

Information Letter / Consent Form for Parents/Caregivers

March 22, 2024

Research Project: Understanding Care Coordination Across Primary Health Care Services in a Rural Northern British Columbia Setting for Young Children (aged 0 to 8) and their Families

Who is conducting the study?

Student Researcher: Erica Koopmans, School of Health Sciences, University of Northern British Columbia, Prince George, BC
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Co-Supervisor: Dr. Margo Greenwood, School of Education, University of Northern British Columbia, Prince George, BC Margo.Greenwood@unbc.ca

This research project is for the completion of a doctoral degree in Health Sciences and is part of a dissertation which will be publicly available when completed. No identifying information will be available in this publication.

Why are we doing this study?

In early childhood, children may receive services from healthcare providers, early childhood programs, and other community services to support healthy development. These services that support the health and wellbeing of individuals including health services, income, housing, and education supports are known as primary health care. A lack of coordination across different providers can create a system that is difficult to navigate. Social and economic factors can create challenges in accessing and receiving coordinated care. Social and economic factors can look different for every family, but examples include, limited social support, isolation, discrimination, financial challenges, food insecurity, limited access to transportation, low education, or exposure to violence. Families who are currently experiencing or have experienced social or economic factors may benefit from additional support to navigate services. Care coordination is an approach to service delivery which aims to improve patient and family experiences in navigating services. There has been little research about care coordination provided across primary health care services in rural communities in the early years of childhood. The aim of this research is to understand how care coordination is generated and constrained in a rural primary health care setting for young children (aged 0 to 8) and their families experiencing social and economic factors.

Why are you being asked to participate?

You are being asked to take part in this study because you are a parent or caregiver of a child aged 0 to 8 years old, you live in Fort St James or the surrounding area, and you identified that you have experienced social or economic factors (now or previously) that may have impacted your ability to access or receive coordinated care that could support your child and family. Participation in this study is entirely voluntary, and you do not have to take part.

What happens if you say “Yes, I want to be in the study”?

After contacting the student researcher, they will explain the study and you can ask questions. If you say “Yes, I want to participate” the following steps will happen:

- You will be invited to schedule an interview with the student researcher. The interview will be a conversation with questions asked by the student researcher. We can share the interview questions with you before the interview or they can be viewed online on the SEED website (www.seedbc.ca). The interview will ask about:
 - Current understanding of care coordination
 - Supports offered or received from providers in your community to coordinate care for your child’s health or wellbeing
 - Your experiences as a parent/caregiver with care coordination and how social and economic factors may impact care coordination
 - Demographic questions to help understand characteristics of the participants (such as your age, gender, self-identified race and/or ethnicity)
- The interview can take place over the telephone, videoconference using a secure version of Zoom, or in person in a space where you are comfortable. If you need help using technology, we will provide instructions and assistance.
- We will ask your permission to record the interview and take notes. The audio recording will be transcribed into a written document.
- The interview will take between 30 to 60 minutes.
- At any point during the interview if you do not want to answer a question you do not have to answer it and we can skip to the next question.
- You can choose to withdraw from this study at any time before the study results have been analyzed and published. If you choose to withdraw from the study during your interview or after it is completed, we will ask you what you would like to do with your data, which is the information you have shared. You can choose to have your answers removed and deleted permanently from the study, or with your consent allow the student researcher to use this information in the analysis.
- At the end of the interview, we will also ask:
 - If you would like to receive a copy of the transcript of the interview to review. If you choose to review your transcript you are allowed to clarify statements within your interview. A de-identified transcript or summary will be shared by email using the Sync.com platform which is compliant with Canadian data requirements, or by postal mail. If received by postal mail you will receive a prepaid return envelope to send your transcript with edits back to UNBC. You will have 2 weeks to provide feedback or comments. If you are unable to access via email or postal mail, the student researcher will arrange a time to review the transcript with you virtually using UNBC Zoom or in person if you would like.
 - If you are willing to be contacted for a follow-up interview if additional questions arise during the research study.

Is there any way that participating in this study could harm you?

We do not think there is anything in this study that could harm you but there are potential psychological or social risks of participating. Some of the questions we plan to ask in the interview may be distressing due to personal experiences of social or economic factors. To help reduce this risk, you will have access to the interview questions before the interview. If there are any questions you do not want to talk about, you can inform the interviewer when they ask at the beginning of the interview. During the interview, you do not have to answer any questions if you do not want to. If, at any point, you feel uncomfortable and wish to end your participation,

please tell the student researcher immediately, and your wishes will be respected. A list of health, wellness, and family supports is provided with the information letter, which you can reach out to if needed.

This research is taking place in a community with a small population. While we will not share that you have taken part and will de-identify all data provided, there is the potential social risk of being identified as a participant. You can choose to share that you took part in this project with others. If you choose to share, we recognize there is a potential risk of stigma that can occur related to social or economic difficulties.

What are the benefits of participating?

We do not think taking part in this study will help you directly. In the future, others may benefit from what we learn in this study to help improve care coordination across primary health care and community services in rural communities for families with young children.

How will your data and privacy be maintained?

Your privacy will be respected. Information that identifies who you are will not be released. By participating, you agree that anonymized quotes from your interview can be used in study reporting. You will not be named in any reports of the completed study. Participants will only be identified by a participant number in reports and presentations. No community service providers will be aware if you choose to take part in this study unless you choose to tell them yourself.

