

Support Needs of Families Navigating Childhood Rheumatic Disease in Rural and Remote
Regions of Northern British Columbia

By

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We accept this Final Report as conforming
to the required standard

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Land Acknowledgement

This paper was written on the unceded, ancestral territories of the x^wməθk^wəyəm, Sḵwḵwú7mesh, and səlilwətał Nations. I humbly and gratefully acknowledge my privilege as an uninvited settler to live, learn, work, and play on these beautiful lands. Huy ch q'u.

Executive Summary

This executive summary summarizes the engaged leadership project (ELP) I conducted in partnership with Cassie and Friends Society (CF, n.d.), a Vancouver-based, nationally reaching, nonprofit organization whose vision is a pain-free future for children living with rheumatic disease. I present the purpose and context of the ELP, the research question and subquestions, an overview of relevant literature, the engaged approach and methods, the ELP findings, conclusions, and recommendations, as well as the implications of the research.

Purpose and Context

CF's organizational vision of a pain-free future for children is upheld by foundational pillars of research, education, connection, and support (CF, n.d.). In early 2021, British Columbia Children's Hospital's (BCCH) Pediatric Rheumatology team approached CF requesting support on a new initiative, the Northern Centre Project (NCP). The purpose of the NCP was to investigate and address the unique challenges faced by children, youth, and families in remote and rural areas in Northern British Columbia (BC) who are navigating a diagnosis of childhood rheumatic disease. In September 2021, CF's Director of Programs and Partnerships accompanied the BCCH Pediatric Rheumatology team during outreach clinic days in Prince George and Terrace, and connected with approximately fifty 50 families from the childhood rheumatic disease community. During these initial conversations, themes emerged relating to gaps in community support, limited mental health services, and a general lack of awareness of childhood rheumatic disease in the region. I conducted this ELP with the aim to advance this initial needs assessment and inform plans for future phases of the NCP.

Research Question and Subquestions

Beckhard and Harris (2009) encouraged leaders to consider an organization's current and future states to help clarify, understand, and manage the transition through change interventions (see also Burns, 2015). Thus, the purpose of this ELP was to investigate and identify the current and ideal future states of support in Northern BC for families navigating a childhood rheumatic disease diagnosis, from the parent caregiver perspective. As such, the following principal inquiry question guided the ELP: How might Cassie and Friends Society effectively support families impacted by childhood rheumatic disease who are living in Northern British Columbia? Taking an appreciative stance, I sought to find answers to the following subquestions:

1. What are the needs of families living in Northern BC impacted by childhood rheumatic disease?
2. How are needs currently being met, or partially met?
3. What needs are not currently being met?
4. What strategies could CF initiate to support children and families living in remote areas of Northern BC in ways that are meaningful to the community?

Relevant Literature

My literature review focused on two topics: accessing care in northern and rural communities and patient voice in healthcare. The literature provided insight into the existing conditions impacting rural and remote community access to healthcare services as well as the implications of including patient perspectives in the design and delivery of healthcare education and services.

Engaged Approach and Methods

This engaged, action-oriented research project was guided by principles of participatory action research. As the principal researcher I continuously and collaboratively engaged with key stakeholders through cyclical phases of inquiry and reflection to facilitate the cocreation of actionable recommendations for positive, meaningful change (Rowe et al., 2013). I engaged with research participants via two methods, an online survey followed by semistructured interviews.

Findings

I thematically analyzed the data from each engagement method, which led to the development of five key findings:

1. Navigating childhood rheumatic disease can be traumatic and overwhelming, evoking feelings of isolation, uncertainty, and grief.
2. Gaps in disease awareness exist across the Northern BC healthcare sector and the general public.
3. Connecting with other parents and children who have experience with childhood rheumatic disease is valuable.
4. Families impacted by childhood rheumatic disease in Northern BC often experience significant hurdles to access timely care.
5. Advocacy is a necessity when navigating life with childhood rheumatic disease.

Conclusions

Grounded by the themes noted in the literature and the findings, I developed the following four conclusions:

1. Mental health supports are needed for children and families affected by childhood rheumatic disease in Northern BC.

2. Northern BC families living with childhood rheumatic disease need accessible disease-specific information, resources, and supports.
3. Families in Northern BC spend significant time and resources travelling to receive equitable healthcare.
4. Families impacted by childhood rheumatic disease would benefit from a navigator to help them identify and access available resources and services.

Recommendations

Supported by the findings, conclusions, and relevant literature, I established the following four actionable recommendations for CF's consideration:

1. Elevate parent caregiver voices through inclusion in Continuing Medical Education session.
2. Invest in facilitating connections with and among the Northern BC childhood rheumatic disease community.
3. Develop a knowledge hub on the Cassie and Friends website specifically tailored to Northern BC community needs.
4. Consider recruitment of two parent navigators based in Northern BC to initiate welcome and connection into the community.

Implications

These recommendations align with ways CF might effectively support Northern BC families impacted by childhood rheumatic disease. CF is currently well positioned to strengthen connections with Northern BC healthcare providers and the Northern Health Authority, while enhancing collaborative relationships with the BCCH Pediatric Rheumatology team. Failure to move forward with the proposed recommendations may weaken the momentum gained through

this inquiry as well as the existing connections CF has made so far with key partners and stakeholders. It is my hope that the outcomes of this inquiry may be used to help CF effectively support families living in rural areas who are impacted by childhood rheumatic disease.

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“The life I touch for good or ill will touch another life, and in turn another, until who knows where the trembling stops or in what far place my touch will be felt.”

— Frederick Buechner

This project could not have happened without my ELP partner, Brittany Barnes, Director of Programs and Partnerships at Cassie and Friends; thank you for putting your trust and support in me.

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List of Abbreviations

AKP	Associated knowledge product
AOR	Action-oriented research
BC	British Columbia
BCCH	BC Children's Hospital
CF	Cassie and Friends Society
CME	Continuing Medical Education
ELP	engaged leadership project
GP	General practitioner
NCP	Northern Centre Project
PAR	Participatory action research

Section One: Focus and Framing

Cassie and Friends Society (CF) is a Vancouver-based, nationally reaching, nonprofit organization whose vision of a pain-free future for children is upheld by foundational pillars of research, education, connection, and support (CF, n.d.-b). General donations and fundraising events account for almost 70% of CF's annual revenue, while grants and foundations contribute the rest (CF, n.d.-c). CF's (n.d.-b) organizational mission, to improve supports, services, and community connections for youth and families navigating life with childhood rheumatic disease, is embedded in everything they do. From Victoria to Halifax, CF leads and facilitates run and walk events, parent support networks, youth mentorship training sessions, and an engagement program for future leaders, while continuously managing and producing content for their resource-rich website. CF is operated out of Vancouver by a small team of six individuals, governed by a board of directors whose 10 members are located across Canada, and further supported by several advisory committees. I partnered with the Director of Programs and Partnerships, Brittany Barnes, for my engaged leadership project (ELP), and I refer to her as my ELP partner, or the Director of Programs and Partnerships, throughout this report.

In early 2021, the division head of Pediatric Rheumatology at British Columbia Children's Hospital (BCCH) approached CF requesting support on a new initiative, the Northern Centre Project (NCP). The purpose of the NCP was to investigate and address the unique challenges faced by children, youth, and families navigating a childhood rheumatic disease diagnosis, living in rural and remote areas of Northern British Columbia (BC). The NCP currently consists of three phases. The first, which was CF's entry into the project, included an initial needs assessment conducted in September 2021. CF's Director of Programs and Partnerships accompanied the BCCH Pediatric Rheumatology team during outreach clinic days

in Prince George, and Terrace, and connected with approximately 50 families from the childhood rheumatic disease community. It was during these initial conversations that themes emerged relating to gaps in community support, limited mental health services, and a general lack of awareness of childhood rheumatic disease in the region. Phase 1 of the NCP concluded with a summary of initial findings and plans for CF to implement initiatives around increasing awareness of childhood rheumatic disease in the region and improving supports for families in Northern BC.

Phase 2 of the NCP began in the fall of 2023, as the BCCH Pediatric Rheumatology team began to develop a continuing medical education (CME) session for healthcare providers in Northern BC; this phase was initially planned to occur in March 2024 but was later rescheduled to September 2024, on recognizing signs and symptoms of childhood rheumatic disease. My ELP partner and I felt passionately about the inclusion of parent perspectives to this learning opportunity, sensing their input could enhance the overall impact of the project, potentially leading to improved supports and services for the childhood rheumatic disease community in the region. By developing a deeper understanding of what families experience when seeking and receiving a childhood rheumatic disease diagnosis in Northern BC, my ELP sought to advance the initial needs assessment conducted in Phase 1 and inform plans for Phase 2. In addition, this inquiry could potentially inform Phase 3 of the NCP, which may include such plans as a data-informed request to the Provincial Government of BC for increased supports, recruiting a regional parent ambassador, and creating an annual community connection event.

Beckhard and Harris (2009) encouraged the consideration of current and future states to help clarify, understand, and manage the transition through change interventions (see also Burns, 2015). Thus, the purpose of my ELP was to investigate and identify the current and ideal future

states of support in Northern BC for families navigating a childhood rheumatic disease diagnosis from the parent caregiver perspective.

When conducting this research, the following principal inquiry question guided my ELP: How might Cassie and Friends Society effectively support families impacted by childhood rheumatic disease who are living in Northern British Columbia? Taking an appreciative stance, I sought to find answers to the following subquestions:

1. What are the needs of families living in Northern BC impacted by childhood rheumatic disease?
2. How are needs currently being met, or partially met?
3. What needs are not currently being met?
4. What strategies could CF initiate to support children and families living in remote areas of Northern BC in ways that are meaningful to the community?

The scope of my ELP centred on developing a deeper understanding of the unique experiences that families located in remote regions of Northern BC faced when navigating a childhood rheumatic disease diagnosis. My ELP goal was to collaborate with participants and codesign recommendations for how CF might initiate positive change in ways that are meaningful to the community. I presented the information gathered to members of the CF leadership team to further inform NCP goals.

CF understands that those living in more remote regions face additional, unique challenges when attempting to access care than those in urban areas, and it is an organizational vision to improve community support for all families affected by childhood rheumatic disease (CF, n.d.-b). While NCP outcomes were a strategic priority for CF (B. Barnes, personal communication, June

27, 2023) ¹, a combination of competing priorities and limited organizational resources contributed to slower than desired progress on the project. As previously noted, in collaboration with my ELP partner, this inquiry presented an opportunity to explore the needs of families impacted by childhood rheumatic disease that could inform CF's strategic planning and decision making in relation to NCP goals.

I considered first-, second-, and third-person perspectives throughout the design and execution of my inquiry, as well as the interconnected systems that may be impacted by it. In the context of action-oriented research, Torbert and Taylor (2008) described the concepts of these discrete but connected viewpoints as “qualities of attention” (p. 249). A first-person perspective concerns itself with the subjective experience of the researcher (or, self), while the second-person perspective orients the researcher to consider how their inquiry and interactions may impact research partners and participants, and the third-person perspective brings into view how their inquiry may influence, impact, or be impacted by, broader organizational systems (Trullen & Torbert, 2016).

While my ELP was organizationally focused from a first-person practice perspective, leading every aspect of this project offered me the opportunity to stretch and grow my leadership skills. Throughout the inquiry process, I continually reflected upon my subjective reality, my emotions, and areas in which I sensed biases and barriers emerging. I applied Kolb's (1984) experiential learning cycle to help contextualize and frame my reflections, which uncovered personal growth opportunities that I was able to leverage. I felt this approach lent itself well to embedding a sense of quality

¹ All personal communications in this report are used with permission.

throughout my action-oriented research project, as doing so promoted accountability and validity during the process (Marshall, 2016).

