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# SHARED DECISIONS

Not Deciding Alone Team Newsletter



### Who We Are

The Not Deciding Alone Team

We are a team of Inuit-led and Inuit-specific organizations and academic health researchers who are active in health care systems that provide services to communities in the Qikiqtaani region of Nunavut and in Ottawa, Ontario.

We have been working to enhance opportunities for Inuit to participate in decisions about their healthcare, in a research project we call "Not Deciding Alone." Not Deciding Alone aims to support Inuit self-determination [1] by utilizing a process called "shared decision making". Shared decision making is when a person experiencing a health issue works together with healthcare providers, to make decisions about their health [2,3]. Shared decision making upholds personcentred care and supports positive health outcomes [4].

"[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" IN THIS ISSUE

**WHO WE ARE** 

WHAT WE'VE DONE SO FAR

WHAT COMES NEXT

**HOW WE WORK TOGETHER** 



[1] Inuit Tapiriit Kanatami (ITK). (2018). National Inuit Research Strategy.

[2] Makoul, G. and Clayman, M. (2006). An integrative model of shared decision making in medical encounters. Patient Education and Counseling, v. 60(3).

[3] Coulter, A., and Collins, A. (2011). Making Shared Decision-Making a Reality. The King's Fund.

[4] Frosch D, Moulton B, Wexler R, Holmes-Rovner M, Volk R, Levin C (2011). Shared decision making in the United States: policy and implementation activity on multiple fronts. Journal of Evidence and Quality in Health Care: v. 105(4):

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## What We've Done So Far

Over the last few years our team has shared our work in papers and meeting with people.

Our recent paper shares stories about the journey that many Inuit face when traveling to Ottawa for their cancer care [5]. Inuit talked about how they need more information and opportunities to work with others on the journey to receive health care. We are using these stories to guide our work. **Check it out here.** 

[5] Jull et al. (2021) Experiences of Inuit in Canada who travel from remote settings for cancer care and impacts on decision making. BMC Health Services Research, <a href="https://doi.org/10.1186/s12913-021-06303-9">https://doi.org/10.1186/s12913-021-06303-9</a>

We have also shared our work in **The Conversation**: https://theconversation.com/inuit-cancer-patients-often-face-difficult-decisions-without-support-far-from-home-160586

https://theconversation.com/an-inuit-approach-to-cancer-care-promotes-self-determination-and-reconciliation-116900



### What Comes Next...

#### Website

Our team is currently developing a website to be a home for our project initiatives, resources, and a way to connect with community. Launching soon!

#### **Radio Show**

As a next step for the Not Deciding Alone project, we are working with some communities in Nunavut, to develop radio shows. These radio shows will share news about our work in shared decision making.

#### **New Grant**

We have received a new research grant from CIHR (Canadian Institutes of Health Research)! The goal of our study is to develop and test shared decision making (SDM) education for healthcare providers who work with Inuit. We will share our experiences and will be an example for other teams who want to work together to do a research study.



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# **How We Work Together**

Our team research partnerships and ways of working together are structured to ensure inclusion of people from Inuit-led and/or Inuit-specific organizations. Our team consists of a Steering Committee who guides the work, and academic researcher members. The role of the academic researcher members is to take action on the guidance from the Steering Committee. Our team uses a collaborative approach to research to share knowledge and work together for a common goal. We meet regularly, usually once a month, to connect, reflect and make decisions on how to move our work forward.

At a recent monthly meeting, we asked the team to share what they think helps our team work together:



#### ADDITIONAL RESOURCES

The Ottawa Hospital created navigational videos to support patients travelling from Nunavut to Ottawa:

Chemotherapy Navigation (Inuktitut) <a href="https://www.youtube.com/watch?v=iJnMiDYfC-8">https://www.youtube.com/watch?v=iJnMiDYfC-8</a>

Nunavut (Preparation) Navigation <a href="https://www.youtube.com/watch?v=Ny5t-ZIRGpM">https://www.youtube.com/watch?v=Ny5t-ZIRGpM</a>

We welcome comments and questions! If you'd like to learn more, please contact us:

**notdecidingalone@queensu.ca** | Janet Jull, Lead: **janet.jull@queensu.ca** Brittany Hesmer, Research Coordinator: **bh101@queensu.ca** 











