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1. Executive Summary

Introduction The Not Deciding Alone project is a collaborative initiative led by Inuit organizations and academic health researchers dedicated to supporting Inuit self-determination in health and social care systems. We work to enhance opportunities for Inuit to participate in decisions about their care. The project operates in the Qikiqtani region of Nunavut and Ottawa, Ontario, with guidance from a Steering Committee that includes an Elder. Funded by the Canadian Institutes of Health Research, the initiative promotes "shared decision making" (SDM), ensuring that Inuit actively participate in care decisions, leading to improved health outcomes.

Key Achievements

Publications and Research

- Three peer-reviewed open-access papers:
 - *Experiences of Inuit in Canada who travel for cancer care* (2021) identified barriers to decision-making and proposed systemic improvements.
 - *Systematic Review: Interventions for Indigenous Peoples making health decisions* (2023) updated the conceptual framework for Indigenous SDM.
 - *A field-test of Not Deciding Alone to support Inuit with health decision making: Co-production of a mixed methods case study guided by aajiiqatigiingniq* (under review).

Knowledge Translation and Outreach

- *The Conversation Series*: Three widely read articles translating research into accessible formats.
- *Ontario Health Cancer Facts*: Highlighted Inuit healthcare challenges and improvement opportunities.
- *Casebook Paper* (2022): Documented best practices in collaboration and ethical research.
- Thirteen presentations, including at national and international conferences: for example, the Inuit Cancer Conference (Nunavut, 2023), International Shared Decision Making conference (ISDM 2024, Switzerland), and Arctic Congress (Norway, 2024).

Multi-Media and Educational Materials

- *Website (2022)*: Centralized resources and updates on the project.
- *Newsletter (2022-present)*: Regular project updates, available in English and Inuktitut.
- *Comic Series (2023)*: Developed with Design DePlume, featuring Inuit perspectives on SDM.
- *Podcast/Radio Show*: Bilingual broadcast on SDM in Inuit healthcare.
- *Workshops and Training*: Delivered SDM training to Community Health Representatives (CHRs) in Nunavut, fostering local healthcare capacity.
- *Video (2025)*: A video about our team presentation at the 18th International Congress on Circumpolar Health.

Lessons Learned The Not Deciding Alone project team has demonstrated adaptability and resilience in response to the significant challenges of moving the work forward in care systems across jurisdictions (Nunavut and Ontario), managing stresses on resources and people, and despite extraordinary events (a cyber-attack on health systems and the COVID-19 pandemic). Key factors contributing to the success of the project include team knowledge and skills, flexibility, participatory decision-making, collaboration across organizations, and a commitment to Inuit self-determination and sovereignty in research and care systems.

Next Steps The project aims to further advance SDM in Inuit communities by expanding partnerships, refining intervention strategies, and continuing knowledge translation efforts. Future priorities include additional research, policy advocacy, and integrating SDM practices into broader care frameworks.

2. Introduction: Who we are and what we have done

We are a team of Inuit-led and Inuit-specific organizations and academic researchers who are active in health and social care systems that provide services to communities in the Qikiqtani region of Nunavut and in Ottawa, Ontario. The Not Deciding Alone team consists of a Steering Committee, including an Elder, who guides the work, and researchers who operationalize research tasks. Our team works within an extensive (and expanding) network of organizations and people who have an interest in the work we do. We work to enhance opportunities for Inuit to participate in decisions about their care, in a research project we call “Not Deciding Alone.” Our team was funded by a grant from the Canadian Institutes of Health Research (#159483).

To learn more about our team, please visit www.notdecidingalone.com

The purpose of Not Deciding Alone is to work in a community-centred and -driven way to understand how to support Inuit self-determination in care systems. “Shared decision making” is when a person experiencing a health issue works together with healthcare providers, to make decisions about their health. Shared decision making upholds person- centered care and supports positive health outcomes. Our team, called the Not Deciding Alone team, has found that Inuit community and service provider partners find shared decision making to be appropriate and to have potential to be useful for Inuit and their healthcare providers.