This study may provide greater insights into the needs of youth and families who are living in Northern BC and navigating childhood rheumatic disease. Potential outcomes from a second-person perspective included parent participants developing a deeper sense of community, connection, and empowerment from sharing their insights and contributing toward positive change. For CF, this project is aligned with the organization's vision and commitment to the NCP (B. Barnes, personal communication, June 13, 2023). Finally, from a third-person perspective, this inquiry may provide new awareness that will inform regional healthcare providers and clinics, the BCCH Pediatric Rheumatology department, and broader provincial health authorities of the unique needs and challenges faced by members of the childhood rheumatic disease community in Northern BC. My ELP facilitated the inclusion of parent perspectives to enhance opportunities for a larger systems change effort (Senge, 2006; Stroh, 2015), which involved a multitude of interconnected organizations (see Appendix A).

This systems map conveys the interconnectivity between CF, members of the Northern BC community and the broader provincial healthcare system. CF operates as a hub of resources and support for children, youth, and families across Canada who have been impacted by childhood rheumatic disease. CF has an established relationship with the Pediatric Rheumatology team at BCCH, and it is through this connection that many newly diagnosed patients and family members in the province first learn about CF. In the context of this inquiry and the NCP, I took into consideration the broader interconnections of the provincial healthcare system. For example, connections exist between the Northern BC community and the Northern Health Authority by way of the outreach clinics operated by the BCCH Pediatric Rheumatology team. CF operates

within the context of the broader health system, which includes Provincial Health Services Authority and other BC health authorities. Outcomes from this engaged inquiry have the potential to impact each component of this systems map (see Appendix A).

My ELP partner and I have a shared passion for service, advocacy, and providing support to others. Finding it fundamental to my values and the provision of meaningful service, it was important to me that I sought, understood, and included the perspectives of those being served throughout this inquiry.

Section Two: Relevant Literature

To support the findings and next steps related to this study, it is essential to gain a contextual understanding of existing barriers that rural communities face when seeking healthcare information and services in their region. In this section, I provide a brief overview of healthcare accessibility in rural and remote communities. I also discuss how the inclusion of patient perspectives in healthcare related initiatives may help reshape the way providers are trained and healthcare is delivered.

Accessing Care in Northern and Rural Communities

The challenges that people living in rural and remote areas encounter when accessing healthcare services are multifaceted. While Canadians living in rural and remote communities are currently underserved by a low physician-to-population ratio, the recruitment and retention of healthcare providers in these areas remains a chronic issue (Booker, 2023; Johnston & McLean, 2023; Mandal & Phillips, 2022). Fewer options mean that rural residents frequently travel long distances to receive equitable healthcare while bearing the substantial costs associated with doing so (Booker, 2023; Johnston & McLean, 2023; Kornelsen et al., 2021).

Availability of Healthcare Providers

A recent report focusing on primary care needs in Canada found family medicine to be an area that fewer medical students are opting into (MAP Centre for Urban Health Solutions, 2024). This, alongside many physicians approaching retirement age, others leaving family practice after the pandemic, and bureaucratic barriers impacting the integration of medical providers trained internationally, contribute toward 22% of Canadian adults living without a regular primary care provider (MAP Centre for Urban Health Solutions, 2024). These challenges are well understood by rural and remote communities, as the recruitment and retention of healthcare providers in

remote regions remains an ongoing issue that contributes toward equitable healthcare access (Wilson et al., 2020). Unfortunately, as Mandal and Phillips (2022) reported, this lack of access results in worse health outcomes for rural residents when compared to urban communities.

Recruitment and retention of physicians and other healthcare providers in rural regions is a chronic issue (Booker, 2023; Johnston & McLean, 2023; LeBlanc et al., 2020; Wilson et al., 2020). Researchers have cited issues such as limited infrastructure, high rates of professional burnout, and lack of job opportunities for spouses as contributors toward low recruitment and retention of healthcare professionals in rural and remote communities (Johnston & McLean, 2023; LeBlanc et al., 2020).

Costs and Burdens of Travel

Kornelsen et al. (2021) stated, although hospital-to-hospital and emergency patient transport options have improved in rural areas, residents remain responsible for managing all travel arrangements and costs to receive care for nonurgent and chronic health conditions. The burdens associated with such travel include navigating inclement weather and treacherous road conditions and the responsibility of paying out of pocket for gas, buses, trains, ferries, and airline tickets. Rural residents must also manage the coordination and cost of overnight accommodation, often unpaid time away from work, and care for dependents (Booker, 2023; Johnston & McLean, 2023; Kornelsen et al., 2021). As Kornelsen et al. (2021) further determined, these out-of-pocket expenses amount to approximately \$2,044 CAD per person per condition, which are not covered by insurance, resulting in a “rural tax” that remote residents must bear due to inequitable access to care.

Further Implications

These conditions impact the health and well-being of rural Canadians in several ways. Kornelsen et al. (2021) discussed the compounding negative effects of travelling long distances to receive care. The authors cited feelings of anxiety and isolation from individuals who had to leave their home and cover long distances alone while sick and the financial expenses of such travel contributing further stress. Parents, particularly those with young children, also found the experience of being separated from their families to receive care far away to be challenging. Despite the financial and psychosocial implications on rural patients and the well-documented need for improved recruitment and retention of healthcare professionals in their communities, policy change has been slow to progress, while a pan-Canadian strategy remains absent (College of Family Physicians of Canada & Society of Rural Physicians of Canada, 2021; Wilson et al., 2020).

For further consideration, health and healthcare challenges in rural and remote communities are often considered in relation to urban communities and viewed through an urban lens. Such comparisons fail to recognize the diversity across rural communities. As LeBlanc et al. (2020) purported, addressing the complex needs of rural health requires an understanding of the unique characteristics of rural communities, noting that they “cannot be generalized from one community to the next” (p. 4). Furthermore, Lavergne and Kephart (2012) found research focusing on health disparities between urban and rural communities missed rich context relating to variances between rural communities. In other words, it may be reductive to compare urban and rural communities, or to broadly consider all rural communities the same as each other. The authors called for further work in recognizing the differences between rural communities to better understand their disparities in health. I contend the creation and implementation of

effective policy and programs for rural and remote communities relies upon the same consideration. Adopting a one-size-fits-all approach is insufficient, understanding the diverse challenges rural communities face when seeking healthcare services is a necessity for generating meaningful supports.

The subject of healthcare accessibility in rural and remote areas is pertinent to this study as it provides important context to the realities Northern BC families contend with when seeking care. The implications of limited access to healthcare are felt in the Northern BC childhood rheumatic disease community.

Patient Voice in Healthcare

Haigh and Hardy (2011) described storytelling as “the effort to communicate events using words (prose or poetry), images, and sounds” (p. 408) and argued in the healthcare context storytelling offers an opportunity for deeper connections to understanding and empathy between patients and healthcare providers. They also suggested patients’ healthcare-related stories are teeming with information that could reshape the way providers are trained and healthcare is delivered.

The benefits of connecting directly with patients to receive stories of their experiences with disease or interactions with the healthcare system are multifaceted. For example, at an individual level in the context of health education, when a patient’s experience is sought from trainers and students, a sense of satisfaction may be derived from the notion that sharing their experience may help someone else (Haigh & Hardy, 2011). In the context of transforming the health system toward people-centred care, the inclusion of patient-reported outcomes, experiences, and values is fundamental to care model design (de Bienassis et al., 2021; Haigh & Hardy, 2011), while patients’ stories help build compassionate and empathic care practices

(Agarwal et al., 2023). Interestingly, Kumagai (2009) suggested the purpose of initiatives such as the Family-Centered Experience, which connects medical students with volunteer patients, are “not [intended] to teach compassion or idealism” (p. 230) because these students are already brimming with these qualities. However, researchers argued empathic disconnect often occurs over time, as medical practitioners are trained to not get “too close” (Agarwal et al., 2023, p. 1962; see also Towle et al., 2016) to their patients.

Over the past two decades, the impetus within the healthcare system to seek patient voices has grown as services users bring a unique and valuable perspective of the system that providers cannot experience (Agarwal et al., 2023; Kumagai, 2009; Perfetto et al., 2017). Despite the genuine compassion and empathy providers have for their patients, “the physician’s perspective of the patient’s perspective is insufficient” (Agarwal et al., 2023, p. 1963), and thus it is the patient’s subjective voice that needs to be heard (Perfetto et al., 2017). Hoffmann et al., (2021) found patients’ perspectives contain valuable insights into how issues, both at the individual clinic level as well as broader health system infrastructure, may be addressed for better provider and user outcomes. Meanwhile, Lowe et al. (2021) also argued including patient perspectives in healthcare planning, delivery, and evaluation may lead to improved service provision. While both articles encouraged the inclusion of patient perspectives in health service reform, they recommended further research and evaluation into the efficacy of such partnerships (Hoffmann et al., 2021; Lowe et al., 2021).

The topic of including patients’ and caregivers’ voices in healthcare planning and delivery is relevant to this study because service users hold a wealth of experiential and cultural knowledge. For urban-based health systems organizations, seeking rural and remote community members’ perspectives is critically important for understanding the unique circumstances they

face when attempting to access healthcare services. Actively engaging and including these patients' and caregivers' perspectives is a necessity for the design and delivery of effective, accessible healthcare services.

Section Summary

In this section, I presented relevant literature topics related to accessing healthcare in rural and remote communities, alongside the utilization of patient perspectives in health education and delivery methods. In the next section, I engaged approach, ethical considerations, implementation, and knowledge translation for this ELP.

Section Three: Engaged Approach, Ethical Considerations, Implementation, and Knowledge Translation

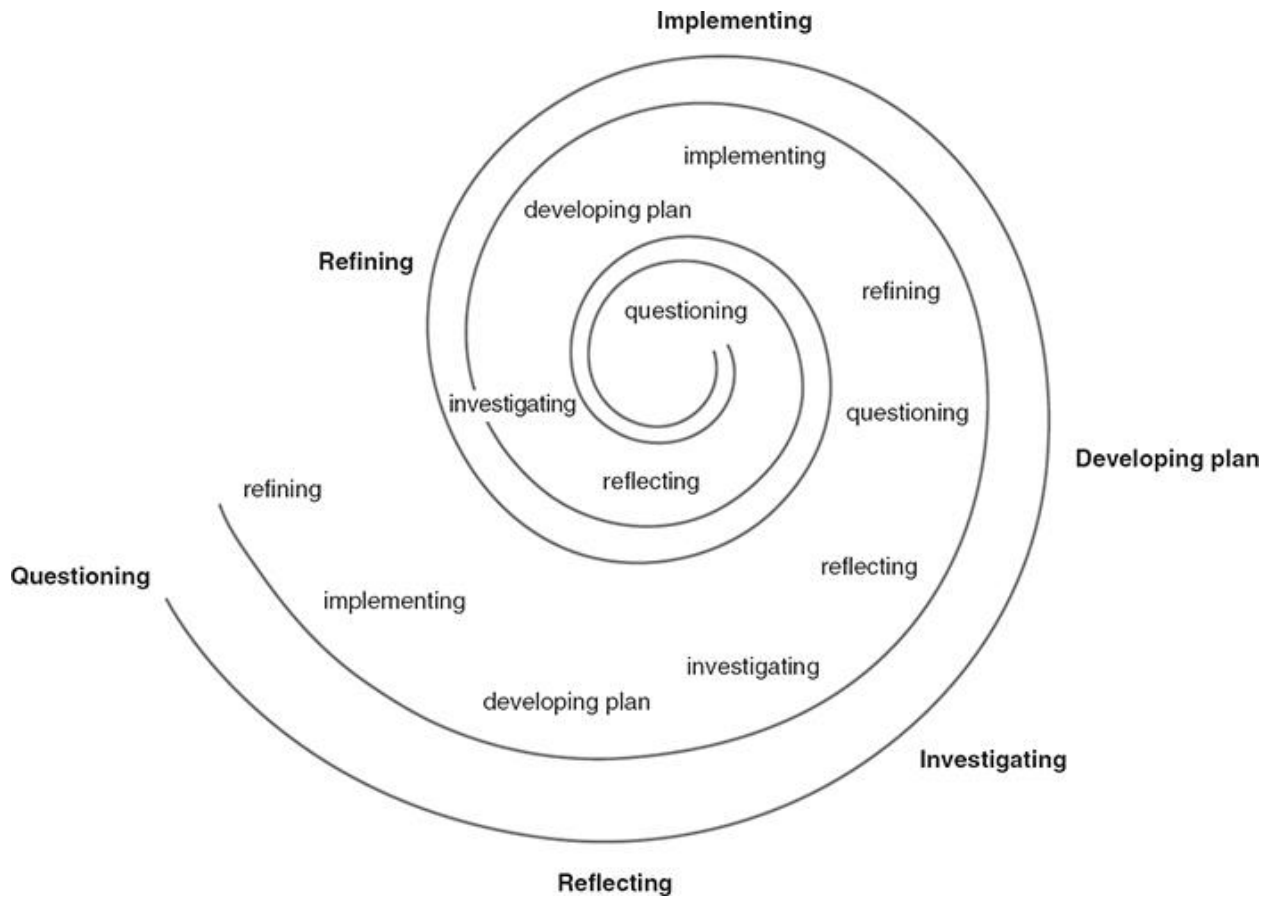
In this section, I outline the engagement methods used to conduct this research and the data analysis techniques used to identify themes that later serve as the foundation for findings, conclusions, and recommendations. I also detail how ethical considerations were managed throughout this ELP, and I conclude this section with information on how the knowledge gleaned from this inquiry might translate into action.

