

RESEARCH PARTNERSHIPS IN CHILD HEALTH

**A mixed methods exploration of the characteristics, dynamics, processes and perceived effects of  
research partnerships in child health**

by

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## Abstract

**Background:** Research partnerships between health researchers and knowledge users (e.g., children and youth, parents and families, healthcare providers) are gaining momentum to promote the uptake and application of research. Yet, comprehensive data on partnerships within child health research that include partnership traditions and knowledge user groups remains limited. This dissertation addresses this gap by exploring child health as a unique context for research partnerships, focusing on their characteristics, dynamics, processes, and effects.

**Methods:** This dissertation adopts an exploratory mixed-methods approach across three concurrent studies, employing multiple data collection and analysis methods while maintaining conceptual coherence and a pragmatic philosophical orientation, integrating findings in the discussion. Objective 1 characterized knowledge user engagement in published child health research through a scoping review, examining characteristics, practices, barriers, facilitators and effects. Objective 2 used interpretive description to provide an in-depth understanding of the experiences, motivations, and relational dynamics of engaging in research partnerships among Canadian child health researchers and knowledge users. Objective 3 employed a concurrent mixed-methods design to explore considerations influencing the individual determinants and perceived effects of partnered child health research compared to other health research contexts, through secondary analysis of a cross-sectional survey of Canadian partnered health research projects funded from 2011-2019 and interviews with child health researchers and knowledge users informed by qualitative description.

**Results:** Objective 1 revealed a growing trend in publications on child health research partnerships, particularly since 2019. Most studies used community-based participatory research approaches and engaged multiple knowledge user groups, though reporting on barriers, facilitators, and effects varied. Objective 2 highlighted role-specific motivations for partnering and underscored the central role of relationships in shaping partnership dynamics, sustainability, and the ability to navigate challenges.

Researchers often balanced evolving partnership practices within academic systems and structures not always conducive to collaboration, resulting in tensions. Objective 3 found no significant differences between child and general health cohorts in survey responses. Child health respondents reported positive perceptions of their capability, opportunity, and motivation to work in partnership, but mixed views on project effects. Interview participants embraced common principles across research contexts while navigating additional logistical (e.g., institutional processes) and practical (e.g., engaging proxies) challenges unique to partnered child health research. Participants noted distinct considerations (e.g., safeguarding vulnerable populations), processes (e.g., tailoring engagement strategies) and effects when engaging children and youth, with the ethos of the child health community facilitating partnerships.

**Conclusion:** Overall, research partnerships in child health share common principles and challenges with those in other health research contexts, but also have unique characteristics, dynamics, and processes that add nuance to the conceptualization and practice of partnering. These findings provide a foundational understanding of child health research partnerships, guiding efforts to optimize partnership research and practice. By deepening our understanding of these elements, partners can work toward meaningful collaborations that enhance child health research uptake and effects.

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## Dedication

*For my grandma Johanna, who navigated life with resilience and grace.*

*(September 2, 1934 – June 24, 2024)*

*For my daughter, Sophie – your sweet but feisty determination inspires me every day. Watching you grow and learn has been my greatest and most rewarding accomplishment.*

*This work is a tribute to you both.*

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## Chapter 1: Introduction

### 1.1 Rationale

Research partnerships, defined as collaborative research activities between academic researchers and individuals, communities, and relevant groups, referred to as knowledge users, are gaining momentum in health research (Hoekstra et al., 2018). This heightened interest is propelled by several factors, including the imperative to optimize research investment and effects, the conceptual shift from viewing patients as passive recipients of health care to active consumers, and broader societal demand for the democratization of scientific processes (Kothari et al., 2022). In response to this evolving landscape, several Canadian funding institutions have championed partnered approaches, increasing the momentum for researchers and knowledge users to work together within and throughout the research process.

However, despite investment in research partnerships, the precise nature, essential components, and overall effects of partnering in health research remain unclear. For example, many primary studies provide scant descriptions of partnership processes and often lack comprehensive evaluations of their effects (Camden et al., 2015; Gagliardi et al., 2016; Hoekstra et al., 2020), and those that do are often confined to small or specific funding networks (Kislov et al., 2018; Sibbald et al., 2019) or outdated analyses that do not reflect maturation of the field. Systematic reviews note infrequent assessment and/or reporting of health research partnership effects, focusing on perceived and self-reported positive effects (Hoekstra et al., 2020). For example, a recent systematic review found that only 38% of studies evaluated specific outcomes or impacts resulting from partnerships, with only 8% reporting on both outcomes and impact (Mrklas et al., 2022).

Similarly, partnerships in child health research, which focus on improving the health and well-being of children and youth from birth to age 18, are growing (Molloy et al., 2019). Parents, families and others often assume roles of advocacy and support (Wadman et al., 2019) and there is increasing

recognition of the value and duty to engage children and youth (Hawke et al., 2020; Rouncefield-Swales et al., 2021; Woodgate et al., 2018). Research partnerships in child health may vary in nature, process and effects compared to those focused on the general population. For example, children possess distinct anatomical, physiological, developmental and psychosocial characteristics that set the foundation for their healthcare needs (Klassen et al., 2008; Larcher, 2017). Longstanding published guidance recognizes the unique methodological, ethical and protective considerations required for conducting child health research (Fernandez et al., 2008; Smyth & Weindling, 1999). Power differentials are also inherent in research partnerships (Plamondon et al., 2022; Wallerstein et al., 2019), and this may be especially pertinent in child health, where the spectrum of interested parties may be expanded for practical or protective reasons.

Consistent with the field as a whole, there is insufficient data exploring the characteristics or benefits of research partnerships with children (Haijes & van Thiel, 2016), adolescents (Fløtten et al., 2021; van Schelven et al., 2020), their caregivers, healthcare professionals, or policy and decision makers. To date, research examining partnered child health research has been confined to specific approaches (e.g., community based participatory research (CBPR), patient and public engagement (PPI)) or restricted to partnering with specific knowledge user groups (e.g., children, parents), limiting our ability to enhance understanding and refine practices across partnership traditions. Notably, research partnership effects have received limited attention in child health. Recently, Vanderhout et al. (2023) explored the impacts of patient and family engagement in child health research, echoing previous findings that measuring and reporting engagement impact remains rare.

A wholesome understanding of child health research partnership processes and dynamics, including underlying principles, engagement practices, and relational processes, is necessary to promote meaningful and effective collaborations and optimize resource utilization, thereby maximizing the effects of partnered research initiatives. The overarching goal of my dissertation was to explore child

health as a context for research partnerships. More specifically, I asked, “is child health a unique context for research partnerships?” and explored this question through three complementary studies of partnership characteristics, dynamics, processes, and effects. Through this work, I am expanding the foundational understanding of research partnerships in child health, which can help clarify structural, process and relational mechanisms underpinning partnership effects.

## **1.2 Research objectives**

The specific research objectives guiding my dissertation were as follows:

1. To examine the scope and breadth of knowledge user engagement, including study and engagement characteristics, barriers and facilitators, and effects, reported in published child health research, inclusive of research partnership approaches and knowledge user groups.
2. To gain an in-depth understanding of the experiences, motivations and dynamics of engaging in partnered research amongst researchers and knowledge users involved in Canadian child health research partnerships.
3. To identify perceived differences in considerations influencing the individual determinants and perceived effects of partnered child health research relative to other health research contexts in Canada.

## **1.3 Dissertation overview**

In the introduction, I have outlined the overarching gaps and fundamental concepts essential for developing this dissertation. I present this dissertation as a sandwich thesis. Following the background (Chapter 2) and description of methodology (Chapter 3), each subsequent chapter includes a manuscript (Chapter 4) or distinct study (Chapters 5 and 6) intended for future publication, focusing on specific aspects of the research project. The preface to each chapter includes information about the manuscript or study, including rationale, authorship, any peer-reviewed presentation abstracts derived from the material, and a suggested citation. The dissertation concludes with an integrated discussion (chapter 7).

Due to the nature of a sandwich thesis, the chapters may have repetition of definitions, concepts, and research methods.

The work outlined in this dissertation establishes a comprehensive basis for understanding research partnerships in child health that provide potential for future scholarly activity and research. The research presented in this dissertation uniquely contributes to the rapidly expanding field of research partnerships through its explicit focus on child health. By examining the characteristics, dynamics, processes and effects, this work strives to enhance our understanding of how research partnerships can be optimized to address complex health challenges and provides guidance for researchers and knowledge users involved in fostering effective research partnerships. By enhancing our understanding of the nuances and potential effects of research partnerships in child health, this dissertation aspires to pave the way for more impactful and equitable approaches to promoting child well-being and health outcomes and serves as a launch pad for future scholarly activity and research.

## Chapter 2: Background

### 2.1 Introduction

Research partnerships are not new and have a long history of development and use (Nguyen et al., 2020). Historically, a dominant biomedical model has prevailed in health research, prioritizing “objective” research led by individuals with university appointments (Wallerstein & Duran, 2017). Over time, changing funding program requirements aimed at fostering collaborative research have catalyzed a transformation in the landscape of health research activities in Canada. This shift reflects a departure from transfer-oriented approaches rooted in evidence-based medicine towards a paradigm centered around research partnerships (Bowen & Graham, 2013). This paradigm emphasizes collaborative and participatory approaches, where stakeholders across various sectors actively engage in the research process. Consequently, efforts to advance research partnerships, mainly through the lens of integrated knowledge translation (iKT), have gained momentum in Canada (Bowen & Graham, 2013; Nguyen et al., 2020). iKT involves researchers and knowledge users working together throughout the research process to promote research uptake and application (Kothari et al., 2017; Tetroe, 2007). My dissertation proposal reflected this orientation, focusing narrowly on the rapidly evolving field of iKT in the Canadian context. However, the need to broaden my focus to closely related approaches became apparent to leverage the accumulated knowledge across traditions and align with ongoing shifts in the field (Graham et al., 2022; Hoekstra et al., 2020; Nguyen et al., 2020). Concurrently, the research partnership literature increasingly emphasizes context specificity, and there is a documented need for an enhanced understanding of how research partnerships function in diverse settings (Dunn et al., 2023; Gagliardi et al., 2017). My focus on research partnerships in child health is timely. In 2020, Canada ranked in the bottom third of high-income countries on numerous indicators of child health and well-being (UNICEF, 2020). Research partnerships in child health are one way to work towards meaningful, impactful, and

relevant solutions. Yet, understanding their unique characteristics, dynamics, processes, and effects is essential for optimizing practice and achieving intended effects.

The purpose of this background chapter is to contextualize my dissertation within the broader research partnership literature. I outline the historical progression of the field, define key terms used throughout the dissertation, discuss theory, model, and framework (TMF) use in research partnerships and close with a review of relevant evidence.

## **2.2 Historical context of research partnerships**

### ***Early origins***

Research partnerships have a rich history that predates the contemporary emphasis on collaborative approaches in health research, particularly within the social sciences. Among the earliest manifestations of these approaches are participatory research (PR) and its subgenres. While action research (AR), credited to Kurt Lewin, emerged in the 1940s as a dynamic cycle of action and reflection involving researchers and *stakeholders*, participatory research (PR) evolved from and expanded upon the principles of AR (Lewin, 1948; Wallerstein & Duran, 2017). PR can be traced to two distinct historical traditions: the Northern and Southern (Wallerstein & Duran, 2017). The Northern tradition of PR furthered the ethos of active engagement and collaboration between researchers and *communities*, seeking to democratize the research process by involving community members in problem definition, data collection, and analysis (Wallerstein & Duran, 2017). The Southern tradition of PR, influenced by scholars and activists such as Freire and Fals-Borda in Asia, Africa, and Latin America, emerged in the early 1970s. This tradition emphasizes empowerment, collective action, and social transformation, challenging prevailing power structures and amplifying the voices and agency of *marginalized communities* in the research process (Freire, 1970; Nguyen et al., 2020). Concurrently, the participatory action research (PAR) sub-genre gained prominence, amalgamating the Southern tradition's

empowerment and social justice focus with the Northern tradition's pragmatic, action-oriented focus (Cornish et al., 2023).

In the 1990s, community-based participatory research (CBPR) emerged as a response to the limitations of traditional research approaches in addressing the complex health and social issues faced by underserved populations (Wallerstein & Duran, 2010). Influenced by the language and history of “community-based” public health practice in the United States and the PR values of the Southern Tradition, CBPR integrates principles from PR, AR, and PAR (Wallerstein & Duran, 2017). It emphasizes long-term collaboration between researchers and community members to equalize power relationships and address health and social disparities, particularly among underserved populations (Minkler & Wallerstein, 2008). These early approaches collectively laid the foundation for collaborative and participatory research models, shaping the research landscape across disciplines and contexts.

#### ***Health research and dominant biomedical approach***

In contrast, the dominant approach in Western health research historically reflected biomedical paradigms, prioritizing positivist research to understand and address health issues (Farre & Rapley, 2017; Wallerstein & Duran, 2017). Often referred to as mode 1 research, knowledge production was largely centralized within academic institutions and characterized by disciplinary specialization, with limited involvement of community members and minimal consideration of the social determinants of health (Estabrooks et al., 2008; Nowotny et al., 2003). This approach was further solidified by the evidence-based medicine movement, which emphasized the systematic integration of evidence from rigorous research designs, such as randomized controlled trials, into clinical decision-making (Sackett et al., 1996). While partnerships existed in specific pockets that often intersected with the social sciences, medical anthropology, and nursing, they remained peripheral within the biomedical paradigm (Minkler, 2005; Wallerstein & Duran, 2006). These partnerships often leveraged experiential forms of knowledge,

such as clinical experience, challenging the exclusivity of biomedical perspectives in health research (Israel et al., 1998).