Our team has been working to understand how shared decision making can support people in care systems.



3. Sharing our work: What we have done

Publications and Presentations

Research Papers in Academic Journals.

Our team has co-authored three peer-reviewed academic papers. These papers are all open access and freely available.

1. In April 2021, the Not Deciding Alone team published a paper, [Experiences of Inuit in Canada who travel from remote settings for cancer care and impacts on decision making](#) in BMC Health Services Research. The focus of the paper is on understanding the experiences of Inuit in Canada who travel from a remote to an urban setting for cancer care, and the impacts on their opportunities to participate in decisions during their journey to receive cancer care.

We used client and medical escort (“participant”) interviews to map the journey of Inuit in need of cancer care, and organized our findings in four themes:

1. It is hard to take part in decisions about getting health care
2. No one explains the decisions you will need to make
3. There is a duty to make decisions that support family and community; and
4. The lack of knowledge impacts opportunities to engage in decision making.

The findings of this study show that the journey to receive cancer care for Inuit consists of a series of connected events that we described as a “decision chain”. We propose there are key points along the decision chain where there are opportunities to build system capacity to prepare people to participate in decisions related to their cancer care.

We identified what could be done to support Inuit making health decisions. This includes a health system that is structured to support clients, medical escorts, their families and communities to collaborate with healthcare providers, and people need to have opportunities to participate in this collaboration and be prepared to engage in decision making along their journey to cancer care.

2. In September 2023, the Not Deciding Alone team and colleagues published our systematic review, [Systematic Review: Interventions for Indigenous Peoples making health decisions](#) in Archives of Public Health. The focus of our review was to identify interventions to support Indigenous Peoples making health decisions. The objectives were to synthesize evidence and identify factors that impact the use of shared decision making interventions.

The results of our review led to the update of our conceptual framework to explain important concepts for shared decision making with Indigenous Peoples:

1. Where shared decision making takes place impacts decision making opportunities;

2. Little is known about the characteristics of health care providers who engage in shared decision making processes;
3. Community is a partner in shared decision making; and,
4. The shared decision making process involves trust-building

The findings of our review include examples of research studies that demonstrate how to support Indigenous self-determination in research about shared decision making with a “nothing about us, without us” approach.

Our review also provides examples of how to develop and evaluate shared decision making with Indigenous Peoples, and extended thinking beyond Western-oriented conceptions of shared decision-making interventions. The findings demonstrate that it is possible to do high quality research to develop and evaluate shared decision-making interventions with potential to support Indigenous Peoples to participate in their health decisions.

3. In December 2024, our team completed a research paper, titled *A field-test of Not Deciding Alone to support Inuit with health decision making: Co-production of a mixed methods case study guided by aajiqatigiingniq*. It is currently under review for publication with the International Journal of Circumpolar Health.

The Conversation Series.

The work of the Not Deciding Alone team has been shared in a series of online articles published in The Conversation, to support knowledge translation by transforming our research into succinct, plain language, and accessible articles that share key ideas and learnings.

These articles supplement our academic publications and offer an alternative way of sharing what we’ve learned as a team in our work. Sharing our work through The Conversation is also a key component of our approach to integrated knowledge translation, to encourage and support the use of our team’s research in policy and practice.

Our three articles include:

- **An Inuit approach to cancer care promotes self-determination and reconciliation** (2019)
- **Inuit cancer patients often face difficult decisions without support far from home** (2021)
- **Person-centred health care means ensuring that affected communities are leaders and partners in research** (2024).

In total, our articles have received more than 21,000 reads on The Conversation website, with international uptake across 10 countries and 15 publishers who reprinted the articles.

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Ontario Health Cancer Facts.