Engaged Approach

My ELP was an engaged, action-oriented research (AOR) project guided by principles of participatory action research (PAR). This means that I, as the principal researcher, continuously and collaboratively engaged with key stakeholders through cyclical phases of inquiry and reflection, to facilitate the cocreation of actionable recommendations for positive, meaningful change (Rowe et al., 2013). PAR is an inclusive approach to AOR, which, in the context of this ELP, began with the identification of an issue. I advanced an understanding of the issue by seeking and including the lived experiences of those impacted by it, which resulted in actionable solutions developed collaboratively with participants (Kuip, 2023). My ELP inquiry was informed by a shared concern regarding gaps in care for families facing childhood rheumatic disease in Northern BC. This aligned with the start of the PAR cycle of questioning, reflecting upon, and investigating the issue, followed by action plan development, implementation, and refinement (McIntyre, 2008). I designed my ELP inquiry to engage participants through the initial stages of the PAR cycle, and it started with questioning the issue, reflecting on it, investigating it, and developing an action plan (see Figure 2).

Figure 1

The Recursive Process of PAR



Note. Participatory Action Research, by A. McIntyre, 2008, Sage (<https://doi.org/10.4135/9781483385679>).

Implementation

Taking a PAR stance, I endeavoured to understand the perspectives and experiences of parents or guardians of children living with childhood rheumatic disease. I conducted two sequential engagement methods to collect data, an anonymous online survey, followed by semistructured interviews. The inclusion criteria for participants of this study were people over 19 years of age who were parents of, or guardians who care for, children with childhood rheumatic disease, and who live in the Northern Health Authority’s regional jurisdiction (Northern Health Authority, n.d.-a, n.d.-b; see Appendix B). I set the exclusion criteria for this

study to include friends of parents or guardians caring for a child with childhood rheumatic disease, anyone 18 years old or younger, and employees of CF.

Online Survey

On my behalf, CF sent a research information letter (see Appendix C) and invitation (see Appendix D) containing a link to the anonymous survey (see Appendix E) to potential participants. The survey remained open for 24 days, after which a total of nine anonymous responses were received along with two participants expressing interest in the second engagement method.

I chose the online survey method, with a selection of closed- and open-ended questions, due to its flexibility and general ease of use. As principal inquirer, the advantages of using the SurveyMonkey® (n.d.) online survey tool included a myriad of design options for me to choose from, raw data collation as a standard function, and results from completed surveys available immediately (Evans & Mathur, 2005). In consideration of reducing potential barriers to participation, online surveys are accessible from a multitude of devices, including personal computers and cellphones, and a self-paced approach may be taken when completing them. Furthermore, online surveys allow participants the option to withdraw at almost any time (Evans & Mathur, 2005; Slattery et al., 2011). I considered the potential disadvantages of this method, which included the perception of online surveys as junk mail, their impersonal nature, and possible variations in Internet and device accessibility for participants (Evans & Mathur, 2005).

Semistructured Interviews

I had originally planned to conduct a virtual focus group as my second engagement method. However, since only two survey respondents indicated interest in participating in the focus group, I conducted semistructured one-on-one interviews. I contacted the two interested

participants via email with a detailed invitation to participate in a semistructured interview (see Appendices F and G), along with the research information letter (see Appendix C) and consent form (see Appendix H). Participants returned their signed consent forms to me prior to the commencement of each interview. This included the spouse of one registered participant, who wished to join their semistructured interview, resulting in a total of three participants for the semistructured interview method. Interview questions were informed by the online survey findings as well as my inquiry subquestions, and I conducted each interview by following my semistructured interview method guide (see Appendix I). Each semistructured interview occurred virtually via Zoom® (n.d.). With permission from participants, I recorded the video and audio of each interview using the built-in audio transcription tool provided by Zoom® to transcribe each conversation.

I chose semistructured interviews as my contingent second method as it was important to me throughout this inquiry to listen to parents' voices. Advantages of conducting semistructured interviews via Zoom® (n.d.) included the opportunity to build rapport with each participant and the ability to witness and respond to visual cues (Alsaawi, 2014; McGrath et al., 2019). Furthermore, the semistructured format aided reflexiveness and reflection during each interview. As cocreators of the data, the interviewee and I, as the interviewer, actively engaged in the process, and a deeper exploration of questions and topics occurred as each interview progressed (McGrath et al., 2019). While the substantial amount of data produced by semistructured interviews may be viewed as a disadvantage (McGrath et al., 2019), I appreciated the richness of information that I was able to collect from this method.

In reflection, I feel the semistructured interview method benefited my inquiry. The focus group setting may have been too vulnerable and uncomfortable for some, possibly resulting in

participants not speaking up or feeling pressured to incongruently agree or disagree with others' feedback and comments (Breen, 2006; Leung & Savithiri, 2009). As principal inquirer, I found I was able to deepen my engagement with each participant throughout the interview process, reflexively responding as dialogue progressed. I would not have been able to engage to this same degree as a focus group facilitator, nor do I feel participants could have opened to the depths they did if they had been in the focus group environment.

Data Analysis

The process of data analysis began upon the closure of the survey. I downloaded the raw data from SurveyMonkey® (n.d.) into a Microsoft Excel spreadsheet and familiarized myself with the data as I formatted the document. I subsequently transferred the data to a Microsoft Word document for a clearer and more accessible view.

With an orientation to my inquiry subquestions, I began the process of thematic analysis by looking for similar patterns in participant responses and use of language to generate initial codes (Norwell et al., 2017). Given that I centred this inquiry around understanding the perspectives of parents of children with childhood rheumatic disease, I applied the process of in vivo coding, using the research participants' own words to generate codes (Saldaña & Omasta, 2021). I used visual workspace software, Miro® (n.d.), to populate a virtual whiteboard and used different coloured sticky notes to symbolize in vivo code type. I then organized the data into emerging themes.

I began to analyze the data collected from semistructured interviews by formatting the automatically generated audio transcription from Zoom® (n.d.). To verify the accuracy of each transcription, I visually scanned, edited, and formatted each transcription document with the respective audio-visual recording playing concurrently. Although time consuming, this task

provided further context to participant responses as it helped remind me of the emotion and emphasis evoked during each interview. Once I reviewed the transcript for accuracy, I used in vivo coding to highlight portions of the text most relevant to my inquiry. I then integrated data from the semistructured interviews with analyzed data from the survey, by incorporating in vivo codes from the interview transcripts onto the Miro® (n.d.) whiteboard.

To ensure trustworthiness, I continuously consulted with my inquiry team members and academic supervisor to check my processes and confirm the emerging themes. I shared the initial themes from the survey with each interviewee to gain greater insights and perspectives. Further rigour was included in this process as I offered each semistructured interview participant the opportunity to review their respective transcript. While they all declined to participate in member checking, each expressed interest in receiving the Executive Summary of this final report. Lastly, to add further reliability to the process, I conducted biweekly meetings with my ELP partner to share project updates and validate next steps.

Ethical Considerations

In conducting this inquiry, I complied with the core principles of the *Tri-Council Policy statement*: respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research et al., 2022). I discuss each of these core principles in the sections that follow.

Respect for Persons

I informed prospective participants about the study, its purpose, how data would be collected, analyzed, stored, and used, and highlighted throughout the inquiry that participation was voluntary. I emphasized the process of informed consent through the dissemination of the research information letter (see Appendix C) when inviting participants to each engagement method, and each semistructured interview participant received, reviewed, and signed a consent

form (see Appendix H). All participants in this inquiry were adults and their consent was freely given prior to the commencement of either engagement method.

Concern for Welfare

I recognized the questions being asked in this study (see Appendices E and I) may have been emotionally triggering for participants. To mitigate this risk, I included links to online wellness resources (see Appendix J) when I invited prospective participants to the online survey, and at each semistructured interview.

Justice

I ensured participants received fair and equitable treatment throughout this study with clear communication regarding their choice to ignore, or withdraw from, the inquiry without prejudice, and I provided clear research information to enable transparent, informed decision making (see Appendix C). To mitigate the risk of an imbalance of power between participants and I, the researcher, I maintained an orientation to learner and follower throughout this inquiry and understood participants as the subject matter experts of their own lives. As the principal investigator, not employed by or otherwise affiliated with CF, I did not encounter any overt power-over concerns between the participants and me.

Artificial Intelligence Transparency

In alignment with Royal Roads University (n.d.) guidelines, and with approval from my academic supervisor, I utilized generative artificial intelligence tools, specifically Otter.ai for Zoom, Zotero, and online search engines throughout this ELP process (see Appendix K).

Knowledge Translation

To translate knowledge into action, I created an infographic that illustrated the process, themes, learnings, and recommendations gleaned from this inquiry. The infographic was

disseminated to my organizational partner, CF, and to those who were invited to participate in the study (see Appendix L). I designed this associated knowledge product (AKP) in collaboration with my ELP partner, who recognized potential opportunities in projecting the learnings from this inquiry to a wider audience. My intention in developing the AKP was to introduce actionable engagement methods to advocates seeking to build supportive connections with the childhood rheumatic disease community living in other rural and remote communities in Canada.

To move from knowing to doing, it is helpful to acknowledge that taking action requires a degree of energy and enthusiasm (McIntyre, 2008). I emphasized this concept during a strategy meeting between my ELP partner, the CF programs officer, and I, to prepare for next steps. In this meeting we reviewed the current state and ideal state for families living with childhood rheumatic disease in Northern BC. We explored barriers to successful implementation of recommendations, risk mitigation strategies, and essential partnerships. Further, we discussed CF's capacity to continue leading this work and the resources required for successful implementation and sustainability to affect positive, meaningful change for the childhood rheumatic disease community in Northern BC.

Section Summary

In this section, I outlined the engagement methods I used to conduct this research and the data analysis techniques I applied to identify foundational themes for findings, conclusions, and recommendations later described in Section 4. I also explained how ethical considerations were managed throughout this ELP. I closed this section with a discussion of how knowledge gleaned from this inquiry might be translated into action.

