👍 Agree: 2 (29%) ⭐ Totally agree: 5 (71%)
	The information was clear	👍 Agree: 2 (29%) ⭐ Totally agree: 5 (71%)
	The content is relevant to my work	👍 Agree: 2 (29%) ⭐ Totally agree: 5 (71%)
Quote: "The presenter was quite soft spoken."		
Workshop activities	The length of the workshop was appropriate	👍 Agree: 4 (57%) ⭐ Totally agree: 3 (43%)
	The workshop met its goals	👍 Agree: 4 (57%) ⭐ Totally agree: 3 (43%)
	There was enough time for the workshop	👎 Disagree: 1 (14%) 👍 Agree: 3 (43%) ⭐ Totally agree: 3 (43%)
	I was able to participate actively	👍 Agree: 4 (57%) ⭐ Totally agree: 3 (43%)
	The information would be useful for others	👍 Agree: 2 (29%) ⭐ Totally agree: 5 (71%)
Quotes: "The example scenarios were all very relatable." "Thank you very much, I found this workshop informative." "Everyone has the right."		

($n = 8$, 24%) indicated this was their first trip outside their community for healthcare (Table 2).

In response to questions about the format of the radio show, most participants indicated the length of the show was just right ($n = 26$, 79%). Some participants felt that the radio show was too long ($n = 2$, 6%) or too short ($n = 5$, 15%). The majority ($n = 29$, 88%) found the radio show to have helpful information with some indicating unsure ($n = 3$, 9%) or that the show is not helpful ($n = 1$, 3%).

In response to questions about their views on the impacts of the radio show, most participants ($n = 27$, 82%) felt that the information from the radio show would help them have their say in health decisions during their next visit, with some ($n = 5$, 15%) indicating uncertainty or that it would not be helpful ($n = 1$, 3%). Most participants ($n = 27$, 82%) reported that the radio show will help their confidence at the next care visit. Some were unsure ($n = 4$, 12%) or did not think it would help ($n = 2$, 6%).

These results provide a broad understanding of the community's views on the radio show as a communication strategy. Participant responses highlight the potential for the radio show to contribute in positive ways to enhance community members' engagement and participation in their care (Table 3).

In summary, the final versions of the radio show, survey, and case studies were developed in a series of consultations with team members and the participating network of CHRs. Over the course of the study, there were more than 40 consultations (two in-person and one online workshop, ~34 on-line team and CHR meetings, three community events, plus additional email exchanges and online and in-person meetings with network members). The process was considered complete and confirmed by the

Facilitation	The facilitators left room for discussion	👎 Disagree: 1 (14%) 👍 Agree: 3 (43%) ☆ Totally agree: 1 (14%) ○ No response: 2 (29%)
	I felt I could share my views and experiences	👍 Agree: 2 (29%) ☆ Totally agree: 5 (71%)
	The facilitators were respectful of participant views	👍 Agree: 2 (29%) ☆ Totally agree: 5 (71%)
	I felt my views were respected in the workshop	👍 Agree: 2 (29%) ☆ Totally agree: 5 (71%)
Quote: "I am new to this, but the other CHRs have great input."		
General Comments	The workshop met my expectations	👍 Agree: 3 (43%) ☆ Totally agree: 4 (57%)
	The workshop structure allowed for discussion	👍 Agree: 3 (43%) ☆ Totally agree: 4 (57%)
	The workshop was guided by IQ	👍 Agree: 4 (57%) ☆ Totally agree: 3 (43%)
	I would recommend the workshop to clients/friends/family/coworkers	👍 Agree: 2 (29%) ☆ Totally agree: 5 (71%)
	I learned something new about shared decision making at this workshop.	👎 Disagree: 1 (14%) 👍 Agree: 2 (29%) ☆ Totally agree: 4 (57%)
Quotes: Resources (n=1, 14%) "I like the resources” Enjoy/appropriate workshop (n=2, 29%) “the context and content were culturally appropriate” Importance of the topic (n=3, 43%) "Everyone should know they have the rights to know what is available"		

team following review of all findings and translations of materials.