### ***Shifting from evidence-based medicine to engaged scholarship***

The transition towards partnership models in health research gained momentum in Canada with the establishment of the Canadian Institutes of Health Research (CIHR) in the early 2000s and the introduction of a knowledge translation (KT) mandate (Bowen & Graham, 2013). Historically, KT efforts in Canada focused on bridging the know-do-gap between research and practice, primarily driven by evidence-based medicine models (Graham et al., 2006). These efforts sought to reduce the substantial time lag between evidence generation and application, prompted by persistent findings indicating that current healthcare practices did not align with the latest evidence (Grimshaw et al., 2012; Straus et al., 2011). However, critiques surfaced regarding the limitations of predominantly uni-directional approaches to promoting knowledge use (Greenhalgh & Wieringa, 2011; Rycroft-Malone et al., 2016). Within Canada, the KT literature increasingly underscored partnerships as an essential feature of effective KT, recognizing that authentic two-way knowledge transfer and use were more likely to occur in partnered relationships (Sibbald et al., 2012). Integrated KT (iKT) was positioned as a critical concept within this framework, highlighting the importance of involving knowledge users – such as policymakers, practitioners, and patients – in the research process from its inception to promote knowledge uptake and application (Graham et al., 2009). Therefore, the CIHR model of iKT helped to integrate the biomedical and action research paradigms (Bowen & Graham, 2013).

Explicit funder-driven initiatives aimed at enhancing impact have contributed, in part, to this transition from a knowledge transfer to a coproduction paradigm in Canada (Bowen & Graham, 2013). Coupled with CIHR's KT mandate, promotion and support for partnered research approaches have incentivized their use in Canada. Large-scale CIHR funding initiatives, such as the Strategy for Patient-Oriented Research (SPOR) in 2011, have significantly influenced the adoption of patient engagement

(PE) practices in Canada. PE is defined as the meaningful involvement of patients, caregivers, and other stakeholders in all aspects of the research process (Canadian Institutes of Health Research [CIHR], 2014). Additionally, initiatives such as team science grants, consortia funding, and private-public partnerships have incentivized researchers to form partnerships across institutional and disciplinary boundaries, promoting mode 2 research (Hall et al., 2006). Since 2004, CIHR has formally incorporated funding opportunities requiring partnerships between researchers and knowledge users (e.g., Partnerships for Health System Improvement, Knowledge Synthesis, and Knowledge to Action grants), thus promoting iKT approaches (Sibbald et al., 2019; Sibley et al., 2023). Concurrently, provincial health agencies have also advocated for research partnerships to varying degrees (Holmes et al., 2012).

### ***Comparison of partnership approaches***

While research partnership approaches share common core values, there are subtle but important differences in their epistemological orientations and historical roots (Nguyen et al., 2020). However, Nguyen et al. (2020) found more perceived diversity within individual research partnership approaches than discernible differences between them. Indeed, researchers have reported difficulty aligning with a single approach due to their similarities (Nguyen et al., 2020). Table 2.1 outlines definitions of research partnership approaches, primary motivations, and origins. Briefly, CBPR and PAR prioritize community involvement and empowerment, often focusing on addressing systemic issues and promoting social justice. This extends the PR focus of the Northern tradition from a focus on stakeholders to communities and centers empowerment, social justice, and action as key.

Conversely, iKT explicitly focuses on health research contexts and emphasizes collaboration with diverse *knowledge users* to enhance knowledge use and impact (Nguyen et al., 2020). Relatedly, PE emphasizes the importance of *patient* input in shaping research priorities, design, and dissemination of health research findings. While patients, families, and members of the public are considered valid knowledge users within the iKT paradigm, they are not the central focus nor are they systematically

engaged (Banner et al., 2019). Despite variations in emphasis and terminology, these approaches collectively contribute to the broader field of research partnerships, encompassing collaborative methodologies that prioritize engagement, equity, and impact (Nguyen et al., 2020).

Table 2.1 Chronology of Research Partnership Approaches

Approach	Definition	Origin	Disciplinary origin	Primary motivation
Participatory research (PR)	“Participatory research is a general term for a school of approaches which share a philosophy of inclusivity and integrate research and non-academic person’s knowledge and experience into partnerships that are meaningful” (Cargo and Mercer, 2008). Participatory research tends to emphasize a bottom-up approach and focuses largely on locally defined priorities and local perspectives (Cornwall & Jewkes, 1995).	Two main branches: <ul style="list-style-type: none"> <li>- Northern tradition, US and UK (Lewin, 1946): cycles of reflection and action, rooted in community empowerment</li> <li>- Southern tradition, South America, Africa, Asia (Freire, 1972): pedagogy of the oppressed, rooted in emancipation of disadvantaged groups</li> </ul>	Social Sciences (psychology in North America; Community Development and Education in South America)	Explicit focus on social and environmental justice and a desire for impact change, particularly to benefit underserved/vulnerable citizens and communities  Strong focus on process and power
Participatory action research (PAR)	Denis & Lomas (2003) define PAR as: “a variation of action research that departs from the Lewinian focus on producing local change and explicitly recognises the interrelationship between knowledge and power. PAR focuses on the generation of broad social change and it is based on a critical epistemology in which the positions of actors in the knowledge processes are systematically and deliberately assessed. PAR strives for a change in the balance of power in society and organizes itself to actively favour the marginal groups in any context” (p.S2:2)	Can be traced to the work of Kurt Lewin (1994), the founder of action research. PAR extends PR by emphasizing action and social change. It involves cycles of reflection, planning, action and evaluation, with the community actively participating in every stage.	Public health, Community Development, Sociology and Anthropology	Explicit focus on community empowerment and social transformation. It seeks to address systemic issues of oppression and inequality.
Community-based	“a collaborative approach to research that equitably involves all partners in	A methodology with 3 main influences:	Originated in public health, but has	Explicit focus on working in partnership with

participatory research (CBPR)	the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities” (Kellogg Foundation, 1992)	<ul style="list-style-type: none"> <li>- Lewin (1944) – action research</li> <li>- Freire (1972) – pedagogy of the oppressed (education research)</li> <li>- Feminist theories</li> </ul>	since been adopted in various disciplines (sociology, anthropology, environmental studies)	<p>marginalized communities to reduce health inequities and promote social justice.</p> <p>Focus on enhancing capacity of partners</p>
Integrated KT	“a different way of doing research with researchers and research users working together to shape the research process – collaborating on setting the research questions, deciding the methodology, being involved in data collection and tools development, interpreting the findings, and helping disseminate the research results” (Tetroe, 2007, p. 6)	A research funder driven innovation, initially advanced by the Canadian Health Services Research Foundation (CHSRF) as Knowledge Exchange (Denis & Lomas, 2003) and more recently by the Canadian Institutes of Health Research	Health, medicine, nursing	<p>Explicit focus on engaging a diverse range of knowledge users in health research to increase knowledge use and impact. Inclusion of health system decision-makers are key.</p> <p>Focus on working together to promote uptake.</p>
Patient engagement (PE)	“the meaningful and active involvement of patients in the governance; priority setting; conducting; and translation of research” (CIHR, 2014)	Reflects the long-standing principle of doing research “with” rather than “on” people Involvement of stakeholders in social and healthcare policy has been well recognized since 1996 with the establishment of INVOLVE. PCORI was established in the US in 2010, while the Strategy for Patient Oriented Research (SPOR) was launched in 2011 in Canada.	Health, medicine, nursing	<p>Explicit focus on engaging patients in health research to increase knowledge use and impact</p>

***Umbrella term: research partnerships***

Increasingly, *research partnerships* have been adopted as an umbrella term that acknowledges the interconnected nature of these approaches. This is reflected in recent review efforts (Hoekstra et al., 2018; Hoekstra et al., 2020; Mrklas et al., 2022; Mrklas et al., 2023), primary studies (e.g., Sibley et al., 2023), and framing within Canada (Graham et al., 2022). These scholarly activities, among others, progressively expand our understanding of research partnerships to encompass diverse historical traditions. Recent work (Jull et al., 2017; Nguyen et al., 2020) underscores the similarities among these approaches, emphasizing common elements such as a commitment to genuine collaboration, substantial time and financial investments, shared core values and principles, and a focus on essential components and processes rather than labels (Graham et al., 2022). Adopting research partnerships as a unifying concept allows for leveraging the strengths and methodologies of each approach while fostering cross-learning and exchange of best practices (Hoekstra et al., 2018).

The emergence of research partnerships and the shift towards a co-production paradigm in Canada signifies a fundamental rethinking of institutions' conduct, application, and research support. By fostering meaningful collaboration between researchers and knowledge users, these partnerships can generate more relevant, impactful research that is responsive to the needs of knowledge users and broader society.

**2.3 Definitions and conceptualizations**

Throughout this dissertation, I will adhere to these terms for consistency while acknowledging the conceptual overlap across various fields related to research partnership approaches (Hoekstra et al., 2020).

***Research partnerships***

In this dissertation, the term *research partnerships* serves as a comprehensive descriptor encompassing various collaborative research approaches that acknowledge and value the different

knowledge, skills, and lived experiences contributed by researchers and knowledge user partners. As previously described, these approaches have evolved through extensive intellectual contributions from numerous disciplines and fields (Hoekstra et al., 2020). Others have also adopted alternative umbrella terms, including health research partnerships (Hoekstra et al., 2020), research co-production (Graham et al., 2022), and partnered health research (Sibley et al., 2022).

### ***Child health***

For this dissertation, child encompasses individuals from birth to 18 years of age, as defined by the World Health Organization (WHO) (2007), unless specific contexts (e.g., mental health, Indigenous health) necessitate broader age parameters. Health aligns with the WHO's comprehensive definition, including physical and psychological well-being and preventative aspects (Grad, 2002). Considered within the realm of research partnerships, this involves producing research in collaboration with knowledge users who may have direct or indirect interests or influences on the health and well-being of this population.

### ***Knowledge user***

I use the term *knowledge user* to refer to individuals, groups, or communities outside of academic settings who may use the knowledge generated through research to make informed decisions about health behaviors, health policies, programs, and practices (CIHR, 2022). Knowledge users include children and youth, parents and families, the public, healthcare professionals, health policy or health system decision-makers, community members, community organizations, and funders. Unlike stakeholders who may have an interest in research findings or advisors who offer guidance to the research team, knowledge users are essential partners for co-producing research who operate autonomously within the research team (Graham et al., 2022). I acknowledge that the term knowledge user is synonymous with an iKT approach. Other partnership traditions may use different terms, such as patient partner, community member, stakeholder, or end-user (Nguyen et al., 2020). However, the

research partnership literature generally accepts the term knowledge user as an appropriate umbrella term to encapsulate the *range* of potential individuals, groups, or communities considered under this approach. As a co-creator of knowledge and not merely a user, the term can be problematic, but it is currently the most widely accepted.

This dissertation broadly examines four key components of research partnerships in child health: partnership characteristics, dynamics, processes, and effects. These components are interconnected and cannot be entirely distinguished from one another. Partnership characteristics influence partnership dynamics and processes, while partnership dynamics and processes affect each other. Collectively, these components influence partnership effects. None of these components exist in isolation, which contributes to the complexity of this area of study.

### ***Partnership characteristics***

Partnership characteristics refer to the features or qualities that define the nature of research partnerships. This could include the variety of expertise, perspectives, and backgrounds among partners (i.e., partnership composition), the geographical setting (e.g., Canada), the research context (e.g., child health), the research focus (e.g., physical activity), and the research partnership approach used (e.g., iKT). Characteristics provide the foundational qualities that define the partnership.

### ***Partnership dynamics***

Partnership dynamics refer to the patterns of interaction and relational aspects (e.g., trust, dialogue, roles, conflict management, power sharing) that develop and evolve between partners. Partnership dynamics are influenced by both individual determinants for working in partnership (e.g., capability, opportunity, motivation) and structural factors (e.g., resources, formal agreements, diversity of relationships, and partnership principles) (Wallerstein et al., 2008; Ortiz et al., 2020). Dynamics refer to and influence how partners work together.

### ***Partnership processes***

Partnership processes refer to the conduct, management, and maintenance of research partnerships through a series of actions or steps. These can include the actions used to form partnerships, secure funding, plan, conduct, and disseminate research and evaluate partnerships. They also include the strategies used to engage knowledge users in these steps. The specific actions will depend on the goals, characteristics, and dynamics of each partnership. Research partnerships also operate within larger systems (e.g., academic, political, organizational, and social contexts) and structures (e.g., research or science, funding, ethics) that influence these actions (Bowen et al., 2022; Hutchinson et al., 2022; Rycroft-Malone et al., 2022). Therefore, processes describe how partnerships “function” in practice. Partnership processes are the structured activities and procedures that partners use to work towards partnership goals.

### ***Effects***

While there is no universally accepted definition of research partnership effects, they include intended or unintended changes due directly or indirectly to an intervention (Belcher & Pallenberg, 2018, as cited in Sibley et al., 2022). The term *effects* has recently been used to refer collectively to outcomes and impacts of research partnerships (Sibley et al., 2022) due to their poor differentiation in the research partnership literature (Hoekstra et al., 2020). Outcomes refer to specific, measurable short- or medium-term effects (e.g., increased research uptake) (Hoekstra et al., 2018), while impacts denote long-term or secondary effects on larger systems, such as the economy, society, or health (e.g., improved health outcomes) (Higher Education Funding Council for England, 2014). Due to the recurring conceptual ambiguity in assessing and reporting outcomes and impacts (Mrklas et al., 2023), the term *effects* is preferred throughout this dissertation. Partnership effects are influenced by the interplay between partnership characteristics, dynamics, and processes.

## **2.4 Theories, models, and frameworks (TMFs) for research partnerships**

Theories, models, and frameworks (TMF) can guide research partnership design, process, and evaluation. These tools offer structured approaches for understanding partnership dynamics, identifying key factors influencing partnership success, and informing decision-making processes (Nilsen, 2015). However, conceptual guidance for research partnerships is still evolving, with no dominant TMF established (Nguyen et al., 2020; Tittlemier et al., 2022). Consequently, TMF use in research partnerships remains limited. For example, a review by Camden et al. (2015) on iKT in rehabilitation found that no iKT activities were grounded in theory. Similarly, a review of iKT by Gagliardi et al. (2016) observed that no studies explicitly referenced using theory as the basis for iKT initiatives or their components.