Section Four: Findings, Conclusions, and Limitations

The purpose of my ELP was to investigate and identify the current and ideal future states of support in Northern BC for families navigating a childhood rheumatic disease diagnosis, from the parent caregiver perspective. In this section, I discuss the findings, conclusions and limitations of this ELP.

Findings

Through analyzing data gathered from online surveys and semistructured interviews, I sought to understand the needs of families living in Northern BC who are impacted by childhood rheumatic disease. The themes harvested from the data provide the foundation for the following findings.

1. Navigating childhood rheumatic disease can be traumatic and overwhelming, evoking feelings of isolation, uncertainty, and grief.
2. Gaps in disease awareness exist across the Northern BC healthcare sector and the general public.
3. Connecting with other parents and children who have experience with childhood rheumatic disease is valuable.
4. Families impacted by childhood rheumatic disease in Northern BC often experience significant hurdles to access timely care.
5. Advocacy is a necessity when navigating life with childhood rheumatic disease.

I explore these findings in more detail throughout this section and are further supported by direct quotations from participants. I have coded participant responses as follows: S1 through to S9 for online survey respondents and I1 through to I3 for semistructured interview participants.

Finding 1: Navigating Childhood Rheumatic Disease Can be Traumatic and Overwhelming, Evoking Feelings of Isolation, Uncertainty, and Grief

The journey families embark upon when seeking and obtaining a childhood rheumatic disease diagnosis is an emotional experience. Comments from 88% of survey participants ($n = 8$) reflected the emotional toll that seeking out and acquiring a childhood rheumatic disease diagnosis for their child takes. Several common experiences were evident among survey respondents. Parents experienced feelings of confusion and frustration due to overall lack of disease awareness. This often resulted in long waits to diagnosis due to multiple visits to healthcare providers before a referral to BCCH occurred. Then, once a diagnosis was confirmed, parents felt overwhelmed.

Journey to Diagnosis. When asked to describe the experience from first noticing symptoms to receiving diagnosis, several participants identified it as a long, confusing, and frustrating process. This was demonstrated in comments such as “Confusion, trips back and forth to see local doctors who thought it was an allergy” (S8), and “Frustrating. First saw a GP [general practitioner] who had said it was viral, [then] X-rays ordered from [another] GP a few months later which led to a diagnosis” (S9). The theme of frustration was evident from respondents who shared, “It was long as I had to keep going back to the doctor to push for answers” (S2), and “Long, explored a lot of unrelated – massage, chiro, nutrition, lots of blood work, repeat visits, no clues until a year later [when my child’s] ankle swelled right up” (S3). One respondent commented, “[The pediatrician] told me to come back in 6 months” (S5), while another indicated, “[Symptoms were] passed off as growing pains for a year” (S6).

Diagnosis Received. Parents’ experiences of isolation, uncertainty, and grief after receiving their child’s diagnosis surfaced as three common findings across the surveys and

interviews. On the survey, I asked participants what they wished others knew about their family's journey. Participants' responses reflected their experiences of isolation, with one respondent stating, "It was so much harder than it looked from the outside" (S3), and another noting, "People don't understand without experience" (S6). In response to additional supports that might have been helpful upon receiving their child's diagnosis, participants shared, "A group that we could do in person would have been helpful" (S2), "Other families to talk to" (S3), and "Connecting with other parents would have been nice" (S4). Participants also commented on the psychosocial impact the diagnosis had on their child, with one respondent stating, "My child has often felt quite different from other kids" (S2), and an interviewee noting, "There's no opportunity for [my child] to connect [with other kids with childhood rheumatic disease]" (I1). In relation to their geographical location, one participant shared, "Because of the size of community, [there is] nobody for our child to really relate with. You kind of become . . . an island" (I3).

When asked about barriers to support, uncertainty was prevalent in respondents' feedback, with comments such as "I didn't know a lot about [the disease] and didn't really know what I needed" (S4). When recalling the time of diagnosis, participants shared the following statements: "In the first few months there was just so much information thrown at me that I didn't quite understand" (I1), and "It's just chaos in the beginning—there's a lot of learning to do" (I2). The theme of uncertainty also surfaced in reflections from when diagnoses were newly received, with participants sharing, "What about their future?" (S4), and "Will they ever dance?" (I1).

Trauma and grief were prevalent threads, with 70% of study respondents ($n = 7$) sharing their experiences of not receiving clear answers from general practitioners (GPs), being sent

away multiple times, and in some cases resorting to emergency care and pushing for diagnostic tests. The following participants' comments highlighted parents' grief and trauma: "I felt depressed because my vision as a parent for my child changed; trying to stay positive and optimistic can be hard" (S4), and "To understand the trauma as a parent, to hold your kid while they're freaking out; trying to hold it all up at the same time and not fall apart myself" (I3).

Three survey respondents remarked upon childhood rheumatic disease diagnosis and mental health. One commented on the impact the disease has had on their child's mental health (S2), another advocated for mental health awareness for parents and children (S4), and one commented on the lack of available mental health supports for families (S8). One semistructured interview participant noted access to mental health support is a huge barrier in Northern BC (I1). Lastly, the topic of marriage counselling arose in the study, with one interview participant remarking upon it as a potentially beneficial resource to guide parents on how to best support each other through the chaos and trauma of navigating their child's diagnosis (I3). Similarly, in response to the question, "What do you wish others knew about your family's childhood rheumatic disease journey?" one survey respondent commented, "Honestly marriage counselling to help couples navigate care of a child with chronic illness - it's very hard on families, siblings, etc." (S3).

In the context of postdiagnosis, parents expressed appreciation toward CF and BCCH's Pediatric Rheumatology team. In response to the question relating to supports found most helpful since diagnosis, participants shared, "Cassie and Friends and online groups were the most helpful" (S6), "Cassie and friends connected me to other parents and offers education webinars for parents, and kids to attend" (S4), "The doctors and nurses [at BCCH] have been amazing in their willingness to answer questions and travel for clinics" (S2), "Children's Hospital doctors"

(S8), and “[the] team at BC Children’s Hospital” (S9). One participant expressed gratitude for their primary care team that responded quickly: “Our local family doctor and pediatrician at the time were both exceptional. Without them going above and beyond their expected duties, we would have felt very alone” (S7).

Finding 2: Gaps in Disease Awareness Exist Across the Northern BC Healthcare Sector and the General Public

The theme of gaps in disease awareness was evident in the data, with 70% of all study participants ($n = 7$) sharing experiences of their child’s symptoms being overlooked or attributed to childhood by primary care providers. Parents reported needing to make multiple visits to their GPs and, in some cases, resorting to emergency room care for diagnosis and referral to BCCH’s Pediatric Rheumatology team. Participants shared the following comments: “I had to keep going back to the doctor to push for answers” (S2), “[we] insisted it be looked into as the pediatrician still wasn’t convinced” (S5), “It was never on any doctor’s radar that we saw. This included our family doctor, pediatrician, and multiple [emergency room] and walk-in clinic visits” (S6), and “I had to fight to get the diagnosis—it wasn’t easy” (I2). One participant expanded upon their own lack of awareness, pointing to its impact on their overall preparedness:

I honestly didn’t even know childhood rheumatic diseases existed before our child’s diagnosis, and neither did the rest of my family. General awareness for the public would probably be helpful for original diagnosis and then being semi-prepared (ha ha) for all that came after diagnosis. (S7)

Further, lack of disease awareness might contribute toward a sense of isolation, as one participant noted,

You stop sharing with other people because you get told so many stupid things, and where you get told you're doing things wrong by people who have no idea what you're going through. I think that aspect of it is also isolating that you just stop talking about it, because it just gets hurtful, it gets frustrating. (I2)

Evidence of more positive experiences came from two participants who each reported their child had received their diagnosis relatively quickly. One participant noted, "Our primary doctor was fast to act and send [a] referral to [BC Children's Hospital]" (S1) while another stated,

I feel like I was extremely lucky that my family doctor recognized signs of a potential auto-immune issue and immediately reached out to our local pediatrician. I also feel very lucky that that pediatrician also recognized the signs and contacted BCCH immediately. (S7)

Finding 3: Connecting With Other Parents and Children Who Have Experience With Childhood Rheumatic Disease is Valuable

Interview participants cited the Prince George Family Day event hosted by CF in 2021 as valuable. This gathering provided an opportunity for families to share their experiences with childhood rheumatic disease, while the information seminars hosted by the BCCH Pediatric Rheumatology healthcare team enabled families to learn and connect.

In identifying most helpful supports, 50% of study participants ($n = 5$) affirmed connecting with other parents and families was helpful following their child's diagnosis. When asked what made them feel most supported since their child's diagnosis, respondents shared the following comments: "Cassie and Friends connected me to other parents" (S4), "Cassie and Friends and online groups were the most helpful" (S6), and "other families to talk to" (S3). Then,

when reflecting on what additional supports might have been helpful, other participants shared, “I remember at the beginning, I was wishing I had the contact information of other people who might have been through the same thing as me” (S7), and “a group that we could do in person would have been helpful” (S2).

While survey respondents and interviewees identified connecting with other parents and families was beneficial, this should be interpreted with caution due to the small numbers of participants in this ELP. For example, one participant shared,

I wouldn't want to get up and share my story. I don't want to share my story with people, because I feel like I would be rubbing it in people's faces that are, you know, [others] that are still struggling. (I1)

Therefore, while one parent or family member may find connection in sharing their story with others, another may experience a sense of disconnect.

Finding 4: Families Impacted by Childhood Rheumatic Disease in Northern BC Often Experience Significant Hurdles to Access Timely Care

Obtaining a childhood rheumatic disease diagnosis in Northern BC often requires multiple visits to primary care providers, multiple diagnostic testing, and multiple referrals. Barriers to receiving timely, ongoing care included difficulty finding a GP, lack of disease and symptom diagnosis, treacherous weather and road conditions, and limited specialist services. On the survey, I asked participants to reflect on hurdles that may have prevented them from receiving the types of support they needed after receiving their child's diagnosis. In response, one participant stated, “Distance. Geographically the north is spread out and winter months can be treacherous for driving” (S4). Similarly, another respondent noted,

Being able to see specialists in person if needed. We have had to send photos of issues and have phone calls, which is a great option but isn't the same quality of care as being able to see someone and have them able to do an exam for proper results. (S6)

Another participant acknowledged the difficulties that families in more remote regions of Northern BC might face when accessing care: "I also think about how hard this would be if we lived more remotely, what a lot of time it would take away from work, life, etc., to travel to appointments" (S7).

Finding 5: Advocacy is a Necessity When Navigating Life With Childhood Rheumatic Disease

Advocacy was a prevalent theme throughout both engagement methods, as 80% of study participants ($n = 8$) either described examples of parental advocacy on their journey to diagnosis or recommended parental advocacy to others who are seeking diagnosis. One participant provided a specific example of their parental advocacy and the impact it had, stating, "The only reason we received a diagnosis was that I showed up to emergency and demanded testing" (S6). This theme surfaced often in participant responses, with respondents stating, "Always advocate for your child and push for answers" (S1), "Push for answers if your gut tells you something isn't quite right" (S2), "Keep advocating for your child, if your doctor is not receptive take your child to someone else for assessment" (S4), and "Insist on it being looked into like we did and ask for resources to learn about it" (S5). Furthermore, an interviewee shared an example of self-advocacy for children impacted by childhood rheumatic disease, noting, "It is important to let the kids advocate for themselves, you know, [speaking up]: "No, I can't. That hurts" (I1).

Conclusions

In this study, I explored the principal inquiry question: How might Cassie and Friends Society effectively support families impacted by childhood rheumatic disease who are living in

Northern British Columbia? My inquiry subquestions informed the questions asked in the online survey (Appendix E), which I then used as core questions during in the semistructured interviews (Appendix I):

1. What are the needs of families living in Northern British Columbia impacted by childhood rheumatic disease?
2. How are needs currently being met, or partially met?
3. What needs are not currently being met?
4. What strategies could CF initiate to support children and families living in remote areas of Northern BC in ways that are meaningful to the community?