The audio recording from the interview will be transcribed by the student researcher or a transcriptionist who has signed a confidentiality and non-disclosure agreement. Once the transcription is complete, the audio files will be destroyed. All interview data and field notes will be identified by participant number only. Any identifiable information (your name, address, email) will be stored separately from the other data collected. All data will be stored as digital files in password-protected encrypted folders on UNBC OneDrive, which meets Canadian data security requirements. Paper copies of signed consent forms will be stored in a locked file cabinet. The data will only be accessible to the student researcher and supervisory committee. The information gathered from this study will be kept for five years. It will then be destroyed by deleting all digital files and shredding paper documents. At any point, you may choose to share your participation; we cannot account for this, and therefore, anonymity cannot be guaranteed.

Will I be paid for my time taking part in this research study?

We will offer you a \$25 honorarium in appreciation for your time taking part in an interview.

How will the results be used and shared?

The results of this study will be reported in a graduate dissertation. We will also share our findings in journal articles, in presentations at conferences, and with our partners in health care, social care, education and not-for-profit organizations. If you would like to receive a summary of study findings, please say this on your consent form with your contact information. The results will also be shared with the SEED network. SEED is an early childhood network (SEED, www.seedbc.ca) in northern BC whose work is guided by a group of individuals working across northern BC in roles that support children and families. This group include healthcare providers, educators, and staff from early years programs and community not for profits. It also includes parents with lived experience who work in family support roles who offer a parent/caregiver lens to the review.

Who do I contact with questions, concerns or complaints about the project?

If you have any questions, please contact the Student Researcher Erica Koopmans by email erica.koopmans@alumni.unbc.ca and/or or Co-Supervisor Dr. Caroline Sanders at 250-640-1012 or by email at caroline.sanders@unbc.ca. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the UNBC Office of Research at 250-960-6735 or by e-mail at reb@unbc.ca.

CONSENT

I have read or been described the information presented in the information letter about the project:

YES NO

I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested.

YES NO

I understand that if I agree to participate in this project, I may withdraw from the project at any time up until the report completion, with no consequences of any kind.

YES NO

I have been given a copy of this form.

YES NO

I agree to be recorded.

YES NO

I agree that strictly anonymized quotes from my interviews can be used in study reporting.

YES NO

I wish to receive a copy of the full transcript or a summary of my interview, once transcription is complete.

YES NO Please indicate which: _____

I am willing to be contacted for a follow up interview to review additional questions that may emerge as important as the research progresses.

YES NO

I agree that follow-up information can be sent to me at the following e-mail or postal address (for mailing hard copy of information): _____

YES NO

Signature (**or note of verbal consent**): _____

Name of Participant (Printed): _____

Date: _____

Supports and Resources for Parent/Caregiver(s)

	Resource	Description	Contact Information
Crisis Supports	310 Mental Health Support	Call 310Mental Health Support for emotional support, information, and resources specific to mental health	Call 310-6789
	BC Crisis Centre	Call if you are experiencing feelings of distress or despair, including thoughts of suicide.	Call 1-800-784-2433
	KUU-US Crisis Response Service	Provides culturally aware crisis support for Indigenous peoples in B.C.	Call 1-800-588-8717
Primary care, mental health, and cultural supports	Northern Health Virtual Primary & Community Care Clinic	Offers access to a family doctor or nurse practitioner, including for mental health needs. And if your employer offers an employee assistance program, we encourage you to reach out to those resources, as needed.	Call 1-844-645-7811
	First Nations Health Authority	Phone and online counselling, support programs, and treatment and healing centres are available virtually for Indigenous people across B.C.	https://www.fnha.ca/Documents/FNHA-COVID-19-Mental-Health-and-Cultural-Supports.pdf
	Virtual Doctor of the Day for First Nations	Virtual access to primary care and mental health supports for First Nations people and their family members who have limited or no access to doctors.	Call 1-855-344-3800 to book an appointment https://www.fnha.ca/what-we-do/ehealth/virtual-doctor-of-the-day
	Carrier Sekani Family Services	Provides holistic health and wellness services and many child and family services for Carrier and Sekani people in North Central BC	Fort St James Office Call 250-996-7640
	Métis Nation BC	Metis Family Connections Early Years program is available for families with Métis children birth to 8 years. The program is focused on helping families build a network of support that provides children with	https://www.mnbc.ca/work-programs/programs-services/metis-family-connections-early-years-birth-8-years

		opportunities for early learning and childhood development.	
Parent / caregiver peer support, navigation, and resources	Family Smart	Peer support, information, and navigation to help B.C. families and caregivers who are parenting children and youth facing mental health challenges.	Call 1-855-887-8004 Email: info@familysmart.ca
	Parent Support Society of BC	Parent Support Services works with Parents, Grandparents & Kinship Caregivers to provide emotional, educational, legal, & child-minding support. Services are free and offered in 7+ languages .	Call 1-877-345-9777 Email: office@parentsupportbc.ca https://www.parentsupportbc.ca/
	Family Support Institute	Supports families who have a family member with a disability. Volunteer resource parents in the north can connect with you via telephone, email, text, or online video meetings	Call 1-800-441-5403 Email: fsi@ffsibc.com https://familysupportbc.com/
	Health Link BC	For resources about pregnancy, parenting and healthy child development	https://www.healthlinkbc.ca/pregnancy-parenting