Ontario Cancer Facts are short monthly fact sheets on cancer and cancer risk modifiers. They are intended for people whose work relates to cancer or other chronic diseases. Our study about the journey Inuit make to receive cancer care was featured in an Ontario Cancer Facts publication, and conveyed the following information:

- Inuit face many challenges when deciding whether to travel from a remote location to an urban centre for cancer care.
- Inuit must navigate complex social, historical and political systems when seeking treatment.
- There are many opportunities for improving cancer care for Inuit

Ontario Cancer Facts (2021): Not Deciding Alone Team. Inuit in remote settings face challenges in getting cancer care. September 2021. [Inuit in remote settings face challenges in getting cancer care | Cancer Care Ontario.https://www.cancercareontario.ca/en/cancer-facts/inuit-remote-settings-face-challenges-getting-cancer-care](https://www.cancercareontario.ca/en/cancer-facts/inuit-remote-settings-face-challenges-getting-cancer-care)

Casebook Paper.

In 2022, the Not Deciding Alone team was featured in the 5th volume of the Integrated Knowledge Translation Research Network's Casebook, "How We Work Together". Our paper *How we work together: Reflections from the Not Deciding Alone team* highlight who we are, how our journey started, and how our team attributes shared purpose, respect, trust, communication and collaboration to our continued success in working together. We also share the lessons we've learned about partnership in research, which include:

1. Collaborate, and stay open to new ways of knowing, being and doing;
2. Take a principled approach to research and have clarity on why it is we keep showing up; and,
3. Listen, reflect, innovate, and learn together.

Our casebook paper provided an opportunity to reflect on our partnerships within the Not Deciding Alone team and articulate the key practices which guide how we work together to achieve our common goals.

Conferences.

The Not Deciding Alone team has presented at 13 national and international conferences.

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

International Congress on Circumpolar Health, Nov.3-5, 2024, Halifax, Nova Scotia.

2. Not Deciding Alone Team. Interventions for Indigenous Peoples making health decisions: a systematic review. International Congress on Circumpolar Health, Nov.3-5, 2024, Halifax, Nova Scotia.
3. Not Deciding Alone Team, Jull J. Interventions for Indigenous Peoples making health decisions: a systematic review. International Shared Decision Making Conference (ISDM) 2024, Lausanne Switzerland, July 7-10, 2024.
4. Jull J, Fairman K, Not Deciding Alone Team. An integrated knowledge translation approach to develop and promote shared decision making by and with Inuit. Arctic Congress Bodø Norway, May 29-June 2, 2024.
5. Jull J, Nungnik R, Not Deciding Alone Team. What is and is not shared decision making. Inuit Cancer Conference. Tungasuvvingat Inuit, December 4, 2023.
6. Not Deciding Alone Team, Fairman K, Jull J. An integrated knowledge translation approach to develop and promote shared decision making by and with Inuit. 18th International Congress on Circumpolar Health, Yellowknife, Canada, June 19-22, 2024. Delayed to November 3-5, 2024 (accepted and cancelled due to wildfires).
7. Not Deciding Alone Team, Davidee I, Jull J. Not Deciding Alone: Our work and people. Nunavut Cancer Conference, May 4-6, 2023. Iqaluit, Nunavut
8. Jull J, Not Deciding Alone Team. Fostering the conduct of ethical and equitable research practices in the development of shared decision making strategies. NunaMed, Nuuk, Greenland, Sept29 – Oct 3, 2022.
9. Jull J, Not Deciding Alone Team. Inuit stories about the health care journey and impacts on shared decision making. International Shared Decision Making Conference, June 19-22, 2022. (Accepted and declined due to conflict with Inuit Studies Conference).
10. Jull J*, Clark W, Fletcher C, Lavoie J. Building evidence in academic research partnerships that is ethical, equitable, and used by and with Inuit who are based in urban settings: A roundtable discussion Inuit Studies Conference June 19-22, 2022: Auviksaqtut. *Not Deciding Alone team member presenters at the roundtable.
11. Jull J, Dorschner D, Jodouin G, Inuit Medical Interpreter Team, Graham I, Shepard M. A qualitative study to understand the experiences of Inuit who navigate the health care system from the Inuit Nunangat region of Nunavut to receive cancer care in an urban setting. Indigenous Health conference, May 21-23. Presentation and workshop rescheduled to