Discussion

Our interdisciplinary team, guided by aajiiqatigiingniq, co-produced a mixed-methods study to field-test a strategy called Not Deciding Alone to support health decision-making. Our findings indicate that Not Deciding Alone is considered acceptable, useful, and relevant by participants who deliver and use care systems in Nunavut and Ontario. CHRs reported positive views and demonstrated learning during the Not Deciding Alone workshop. Community members expressed positive feedback on the format and content of a radio show about Not Deciding Alone. These results suggest that Not Deciding Alone holds promise for preparing and supporting people to participate in health decision-making, and to promote person-centred care. Importantly, research co-production enabled our team to do work that centred on and was driven by local and Inuit knowledge systems.

Research co-production to develop knowledge and resources supportive of person-centred care

Our research highlights the value of co-production to develop knowledge and resources to engage people in their health decisions, and potential for care system transformation supportive of person-centred care. A systematic review of the literature identified examples of how collaborative research approaches may be used to develop

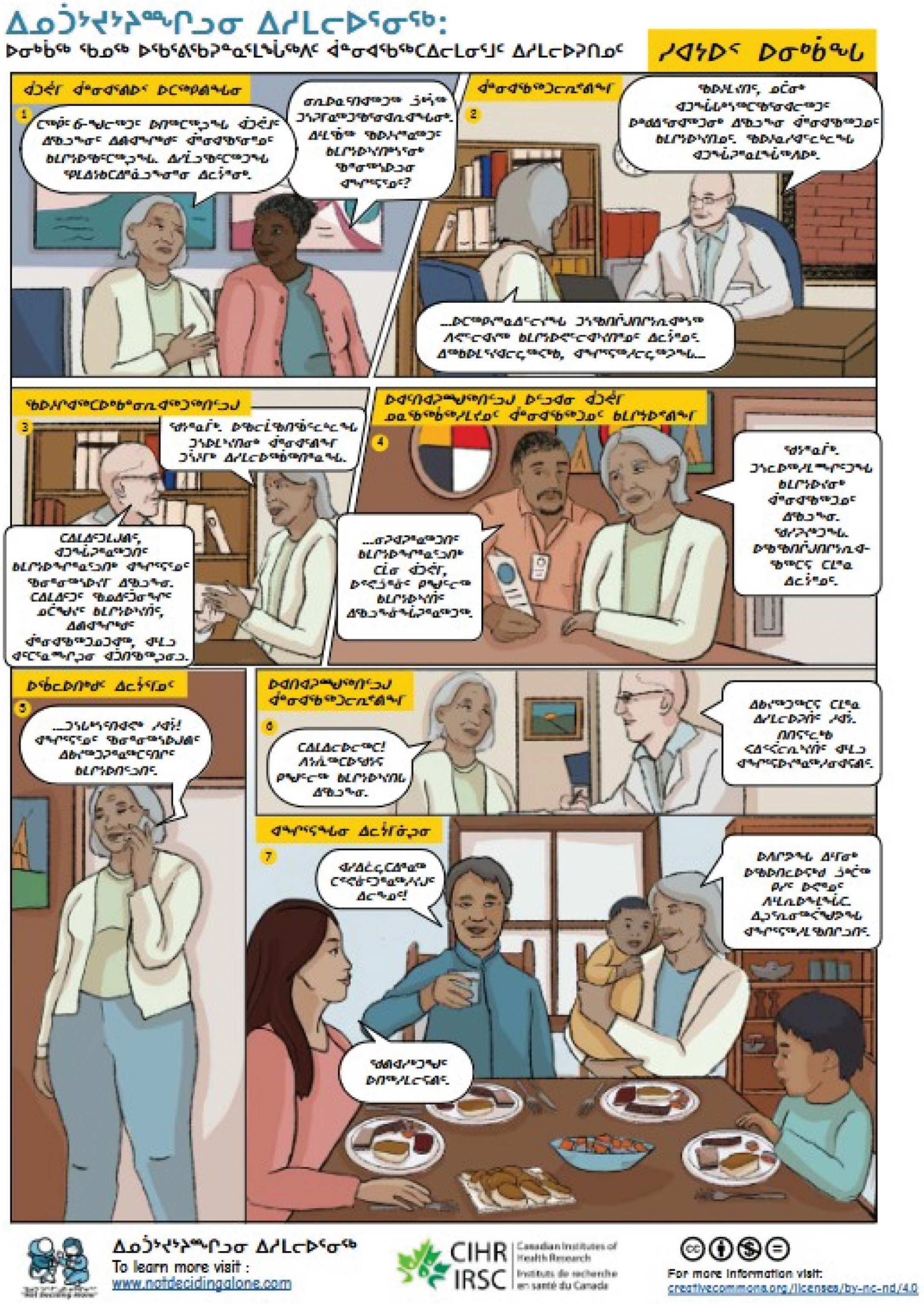


Figure 3. Sarah's story (Inuktitut).

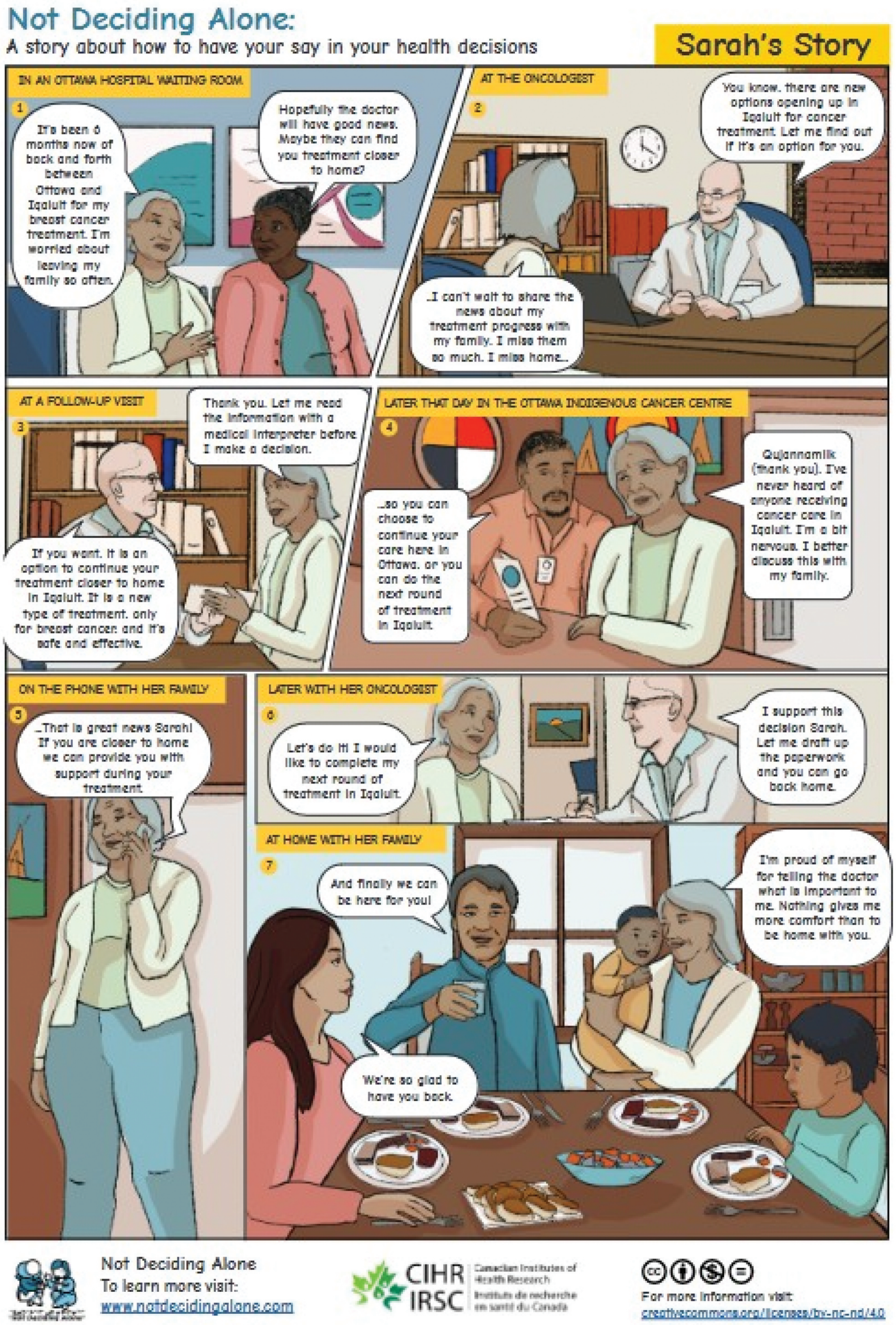


Figure 4. Sarah's story (English).