The absence of a single overarching TMF reflects the diversity and complexity of research partnerships. This absence has several implications. On the one hand, it underscores the need for flexibility and adaptability in designing and executing research partnerships to suit each project's specific needs and circumstances. It also emphasizes the importance of drawing on suitable TMFs from various approaches to inform the development and evaluation of research partnerships (MacFarlane & Salsberg, 2023). For instance, approaches like iKT, CBPR, and PAR may offer valuable insights and perspectives on engaging knowledge users, sharing power, and co-producing knowledge within research partnerships. However, the lack of a unified framework can also challenge consistency, coherence, scalability, and comparability across studies. Without clear guidance, researchers may struggle to navigate research partnerships' complexities and effectively plan, implement, and evaluate their partnerships.

There is a growing recognized need for further research and development of TMFs to provide more comprehensive guidance. Several existing reviews in the field have begun to provide theoretical direction for research partnerships. For instance, Jull et al. (2019) synthesized 54 articles describing frameworks for engagement in health research to identify concepts of knowledge user engagement.

Directed content analysis of frameworks identified 15 concepts reported across 4 research phases of prepare, plan, conduct, and apply, though concepts may be present across phases (Jull et al., 2019). Articles reported an average of 7 concepts per framework (range: 1-13), with the most common being knowledge user – prepare, support (81%), relational process (72%), and research agenda (70%) (Jull et al., 2019). These concepts are intended to serve as a fluid guide whereby teams engage in partnered negotiation to identify where and how knowledge users should be engaged (Jull et al., 2019). However, this review did not describe the identified frameworks' characteristics, limiting the researchers' utility in selecting appropriate TMFs. Therefore, Tittlemier et al. (2022) conducted a scoping review to identify and describe the characteristics of TMFs used in health research partnerships and aligned these with the Jull framework. They identified 39 models and frameworks of research partnerships but found no theories (Tittlemier et al., 2022). Studies predominantly used models and frameworks to guide or manage a research partnership (36%), and the Jull concept of ethical principles and values was the most represented (92%) (Tittlemier et al., 2022). These findings offer a valuable roadmap for research partnership teams to help select models and frameworks to guide the partnership process. Unfortunately, this review was not available when I conceptualized my dissertation.

Although no grand TMF exists for research partnerships, MacFarlane and Salsberg (2023) emphasize the importance of theorizing to facilitate grouping ideas, think about their relationships, and develop building blocks for theory. For example, the work by Nguyen et al. (2020) to enhance conceptual clarity around shared values and principles across traditions provides critical theoretical contributions. Within traditions, a conceptual model for CBPR offers a helpful framework for understanding the contextual and process-related factors that affect project outcomes and goals (Wallerstein et al., 2008; Wallerstein et al., 2017). Moreover, there is value in theorizing about recurring concepts in the research partnership literature, such as trust, inclusivity, and power, to enhance thinking about research partnerships (MacFarlane & Salsberg, 2023).

## **2.5 Current evidence in research partnerships**

Over the past decade, there has been a noticeable shift from promoting research partnerships to a more focused exploration of how partnerships function in practice (Bowen et al., 2016; Gagliardi & Dobrow, 2016), coupled with efforts to guide practice (Gainforth et al., 2021; Hoekstra et al., 2020) and understand their effects (Mrklas et al., 2022). This commitment to advancing the science of research partnerships in the Canadian context is promoted in part by initiatives such as an iKT research network (Graham, Kothari, & McCutcheon, 2018), which proposed a series of interrelated research studies aimed at testing the assumption that partnered research produces beneficial effects. Similarly, commentaries have provided reflections on the current state of iKT (Kothari & Wathen, 2017) and co-production (Oliver, Kothari, & Mays, 2019) while also identifying emerging areas for further scholarly inquiry in this domain (Gagliardi et al., 2017).

### ***Broader reviews adopting research partnership framing***

Reviews adopting a wider research partnership framing (i.e., including various research partnership approaches) provide foundational guidance to understand research partnerships and identify knowledge gaps (Hoekstra et al., 2020; Mrklas et al., 2022). A meta-review of 86 reviews was the first to synthesize diverse research partnership approaches across multiple fields and serves as a first step in developing a classification system to foster reporting consistency and guide practice (Hoekstra et al., 2020). Encompassing studies from inception through 2018, this meta-review employed coding manuals to distill overarching principles, strategies, outcomes, and impacts. Reviews were globally representative, with the majority originating from the US (42%), Canada (20%), and the UK (17%), and broad in foci, with most encompassing population health (40%), health services (29%), and social sciences (19%), with 74% published since 2012. From the 86 reviews, Hoekstra et al. (2020) extracted detailed information on engagement from 18 reviews (21%), representing approximately 870 studies. Knowledge users were predominantly engaged in identifying research questions (54%), developing study

design and methods (47%) and data collection (45%). Findings were synthesized into 98 principles (17 overarching), 111 strategies (11 overarching), and 82 outcomes/impacts (56 beneficial, 26 challenging). While their approach was deliberately high-level due to a lack of reported detail, it offers the potential to guide partnership reporting and practices across disciplines. Nevertheless, the broad findings lack tailoring to specific knowledge users or research contexts. Furthermore, inconsistent terminology and inadequate reporting on partnership processes impeded the synthesis of findings. For example, in the 18 reviews where information was extracted, 15 (83%) indicated a lack of reporting on knowledge user engagement. More granular reporting and standardized terminology used across research partnership literature are required to understand the efficacy of principles and strategies under different circumstances. Moreover, in-depth studies are needed to advance our understanding of partnership dynamics and effects.

Mrklas and colleagues conducted two important studies to understand and assess the effects of research partnerships. In their 2022 study, they conducted a systematic review to explore health research partnership effects, focusing on developing, using, and assessing evaluation tools (Mrklas et al., 2022). The review included 37 articles from inception through 2021, primarily from North America (83%) and published after 2010 (65%). However, most studies focused on identifying, refining, and testing tool constructs, with fewer focused on evaluating specific partnership outcomes and impacts (38%). Few studies reported partnership outcomes (n=9, 24%), impacts (n=2, 5%), or both (n=3, 8%), and 90% reported positive outcomes. A total of 48 outcomes were identified across 12 studies, predominantly at the partnership level (56%), including personal (e.g., ownership, commitment, empowerment), functional (e.g., synergy), and structural (e.g., process, resource sharing) outcomes. Additionally, 55 impacts were reported across four studies, with individual-level impacts being the most frequent (51%). However, most impacts (73%) were reported by a single study. The review authors concluded that there is substandard reporting of outcomes and impacts and diverse use of terms and frameworks (Mrklas et

al., 2022). In a complementary review, Mrklas et al. (2023) further identified and characterized tools for assessing partnership outcomes and impacts, providing enhanced access to evaluation tools for research partnership teams. The review identified 205 partnership assessment tools from 166 unique papers, primarily from North America and published after 2015. Most tools were developed using mixed methods designs, with partnerships frequently initiated by researchers and funded by government agencies. Despite being moderately comprehensive and usable, tools exhibited low scientific rigour, and the interchangeability of terms added complexity to measurement and comparison (Mrklas et al., 2023). Furthermore, most tools were single use, requiring further development and testing. Both studies underscored the need for clearer reporting, standardized terminology, and increased rigor in assessing partnership outcomes and impacts (Mrklas et al., 2022; Mrklas et al., 2023). Moreover, they highlight the need for future research to explore whether distinct partnership types require tailored assessment tools or if standardized tools can be developed and applied across diverse partnership contexts (Mrklas et al., 2023).

While these reviews advance our understanding of research partnerships across contexts, their intentionally high-level focus also presents challenges (Hoekstra et al., 2020). For example, the focus on psychometrically sound evaluation tools, as emphasized by Mrklas et al. (2022), may be pre-emptive to achieving a basic understanding of partnership effects in child health research partnerships, which are currently lacking (Vanderhout et al., 2023). Second, the broad scope of these reviews may fail to account for the nuanced processes and dynamics specific to child health contexts, where tailored approaches may be required to effectively engage a range of knowledge users, navigate ethical considerations, and address the unique needs of children and families. Therefore, a comprehensive understanding of partnership dynamics and processes within child health research is imperative to maximize partnership effects. Additionally, there is an ongoing need to address existing challenges in comprehensively reporting and synthesizing the research partnership literature.

### ***Primary studies***

Several primary studies describe research partnerships' characteristics, dynamics, processes, and effects, overcoming challenges encountered using review methods. An evaluation of the CIHR's Knowledge Translation Funding Program (McLean & Tucker, 2013) remains the most extensive primary assessment of a health funder's research program on research co-production in health. This comprehensive evaluation, which surveyed CIHR projects funded between 2005 and 2009, highlighted a widespread belief among researchers and knowledge users that partnerships enhanced the uptake of study results, increased the likelihood of impact, and established the groundwork for future collaborations (Sibbald et al., 2019). Furthermore, it revealed differing perceptions of the partnership process between researchers and knowledge users (Sibbald et al., 2019). Semi-structured interviews conducted as part of this evaluation found that many partnerships formed in non-linear ways, with most based on pre-existing relationships (Sibbald et al., 2014). Partnerships were diverse and facilitated by established relationships, goal alignment, skilled researchers, and communication, and challenged by lack of role clarity, organizational change, and competing agendas (Sibbald et al., 2014). However, they noted the need for further research to identify factors that support partnership processes, dynamics, and effects (Sibbald et al., 2019). Sibley et al. (2023) recently analyzed 1153 Canadian federal and provincial partnered health research projects funded between 2011 and 2019. Findings revealed a broad spectrum of partnered health research spanning numerous fields and disciplines, with evolving trends, including decreased required partnerships, longer project durations, and higher funding allocations (Sibley et al., 2023). This foundational work provides important insights into the conduct of research partnerships within the Canadian context from the past decade. Presently, Sibley and colleagues conducted the most extensive analysis of partnered research to date within the Canadian context to enhance our understanding of factors predicting perceived effects among provincially and federally funded partnered health research projects, addressing temporal limitations of the previous CIHR

evaluation (Sibley et al., in review). This provides an opportunity to examine partnerships across research contexts (e.g., child health) and explore the interplay between partnership characteristics, dynamics, processes and effects.

Across other partnership traditions, a body of long-standing evidence exists. Extensive CBPR work from the University of New Mexico's Center for Participatory Research over the past two decades has engaged in targeted investigations to identify which partnering practices, under which contexts and conditions, contribute to outcomes (Wallerstein et al., 2020). To highlight a few key studies, Duran et al. (2019) identified promising practices for CBPR system and capacity outcomes, focusing specifically on the relationship between context, processes, and outcomes. Similarly, Dickson et al. (2020) conducted a cross-sectional study from 2015-2016 of 179 CBPR and community-engaged research projects that received federal funding in 2015, examining partnership characteristics and practices relative to the partnership stage. They found that more established partnerships were more likely to exhibit these promising practices (Duran et al., 2019), such as formal discussions on values and power, stewardship for community benefit, and advisory group roles, strengthening relationships, and improving capacity to achieve aspired outcomes (Dickson et al., 2020).

Evidence is needed to identify how partnerships operate in practice, including how and when knowledge users are engaged in the research process and which strategies are effective (Camden et al., 2015; Gagliardi et al., 2016; Lawrence et al., 2019; Hoekstra et al., 2020). Further research is needed to identify factors supporting relationship-building, partnership quality, and sustainability (Sibbald et al., 2019). Enhancing our understanding of partnership dynamics and processes is crucial for elucidating how partnerships function and explaining the mechanisms driving partnership effects (Hoekstra et al., 2022).

***Child health research partnership reviews: a siloed approach***

At the outset of my dissertation, the landscape of child health research partnership reviews was relatively sparse. Early reviews focused on PE (Bailey et al., 2015; Bradbury-Jones et al., 2018; Flynn et al., 2019), PR (Bradbury-Jones et al., 2018) and CBPR (Vaughn et al., 2013) approaches. These early reviews provide a foundation for understanding research partnerships within specific child health contexts but focused exclusively on engagement with children, youth, parents, and families within the community (Vaughn et al., 2013; Bradbury-Jones et al., 2018) or acute and tertiary healthcare settings (Shen et al., 2017; Flynn et al., 2019). Vaughn et al. (2013) reviewed CBPR involving youth in child health research, including 34 articles published from 1985 to 2012. While the review highlighted the empowering effects of youth involvement, it noted limitations in reporting specific types of involvement and measuring youth development (Vaughn et al., 2013). For example, only 1 study measured youth development, and most studies merely mentioned youth involvement without providing details on their involvement. However, being the sole review focused on CBPR approaches, it provides evidence of partnerships in community settings, albeit with temporal and methodological limitations. For example, the authors do not appear to use established review methodologies, and their dated findings may not reflect recent developments in CBPR practice. Furthermore, due to the longitudinal nature of CBPR partnerships often spread over time and across publications, Vaughn et al. (2013) highlighted the need for longitudinal analyses to understand partnership practices and long-term effects better.

Two reviews examined partnerships involving vulnerable children and young people using PE (Bailey et al., 2015) and PR approaches (Bradbury-Jones et al., 2018). Bailey et al. (2015) investigated the involvement of disabled children and young people (DCYP) as research partners across 22 studies. Although the review collated recommendations for involving DCYP in research, it highlighted few well-reported examples, low-quality evidence, and underreporting of involvement practices, limiting the utility of these recommendations. In contrast, Bradbury-Jones et al. (2018) conducted a qualitative

systematic review to identify, synthesize, and critically examine the methodological, ethical, and practical issues involved in PR with vulnerable or marginalized children. The 13 included articles were international in scope and highlighted methodological (e.g., increasing relevance, novelty, and integrity of research findings) and ethical reasons (e.g., equalizing power differences, giving voice) for adopting a PR approach. This review emphasized the significance of power, empowerment, and voice in critiquing participatory approaches, showcasing how vulnerable children can exert agency through participatory activity (Bradbury-Jones et al., 2018). However, it also identified challenges in defining vulnerability and recommended flexible, context-specific approaches to PR. While this study offered guidance on partnership principles and processes, it had conceptual limitations, such as assuming homogeneity across vulnerable children's groups, and noted few systematic or critical evaluations of participatory research with vulnerable children. Thus, while providing conceptual insights on power, ethics, and practical aspects of engagement, the study focused primarily on engagement with disabled youth from the PR perspective, suggesting the need for expansion to encompass other approaches and populations.