In this section, I outline the conclusions based on the study's findings. These four conclusions are presented with supportive literature presented in Section 2:

1. Mental health supports are needed for children and families affected by childhood rheumatic disease in Northern BC.
2. Northern BC families living with childhood rheumatic disease need accessible disease-specific information, resources, and supports.
3. Families in Northern BC spend significant time and resources travelling to receive equitable healthcare.
4. Families impacted by childhood rheumatic disease would benefit from a navigator to help them identify and access available resources and services.

Conclusion 1: Mental Health Supports are Needed for Children and Families Affected by Childhood Rheumatic Disease in Northern BC

This conclusion was informed by the sense of isolation, uncertainty, and grief felt by families navigating childhood rheumatic disease. In discussing the impact of a childhood

rheumatic disease diagnosis on families, Rapoff et al. (2017) commented, “Parents of children with active arthritis report worse quality of life regarding daily activities, poorer cognitive function, and increased emotional distress” (p. 342), and siblings are negatively impacted by emotional distress and a sense of vicarious adversity.

Rural and remote communities in Canada experience gaps in mental health services. Compared to their urban counterparts, rural and remote communities in Canada are less likely to self-report mental health issues while facing larger obstacles to accessing needed supports (Masse et al., 2023). While the provision of conventional mental health services might be difficult for rural communities to access, alternatives such as telehealth, virtual care, and community-based approaches to mental healthcare may be options worthy of further exploration (Mahling et al., 2020; Masse et al., 2023; MAP Centre for Urban Health Solutions, 2024). By investigating ways to increase awareness of available and alternative mental health program options in Northern BC, CF can support the community by potentially reducing barriers and stigma related to seeking mental health care.

Conclusion 2: Northern BC Families Living With Childhood Rheumatic Disease Need Accessible Disease-Specific Information, Resources, and Supports

This conclusion was informed by findings related to gaps in disease awareness and navigating the system, which highlights the need for information. According to international guidelines, patients with suspected childhood rheumatic disease should be seen by a pediatric rheumatologist within 4 weeks of referral (Chausset et al., 2023). However, a lack of disease symptom recognition exists among Canadian primary and community healthcare providers, which may detrimentally impact the referral process and the overall patient prognosis (Shiff et al., 2009; Shiff et al., 2010). Not only do delays in diagnosis pose a significant risk to patient

health outcomes, trust between families and the healthcare providers may also be negatively impacted (Chausset et al., 2023; Shiff et al., 2010). Many participants of this study shared experiences of their child's symptoms being dismissed by their GP, of being sent away only to return when things either did not improve or had escalated with their child, to then eventually seeking urgent or emergency care for diagnosis. To expedite diagnoses and treatment for new suspected patients, it is crucial to equip Northern BC healthcare providers with knowledge about the signs and symptoms of childhood rheumatic disease as well as the referral pathway.

The study findings also highlighted gaps in awareness regarding helpful resources for Northern BC families. Participants reported it would have been beneficial to have known about supports such as Hope Air (n.d.), the Northern Health Connections (n.d.) bus, and Ronald McDonald House (n.d.) at the time of receiving their child's diagnosis.

By sharing knowledge related to disease signs and symptoms between pediatric rheumatology experts and Northern BC healthcare providers, time to referral and diagnosis may be reduced for new patients. Improving access to information regarding supports and services available to Northern BC families faced with the financial burdens of travelling out of town to receive specialist services may help promote a sense of relief and well-being.

Conclusion 3: Families in Northern BC Spend Significant Time and Resources Travelling to Receive Equitable Healthcare

This conclusion was informed by findings surrounding the challenges parents encountered when seeking care for their child's rheumatic disease. Rural and remote regions suffer from a lack of healthcare professionals, leaving communities without equitable access to care services (Mahling et al., 2020; Wilson et al., 2020). Being served by only 8% of practising physicians in Canada, people living in rural regions are disproportionately affected by the low

physician-to-population ratio (Booker, 2023; Fleming & Sinnott, 2018). Participants noted distance to services and treacherous travel conditions as unique hurdles when seeking specialist care. While 66% of survey respondents ($n = 6$) reported the location of their child's primary care provider as less than 10 km away, one family travels between 25–50 km and another between 50–100 km to access primary care. For specialist appointments, four survey respondents reported travelling more than 200 km to receive care. The frequency of specialist appointments varied widely between respondents, one noting this degree of travel happens once annually, while another reported making the journey monthly. Financial costs associated with these travel requirements include transportation, overnight accommodation, and time away from work, with one appointment in Vancouver involving a minimum of 3 days and 2 nights away from home in addition to 2 full days of driving. With fewer options available, Northern BC populations spend more time when travelling to urban centres to receive specialist care, with an average of \$2,044 CAD in out-of-pocket expenses (Kornelsen et al., 2021).

Conclusion 4: Families Impacted by Childhood Rheumatic Disease Would Benefit From a Navigator to Help Them Identify and Access Available Resources and Services

This conclusion was informed by findings related to the overwhelm that comes with receiving a childhood rheumatic disease diagnosis and the value of community connections with others who understand the experience. As previously reported, the journey to obtaining a childhood rheumatic disease diagnosis in Northern BC can be lengthy and difficult. Then, at the point of diagnosis, some participants shared their feelings of overwhelm and uncertainty, wishing they had been able to connect with others who understood what they were going through, noting that engaging with other families after diagnosis was a helpful support. Overall, it appeared that obtaining information about childhood rheumatic disease was an endeavour. Furthermore, one

participant noted, “There’s a lot of misinformation on internet” (S9), which raised an important consideration regarding the trustworthiness of information sources. Indeed, Stinson et al. (2012) affirmed many parents found the process of searching for information on childhood rheumatic disease to be overwhelming, while also pondering its reliability.

According to Carter et al. (2018), a navigator “can be a health care professional, or a non-professional (lay person) who is trained to perform specific activities related to system navigation functions” (p. 2). Based on family needs, a navigator could share helpful, trustworthy information, aid access to appropriate resources and supports, facilitate introductions, and offer guidance to new families joining the childhood rheumatic disease community. Overall, navigating a life with a new diagnosis of chronic rheumatic disease is multifaceted and families in Northern BC face additional challenges that might complicate their ability to adjust and cope. By considering the benefits of connecting newly diagnosed families with a navigator, a parent with lived experience who understands Northern BC culture may make their journey with childhood rheumatic disease easier to manage.

Limitations

This research project was limited by the timing of the study and the number of participants. With respect to the timing, I sent invitations to potential participants and began data collection during the holiday season (December 2023–January 2024). This may have limited the number of participants. Out of 28 families invited to participate, nine individuals completed the online survey, and two volunteered to take part in semistructured interviews. One of the semistructured interview participants was joined by their spouse, who fully engaged in the dialogue. As a result, the findings and recommendations are based on the lived experiences of 10

people. With this limited number, it would be useful for CF to continue to include as many perspectives of the Northern BC childhood rheumatic disease community as possible.

Section Summary

In this section, I discussed the findings resulting from the data collected and shared conclusions supported by the findings and related literature. I also summarized the limitations of this study and recommended continued engagement with the Northern BC childhood community. I outline related recommendations and implications in the next section.

Section Five: Next Steps: Recommendations, Implications, and Associated Knowledge

In this section, I present the inquiry recommendations. I also discuss the implications of these recommendations as well as the associated knowledge product, an infographic, which I presented to CF prior to completing this project.

Recommendations

I outline four actionable recommendations for CF to consider as they further NCP initiatives. These recommendations are grounded in the findings, conclusions, and literature reviewed in this study in response to the principal inquiry question: How might Cassie and Friends Society effectively support families impacted by childhood rheumatic disease who are living in Northern BC?

1. Elevate parent caregiver voices through inclusion in Continuing Medical Education session.
2. Invest in facilitating connections with and among the Northern BC childhood rheumatic disease community.
3. Develop a knowledge hub on the Cassie and Friends website specifically tailored to Northern BC community needs.
4. Consider recruitment of two parent navigators based in Northern BC to initiate welcome and connection into the community.

Recommendation 1: Elevate Parent Caregiver Voices Through Inclusion in Continuing Medical Education Session

According to Haigh and Hardy (2011), “There is a growing realization that patients and service users are a rich source of healthcare-related stories that can affect, change and benefit clinical practice” (p. 411). As such, I recommend CF work with the BCCH Pediatric

Rheumatology team to include parent perspectives in the design and delivery of CME sessions related to childhood rheumatic disease for healthcare providers in Northern BC. This recommendation is supported by the findings in this inquiry and the environmental scan conducted in 2021 by CF (B. Barnes, personal communication, February 6, 2024).

The motivation within the healthcare system to seek patient voices has grown in recent years as services users hold unique perspectives that healthcare providers cannot experience (Agarwal et al., 2023; Kumagai, 2009; Perfetto et al., 2017). The inclusion of parent voices in the CME enhances the transfer of knowledge between BCCH and healthcare providers in Northern BC by adding richer context to the journey families embark upon when seeking a childhood rheumatic disease diagnosis. Patients' healthcare related stories are abundant with information that could reshape the way providers are trained and healthcare is delivered (Haigh & Hardy, 2011). Therefore, the inclusion of parent perspective in the CME may positively impact the amount of time, energy, and resources families in the region spend seeking a childhood rheumatic disease diagnosis in the future.

Recommendation 2: Invest in Facilitating Connections With and Among the Northern BC Childhood Rheumatic Disease Community

To understand a community is to recognize how its members are connected (Gloger, n.d.). This recommendation is focused on the opportunity for CF to lead sustainable programs that strengthen connections with the Northern BC childhood rheumatic disease community. Examples of ways to build connections include (a) hosting an annual Family Day in Northern BC, (b) leading alternative events to raise funds and disease awareness, and (c) developing a long-term strategy for sustainable engagement between CF and the Northern BC community.

Family Day is CF's flagship event that brings families impacted by childhood rheumatic disease together and connects them with healthcare specialists to exchange information (CF, n.d.-a). These annual conferences are held in different locations across Canada, and in 2022 CF hosted a Family Day event in Northern BC that coincided with a BCCH Pediatric Rheumatology outreach clinic (B. Barnes, personal communication, March 4, 2024). While the sample for this inquiry was small, several participants remarked on the value of Family Day in terms of learning and connection with other families living with childhood rheumatic disease.

While CF provides many fundraising suggestions on their website, there is an opportunity to build connections through leading initiatives that include the Northern BC culture while raising funds and awareness of childhood rheumatic disease. Some inquiry participants commented on the challenges of joining fundraising events that are geared toward urban communities. An example of an inclusive fundraising opportunity might be for CF to host a virtual auction that includes prizes from Northern BC vendors and creators.

As Mahling et al. (2020) emphasized, continued community engagement is essential when creating rural-centred programs and policies. While considering the purpose of the NCP, "to create a vibrant, connected, and well-supported childhood rheumatic disease community in Northern BC" (CF, n.d.-e, para. 3), it is important for CF to assess how the organization can connect with the Northern BC community in a sustainable way.

Recommendation 3: Develop a Knowledge Hub on the Cassie and Friends Website Specifically Tailored to Northern BC Community Needs

While the CF (n.d.-d) website contains a wealth of information regarding childhood rheumatic disease, there may be an opportunity to provide resources and information specific to the needs of Northern BC families. Research participants described experiences of overwhelm

and uncertainty when seeking knowledge and resources following their child's diagnosis, particularly information related to their regional location. A Northern BC knowledge hub could provide information and links to out-of-town travel and accommodation such as Hope Air (n.d.) and Ronald McDonald House (n.d.). A dedicated space listing accessible mental health supports in the northern region would also be a valuable resource. Current events such as community events and fundraising activities in the region could also be posted on the hub. While they may share common characteristics, the needs of rural and remote populations vary by community (Mahling et al., 2020); therefore, I recommend continued engagement with users to ensure content is relevant. A knowledge hub collaboratively developed with families in Northern BC will offer an opportunity for CF to facilitate access to valuable and trustworthy information and demonstrates a growing understanding of their unique needs.