December 3-5 2020 due to COVID-19 <https://www.cpd.utoronto.ca/indigenoushealth/>

12. Jull J, Hizaka A, Jodouin G, Inuit Medical Interpreter Team members. Special Interest Group for ISDM 2019: Sharing what we have learned with “Not Deciding Alone”: The development of approaches to Shared Decision Making with Inuit community. International Shared Decision Making Conference 2019, Quebec City, Quebec, Canada, July 7-10, 2019.
13. Malaya Zehr, Janet Jull for the Not Deciding Alone Team. The experiences of Inuit in the health care setting who travel from the Inuit Nunangat region of Nunavut to receive cancer care in an urban setting. Ontario Health Clinical Council Meeting, May 28.

Multi-Media and Educational Products

Website.

In April of 2022, the Not Deciding Alone team launched our website, www.notdecidingalone.com. This website is the home of our project initiatives and products, in addition to providing a space for individuals, communities and organizations to learn more about our team and work. When developing our website, our team jointly determined the purpose of the website and the features important to fulfill our agreed-upon purpose: to share the news about our work widely.

Some of these features include information on how our team came together and background on team members; a blog that features regular updates and hosts products like our newsletter; a resource page where all our resources (and some partner resources) are available in a central location; the capacity to have a variety of different media (podcasts, videos, documents, photographs); and lastly, visuals (graphic and photography) that distinctly reflect Inuit culture in both the North and South regions of Canada.

Newsletter.

In April of 2022, the Not Deciding Alone team launched the first volume of our newsletter. The newsletter initiative was intended to build community connections to our project and communicate project updates to our network of partners and communities. It is possible to subscribe to our newsletter, from our website.

The newsletter, currently referred to as “Shared Decisions”, is released 2-4 times per year (typically seasonally) and includes topics such as project updates (e.g. new publications, website features or product releases), special features (e.g. reflections on a recent conference, or more in-depth details about a new product), and team spotlights, which is a dedicated space to acknowledge and share the work and successes of our project partners. The newsletter is released in both English and Inuktitut, to ensure that the newsletter is accessible to Inuit in the community who express interest in our work.

Our newsletters provide an opportunity to share project updates, invite engagement, and link the team's research activities to everyday work and activities in our communities. We will continue to use the newsletter as a project communication tool. All versions of the newsletter are available on our website.

Comics.

In January 2023, the team initiated a collaboration with Design DePlume (an Indigenous and women-owned creative agency) to develop a series of comic strips on shared decision making and how to have a say in health decisions. As a team, we discussed the importance of visual methods to share our work. Our team members are also interested in finding ways to introduce our work to youth and younger people that may be more likely to resonate with them. The comics were inspired by case study stories developed in partnership with the Not Deciding Alone Steering Committee and Community Health Representatives (CHRs) in Nunavut.

Our team wanted the stories to be true to the experiences many Inuit face in health systems. We also wanted to emphasize how health decisions often extend to consider views and values of the individual and their family and community. The team (that included CHRs) developed [the stories of Sarah and Simon](#).

Sarah's Story tells her experience with breast cancer and working with her doctor to try a new cancer treatment that will allow her to be closer to home with her family. Simon's Story tells his experience of figuring out how he will continue to support his family and community while also seeking care for an injury. Sarah and Simon demonstrate why it matters that people have a say in their health decisions, and how to engage in processes of shared decision making with healthcare providers, to do what is best for them, their families and their communities. The comics are available in both English and Inuktitut (Syllabics).

Podcast/Radio Show.