Two reviews focused on engaging with parents and families in acute and tertiary health care settings. Shen et al. (2017) focused on engaging parents as co-researchers in child health research, highlighting benefits such as enhanced research quality and dissemination. Parents were primarily recruited through existing relationships, with studies involving parents across various research stages, most commonly in developing research questions, study aims, and setting research priorities, and less so in project conceptualization or grant writing (Shen et al., 2017). Nine of 10 articles reported benefits to researchers, including the development of more sustainable interventions and improved research quality, while also noting parent empowerment and increased awareness of health issues (Shen et al., 2017). Commonly identified challenges included power imbalances, disconnects between parents and researchers, and increased resource demands (Shen et al., 2017). The review emphasized the need for more high-quality research to inform best practices in parent engagement (Shen et al., 2017).

Similarly, Flynn et al. (2019) conducted a scoping review examining strategies for engaging patients and families in pediatric health research, encompassing 17 articles, with most published after 2009. Engagement often involved parents and children (29%) or solely parents (29%), with activities reported at consultative and involvement levels across the research process. Themes addressing power dynamics between researchers and partners emerged in a minority of studies (n=4, 24%), alongside strategies such as team meetings and fostering trusting relationships to mitigate power imbalances. Benefits to PE in child health research included enhanced empowerment, confidence, and enthusiasm among the engaged population and the generation of more relevant and applicable research findings. However, limitations in reporting and lack of evaluation were noted across the included studies, hindering the description of PE practices (Flynn et al., 2019).

Recent reviews signal a growing recognition of the importance of incorporating children's voices in health research through partnerships (Rouncefield-Swales et al., 2021; Freire et al., 2022) and in furthering our understanding of PE effects (Vanderhout et al., 2023). Rouncefield-Swales et al. (2021) conducted a comprehensive scoping review of patient and public involvement and engagement (PPIE) in child health research, emphasizing the importance of flexibility and authenticity in involving children and young people in research. Data was collated on 38 primary research studies, mainly from the UK (84%), with most published after 2009 (97%). The review revealed ambiguities in the quality of reporting of PPIE with children, with transparent reporting on demographics and involvement methods (92%), but mixed reporting on PPIE definition (58%), impact, contextual and process factors affecting PPIE (72%), and critical learning from the PPIE (71%). There was low-quality reporting on TMF use (42%) and the methods of evaluating impact (18%). While studies engaged children and young people throughout the research process, there was considerable variation in the level of involvement and limited formal evaluation of impact (3%). Fourteen studies (37%) directly reported impacts on children and young people (e.g., gaining skills, confidence, employment opportunities), 32 (84%) reported impact on the

research (e.g., strengthening study design, conduct and rigor, greater resonance) and researchers (e.g., skills, further funding) as well as clear impacts on the different stages of the research process (e.g., improving ethical basis, identifying priorities, change in language). Despite their thorough examination, the review highlighted challenges in reporting and evaluating PPIE activities. It emphasized the need not to view 'more' PPIE as better but rather to accommodate flexible PPIE based on preferences (Rouncefield-Swales et al., 2021). Freire et al. (2022) synthesized methods for involving children and adolescents in PR across 26 studies, emphasizing diverse approaches. Most studies (85%) involved children or adolescents as co-researchers alongside family, carers, and other co-researchers. Most studies (85%) used multiple activities, with focus groups (58%), interviews (38%), and photovoice (35%) being the most common (Freire et al., 2022). Despite providing practical insights into engaging children and families in research, the review was limited in methodological quality, underscoring challenges in assessing participatory approaches using review methods. This review was also limited in scope, focusing on health resources and intervention design, limiting generalizability, and providing no detail on the 'other' co-researchers.

Finally, Vanderhout et al. (2023) conducted a scoping review of studies describing at least one impact of patient and family engagement in child health research. They found positive effects on research relevance, feasibility, and empowerment of researchers, children, and families. However, the review highlighted limitations in evaluating impact and searching the field. For example, less than half (44%) had a primary purpose of determining impact, and no study used a specific evaluation tool. Most reported impacts were on the research process (n=24, 96%), 11 (44%) determined impacts on the research team, and 17 (68%) reported impacts on patient and family partners. Reported impacts were similar among studies that engaged children or youth compared with those that engaged parents or family members in research. While this research extends previous reviews of PE in adult health research settings, there is a need to assess impacts from a broader research partnership lens, including diverse

stakeholders (Vanderhout et al., 2023). Similarly, Rouncefield-Swales et al. (2021) report the need for broader conceptualizations of impact.

### ***Challenges and limitations: reporting and measurement challenges***

Navigating through child health research partnership literature mirrors challenges encountered in general partnership reviews that are not specific to any specific population or condition. Variability in terminology, publication aims, and reporting practices complicate the identification and synthesis of studies. Additionally, the diverse nature of child health research partnerships, spanning different disciplines and knowledge user groups, further complicates the review process. Despite these challenges, the increasing body of literature on child health research partnerships emphasize the need for continued attention. Future reviews should overcome isolated approaches and adopt inclusive methodologies to capture the diverse spectrum of partnership models and practices within child health contexts. Moreover, enhancing reporting standards and methodological rigor is crucial for advancing the evidence base and facilitating effective collaboration in child health research. Several reviews underscore the importance of delving deeper into tensions within child health research partnerships, such as ethical considerations (Bradbury-Jones et al., 2018) and power dynamics (Flynn et al., 2019; Rouncefield-Swales et al., 2021). Moreover, there remains a lack of studies elucidating the intricacies of partnerships in child versus adult contexts.

### ***Summary of gaps***

Recognized challenges to partnering include navigating power dynamics, addressing divergent problem-solving styles (Sibbald et al., 2019), grappling with limited resources (Sibbald et al., 2014), and identifying the necessary infrastructure, timelines, and researcher qualities essential for cultivating meaningful relationships with knowledge users (Kothari, McCutcheon & Graham, 2017). Furthermore, most barriers to research partnerships relate to the process of engaging between researchers and research users (Sibley et al., 2022). There remains a need to systematically explore the characteristics,

dynamics, processes, and effects across diverse child health research partnerships, encompassing diverse knowledge users. A case study of six research partnerships with young people revealed shared values (i.e., dynamics) but different approaches (i.e., processes) in how project teams implemented them (Nguyen et al., 2022). For example, projects demonstrated respect for each other's contributions in diverse ways. Some projects offered financial compensation and access to training and networking to recognize young people's efforts, while others used verbal and written recognition, leadership opportunities, and collaborative decision-making opportunities (Nguyen et al., 2022).

Moreover, there is a need to move beyond the focus on limited knowledge user groups. A recent convergent mixed-methods study aimed at understanding the priorities, practices, and perceptions of successful knowledge mobilization activities in pediatric pain highlighted unique and common perspectives among healthcare professionals, patients, and researchers (Mackenzie et al., 2024). For example, there was agreement across groups on the role of team dynamics but partial agreement on the role of leadership, policy influence, and social influence (Mackenzie et al., 2024). These findings underscore the need to delineate and tailor processes to meet the specific needs and priorities of different knowledge user groups involved in child health research partnerships. Lastly, there is a dearth of evidence on child health partnership effects and a documented need for continued study on child health research partnerships to legitimize their use (Mackenzie et al., 2024; Vanderhout et al., 2023). By synthesizing existing evidence from a broader perspective and addressing persistent methodological challenges using complementary methods, this dissertation aims to contribute to a deeper understanding of research partnerships in child health contexts and address identified gaps in the field.

## **2.6 Conclusion**

As I conclude this chapter, I find myself grappling with the complexities of the field. However, reflecting on the historical origins of research partnerships underscores a sustained commitment to

conducting socially responsive, impactful research. Conducting research partnerships remains challenging, but it is valuable work not meant for all researchers. Described by Langley et al. (2022) as a way of 'being,' researchers undertaking partnered research approaches require a unique set of qualities, dedication and resources. Given the complex nature of research partnerships, studying it remains equally tricky. The gaps identified in this chapter highlight the evolving nature of the field and the ongoing efforts of researchers and knowledge users to advance it. The subsequent chapters of this dissertation aim to address some of these gaps from the purview of child health, contributing to its continued growth and development.

### **Chapter 3: Methodology**

This chapter provides an overview of the methodology underpinning my study of research partnerships' characteristics, dynamics, processes, and effects in child health. This chapter outlines the philosophical underpinnings and use of guiding frameworks, introduces the concurrent mixed-methods approach employed, and sets the stage for the detailed data collection and analysis procedures presented in subsequent chapters.

#### **3.1 Positionality statement**

As the researcher undertaking this study, it is important to acknowledge my positionality and its influence on the research process and findings (Hesse-Biber, 2017). This importance stems from the 'researcher as instrument' concept, emphasizing the influence of my knowledge, perspective, and subjectivity in all stages of the research process (Given, 2008). Therefore, my interest in this research comes from experiences in my professional and personal life, which I share below.

My ancestry and upbringing inform my perspective on the importance of research partnerships. I acknowledge and embrace my ancestral heritage, which includes both settler and Indigenous ancestry. My family history reflects the intersecting legacies of colonization and Indigenous resilience, and I recognize the responsibilities and privileges that come with this heritage. Growing up in a small community in northern Manitoba with parents involved in health care, health promotion, and community development, I learned the significance of reciprocity, respect, and community engagement from an early age. This background instilled in me the importance of working with and learning from those in the community to address local needs. These experiences inform how I navigate the complexities and sensitivity required to study research partnerships. While my research does not specifically focus on Indigenous health, I approach my research with respect for Indigenous knowledge and perspectives, recognizing the ongoing impacts of settler colonialism on Indigenous peoples.

My exposure to knowledge translation and research partnerships began in my master's training. At this time, I had practical exposure to the intersection of research and health policy. I also worked in Kenya for three months with the Centre for Global Public Health on a maternal child health project using a program science approach. Through the Manitoba Training Program for Health Services Research at both the MSc and PhD levels, I also had two opportunities where I spent four months embedded in research to practice roles at Manitoba Health, the latter focused specifically on knowledge translation (KT). At the tail end of my master's training, I was offered a joint knowledge broker role with the George and Fay Yee Centre for Healthcare Innovation and a national knowledge mobilization network in pediatric emergency care, focusing on bridging these 'two worlds.' At the time, I had no clue what a knowledge broker was, nor did I fully understand the field of KT. During this time, I had the opportunity to learn both the practice and science of KT, which became my impetus for my PhD training focused on research partnerships in child health. Practically, conceptual blurring was evident even in my brief exposure (knowledge mobilization, knowledge translation, program science). Even when preparing for my interview, I remember reflecting on KT and thinking, "Oh, I've done that.... It was just named something different". Little did I know that it would start the next decade of my life and likely much longer.

As someone who has worked as a knowledge broker, student, and staff member involved in various partnered health research projects, I have gained firsthand insight into the intricate workings of partnering. From individual research interactions to network, policy, and global health initiatives, I have witnessed the extensive coordination, effort, and ongoing relationship-building required to sustain partnerships. Through these experiences, I have directly encountered the dynamic nature of engagement, ranging from varying levels of partner involvement to fluctuating activity levels within partnerships. I have observed and navigated the numerous internal and external personal, systemic, and political factors influencing these partnerships. Additionally, I have grappled with the challenge of

measuring and reporting on partnership effects for funders and year-end reports. Throughout my academic journey, particularly during my graduate studies, I have observed a notable progression in the field's science and practice. However, partnered research practices are still evolving and far from standard. Based on these early experiences, I began this thesis journey from the perspective of iKT, which has since expanded to research partnerships. This early iKT framing is evident in how I talk about research partnerships, their history, and my methodological decision-making. Due to my experiences and training environment, it is challenging to disengage from this perspective. As a result, the influence of iKT thinking permeates my perspectives.

While conducting this research focused on research partnerships in child health, I have considered myself within, outside, and neither. My role in and understanding of research, KT, research partnerships, and the child health context has been dynamic throughout my time conducting this research. As a novice researcher involved in research partnerships but with little experience *leading* a research partnership, I consider myself both an outsider and within. Throughout my education and career, I have always been drawn to and involved in child health research and initiatives without a real driver for why. I also became a mother while conducting this research, shifting my position from an outsider to within and providing additional richness to my insight. It is my new role as a mother, in particular, that drives my passion for ensuring health research is relevant, meaningful, and used in practice. And a key component of this is advancing the science of research partnerships.

### **3.2 Philosophical underpinnings: pragmatism**

At the core of this study lies a commitment to the philosophical stance of pragmatism. As early first and second-wave pragmatic philosophers such as James and Dewey theorized, pragmatism emphasizes the practical consequences of beliefs and actions, departing from notions of absolute truth and reality (Dewey, 2008). Within the context of research partnerships, pragmatism offers a flexible and adaptive philosophical orientation that acknowledges the dynamic and ever-evolving nature of

collaboration. As a research paradigm, pragmatism supports using methodological approaches that work best for the research problem(s) and embraces a plurality of methods (Kaushik & Walsh, 2019).

Epistemologically, pragmatism operates under the premise that research can sidestep metaphysical debates concerning truth and reality (Kelly & Cordeiro, 2020). Instead, it prioritizes practical understanding of tangible, real-world issues (Kelly & Cordeiro, 2020), recognizing that complex social problems require multipronged approaches (Allemang, Sitter, & Dimitropoulos, 2021). Allemang and colleagues (2021) highlight the connections between the principles of pragmatism and patient-oriented research, including democratic values, collaborative problem-solving approaches, and the pursuit of social justice, reinforcing its suitability for understanding research partnerships.