Recommendation 4: Consider Recruitment of Two Parent Navigators Based in Northern BC to Initiate Welcome and Connection into the Community

In this inquiry, participants suggested parent navigators be hired to assist families managing a new childhood rheumatic disease diagnosis in Northern BC. Research participants reported feeling overwhelmed and isolated during the journey to diagnosis and noted it would have been helpful to connect with other parents for support.

CF could consider several options for the parent navigator role. For example, Carter et al. (2018) described layperson navigators as nonprofessionals trained to facilitate access to relevant healthcare services, working to improve the overall wellness of those seeking support. A family support specialist is a professional who “works with families to provide empathy, understanding, to make the parent feel more comfortable, to describe their personal experience when relevant and appropriate, and to provide knowledge to assist the family in caring for themselves and their

child” (Wisdom et al., 2014, p. 26). In addition, peer paraprofessionals are supportive individuals with “relevant lived experience and cultural familiarity with the population intended to be served” (Robertson et al., 2023, p. 2).

When determining the appropriate role title and description, CF may wish to consider the goals of comparable patient navigation models that include the provision of “support, education and improved access to resources and services” (Luke et al., 2018, p. 54) to health system users. Further consultation with the childhood rheumatic disease community in Northern BC may be required to ensure role suitability.

Implications and Associated Knowledge

The intention of this ELP was to identify support needs of families navigating a childhood rheumatic disease diagnosis in Northern BC, from the parent caregiver perspective. The recommendations identified in this section align with ways CF might effectively support Northern BC families impacted by childhood rheumatic disease. Throughout this study, I worked with CF’s Director of Programs and Partnerships to develop engagement methods and questions, share themes and findings, discuss conclusions and recommendations, and advance next steps. In moving forward with these recommendations, CF has an opportunity to improve supports for both the established community in Northern BC and future children and families who may be impacted by childhood rheumatic disease. The recommendations also position the organization well to create and strengthen connections with Northern BC healthcare providers and the Northern Health Authority, while enhancing collaborative relationships with the BCCH Pediatric Rheumatology team. Failure to move forward with the proposed recommendations may weaken the momentum gained through this inquiry as well as the existing connections CF has made so far with the community.

During a strategy meeting conducted at the end of this inquiry, my ELP partner identified engagement with BCCH Pediatric Rheumatology and Northern Health Authority stakeholders to reestablish NCP purpose and vision as next steps. Concurrently, CF's program officer will develop an activities timeline to bring renewed structure and clarity to the project. This report and AKP, an infographic illustrating the process, themes, learnings, and recommendations gleaned from this inquiry (see Appendix L), have created conditions for CF to continue their NCP leadership efforts. Implementing these recommendations while continuously seeking the voices of those they are serving will enable CF to be well positioned to develop and deepen trusting, reciprocal relationships with Northern BC families.

Section Summary

In this section, I summarized the recommendations and implications derived from this study. In the next section, I provide a summary of this report.

Section Six: Report Summary

CF (n.d.-b) is a Vancouver-based, nationally reaching, nonprofit organization with a mission to transform the lives of kids and families affected by juvenile arthritis and other childhood rheumatic diseases across Canada. In 2021, CF joined with BCCH's Pediatric Rheumatology team to work on the NCP, the purpose of which was to "create a vibrant, connected, and well-supported childhood rheumatic disease community in Northern BC" (CF, n.d.-e, para. 3). This ELP sought to advance NCP work by investigating and identifying the current and ideal future states of support in Northern BC for families navigating a childhood rheumatic disease diagnosis, from the parent caregiver perspective. I sought to answer my principal inquiry question: How might Cassie and Friends Society effectively support families impacted by childhood rheumatic disease who are living in Northern British Columbia? The proposed recommendations are the result of participant engagement, a review of the relevant literature, and ongoing consultation with my ELP partner.

Data collected and thematically analyzed from two engagement methods, an online survey followed by semistructured interviews, led to five key findings. These findings focused on the emotional toll of childhood rheumatic disease, the lack of overall disease awareness in Northern BC, the value of parent advocacy and community connections, and the significant obstacles Northern BC residents face when accessing healthcare services. The findings led to conclusions highlighting the need for mental health services, accessible disease-specific resources and supports, and parent navigators based in Northern BC. Conclusions informed four actionable recommendations for CF to consider for implementation. One recommendation focused on advocacy and the opportunity to reshape the delivery of care by including parent perspectives in the design of CMEs related to childhood rheumatic disease for Northern BC

healthcare providers. A further recommendation focused on opportunities that may enable CF to invest in building connections with the Northern BC community. I recommended the development of a knowledge hub on the CF website specific to Northern BC to help facilitate easy access to valuable and trustworthy information. The final recommendation focused on the recruitment of Northern BC-based parent navigators to welcome and support new families entering the community.

These recommendations align with ways CF might effectively support Northern BC families impacted by childhood rheumatic disease and, through implementation, provide CF an opportunity to strengthen organizational connections with BCCH and Northern Health Authority. Conversely, there is a risk that the momentum gained through this inquiry and existing connections CF has made so far with the Northern BC community may weaken if proposed recommendations do not move forward.

Leading each aspect of this ELP provided an opportunity for me to stretch my leadership skills. Throughout the inquiry process, I continually reflected upon my subjective reality, my emotions, and when I sensed biases and barriers emerge. I applied Kolb's (1984) experiential learning cycle to help contextualize and frame my reflections, which uncovered personal growth opportunities that I was able to leverage. This inquiry facilitated the possibility for new awareness to inform regional healthcare providers and clinics, BCCH's Pediatric Rheumatology department, and broader provincial health authorities of the unique needs and challenges faced by members of the childhood rheumatic disease community in Northern BC. I am hopeful the inclusion of parent perspectives in this ELP might enhance opportunities for larger systems change (Senge, 2006; Stroh, 2015).

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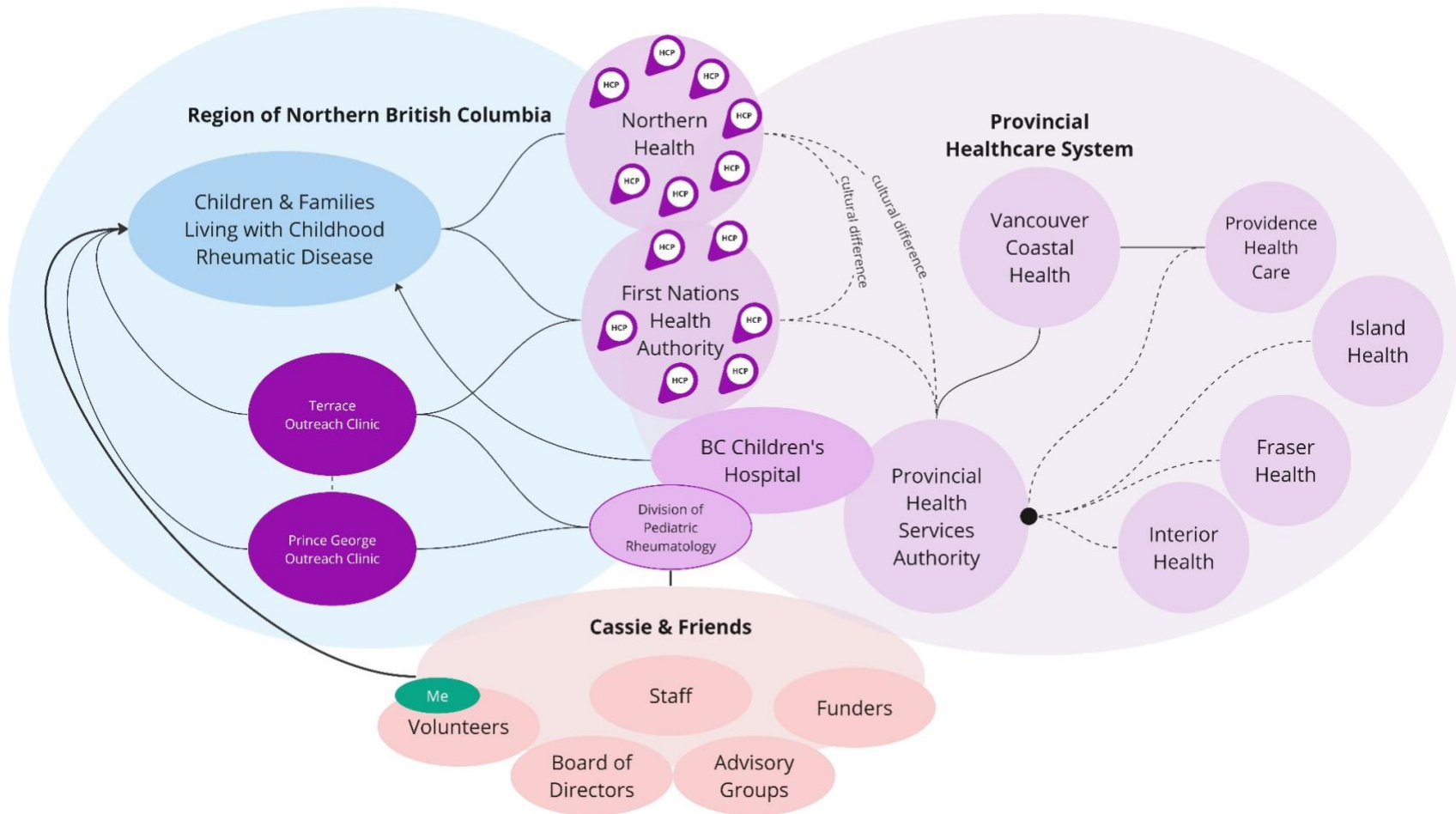
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Appendix A: Systems Map



Note. BC = British Columbia; HCP = Healthcare Professional.

Appendix B: Northern Health Regional Jurisdiction



Note. Northern Health Map (p. 1), Northern Health, n.d. (<https://careers.northernhealth.ca/sites/careers/files/documents/nh-map.pdf>).

Appendix C: Research Information Letter

Support Needs of Families Navigating Juvenile Idiopathic Arthritis in Rural and Remote Regions of Northern British Columbia

Hello,

This letter is to invite you to be part of a research project exploring the needs of families navigating a juvenile idiopathic arthritis or other childhood rheumatic disease (JIA) diagnosis in Northern British Columbia. The objective of the research is to generate a set of actionable recommendations for Cassie and Friends regarding how to better support those living with JIA in Northern BC.

My name is Georgina Clarkson. This project is part of the final Capstone project for a Master of Arts in Leadership program, and is supported by my inquiry partner Brittany Barnes, Director of Programs and Partnerships at Cassie and Friends. You can confirm my Royal Roads University credentials by contacting the Program Head, Dr. Tammy Pozzobon at [email address].

The purpose of my research is to provide answers to the research question, “How might Cassie and Friends Society effectively support families impacted by juvenile idiopathic arthritis who are living in remote areas of Northern BC?” by exploring the following questions:

- What are the needs of families living in Northern BC, impacted by JIA?
- How are needs currently being met, or partially met?
- What needs are not currently being met?
- What strategies could Cassie and Friends initiate to support children and families living in remote areas of Northern BC, in ways that are meaningful to the community?

Your participation and how information will be collected

This research project will consist of two phases, an online survey and semi-structured interviews.