Figure 5. Simon's story (English).

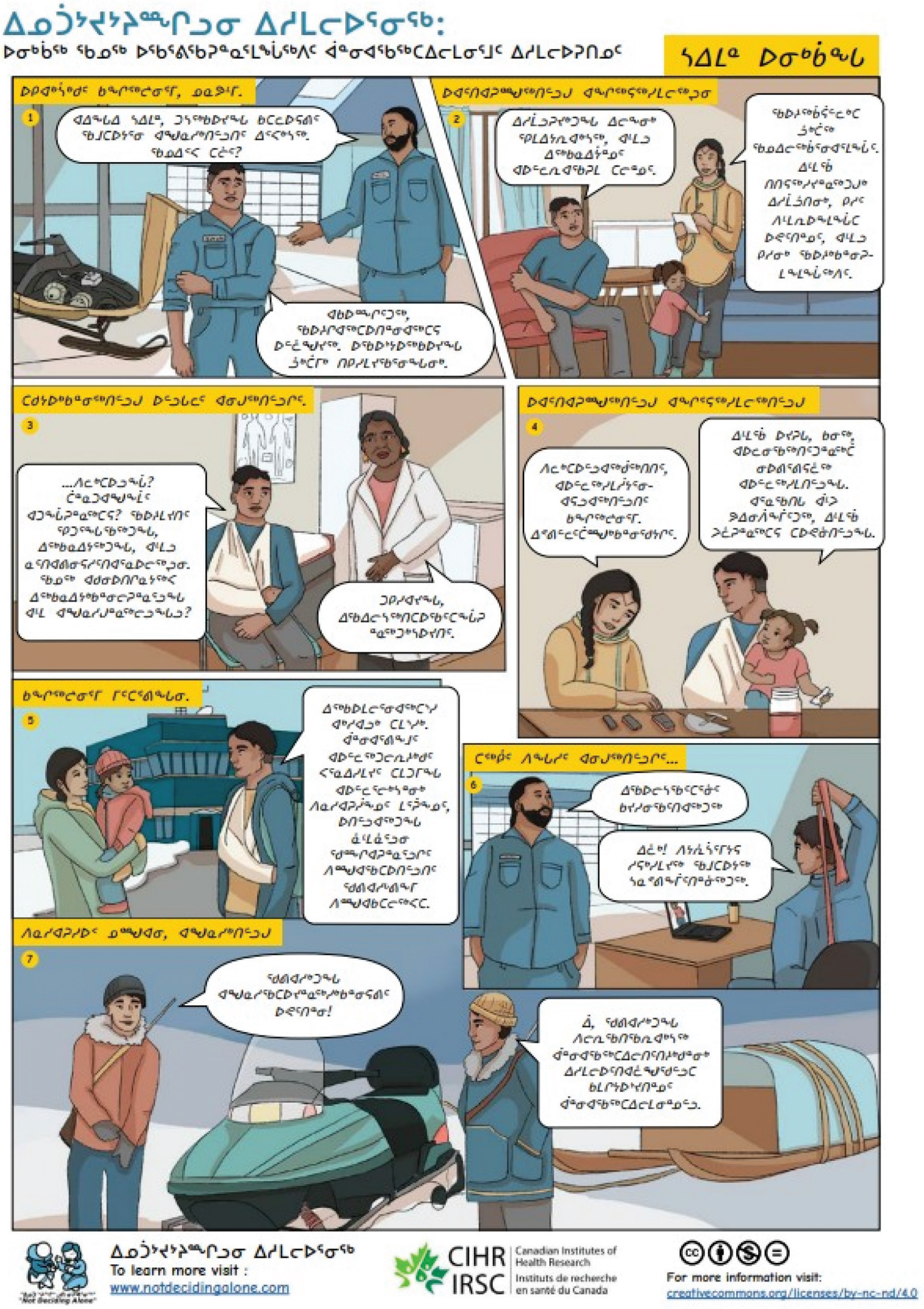


Figure 6. Simon's story (Inuktitut).