In contrast to philosophies that emphasize the nature of reality, pragmatists emphasize the nature of experience and practical relevance (Morgan, 2014). Three ideas central to pragmatism render this theoretical approach appropriate for research partnerships, including context, a focus on practical outcomes, and pluralism of perspectives (Morgan, 2014). First, pragmatism emphasizes our beliefs and actions as they relate to the situations and contexts in which they occur. Second, our actions or practices change over time and link to consequences or outcomes. Finally, these actions or practices depend on worldviews that include socially shared sets of beliefs as well as individually unique experiences (Morgan, 2007). When exploring the experiences of researchers and knowledge users engaged in research partnerships, this interplay of experience, context, beliefs, practices, and worldviews is critical to understanding current practices.

Pragmatism also underscores the significance of interdisciplinary collaboration and the integration of diverse perspectives. This aligns with the inherently multidisciplinary nature of child health research, where stakeholders from various disciplines must come together to improve outcomes for children and families. My positionality as a researcher aligns with pragmatism in several ways. First, my background gives me a nuanced understanding of the complexities partnered child health research,

allowing me to understand how partnerships function in practice. Second, my professional experiences have shaped my research approach, emphasizing the importance of practical research and actionable outcomes. Although I hold inherent biases and perspectives, I hold a pragmatic view that truth is context-dependent and is shaped by its practical implications. By embracing pragmatism, I recognize the potential for research partnerships to drive meaningful change in child health research, practice, and policy. I aim to incorporate diverse perspectives in my research to develop insights that address real-world challenges.

### **3.3 Conceptual underpinnings**

#### ***Jull Concepts for Knowledge User Engagement***

In conjunction with my methodological stance of pragmatism, Jull's conceptual framework for knowledge user engagement informed my methodology. The 15 concepts identified by Jull et al. (2019) can help researchers operationalize knowledge user engagement while recognizing their fluidity. The Jull framework informed my study design, data collection instruments, and interpretation of findings. By grounding the design of my data collection instruments in the Jull concepts, I ensured that my study remained responsive to the key components. Additionally, the Jull framework provided a theoretical framework for interpreting my findings, allowing me to contextualize research partnership processes and effects within a generalizable framework. I map the constructs to my objectives in table 3.1.

The Jull framework serves as a lens through which I structured my study of research partnership processes in child health. The framework outlines stages of the research process where knowledge user engagement is essential. By weaving these throughout my data collection instruments (e.g., research stage, engagement practices), I aimed to identify common themes and patterns that characterize research partnerships in child health. For example, I included various Jull concepts, such as defining the research question, choosing study methods, and involvement in data analysis, in both the development of the data extraction form for objective 1 and in variables used for analysis in objective 3 (see Table 3.1

for a mapping of Jull concepts to research objectives). The framework helped identify patterns and variations in knowledge user involvement across various research partnerships. By identifying where a concept was examined multiple ways across study objectives, I was able to examine areas of convergence and divergence more thoroughly. Through this lens, I sought to elucidate the conditions facilitating collaboration within the child health context.

Jull concepts not captured in the scoping review or survey, such as ethical principles and relationship processes, were incorporated into the semi-structured interview guide. By deconstructing the various principles and relational processes using qualitative methods, I sought to understand the dynamics and processes that influence partnership effects. Through this analysis, I aimed to illuminate the interplay of factors that shape the success or failure of research partnerships in advancing child health research and practice.

Finally, the Jull framework emphasizes the importance of evaluation and can help understand the effects of research partnerships. While the 'evaluate' category within the framework may lack specificity and utility, the framework enables a comprehensive understanding of the various partnership processes that may contribute to or hinder achieving desired partnership effects. By identifying strengths and weaknesses across concepts and contextualizing them within the broader study findings, I can pinpoint areas for improvement and provide recommendations to optimize partnership effectiveness.

I initially chose the Jull framework during the early conceptual phases of this study due to a perceived lack of theoretical guidance in the field at the time, particularly from my earlier stance of iKT, where guidance was limited. However, it is worth commenting on its perceived utility retrospectively. The Jull framework's lack of specificity in its described concepts limits its application. Having practical knowledge of research partnerships, I feel this framework provided little additional insight to my thinking. However, it is challenging to discern whether my understanding of these concepts had

sufficiently evolved by that stage or if its limitations only became apparent in conjunction with my intellectual growth and the benefit of hindsight. The availability of the review conducted by Tittlemier et al. (2022) might have led me to adopt different theoretical guidance. Likewise, leveraging frameworks in other research partnership approaches may have led me to adopt more useful theoretical guidance. For example, the CBPR conceptual model (Wallerstein et al., 2008) would have been relevant due to its focus on the relationship between processes (contexts, group dynamic processes, research design) and effects.

Table 3.1 Mapping of Jull (2019) Concepts to Research Objectives

Jull Concept	Description of concept	Objective		
		1	2	3
Researcher: prepare, support	Initiate/support researcher capacity/behaviour for power sharing, expertise, engagement - includes language and knowledge differences, learning (e.g. attending meetings with community groups, volunteering, and working with groups to understand knowledge user perspectives)	✓	✓	✓
Knowledge user: prepare, support	Initiate/support knowledge user/community organizational capacity/behaviour for power sharing, expertise, engagement (e.g. develop resource manual, provide training in research methods)	✓	✓	✓
Relational process	Initiate and/or sustain a relational process (relationship building) between knowledge user-researcher to promote respect, reciprocity, trust and partnership synergy		✓	
Research agenda	Engage in a process to define study agenda: scope, priorities, objective(s)	✓		✓
Ethics: principles/values	Conduct knowledge user-researcher partnership work in an ethical way demonstrated by reflection on ethical concepts, and/or concern with particular values and research conducted in ways reported as meaningful, respectful, inclusive of those in the research partnership. Evidence of principled (versus policy, rules) research conduct		✓	
Research questions	Define research questions to identify what, specifically, the research project aims to achieve to justify the need to conduct the research (i.e. how/why was this topic chosen? What gap will it fill?)	✓		✓
Resources	Develop funding applications/grant proposals for and/or to obtain resources (e.g. funding, time) to support knowledge user-researcher engagement	✓	✓	✓
Ethics: policy/rules	Conduct knowledge user-research partnership work in an ethical way demonstrated by participation in an ethical application development (e.g. writing consent forms), review (e.g. research ethics board, community review) and/or development and/or use of an ethical framework (e.g. knowledge user role in the use of particular protocols, processes)	✓		✓
Methodology	Decide on the research methodology (approach) or report process to justify the use of the proposed methodology	✓		✓
Methods	Decide on research methods and a justification for the use of the proposed methods; selection of outcome measures	✓		✓
Collect data	Collect data and includes tool development	✓		✓
Analysis	Decide about the analysis and interpretation of data (e.g. what form of analysis and how will be conducted)	✓		✓

Disseminate	Identify the appropriate audience to disseminate the research findings and tailoring the message and medium to the audience to create tangible products (e.g. publication of findings, community meetings, et cetera)	✓		✓
Evaluate	Evaluate the research study processes	✓	✓	✓
Sustain	Maintain study benefits at a certain rate, level [i.e., make deliberate efforts to sustain study intervention(s)]		✓	✓

\* Meta-framework by Jull et al. (2019) postulates that partnered negotiation occurs throughout to jointly consider and these concepts as appropriate

### ***Relationship to other work***

Conceptually, this research stands independently but is strategically aligned with a larger CIHR project grant led by my advisor, Dr. Kathryn Sibley (CIHR project PJT #156372), which examines the conduct and evaluation of research partnership practices in Canada. The project grant seeks to: 1) develop a comprehensive understanding of current research partnership practice and 2) develop recommendations for conducting and evaluating research partnerships. The project team uses an iKT approach and involves people with lived experience of a health condition and people with lived professional experience, including health professionals, KT practitioners, research funding organization representatives, trainees, and academic researchers. Throughout this dissertation, I refer to a cross-sectional dataset of Canadian-funded partnered health research projects from 2011-2019 from this project grant. I leveraged this dataset to identify research partnership projects comprising the child health cohort (objective 3), for secondary analysis of respondent characteristics, perceived effects, and capability, opportunity, and motivation for working in partnership (objective 3) and use the concluding question of the questionnaire as the sampling frame to recruit researchers and knowledge users of child health research partnerships as interview participants (objectives 2 and 3). Due to my involvement in both projects, there is clear alignment in the design and analysis procedures, ensuring synergy and coherence between my dissertation and the broader CIHR project.

### **3.4 Research Design Overview**

I used an exploratory concurrent mixed-methods design. Mixed-methods research is frequently rooted in a pragmatic philosophy (Morgan, 2014), focused on the connection between the research questions, methods, and knowledge gained rather than the issue of competing epistemologies (Bryman, 2006; O'Reilly & Kiyimba, 2015). The research questions and objectives of the study inform my decision to use mixed methods within the pragmatic framework. Mixed-methods research allows a flexible approach, selecting and combining quantitative and qualitative methods based on the specific research

questions, objectives, and context. This flexibility enables researchers to tailor their methods to the study's unique needs, maximizing the findings' relevance and usefulness. By combining quantitative and qualitative approaches, I aimed to capture the complexity and richness of research partnerships in child health and address the limitations of each method when used alone (Castro et al., 2010). Quantitative methods provide breadth and generalizability (Creswell, 2009), allowing me to identify patterns and trends across various research partnerships. Qualitative methods offer depth and context (Creswell & Poth, 2016), enabling me to explore the nuances of research partnership dynamics and processes from the perspectives of researchers and knowledge users. Mixed methods align with pragmatism's emphasis on the importance of practical consequences and context by allowing triangulation of findings from different sources and perspectives, enhancing the validity and reliability of the study outcomes (Creswell & Plano Clark, 2018). By integrating mixed methods rooted in pragmatism, I intend to produce research responsive to the needs and priorities of those engaging in research partnerships, ultimately contributing to actionable insights and improved child health outcomes.

I undertook independent data collection and analysis procedures for each study (see Figure 3.4.1), with integration occurring in the discussion for expansion and elaboration (Creswell & Plano Clark, 2011). To address objective 1 (identify established characteristics of partnerships), I conducted a scoping review to systematically map published literature on research partnerships in child health, identifying key themes and trends. To address objective 2, I used interpretive description to explore experiences, motivations, and partnership dynamics. To address objective 3, I conducted a concurrent mixed-methods study to examine the role of the research context (i.e., child health) by comparing survey responses between child and general health cohorts on their perceptions of partnership effects and capability, opportunity, and motivation to work in partnership, along with interviews to explore perceived differences and considerations when partnering in child health research. Their contributions help answer my overarching question of "is child health a unique context for research partnerships?"

Each study advances understanding of research partnerships from different perspectives, contributing to a more holistic picture of research partnerships in child health (see Figure 3.4.2).

Although the studies exhibit both temporally concurrent and sequential elements, they follow a predominant concurrent design due to their independent design and analysis (Schoonenboom & Johnson, 2017). That is, their design was not dependent on or redirected due to the analysis results of another component. Sequential elements included in the study design include: 1) phase I of the scoping review, which occurred temporally before beginning survey analysis and conducting of the interviews, and 2) the sampling frame for the interviews was obtained from the primary survey responses. However, I updated the scoping review during my dissertation work, which occurred in tandem. While primary data collection for the survey occurred temporally before the interviews, creating the child health subset and subsequent analyses occurred concurrently alongside other study strands.

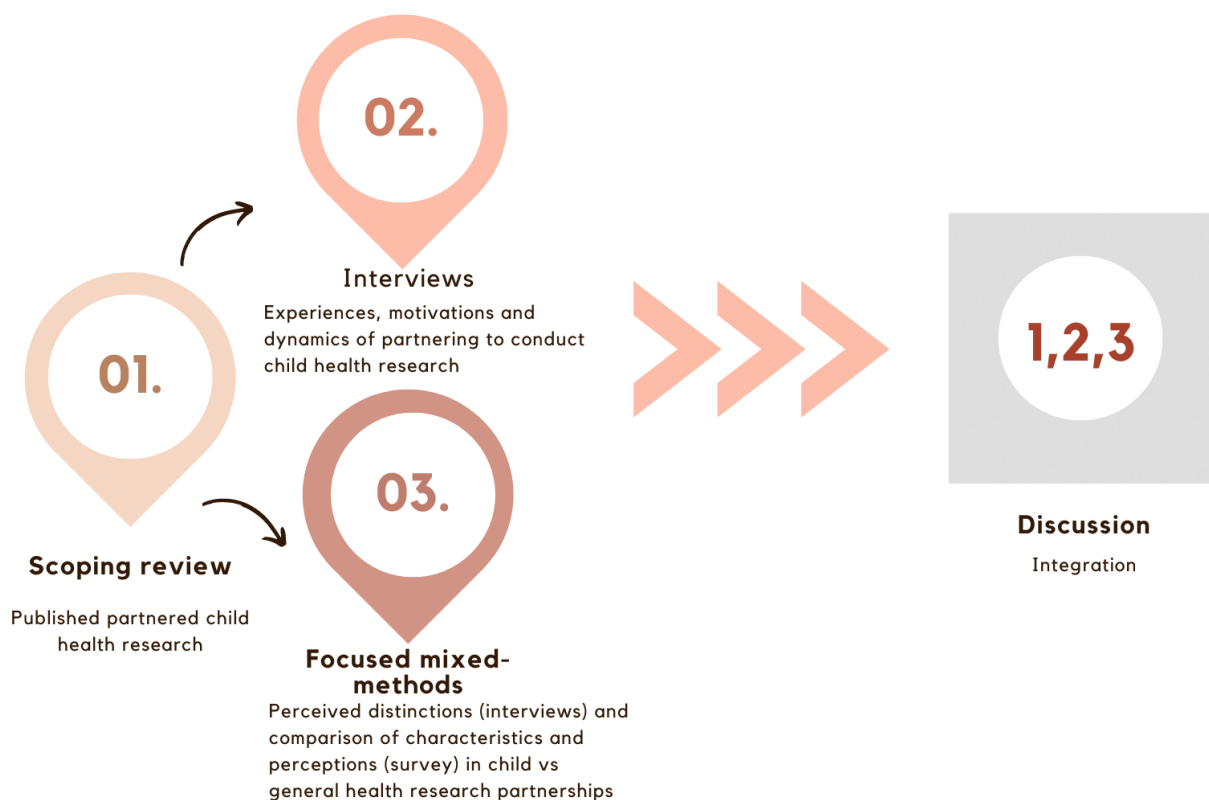


Figure 3.4.1 Concurrent mixed-methods research design with temporally sequential elements

Integrating quantitative and qualitative findings is a primary focus of the thesis discussion. This integration will enable me to explore the underlying mechanisms and contextual factors that shape research partnerships, providing a deeper understanding of the research topic. By integrating findings from different study strands, I aim to develop a more comprehensive understanding of research partnerships in child health, considering their diverse characteristics, dynamic interactions, operational processes, and resultant effects. Triangulating data from multiple sources and methods will facilitate cross-validation of findings, enhancing the trustworthiness of the study results (Creswell & Plano-Clark, 2016). This integration process may also lead to new insights and hypotheses that may not have surfaced through a single method. Ultimately, synthesizing findings from different study strands can uncover latent connections and relationships, contributing to advancing knowledge on child health research partnerships.