Phase 1

Online Survey

The survey will be conducted using SurveyMonkey. It is self-paced online survey that will take approximately 20 minutes to complete. I am collecting responses until **Thursday December 14, 2023**, after which this survey will close.

Phase 2

One-on-One Interviews

Interviews will be conducted virtually via Zoom in January 2024. These individual sessions will be to review themes from the online survey, an opportunity for you to provide further insights into your experiences navigating life with a childhood rheumatic

disease diagnosis in Northern BC and discuss ideas for the future. Interviews are expected to last around one hour.

Benefits to Participation

Your input is important to help Cassie and Friends better understand supports needed by families impacted by juvenile idiopathic arthritis, who are living in Northern BC. This will result in a set of actionable recommendations that Cassie and Friends may implement to improve the lives of the JIA community in Northern BC. The recommendations will be presented to the senior team of Cassie and Friends who are supportive of this research.

This study may help you and your family, and others, as Cassie and Friends is committed to better supporting families navigating life with a JIA diagnosis.

This study will also contribute to the body of knowledge regarding support needs of families living with JIA in rural and remote areas.

As researcher, I will benefit from this research as it forms part of the requirement for my Master of Arts in Leadership degree.

Risks to Participation

This project is deemed to be of low risk to participants. There is a risk that participants have heightened expectations that Cassie and Friends will implement the recommendations generated. While Cassie and Friends is supportive of this inquiry, there is no guarantee that participant recommendations will be acted upon, or that recommendations will be implemented to the satisfaction of participants.

There is a slight risk that your participation may trigger uncomfortable memories or feelings. Please consider this as part of your decision on whether or not to participate. Many supportive resources for youth and caregivers offered by Cassie and Friends can be accessed by clicking the following links:

- **Mental Health Resources for Caregivers:** <https://cassieandfriends.ca/caregivermentalhealth/>
- **Mental Health Resources for Youth:** <https://cassieandfriends.ca/youthmentalhealth/>

Further mental health resources, including immediate crisis support, can be accessed through the **Wellness Together Canada** website, here: <https://www.wellnesstogether.ca/en-ca/>

Inquiry Team

My inquiry team consists of Anne Millerd and Corinna Salvail, two fellow classmates from the Master of Arts in Leadership program who will provide support to me throughout this study. They will help me validate data analysis techniques and findings, review recommendations, and provide critical feedback as I develop my Final Report.

Real or Perceived Conflict of Interest

I am not an employee of Cassie and Friends, though I have served as a volunteer for several projects, I do not receive pay or benefit. I am not acting in a volunteer capacity in this research study, but as a Royal Roads University student. I am the principal investigator of this study; I will conduct the online survey and facilitate the semi-structured interview. I disclose this information here so that you can make a fully informed decision on whether to participate.

Confidentiality, security of data, and retention period

I will protect your privacy throughout this study. All information collected will be maintained in confidence. Electronic data (such as transcripts or audio files) will be stored on a password protected computer in my home which only I have access to. Audio recordings will be transcribed by me and anonymized. Survey data will be recorded in an anonymous online survey platform. The online survey tool is SurveyMonkey®, which has its servers in the USA. Your anonymous survey data may be subject to seizure by the US government under the USA Patriot Act. While the likelihood of this happening is very small, I am required to advise you of this potential risk.

Interview data will be in both auto-transcribed and audio recorded format and aggregated and anonymized in the body of the final report. Quotations may be used but will not be attributed to an individual. All documentation will be kept strictly confidential. Raw and analyzed data will be kept until one year after the report has been handed in, then destroyed. Any identifiable information pertaining to an individual who has withdrawn from the study will not be included in the anonymized data collected. I will be using Zoom for the virtual semi-structured interview. Data collected by Zoom may be stored on, or accessible by, servers in the United States and may be subject to examination by government or law enforcement under the Patriot Act. While this likelihood is small, I am required to let you know this possible risk so that you can make a fully informed decision of whether or not you wish to participate.

Please note that your valuable insights will appear in the final report and recommendations I will present to Cassie and Friends and submit for my Capstone project. However, no personal information such as your name or personally identifiable information will be used to attribute comments or findings to you.

Sharing results

In addition to submitting my final report to Royal Roads University in partial fulfillment for the Master of Arts in Leadership, anonymous results may also be disseminated to the public via the Cassie and Friends website, and may potentially be included in future presentations, publications, or conferences.

Procedure for withdrawing from the study

You are not required to participate in this research project. If you choose to participate, there are many opportunities for you to withdraw, including partial completion of the online survey, or during the semi-structured interview, without prejudice.

- **Online Survey:** By responding directly to the online survey, you indicate that you have read and understood the information provided here and give your free and informed consent to participate. You are free to withdraw from the online survey at any point up

until you click the “DONE” button on the last page. As your responses will be anonymous, once you submit, it will not be possible to withdraw them from this study.

- **Semi-structured Interview:** If you have expressed interest in participating in the interview and have received an invitation, you can withdraw by notifying me via email any time before the interview begins, or even while it is in progress. When the interview session ends, I will begin anonymizing and aggregating the data collected. Once this step is complete it may not be possible to remove your data from this study, however, all data will be completely anonymous.

I will hold your decision whether or not to participate in confidence and Cassie and Friends will not know who has participated, who has not participated, and who has withdrawn.

If you have any questions, I can be reached via email at [email address].

Please keep a copy of this information letter for your records.

With appreciation,
Georgina

Appendix D: Invitation to Online Survey

You are invited!

Hello, my name is Georgina Clarkson, and I am writing to invite you to participate in a research project that I am conducting in partnership with Cassie and Friends. This project is part of the requirement for my Master's Degree in Leadership at Royal Roads University, and it has been approved by Brittany Barnes, Director of Programs and Partnerships at Cassie and Friends.

The purpose of my research is to identify support needs of families navigating a juvenile idiopathic arthritis or other childhood rheumatic disease diagnosis in Northern British Columbia, from the parent/caregiver perspective.

My project includes an online survey that will take approximately 15 minutes to complete. I will be collecting responses until Thursday December 14, 2023, then the survey will close.

An enclosed Research Information Letter contains further information about the study to enable you to make a fully informed decision on whether or not you wish to participate. Please review this information before completing the survey.

You are not required to participate in this research project. If you do not wish to participate, simply do not respond to this request.

If you choose to participate you are free to withdraw at any time before submitting your completed survey. You may withdraw from the survey by not saving your answers while you are in the process of completing it. Once you have completed the survey, as it is an anonymous survey, it will not be possible to remove your responses from the anonymously collected data. Any information you provide will be summarized, in an anonymous format, in the final report of my research project. At no time will any specific comments be attributed to any individual, and all information will be kept confidential.

If you wish to participate in this survey, please click on the link below. At the end of the survey, you will be invited to participate in a focus group that will further explore this topic, please complete the registration form for further information and an invitation to the event.

Here is the link to the survey: [Link to survey]

Thank you so much for your time and interest. **Your voice is important.**

Georgina

Please note, the survey is hosted on the US online survey tool, SurveyMonkey®, and information you submit may be subject to seizure by the US government under the US Patriot Act. Although the likelihood of this occurring is small, participants need to be aware of this risk.

Appendix E: Online Survey Questions

Welcome!

In learning from parents and caregivers of children with Juvenile Arthritis and other childhood rheumatic diseases living in Northern British Columbia, we hope to better understand your unique needs and experiences, and how you think things could be improved.

Your input will benefit other children, youth, and families in your region who are also navigating life with rheumatic disease and will help us make recommendations for improving access to care and support in Northern BC.

You are not required to participate in this research project, if you choose not to, please feel free to simply close this survey.

If you do choose to participate, you can withdraw at any time by simply closing this survey before clicking the final “DONE” button at the end. No information will be recorded.

If you wish to participate, click the “OK” button below.

Thank you for your interest in completing this survey. Your voice is important.

-

Section One: Demographic Information

This section focuses on the time and distance required to access care and treatment for your child.

1. Please select the age of your child when they received their rheumatic disease diagnosis
 - Under 2 years old
 - 2 - 5 years old
 - 6 - 10 years old
 - 10 - 16 years old
 - 16+ years
2. What is your child’s age now?
[Text Box]
3. Which region of Northern BC do you live in?
 - Northwest
(Atlin, Dease Lake, Stewart, Masset, Daajing Giids, Prince Rupert, Terrace, Kitimat, Hazelton, Smithers, Houston)
 - Northern Interior
(Granisle, Burns Lake, Southside, Fraser Lake, Vanderhoof, Fort St. James, Prince George, Mackenzie, Prince George, Quesnel, McBride, Valemount)
 - Northeast
(Fort Nelson, Fort St. John, Hudson’s Hope, Dawson Creek, Chetwynd, Tumbler Ridge)

- Other (please specify)
[Text Box]
4. Approximately how far away from home is your child's **primary care provider**?
- Less than 10km
 - Between 10km – 25km
 - Between 25km – 50km
 - Between 50km – 100km
 - Between 100km – 200km
 - More than 200km
5. Which mode(s) of transport do you most often use when travelling to see your **child's primary care provider**?
- (Please select all that apply)
- Personal Car/Motorcycle
 - Carpool
 - Taxi
 - Bus
 - Airplane
 - Boat
 - Bicycle
 - Walking
 - Other (please specify)
[Text Box]
6. Approximately how far away from home are your child's **specialist appointments**?
(e.g., ophthalmology, physiotherapy, infusions, pediatric rheumatology)
- Less than 10km
 - Between 10km – 25km
 - Between 25km – 50km
 - Between 50km – 100km
 - Between 100km – 200km
 - More than 200km
7. Which mode(s) of transport do you most often use when travelling to see your **child's specialist appointments**?
- (Please select all that apply)
- Personal Car/Motorcycle
 - Carpool
 - Taxi
 - Bus
 - Airplane
 - Boat
 - Bicycle
 - Walking
 - Not Applicable
 - Other (please specify)

[Text Box]

8. On average, how often does your child attend **specialist appointments**?
- Less than once per year
 - Once per year
 - Twice per year
 - Three times per year
 - Four times per year
 - Monthly
 - Weekly
 - Other (please specify)

[Text Box]

Section Two: Journey to Diagnosis

This section focuses on your experiences from first noticing signs and symptoms to receiving a diagnosis.

9. Approximately how long was it between you (or your child) first noticing symptoms, to receiving a diagnosis?
- Less than 2 weeks
 - 2 – 4 weeks
 - 1 – 3 months
 - 3 – 6 months
 - 6 – 12 months
 - More than a year

10. What sign(s) or symptom(s) did you first notice in your child?

[Text Box]

11. How would you describe your experience from when you (or your child) first noticed those symptoms, to when the diagnosis was made?

[Text Box]

12. Do you feel that you received a diagnosis in a timely manner? If no, what do you feel could have been done differently to speed up the process of reaching a diagnosis?

[Text Box]

Section Three: Journey Since Diagnosis

This section focuses on your family's experience and support received since diagnosis. What helped, what might have been missing, and what you need going forward?

13. Since receiving your child's diagnosis, what have you found has helped you feel the most supported?

(This may include friends, family, community support, online resources...)

[Text Box]

14. Since receiving your child's diagnosis, what *additional* supports or resources do you think might have been helpful for you (if applicable)?

[Text Box]

15. Since receiving your child's diagnosis, what barriers do you feel have prevented you from receiving the types of support and resources you need (if applicable)?

[Text Box]

Section Four: Raising Awareness

This section focuses on what you would like others to understand about your family's journey navigating childhood rheumatic disease.

16. What do you wish others knew about your family's childhood rheumatic disease journey?

[Text Box]

17. What advice would you give someone who thinks their child has started to have symptoms of childhood rheumatic disease?

[Text Box]

18. Is there anything else that I haven't asked about here, that you would like to share with me?

[Text Box]

-

Thank you so much for participating in this survey. To complete this survey click the "OK" button, and then "DONE".