Table 2. Demographics of radio show survey participants ($N = 33$).

Topic		Value (#, %)
How participants self-identify:		
Cultural background		
	Self-identify as Inuk	33 (100%)
	Self-identify in another way	-
Sex and/or Gender		
	Self-identify as a woman	25 (76%)
	Self-identify as a man	6 (18%)
	Self-identify in another way	-
	Prefer to not self-identify	2 (6%)
Decade of birth		
	1950	3 (9%)
	1960	7 (21%)
	1970	3 (9%)
	1980	1 (3%)
	1990	1 (3%)
	2000	3 (9%)
	Prefer not to say/no response	15 (45%)
Health service access:		
Last trip to local health centre for health care, for self or someone they support		
	Past month	20 (61%)
	Between 2 and 6 months ago	5 (15%)
	More than 6 months ago	3 (9%)
	Have never been to the local health centre for health care	5 (15%)
Last trip outside the community for health care, for self or someone they support		
	Past month	17 (52%)
	Between 2 and 6 months ago	5 (15%)
	More than 6 months ago	3 (9%)
	Have never travelled outside the community for health care before now	8 (24%)

Table 3. Participant views on radio show format and content ($N = 33$).

Topic		Value (#, %)
Radio show format:		
The length of the radio show is:		
	Just right	26 (79%)
	Too long	2 (6%)
	Too short	5 (15%)
The radio show has helpful information:		
	Yes	29 (88%)
	No	1 (3%)
	Not sure	3 (9%)
Radio show content:		
The information will help me have my say in health decisions, at the next health care provider visit 33		
	Yes	27 (82%)
	No	1 (3%)
	Not sure	5 (15%)
The information will help my confidence at next health care visit 33		
	Yes	27 (82%)
	No	2 (6%)
	Not sure	4 (12%)

shared decision-making strategies to reflect the needs, values, perspectives and knowledges of the people and communities they aim to benefit to attain person-centred care [59,60]. Engaging end-users in the development of shared decision-making tools is identified as essential for their successful implementation [61]. Our study used an approach to research co-production by and with Inuit and is an example of a consensus-based approach to address issues in care systems.

Through collaborative research practices grounded in aajiiqatigiingniq, our team ensured research outputs were contextually relevant and aligned with community priorities. Other research teams have used Inuit methodologies and consensus models to support collaboration between Inuit community members and academic researchers, to support Inuit health and wellness [45,47,62,63]. These teams and their projects provide examples of how to value local and Inuit knowledges and create space and opportunities for people to participate in research processes. Furthermore, these collaborative research practices attend to power dynamics and contexts that are associated with academic research structures and norms, to centre on knowledge generation processes that are inclusive and reflect equitable knowledge co-production [32].

Ferrazzi et al. (2019) describe aajiiqatigiingniq as achieved through respectful communication, narrative discourse, personal engagement, and the gradual inclusion of group members, fostering consensus through an unhurried, reflective process [47]. The iterative and inclusive nature of aajiiqatigiingniq has enabled our team to co-develop practical resources, including guided questions, informational cards, posters, and a radio show. These resources reflect the experiences and values of Inuit participants and are designed to enhance engagement with care systems and to support person-centred care processes. For example, radio shows that are developed by or with Indigenous people have been identified as an appropriate way to share information on issues affecting communities, and to support health and wellness [64,65]. We propose that further research is needed to explore the integration of such resources into care systems, including embedding them in medical travel packages or other accessible formats.

Limitations and strengths

Our findings show there is a need to engage a broader and more diverse range of participants in research about Not Deciding Alone. Limitations of our study include that we engaged a small group of participants who are from a particular region of Inuit Nunangat, and most participants identified as women. Inuit might travel from a range of communities to very different urban settings for care, within unique care delivery systems and supports, and our study holds limited scope for use of the results elsewhere. As well, while many community members met with the team to learn about and discuss the study, most were reluctant to engage formally in the research.