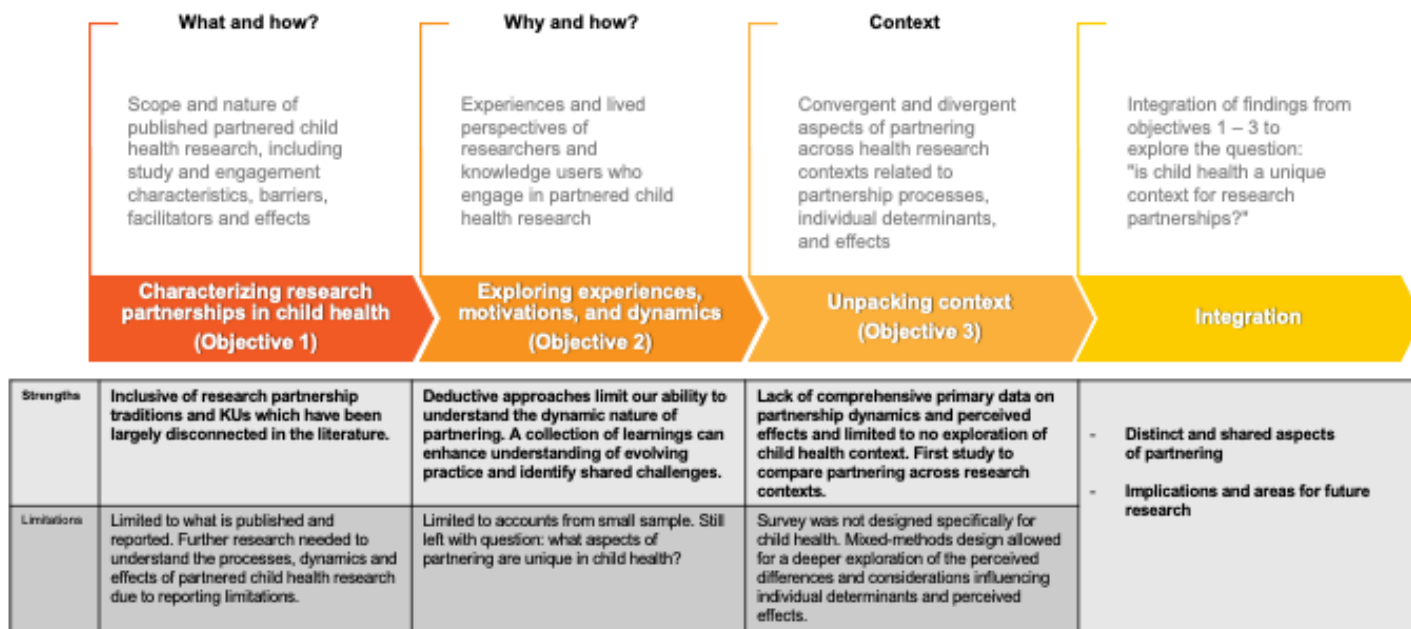


Figure 3.4.2 Chapter Integration

### **3.5 Ethical considerations**

Ethical considerations were upheld throughout the conduct of this research to ensure the protection of participants' rights and confidentiality. Before participating in any study activities, I provided participants with detailed information about the research's purpose, procedures, risks, and benefits. Informed consent was obtained from all participants, ensuring they were fully informed about their involvement and voluntarily agreed to participate. I maintained the confidentiality of participant data throughout the research process. Data collected from participants were anonymized and stored securely, with access restricted to authorized personnel only. In the scoping review, ethical considerations included adherence to established guidelines for systematic literature reviews and proper citation of sources to respect intellectual property rights. In interviews with researchers and knowledge users, I upheld ethical principles through respectful and non-coercive recruitment practices, informed consent procedures, and respectful treatment of participants' experiences and perspectives. In the mixed methods study, ethical considerations included obtaining approval from relevant ethics committees, maintaining confidentiality of participant data, and ensuring that participants were respected throughout the research process. Detailed ethical procedures, including approvals, are highlighted in subsequent chapters.

### **3.6 Knowledge User involvement**

I integrated knowledge user perspectives in several ways. First, I involved a knowledge user during the interview's data analysis and interpretation phase (objective 2) and mixed-methods study (objective 3). Through one-on-one discussions, the knowledge user provided valuable insights grounded in lived experience within the child health system and engagement in research projects. For instance, the knowledge user reviewed two transcripts and offered written reflections, and we engaged in discussions to refine early interpretations and coding. Throughout the analysis process, we met to discuss theme development and interpretation. This collaborative process helped me consider topics

such as the ethics of parental proxies, divergent perspectives between children and parents, power dynamics within parent-child relationships, and systemic challenges knowledge users face, such as compensation processes. His input, particularly during the initial coding stages, offered valuable insights from a different perspective.

Additionally, due to the secondary nature of two data sources leveraged in this study (objectives 1 and 3), there was indirect engagement of knowledge user perspectives in parallel research efforts occurring alongside my dissertation work that contributed to this study's foundation. For instance, the conceptualization of objective 1 was built upon earlier conceptual work (Hoekstra et al., 2018), incorporating input from knowledge users. Secondly, developing of the cross-sectional survey in objective 3 used an iKT approach with knowledge users on the study team. However, I acknowledge that I did not actively seek knowledge user input to shape these studies' specific child health focus, representing a missed opportunity to align my research objectives with the needs and priorities of those directly affected by child health issues.

I am conscious of the limitations of studying research partnerships without fully embracing this approach in my research design, particularly in study conceptualization. However, there are inherent tensions in involving knowledge users in trainee research. This requires balancing the need to demonstrate the ability to lead research independently, limited resource availability, and the challenge of fully integrating knowledge user input across all research stages while adhering to completion deadlines (Cassidy et al, 2021).

### **3.7 Conclusion**

In conclusion, this chapter serves as the methodological foundation guiding my subsequent investigation into research partnerships in child health. Through an exploratory concurrent mixed-methods approach rooted in pragmatism and informed by the Jull conceptual framework for knowledge user engagement, this series of studies seeks to explore the characteristics, dynamics, processes and

effects of research partnerships in child health. The research design overview outlined the high-level structure of the study, comprising three distinct and interconnected studies employing independent data collection and analysis procedures with integration in the discussion chapter for expansion and elaboration. Detailed data collection and analysis procedures for each study is provided in subsequent chapters.

#### Preface to Chapter 4

This chapter includes the manuscript “Characterizing research partnerships in child health: a scoping review.” This manuscript was published in the *Journal of Child Health Care* in 2024 and is intended for an audience of child health practitioners and researchers. Results were shared at the 2022 Knowledge Translation Canada conference.

This manuscript explores the study and engagement characteristics, barriers and facilitators, and effects of research partnerships reported in published child health research. Knowledge synthesis is considered the cornerstone of knowledge translation and a critical starting point for informing research, policy, and practice (Grimshaw et al., 2012). Scoping reviews are instrumental in evaluating emerging evidence across diverse study designs, identifying research gaps, and highlighting areas needing further inquiry (Munn et al., 2018). Previous reviews on research partnerships in child health have been narrow in scope, concentrating on specific partnership approaches (e.g., PPI and CBPR) and knowledge user groups, limiting cross-learning across research partnership traditions. This objective characterized research partnerships in child health and focused on the *what* and *how* of research partnerships reported across published primary research studies. Using established scoping review methodology, this study generates a contemporary picture of what is reported and published in the child health research partnership literature globally, inclusive of partnership approaches and knowledge user groups.

I conceptualized the study, conducted, and led abstract and full-text screening, data extraction and analysis and wrote all manuscript drafts. Dr. Kathryn Sibley, Dr. Shannon Scott, and Dr. Michelle Driedger informed this project’s research design and conceptual considerations. Due to the large volume of evidence requiring review, the following research staff and students were also integral to the completion of this project through their assistance in screening and data extraction: Masood Khan,

Devashree Prabhu, Nicole Askin, Dawn Steliga, Olivia Tefft, Ann Jansson, and Sarah Turner. All team members provided critical feedback on manuscript drafts.

**Conference Acceptance:**

Crockett LK, Scott SD, Driedger SM, Sibley KM. (2022, May 4 – 6). *Characterizing health research partnerships in child health: a scoping review* [poster presentation]. KT Canada Scientific Meeting.

**Citation:**

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## Abstract

**Background:** Research partnerships between researchers and knowledge users (KUs) in child health are understudied. This study examined the scope of KU engagement reported in published child health research, inclusive of health research partnership approaches and KU groups.

**Methods:** Search strategies were developed by a health research librarian. Studies had to be in English, published since 2007, and were not excluded based on design. A two step, multiple-person hybrid screening approach was used for study inclusion. Data on study and engagement characteristics, barriers and facilitators, and effects were extracted by one reviewer, with 10% verified by a second reviewer. Results were summarized using descriptive statistics.

**Results:** Three hundred fifteen articles were included, with 77.1% published between 2019-2021. Community-based participatory research was the most common approach used (38.3%). Most studies (74.6%) engaged multiple KU groups (range 1-11), with children/youth (54.3%), healthcare professionals (38.4%), and parents/families (37.8%) being the most frequently engaged. Reporting of barriers and facilitators and effects were variable, reported in 53.8% and 62.5% of studies.

**Conclusion:** Publications describing research partnerships in child health have increased exponentially over time. There is ongoing need to optimize evaluation and reporting consistency to facilitate growth in the field. Additional studies are needed to examine the specific nuances of conducting research partnerships with various KUs in child health.

**Keywords:** *collaborative research, children and youth, integrated knowledge translation, community-based participatory research, patient engagement, co-creation*

## Chapter 4: Characterizing research partnerships in child health research: A scoping review

### 4.1 Background

Collaborations between researchers and knowledge users (KUs) have advanced in recent decades to bridge evidence to practice gaps in health care and promote more relevant, meaningful and impactful research (Kothari et al., 2017). These collaborative research approaches may include integrated knowledge translation (iKT), community-based participatory research (CBPR) and patient and public engagement (PPE) – distinct terms with often overlapping principles and constructs (Nguyen et al., 2020). In this paper we refer to these approaches collectively as *research partnerships* (Hoekstra et al., 2018), which we define as actively involving KUs in research governance and activities that leads to knowledge co-production and use (Graham & Tetroe, 2009; Jull et al., 2019). Those considered KUs can include healthcare professionals, policy makers, educators, decision makers, administrators, community members, and patients and the public, who are likely able to use knowledge generated through research to make informed decisions about health behaviours, health policies, programs and/or practices (Canadian Institutes of Health Research, 2021a). Existing syntheses suggest that research partnerships may contribute to improved relevance, acceptance, and application of research findings, with tangible effects on health system outcomes, policy and practice (Hoekstra et al., 2020). However, comprehensive syntheses of research focused on partnerships in child health has yet been undertaken.

Just as pediatric healthcare is distinct from adult (Klassen et al., 2008; Larcher, 2017), we propose that research partnerships in child health possess features that may be unique relative to partnerships addressing adult health. Engaging children and youth themselves requires addressing a range of developmental, ethical, and practical considerations (Clarke, 2015; Jacquez et al., 2013; Larsson et al., 2018; McLaughlin, 2006). Parents and caregivers are often important advocates for young children in research who may not be able to speak for themselves (Banner et al., 2019; Curran et al., 2018; Vaughn et al., 2013). Similarly, policy and decision makers, and school representatives often serve as

proxies to support the well-being and interests of children and youth in research processes (Hamdani et al., 2021). Healthcare professionals are also important advocates for families and children (Molloy, 2018). These important but indirect stakeholders in child health add complexity to partnering in research (Curran et al., 2018).

Children and their families have indicated a desire for engagement in planning, designing, and implementing research projects (Ennis & Wykes, 2013), and there is evidence that engagement is increasing (Bradbury-Jones et al., 2018; Freire et al., 2022). However, many existing frameworks equate engagement with adult models of engagement and do not give special consideration to how research should be conducted with children and youth, parents and families (Woodgate et al., 2018) or healthcare professionals (Molloy et al., 2018) in child health. Further, available guidance and examples of research partnerships in child health research remains substantially smaller than that of adult work (Bradbury-Jones et al., 2018).

Existing syntheses focusing on research partnerships in child health have been limited in scope. Reviews have identified a lack of robust descriptions of strategies used to engage (Bailey et al., 2015; Flynn et al., 2019; Shen et al., 2017), limiting our knowledge of effective engagement strategies within child health. These are compounded by the predominant focus on PPE with specific KUs (e.g., parents and families, children and youth). Although several studies have identified benefits and challenges to engaging parents (Flynn et al., 2019; Shen et al., 2017) and young people (Flynn et al., 2019; Jacquez et al., 2013; Vaughn et al., 2013) in research, evidence often relied on anecdotal and subjective accounts and limited evidence to support our understanding of their effects (Jacquez et al., 2013; Shen et al., 2017; Vaughn et al., 2013). Reviews have also noted limited evaluation and reporting of outcomes (Bailey et al., 2015, Rouncefield-Swales et al., 2020), and ambiguities in reporting quality (Freire et al., 2022). Describing factors affecting engagement can facilitate our understanding of research partnership

outcomes; yet, reporting of barriers and facilitators in extant literature has been low (Freire et al., 2022).