(It is not too late if you wish to withdraw, simply close the study to do so.)

Before you go...

If you would like to explore this topic further by participating in the upcoming focus group (via Zoom), please sign up here: [Focus Group Registration Form](#)

Thank you again for sharing your time and experiences with me.

Your voice matters.

Appendix F: Email Invitation to Semistructured Interview**Subject: A Research Project to Better Northern BC Care – Interview Invitation**

Hi [participant name],

I hope you and your family are keeping well this holiday season. Thank you so very much for taking the time to complete our online survey, and for your interest in participating further by registering for the focus group in January, it means a lot.

Shifting gears just a little, we did not receive enough interest from folks to go ahead with the focus group, therefore I would like to instead invite you to participate in a one-on-one interview.

It would take place over Zoom and would last approximately one hour. If you are interested, please reply and let me which of the following dates and start times would work the best for you:

- Monday Jan 8, any time from 9:00am - 5:00pm
- Tuesday Jan 9, any time from 9:00am - 8:00pm
- Wednesday Jan 10, any time from 9:00am - 8:00pm
- Thursday Jan 11, any time from 9:00am - 5:00pm
- Friday Jan 12, any time from 9:00am - 8:00pm
- Saturday Jan 13, any time from 9:00am - 8:00pm
- Sunday Jan 14, any time from 9:00 - 8:00pm
- Monday Jan 15, any time from 9:00am - 8:00pm
- Tuesday Jan 16, any time from 9:00am - 8:00pm

For more details, please take a look at the attached invitation letter and updated research information letter.

I look forward to hearing more from you.

Warmly,
Georgina

Appendix G: Invitation to Semistructured Interview

Dear [participant name],

Thank you for your continued interest in this research project, here are more details!

What: A one hour semi-structured interview to explore ways to improve supports and awareness of childhood rheumatic disease in Northern British Columbia.

Where: Zoom

RSVP: by reading the attached information letter and replying to this email by January 2, 2024, letting me know you would like to attend the interview, you will then be sent a Zoom meeting invitation.

The purpose of this interview is to identify support needs of families navigating a childhood rheumatic disease diagnosis in Northern British Columbia (BC), from the parent/caregiver perspective, and will take approximately one hour.

You will have the opportunity to review the transcript of our interview, if you wish, to ensure your thoughts have been captured accurately. I will begin analyzing the data collected from our interview on January 19, 2024. Up to January 25, 2024, you may request that data collected from our interview be removed from the study, after January 25, 2024, your anonymized data will be included in my study.

As a reminder, you are not required to participate in this research project. If you choose to participate, your participation is completely voluntary, and you are free to withdraw at any point before the interview, or even while it is in progress, without prejudice. Your withdrawal will remain confidential.

I have reattached the information letter containing further details about the study, updated to reflect the change from the focus group to a semi-structured interview, to ensure you are able to make a fully informed decision on whether to participate, please review it before responding. If you do not wish to participate, simply do not respond to this request.

Please feel free to contact me at any time should you have additional questions regarding my research and its outcomes. I can be reached via email at [email address].

With appreciation,
Georgina

Appendix H: Individual Semistructured Interview Consent Form

By signing this form, you confirm that you are over the age of 19 and have read and understood the information letter for this study. Your signature states that you are giving your voluntary and informed consent to participate in this project and have the data you contribute used in the final report and any other knowledge outputs (general presentations, Cassie and Friends website, newsletters, etc.).

By consenting, you have not waived any rights to legal recourse in the event of research-related harm.

- I consent to the audio recording of the semi-structured, one-on-one interview being used in this study
- I consent to the notes taken during the semi-structured, one-on-one interview being used in this study
- I consent to quotations and excerpts expressed by me through audio, Zoom, and written transcription be included in this study, provided that my identity is not disclosed
- I acknowledge that I fully understand my right to withdraw from this study, and how my contributions up to that time will be used

Name (please print): _____

Signed: _____

Date: _____

To consent to participation, please return this signed form to [email address].

Appendix I: Method Guide – Semi-Structured Interview

Zoom Semi-Structured Interview Process

(Approximately 60 – 90 minutes)

Introduction

- Welcome – Land Acknowledgement
- Ensure participant is comfortable and oriented to Zoom
- Restate confidentiality, reconfirm informed consent, reconfirm that they are free to withdraw at any time, without consequences
- Inform participant that once data has been anonymized and aggregated (after January 19), it may not be possible to remove an individual's data, but that any inclusion in final report will be completely anonymous
- **Member checking. Option to review transcript. Would they like to receive the Exec Summary? Full report?**
- Acknowledge appreciation for their presence and willingness to be part of this discussion
- Begin recording

Interview

- Provide an overview of the topic:

Your participation will go toward helping Cassie and Friends better understand supports needed by families impacted by juvenile idiopathic arthritis and other childhood rheumatic disease, who are living in Northern BC.

This will result in a set of actionable recommendations that Cassie and Friends may implement to improve the lives of the JIA community in Northern BC. Recommendations will be presented to the senior team of Cassie and Friends who are supportive of this research.

- Reintroduce your inquiry question:
How might Cassie and Friends Society effectively support families impacted by juvenile idiopathic arthritis who are living in remote areas of Northern BC?

[Maintain orientation to initial themes: **awareness/access to (trustworthy) information; systems navigation; advocacy** (parent, acquisition of self-advocacy skills); **mental health supports – marriage/family counselling**]

1) How did you hear about/first connect with Cassie and Friends?

- Move on to your subquestions

- 2) **From your perspective, what are the needs of families living in Northern BC who are impacted by childhood rheumatoid disease?**
- 3) **How would you say those needs are being met (or partially met) right now?**
 - a. For example, please describe how you access/interact with [resource mentioned]; what might make that process easier?
- 4) **What needs would you say are not currently being met?**
 - a. For example, please expand on [the earlier need mention]; how might that be best introduced/improved?
- 5) **What strategies could Cassie and Friends Society initiate to support children and families living in remote areas of Northern BC, in ways that would be meaningful to you and the community of families navigating childhood rheumatoid disease?**
 - a. What services might Cassie and Friends look into introducing, or improving?
- 6) **Is there anything else that we haven't talked about/haven't asked about that you would like to share today?**

- Use prompts, where appropriate such as “tell me more”, and “please expand on that”.
- When you home in on something, “please tell me more about...”
- Be mindful of anxiety, distress, or disinterest and be prepared to slow down or increase the meeting pace as needed; take a break at the halfway point (around 45-60 minutes into the session)

Closure

- Ask if participant wishes to add anything else
- Express gratitude, share a reminder of confidentiality and reiterate that all input will be anonymized, also reiterate withdrawal opportunities
- Inform participant of the resources available that they may wish to seek as a result of their involvement in this interview
 - Mental Health Resources for Caregivers: <https://cassieandfriends.ca/caregivermentalhealth/>
 - Mental Health Resources for Youth: <https://cassieandfriends.ca/youthmentalhealth/>
 - Further mental health resources, including immediate crisis support, can be accessed through the **Wellness Together Canada** website, here: <https://www.wellnesstogether.ca/en-ca/>
- **Member checking! Option to review transcript. Would they like to receive the Exec Summary? Full report?**
- One final word of thanks and well wishes

Appendix J: Wellness Resources

You can explore the many supportive resources for youth and caregivers offered by Cassie and Friends by clicking the following links:

- **Mental Health Resources for Caregivers:** <https://cassieandfriends.ca/caregivermentalhealth/>
- **Mental Health Resources for Youth:** <https://cassieandfriends.ca/youthmentalhealth/>

Further mental health resources, including immediate crisis support, can be accessed through the **Wellness Together Canada** website, here: <https://www.wellnesstogether.ca/en-ca/>

Appendix K: Use of Artificial Intelligence Transparency Statement

In undertaking this ELP, I utilized generative artificial intelligence (AI) tools, specifically Otter.ai for Zoom, Zotero, and online search engines. I received approval from my academic supervisor to use these generative AI applications in this manner, and my application of these tools was consistent with the School of Leadership Studies' Provisional Guidelines for Utilizing Generative AI in Graduate Course Work (Royal Roads University, n.d.). This represents applying emerging technologies within academic settings in a balanced and thoughtful manner. Details on how each application was used in this report are presented in the sections that follow.

Otter.ai for Zoom

I held semistructured interviews virtually over Zoom and auto-transcribed the recordings using Otter.ai, an AI transcription service offered as part of Zoom's suite of services. To improve accuracy, I human-verified the transcripts. The verification process included reviewing the audio and video recording while following the auto-generated transcript and making required edits.

Zotero

I used Zotero as a research database for the duration of this project. This application aided in organizing scholarly literature and auto-generating citations in American Psychological Association (APA, 2020) format using a Microsoft Word plug-in. While the citation was autogenerated in APA formatting, as the primary researcher on this project, I determined the choice of what material to use and who to cite in this final report.

Online Search Engines

I curated scholarly literature, articles, and other sources by conducting comprehensive online research. In addition, I used search tools, such as Google Scholar, to find relevant information related to the research question and critically analyze sources for relevance.

Sources

American Psychological Association. (2020). *Publication manual of the American Psychological Association* (7th ed.).

Royal Roads University. (n.d.). *Generative artificial intelligence*.
<https://www.royalroads.ca/about/centre-teaching-educational-technologies/teaching-resources/generative-artificial>

Appendix L: Associated Knowledge Product – Infographic

Supporting Rural & Remote Communities

navigating childhood rheumatic disease




WHAT WE DID

ENGAGED WITH COMMUNITY MEMBERS

We conducted in-person meetings, online surveys, and Zoom interviews to build connections with families in Northern BC impacted by childhood rheumatic disease. We asked parents and caregivers to share their experiences in seeking and receiving a diagnosis for their child in the rural context.



LISTENED TO STORIES SHARED

Parents described their experiences of first noticing their child’s symptoms, to seeking help, to receiving a diagnosis, then beyond. We learned what supports were found to be helpful, and where things could have been better for their families.



WHAT WE LEARNED

NAVIGATING THE DISEASE TAKES AN EMOTIONAL TOLL

The journey to diagnosis can be traumatic, confusing, and overwhelming. Families may encounter feelings of isolation, uncertainty, and grief as they confront childhood rheumatic disease.



RURAL FAMILIES BEAR THE COST OF LIMITED ACCESS TO CARE

The low physician-to-population ratio and lack of specialist care in rural and remote regions means families spend a significant amount of time, money, and energy seeking equitable care for childhood rheumatic disease.



GAPS IN DISEASE AWARENESS IMPACTS EXPERIENCE

Lack of disease awareness in rural and remote communities mean parents and caregivers spend a significant amount of time seeking answers while disease symptoms persist.



IT HELPS TO CONNECT WITH OTHER FAMILIES

The opportunity to share experiences and hear from families who understand what it is like to navigate life with childhood rheumatic disease is supportive and reassuring.



WHAT WE RECOMMEND

SEEK OUT PARENT AND CAREGIVER PERSPECTIVES

Parents and caregivers are the subject matter experts of their own lives. Engage with community members to build connections, generate ideas, and discover what supports they need.



EXPLORE WAYS TO FACILITATE COMMUNITY CONNECTIONS

Increase opportunities for community connection and raising disease awareness by planning accessible events that bring people together. Consider how to reflect the unique characteristics of the community to promote inclusivity and learning.



BUILD A KNOWLEDGE HUB

Create an accessible repository of useful information and supports for the community. Seek input from users to ensure resources are relevant and useful. Ensure it can be easily maintained.



RECRUIT PARENT NAVIGATORS

Explore recruiting navigators to provide families support, information, and access to useful resources. Consider those with lived experience to welcome new families to the community.



created by Georgina Clarkson