Our current approaches to engagement in research may not adequately include people of all sexes and/or genders, particularly gender-diverse individuals. Sex and gender significantly influence health risks, care experiences, outcomes [66], and shapes health-seeking behaviours and interactions with care systems. For example, Pauktuutit Inuit Women of Canada (2013) reported that Inuit men may be less likely to talk about their health or to engage in help-seeking behaviours such as cancer screening [67]. Similarly, health centre data indicate higher referrals for Inuit women than men for lung and colorectal cancers, despite these being non-sex-specific cancers [68]. These patterns highlight the interplay of gender and cultural dimensions in health and wellness [69]. Building our capacity to include and support all people to participate in research about shared decision making, regardless of sex or gender, is critical to ensure equitable access to health decision-making tools and resources.

The strengths of our study include the engagement of an interdisciplinary team who are committed to supporting self-determination and Inuit sovereignty in research. The team members, who are active members of the Inuit community or who provide services to the Inuit community, were engaged throughout the entire research lifecycle: from the preparing and planning, design, conduct, interpretation, and dissemination of the work. Furthermore, our team is committed to strengths-based, collaborative research approaches that prioritise gender diversity throughout the research lifecycle [70]. The study we present builds on previous work to adapt shared decision making strategies with Indigenous people [17]. It emphasises the importance of a research governance model and processes that centre on Indigenous knowledges, priorities, and partnerships.

Conclusions

Guided by aajiiqatigiingniq, our interdisciplinary team co-produced a mixed-methods study to field-test a strategy called Not Deciding Alone to support health decision making. The study demonstrates that Inuit participants view Not Deciding Alone as an acceptable, useful, and relevant strategy for preparing and supporting people to engage with care systems and to participate in their health decision-making. The findings also suggest that research co-production has the potential to transform health systems to advance person-centred care. The research approach of our interdisciplinary team centred on local and Inuit knowledge systems, to develop practical, relevant resources that promote engagement with care systems. Our findings identify the need for further research to extend and enhance engagement of participants with Not Deciding Alone to support care that is welcoming and inclusive for all.

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Authorship statement

All co-authors of this paper meet the authorship criteria according to the latest guidelines of the International

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Appendix A:

Reporting on the five priority areas for research identified by Inuit Tapiriit Kanatami (ITK) in the National Inuit Strategy on Research, and research actions in our study (26).

Priority areas for research	Research actions in our study
1) Advance Inuit governance in research	Inuit leadership and governance are an integral feature of our study governance and conduct. We have structured the partnerships between researchers and Inuit community and organisations to support self-determination and Inuit sovereignty in the research conduct. Our work has been developed and conducted to address community priorities and to be founded on the Inuit Qaujimajatuqanigit principles and guidance of Inuit members.
2) Enhance the ethical conduct of research	The development and conduct of our research reflect the guidance of the National Inuit Strategy on Research [26] and other key ethics guidance documents for Indigenous health 35,36,38). We sought and received ethical approvals from community-based research ethics boards (Nunavut Research Institute, Clyde River Research Institute). The ethical conduct of our work is a process, and we are actively reflecting on how to better our work, to advance self-determination of Inuit in research. We aim for transparency in the conduct of our work.
3) Align funding with Inuit research priorities	The development and conduct of our study were in response to and in alignment with Inuit community and organisational priorities. Steering community members consist of Inuit community and members of service organisations, who set priorities and lead our work.
4) Ensure Inuit access, ownership, and control over data and information	We are working to advance self-determination and Inuit sovereignty throughout the research lifecycle. We prioritise Inuit community members and organisations as partners in the research; we ensure Inuit leadership and participation in the development of the study protocol, data collection, interpretation and dissemination; data is stored in mutually-agreed upon ways that protects privacy and confidentiality of participants; researcher-Inuit community and organisational partners behave in a collaborative manner (e.g. create opportunities for meetings, informed questions about study procedure, email and in-person contact for dialogue and agreements about how and who to disseminate knowledge in mutually-agreed upon ways).
5) Build capacity in Inuit Nunangat research	We strive to conduct our work in full partnership with members of Inuit Nunangat society as team members; we build relationships with institutions located in Inuit Nunangat and who serve members of Inuit Nunangat, for their research leadership in current and future steps of the research process.