During discussions on how the team wanted to share our work, the interest in creating a radio show was brought forward. In many Inuit communities (both Northern and Urban), radio continues to be an important way of sharing information, learning, and connecting with one another – across all age groups. Similarly, podcasts have become one of the most popular ways of sharing information and building connections in today's society. Radio, or voice recording, very quickly became a new avenue in which we wanted to share our work with others.

With the support of the Steering Committee, CHRs and other project partners in Nunavut and Ontario, our team developed and agreed upon a script that introduces the Not Deciding Alone project, what shared decision making is, and how to do it (e.g. questions to consider ahead of a healthcare appointment). The radio show is based on our team's research findings, and our experiences in working with people and communities who have asked for ways to share the news

about Not Deciding Alone. The podcast is bilingual, presented in both English and Inuktitut and available on our website.

Workshop.

In November 2021 our team received an invitation to participate in the CHR's Annual General Training in Iqaluit, Nunavut. Our team worked with feedback and approvals from the CHRs to plan and prepare the workshops. Two team members provided in-person training in shared decision making and decision coaching to 11 CHRs the Qikiqtani Region in Nunavut. There was a second, online follow up workshop with 2 CHRs who could not participate in person. During the two one-day sessions, topics such as what is shared decision making and decision coaching, why shared decision making is important, and how to support shared decision making as a healthcare worker were covered. Additionally, the CHRs worked through case studies developed by the team to apply their knowledge to practice.

The workshops provided an opportunity to build capacity with CHRs and team together, to understand shared decision making and learn collaboratively about experiences supporting Inuit with health decisions in Nunavut, contributed greatly to future project initiatives. For example, with the direction and input from CHRs, the workshop case studies were further developed to become stories that would later evolve into comics.

In November 2022, there was a second workshop held at the CHR Annual General Training in Iqaluit, Nunavut. At this meeting the topic of shared decision making was revisited and discussed. In addition, a radio script was confirmed, and information about the study that was underway was shared.



Community Health Representatives sewing seal skin at our workshop in Iqaluit, November 2021

4. Lessons Learned

Over time, our team has grown, evolved and adapted to many changes.

Our team overcame challenges at the start of our work together. Due to events with significant impacts (a health systems' cyber-attack, followed by the pandemic) our team had to adjust and adapt plans for Not Deciding Alone, to accommodate the needs of our team members and society. In addition to the substantial challenges faced by people during the pandemic, most of the Not Deciding Alone team members provide direct care to communities. Our team members held many conversations about the best way forward with Not Deciding Alone, both for those participating in the work and for the wider community.

We recognize and share the facilitators of our success in how we work together in working towards our common goals. As a team, we value and make space for flexibility that allows us to meet the needs of the communities in which we work, adapt to external changes and events that impact our work (e.g. the Pandemic, organizational needs), and are innovative in our approaches as we learn. We have found ways to collaborate across organizations, time zones, geography and changing contexts. We collaborate in ways that foster participatory decision making, shared ownership, and active collaboration. Built on long-term relationships, our project creates space for collaboration to thrive, a shared vision, for different knowledges to co-exist in our work, and a continued commitment to doing good work in ways that support Inuit self-determination and sovereignty in research and society. Our work has been guided by the [National Inuit Strategy on Research](#), and we will continue to work in ways that strengthen the impact and effectiveness of research that is done by and with Inuit.

5. Next Steps

In the Not Deciding Alone project, we have learned what 'shared decision making' means to Inuit and have developed knowledge and resources to share that learning. We have also learned to work together and with others in our networks, across care systems, and in challenging situations. We will further advance the learning from Not Deciding Alone by expanding partnerships, refining intervention strategies, and continuing knowledge translation efforts. Future priorities include additional research, policy advocacy, and integrating SDM practices into broader care frameworks. We are engaging in consultations within care networks, with partners and communities, so that we can take next steps in our learning about Not Deciding Alone, together.