Despite differences in terminologies, concepts and origins among research partnership approaches, their similarities have been described (Nguyen et al., 2020), supporting need for a comprehensive review. Further, evidence suggests that researchers use of a combination of principles from multiple approaches when conducting research partnerships, and report challenges in aligning with a single approach (Nguyen et al., 2020). While it is important to highlight research partnerships within specific child health contexts (e.g., disability, medical research), with specific KU groups (e.g., parents and families) or using specific research partnership approaches (e.g., CBPR), these traditionally siloed approaches limit our ability to advance broader understanding and mutual learning across research partnership approaches (Hoekstra et al., 2020).

### ***Aim***

To examine study engagement characteristics, barriers and facilitators, and effects of research partnerships in child health, inclusive of research partnership approaches and KU groups.

## **4.2 Materials and methods**

### ***Review framework***

This scoping review was guided by the Arksey and O'Malley scoping review framework (Arksey & O'Malley, 2005; Levac et al., 2010) which lends structure for identifying research questions and relevant studies, selecting studies, charting data, and collating, summarizing and reporting results. Reporting of scoping review processes and findings were guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping reviews (PRISMA-ScR) (Tricco et al., 2018). A PRISMA-ScR checklist is provided in Appendix A. Given noted limitations across research partnership literature, including poor indexing of various approaches (Camden et al., 2015; Gagliardi et al., 2016), this review aligns and builds on a search strategy and conceptual framework collaboratively developed by Hoekstra,

Mrklas and colleagues (2018) focusing on strategies, outcomes and impacts of health research partnerships.

### ***Identifying relevant studies***

A medical librarian (NA) developed and executed a search strategy (Appendix B) comprising subject headings and free-text terms, developed collaboratively for use across a range of research partnership syntheses (Hoekstra et al., 2018), with additional constraints set to limit partnerships to the child population (from birth to 18 years). Studies were identified through a search of the following databases: Medical Literature Analysis and Retrieval Online System (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica Database (EMBASE) and Psychological Information Database (PsycINFO). Searching was initially conducted in April 2019 and updated in October 2021.

### ***Inclusion criteria***

Primary peer-reviewed studies written in English were eligible for inclusion. Studies were not excluded based on study design and included studies using quantitative, qualitative, or mixed methods. For inclusion, articles needed to describe involvement of KUs in at least one phase of research, conducting research focused on child and/or youth health. Additionally, articles needed to describe at least one aspect of study or engagement characteristics, barriers and facilitators, or effects of this partnership. Results were included dating back to 2007 for feasibility. Articles without a focus on children or youth (from birth to 18 years) or a focus on health (e.g., academic outcomes) were excluded. Studies that focused on youth, but included some participants ages 18+ (e.g., mental health), were included if child health was of predominant focus. Commentaries, protocols, reviews and grey literature were not included.

### ***Study selection***

After de-duplication, we screened eligible articles for inclusion. Screening was managed using Rayyan (Ouzzani et al., 2016). Level 1 screening was conducted by multiple reviewers (LKC, MK, DP, OT, DS, ST). Each reviewer was initially assigned a random sample of 100 title and abstracts, which were screened in duplicate with the principal author (LKC) and any remaining discrepancies were resolved by discussion. Articles were then screened independently and assigned to categories of “include,” “exclude,” or “unsure.” During level II screening, full-text articles were retrieved and reviewed by multiple reviewers (LKC, MK, DP) in a similar fashion. A second reviewer (LKC, MK) independently reviewed 10% of all articles at both level I and II of screening to assess screening reliability.

### ***Data extraction and analysis***

A data extraction form was developed and tested by LKC on a sample of 10 included studies and refined iteratively (Levac et al., 2010). Data extraction variables were pre-defined categorically based on existing literature (Table 4.1), with an ‘other’ option, which were organized into additional categories by LKC and summarized. Data were extracted by LKC in 4 broad categories outlined in Table 4.1. A second reviewer (KMS) independently extracted data from 10% of articles for quality assurance and any discrepancies were discussed and resolved. LKC revised extraction protocols as needed per discussion and unclear items were discussed and resolved with KMS.

*Table 4.1 Description of data extraction variables*

<b><u>Variable</u></b>	<b><u>Description</u></b>	<b><u>Variable type</u></b>	<b><u>References</u></b>
<b>Study characteristics</b>			
Year	Year of publication	Multiple choice	N/A
Country	Country of corresponding author	Multiple choice	N/A
Research design	Broad study design used to conduct research in partnership with researchers and KUs. Research design was classified as quantitative, qualitative, multi or mixed methods.	Multiple choice	N/A

Study population	Study population of research focus. Study population was classified as multiple (e.g., spanning multiple age ranges), infant (ages 0-1), child (ages 2-11), adolescent (ages 12-17), or unclear.	Multiple choice	(Public Health Ontario, 2013)
Research focus	Focus of research study. Study topic area was described in open ended format for the first 75 articles, then classified thematically. Categories were used for all subsequent data extraction.	Open ended; multiple choice	N/A
Partnership terminology	Terminology used to describe the partnership. Categories were pre-defined based on existing literature as: IKT, CBPR, PPE, participatory action research, participatory research, action research, collaborative research, co-production, and other.	Multiple choice	Hoekstra et al., 2020
KU groups engaged	KUs engaged within the research process. Categories were pre-defined based on existing literature as: parents and families, children and youth, healthcare professionals, community members, school representatives, community-based organizations, healthcare manager or administrator, funding organization representative, and other.	Select all	Hoekstra et al., 2020; Flynn et al., 2019
Multiple KU groups	More than one knowledge user group engaged within the research process.	Binary	N/A
Number of KU groups engaged	Number of knowledge user groups engaged within the research process. This variable was a sum of the variable 'knowledge user groups engaged'.	Numerical	N/A
Primary KU group	Where more than 1 knowledge user was engaged, the knowledge user group of prominent focus or most actively engaged within the project. Categories were pre-defined, as per variable 'KUs engaged.'	Multiple choice	Hoekstra et al., 2020; Flynn et al., 2019
<b>Engagement characteristics</b>			
Level of engagement	Level of engagement of KUs within the research process, based on the following definitions: <u>consult</u> (to obtain feedback on analysis, alternatives, and/or decisions); <u>involve</u> (to work directly through the process to ensure that concerns and aspirations are consistently understood or considered); <u>collaborate</u> (to partner in each aspect of the decision including development of alternatives and identification of preferred solutions), and <u>empower</u> (to place final decision making power in the hands of KUs; partnership initiated by KUs). Each article was classified based on the authors' report of engagement and its alignment with the above noted definitions.	Multiple choice	International Association of Public Participation [IAP2], 2018
Research stage	Engagement of KUs in the planning, conduct and dissemination of research. Categories were pre-	Select all	

	defined as: planning, conducting, and dissemination.		
Research activities	Research activities in which KUs were engaged. Categories were pre-defined as: setting research priorities, choosing research questions, developing study design and methods, development of research ethics documents, participant recruitment, data collection, data analysis and interpretation, dissemination to academic audiences, and dissemination to non-academic audiences.	Select all	Hoekstra et al., 2020
Engagement strategies	Strategies used to engage KUs in the research process. Categories were predefined as: formal meetings, establishment of formal working groups, formal updates, distribution of study documents, provision of training opportunities or resource materials, informal conversations, development of formal documentation of processes, honorariums for KUs, researchers attending knowledge user meetings or events, provision of social opportunities, shared electronic space, sharing of research funds with KUs, and not specified.	Select all	Hoekstra et al., 2020
Evaluation	Evaluation of the research partnership before, during or after the research partnership.	Binary	
<b>Barriers and facilitators</b>			
Barriers and Facilitators	Barriers and facilitators of engaging KUs in the research process. Barriers and facilitators were extracted and categorized based on known barriers and facilitators reported in research partnership literature. Initial categories were pre-defined and refined iteratively throughout the data extraction phase for all data categorized as "other".	Select all	Bird et al., 2020; Brush et al., 2020; Anna R. Gagliardi et al., 2016; Anna R Gagliardi & Dobrow, 2016; Hofmeyer, Scott, & Lagendyk, 2012; Kendall et al., 2018; Lawrence et al., 2019; Mitton, Adair, McKenzie, Patten, & Perry, 2007; Shannon L Sibbald et al., 2014)
<b>Effects</b>			

Beneficial and challenging effects	Beneficial and challenging effects of the research partnership at the individual, society and community, research partnership, and research process subcategory levels. Variable options were categorized based on the taxonomy proposed by Hoekstra et al. (2020) of effects on: 1) researchers conducting partnership research, 2) knowledge users involved in research partnerships, 3) the relationship between researchers and knowledge users, 4) the community and/or society, and 5) the research process. The term 'effects' was chosen due to poor differentiation of outcomes and impacts in the published literature (Hoekstra et al., 2020). Full definitions are provided in Appendix C.	Select all	Hoekstra et al., 2020
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Results were summarized quantitatively using descriptive statistics (frequencies and proportions) and are presented through tables and a narrative summary (Grant & Booth, 2009). Due to secondary analysis of published data, ethics permission was not sought for this review.

### 4.3 Results

#### *Study characteristics*

Screening and selection are depicted in Figure 1. Records (n=39.557) were identified through database searching. After deduplication and year restriction, 22,077 articles were identified for screening and 841 full-text articles were subsequently obtained for review. A total of 315 articles were included.

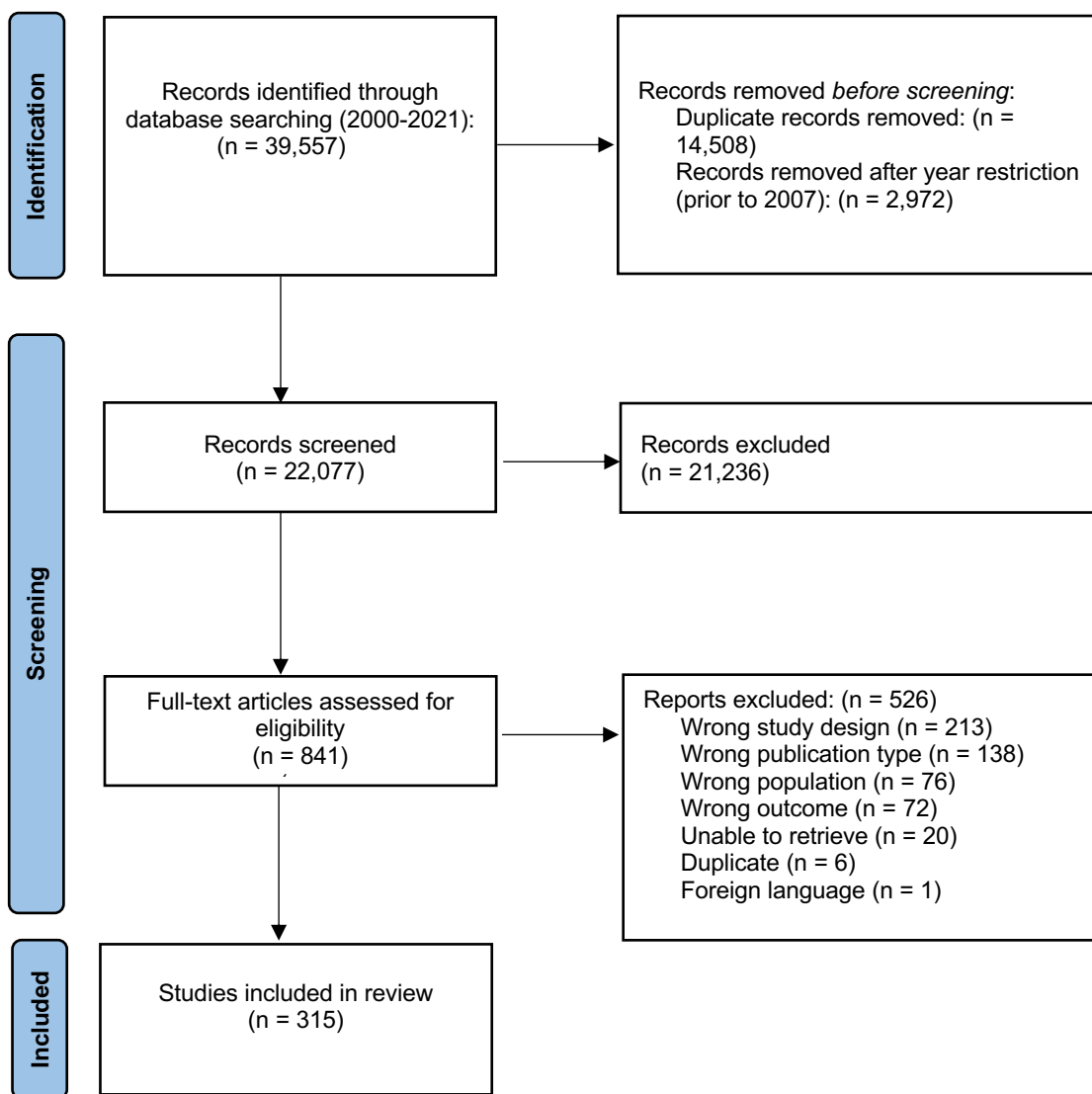


Figure 4.1 PRISMA flow diagram

Study characteristics are reported in Table 4.2. Most articles originated from the United States (n=148, 47.0%). Publication volume increased across each time period, with 243 (77.1%) published between 2019-2021. Most studies used mixed methods (n=128, 40.6%) research designs. Most studies address issues crossing multiple age ranges (n=156, 49.7%). Research partnership approaches were described using numerous terms, with community based participatory research (CBPR) (n=122, 38.3%)

used most frequently. Children or youth (n=171, 54.1%) were most frequently engaged; however, most studies engaged with more than one KU group (n=235, 74.4%; range: 1-11). The most common research focus was physical activity, obesity, diabetes and nutrition (n=55, 17.5%).

Table 4.2 Study characteristics

Variable	n (%)
<b>Publication year</b>	
2007 – 2010	10 (3.2%)
2011 – 2014	21 (6.7%)
2015 – 2018	41 (13.0%)
2019 – 2021	243 (77.1%)
<b>Region of primary author</b>	
North America <i>United States (n=148); Canada (n=46)</i>	194 (61.6%)
Europe <i>United Kingdom (n=44), Netherlands (n=7), Ireland (n=4), Italy (n=4), Denmark (n=2), Finland (n=2), Germany (n=2), Spain (n=2), Sweden (n=2), France (n=1), Austria (n=1), Finland (n=1), Estonia (n=1)</i>	73 (23.2%)
Oceania <i>Australia (n=21), New Zealand (n=4)</i>	25 (7.9%)
Africa <i>Kenya (n=5), South Africa (n=3), Zimbabwe (n=2), Nigeria (n=1), Uganda (n=1)</i>	12 (3.8%)
Middle East <i>Israel (n=4), Iran (n=1)</i>	5 (1.6%)
Asia <i>Thailand (n=3), South Korea (n=1)</i>	4 (1.3%)
South America <i>Peru (n=1), Columbia (n=1)</i>	2 (0.6%)
<b>Research design</b>	
Mixed-methods or multi-methods	128 (40.6%)
Qualitative	122 (38.7%)
Quantitative	65 (20.7%)
<b>Study population</b>	
Spanning multiple age groups	156 (49.7%)
Adolescence (12-18 years)	90 (28.5%)
Child (2-11 years)	35 (11.1%)
Infant (0-1 years)	10 (3.1%)
Unclear	24 (7.6%)
<b>Partnership approach listed by authors</b>	
Community-based participatory research (CBPR)	121 (38.3%)
Participatory research	37 (11.7%)
Participatory Action Research (PAR)	31 (9.8%)
Collaborative research	24 (7.9%)

Co-creation/co-design/co-production	22 (7.0%)
Patient engagement (PE) or patient and public engagement (PPI)	15 (4.7%)
Integrated KT (iKT)	10 (3.2%)
Action research (AR)	6 (1.9%)
Other terms <i>Stakeholder engagement (n=2), community-engaged research (n=2), community-based KT (n=1), academic-practice partnership (n=1), community-academic partnership (n=1), integrated research-practice partnership (n=1), integrated participatory approach (n=1), participatory community engagement (n=1), researcher-community partnership (n=1), community-based and collaborative research (n=1), integrated research-practice partnership (n=1), consumer and community involvement (n=1)</i>	14 (4.4%)
No term used	35 (11.1%)
<b>Knowledge user groups engaged*</b>	
Children and youth	171 (54.3%)
Healthcare professional(s)	121 (38.4%)
Parents and families	119 (37.8%)
Community member(s)	102 (32.4%)
School representative(s)	67 (21.3%)
Community-based organization	63 (20.0%)
Community organization representative	47 (14.9%)
Healthcare manager or administrator	43 (13.6%)
Government representative	40 (12.7%)
Municipal/provincial/state health agencies	30 (9.5%)
Indigenous representative(s) (eg. elders)	30 (9.5%)
Social services (eg. justice)	19 (6.0%)
Non-governmental organization (NGO)	19 (6.0%)
Funding organization representative	7 (2.2%)
Faith-based representative(s)	5 (1.6%)
<b>Multiple knowledge user groups engaged</b>	
Yes	235 (74.6%)
No	80 (25.4%)
<b>Number of knowledge user groups engaged</b>	
1	80 (25.4%)
2	82 (26.0%)
3	78 (24.8%)
4	27 (8.6%)
5+	48 (15.2%)
<b>Research Focus</b>	
Physical activity, obesity, diabetes and nutrition	55 (17.5%)
Pediatric subspecialties (eg. acute care, cancer care, rehabilitation)	54 (17.1%)
General health (eg. chronic pain, well-being, sleep)	50 (15.9%)
Mental health	39 (12.4%)
Public health (eg. health promotion, immunization, injury prevention)	36 (11.4%)
Sexual and reproductive health (eg. HIV, STI, pregnancy)	34 (10.8%)
Substance use & addiction	21 (6.6%)

Health Services	20 (6.3%)
Youth violence	6 (1.9%)

\*more than one option could be selected; percentages do not equal 100%

### **Engagement characteristics**

Engagement characteristics are summarized in table 4.3. KUs were most commonly engaged at the IAP2 level of *involve* (i.e., *working directly through the process to ensure that concerns and aspirations are consistently understood or considered*) (n=129, 41.0%). Engagement was documented at every stage of the research process, most often in *conducting* (n=258, 81.6%) research. KUs were most frequently engaged in data collection (n=205, 65.1%), developing study design and methods (n=188, 59.7%), and data analysis and interpretation (n=170, 59.7%), and least in research ethics development (n=47, 14.9%). Numerous strategies (range: 1-10 per article) were reported for engaging with KUs, with formal meetings being most frequent (n=261, 82.9%). However, most (n=227, 72.1%) reported using multiple strategies to engage (mean=3.42, SD=2.67). Thirty-nine studies (12.4%) did not report on strategies used to engage.

*Table 4.3 Engagement characteristics*

Variable	n (%)
<b>Level of engagement</b>	
Consult	68 (21.6%)
Involve	129 (41.0%)
Collaborate	106 (33.6%)
Empower	12 (3.8%)
<b>Research stage</b>	
Planning	238 (75.3%)
Conducting	258 (81.6%)
Disseminating	133 (42.1%)
<b>Research activities</b>	
Data collection	205 (65.1%)
Developing study design and methods	188 (59.7%)
Data analysis and interpretation	170 (54.0%)
Choosing study outcomes	140 (44.4%)
Setting research priorities	125 (39.7%)
Choosing research questions	124 (39.4%)
Dissemination to non-academic audiences	102 (32.4%)
Participant recruitment	102 (32.4%)

	Dissemination to academic audiences	62 (19.7%)
	Development of research ethics	47 (14.9%)
<b>Strategies for engaging</b>		
	Formal meetings	261 (82.9%)
	Establishment of formal working groups	140 (44.4%)
	Formal updates	118 (37.5%)
	Distribution of study documents	116 (36.8%)
	Provision of training opportunities or resource materials	113 (35.9%)
	Informal conversations	105 (33.3%)
	Development of formal documentation of processes	84 (26.7%)
	Honorariums for KUs	38 (12.1%)
	Researchers attending KU meetings or events	39 (12.4%)
	Provision of social opportunities	37 (11.7%)
	Shared electronic space	25 (7.9%)
	Sharing of research funds with KUs	4 (1.3%)
	Not specified	39 (12.4%)
<b>Evaluated partnership</b>		
	Yes	98 (31.1%)
	No	217 (68.9%)

### **Barriers and Facilitators**

Barriers and facilitators were reported in just over half of included studies (n=170, 53.8%) and are reported in Table 4.4. Most frequently reported facilitators of KU engagement included maintaining good communication between researchers and KUs (n=107, 34.0%) and having clearly defined roles and expectations (n=106, 33.7%). The most frequently reported barrier was time (n=29, 9.2%).

*Table 4.4 Barriers and facilitators of knowledge user engagement in child health research*

Barriers and facilitators reported		
	Yes	170 (53.8%)
	No	145 (46.2%)
<b>Facilitators</b>		
<b>Facilitators</b>	<b>Description</b>	<b>n (%)</b>
Communication	Maintaining good communication between researchers and KUs	107 (34.0%)
Roles & expectations	Clearly defined roles and expectations	106 (33.7%)
Facilitation	Involving professional facilitators or knowledge brokers to support researchers and/or KUs	97 (30.8%)
Capacity (resources)	Having sufficient infrastructure and resources to conduct research partnerships	80 (25.4%)
Valuing expertise	Equitable engagement, including valuing all knowledge, experiences and perspectives	79 (25.1%)
Skills	Having expertise and skills to conduct research partnerships	69 (21.9%)

Alignment	Having aligned goals, objectives and priorities between researchers and KUs	68 (21.6%)
Opportunities	Having training and education opportunities	56 (17.8%)
Cultural considerations	Attention and alignment to cultural values, customs, and priorities	54 (17.1%)
Commitment	Having commitment, buy in and support for the project; researchers attending events without research-specific activities	44 (14.0%)
Fostering relationships	Spending time and effort to build and nurture trustful, respectful relationships	31 (9.8%)
Compensation	Compensation of partners for their time and accommodating needs	26 (8.3%)
Pre-existing relationships	Having pre-existing/established relationships between researchers and KUs	18 (5.7%)
Ongoing partnership	Ongoing collaboration between researchers and KUs beyond the research project	11 (3.2%)
Early partnership	Establishing partnerships early in the research process	10 (3.2%)
Technology	Leveraging e-technology	9 (2.9%)
Flexibility	Accommodating schedules, allowing time, flexibility within research agreements	6 (1.9%)
Power differentials	Awareness and attention to power differentials	5 (1.6%)
Shared governance	Having shared governance/decision-making structures	4 (1.3%)
<b>Barriers</b>		
<b>Barriers</b>	<i>Description</i>	<b>n (%)</b>
Time	Having time constraints, time required to build relationships	29 (9.2%)
Competing agendas, interests, priorities	Competing agendas, interests and priorities	25 (7.9%)
Capacity (resources)	Having a lack of resources to support research partnerships	19 (6.0%)
Power imbalances	Managing power and group dynamics	13 (4.1%)
Retention	Frequent turnover of KUs and/or ongoing organizational/leadership change	10 (3.2%)
Inconsistent engagement	Inconsistent or unequal engagement of KUs	9 (2.9%)
Geography	Having a large geographical distance between researchers and KUs	9 (2.9%)
Skills	Lack of skills, expertise, and/or capacity of researchers or KUs to engage in research partnerships	7 (2.2%)
Institutional and funding	Limitations or challenges imposed by institutional regulations or grant funding timelines or regulations	6 (1.9%)
Attendance	Meetings poorly attended	6 (1.9%)
Unclear goals, roles and expectations	Having unclear goals, roles and expectations	4 (1.3%)
Health challenges	Competing or existing health challenges among team members	3 (1.0%)

### ***Effects***

Effects of engaging KUs within the research process were reported in 197 (62.5%) studies. Of articles reporting effects, all (n=197, 100.0%) reported beneficial effects while only 15 (4.8%) reported effects that were challenging. The most frequent beneficial effects were related to the research process, including developing relevant and useful research findings (n=125, 39.7%) and creating high-quality research, such as generating new projects (n=111, 35.2%). While few reported challenging effects of research partnerships (n=15, 4.8%), the most common were at the partnership level including conflicts between researchers and KUs (n=14, 4.4%). Further details are provided in table 4.5 and full definitions can be found in Appendix C.

Table 4.5 Effects of child health research partnerships

<b>Effects reported</b>				
Yes				197 (62.5%)
No				118 (37.5%)
Subcategory	Beneficial Effects	n (%)	Challenging Effects	n (%)
<b>Individual level</b>				
Effects on <b>researchers</b> conducting partnership research	Increased capacity, knowledge and skills	92 (29.2%)	Personal challenges	11 (3.5%)
	Personal benefits	24 (7.6%)		
Effects on <b>KUs</b> involved in research partnerships	Increased 'capacity, knowledge and skills'	100 (31.7%)	Personal challenges	5 (1.6%)
	'Positive attitude' towards research and researchers	27 (8.6%)	Feeling overburdened by tasks and responsibilities	1 (0.3%)
	Better access to information	71 (22.5%)		
	Personal benefits	64 (20.3%)		
<b>Partnership level</b>				
Effects on the relationship between researchers and KUs (partnership level)	Positive outcomes/impacts on the relationship between researchers and KUs	86 (27.3%)	Conflicts between researchers and KUs	14 (4.4%)
<b>Community or society level</b>				
Effects on the community or society	Increased acceptability and trust of the research	80 (25.4%)	Challenging outcomes or impacts on the community	0 (0.0%)
	Increased capacity in the community	79 (25.1%)		
	Increased community ownership of the research	52 (16.5%)		
	Creating system changes or action	50 (15.9%)		
	Increased community empowerment	35 (11.1%)		
<b>Research process level</b>				

Effects on the research process	Creating 'relevant and useful research findings'	125 (39.7%)	Biased data or tokenism	8 (2.5%)
	Creating 'high quality research'	111 (35.2%)		
	Increased capacity to conduct and disseminate research	79 (25.1%)		

#### 4.5 Discussion

This scoping review examined study engagement characteristics, barriers and facilitators, and effects of research partnerships in child health, inclusive of research partnership approaches and KU groups. We highlight 4 findings of interest: 1) exponential growth in publications reporting research partnerships in child health over time, with primary origins from the United States, Canada, United Kingdom, and Australia; 2) predominant reporting of CBPR as an approach within included studies; 3) engagement of multiple KU groups at varying levels of engagement; and 4) variable and selective reporting of facilitators and positive effects of engaging.

Data indicate a doubling in publications on child health research partnerships across each time period, with a five-fold increase between 2015-2018 and 2019-2021. Our findings suggest that research partnerships in child health are increasing, regardless of approach or geographical region, though most publications originate from the United States, Canada, the United Kingdom, and Australia. Growth in publication over time predominating mainly from these countries may be reflective of targeted funder-driven efforts to encourage and promote research partnerships to maximize impacts of research investment (Canadian Institutes of Health Research, 2015; Canadian Institutes of Health Research, 2016; Rycroft-Malone et al., 2011). Other studies have indicated an increase in published literature using participatory approaches with children and youth (Bradbury-Jones et al., 2018). Similar to Hoekstra et al. (2020), we observed differences in approaches based on origin of the primary author and by time period. For example, all studies using an iKT approach originated from Canada and were published from 2016 onwards. This likely relates to iKTs' origins as a funder-driven approach advanced by the federal health research funding agency, the Canadian Institutes of Health Research (CIHR) (Nguyen et al., 2020). In contrast, studies using a PPE approach were more evenly distributed across countries, and studies using a CBPR approach were present across all time periods and geographical locations.

CBPR was the most frequently identified approach within the corpus of included studies. Frequent reported use of CBPR as an approach in child health may be noteworthy given its' theoretical differences relative to other research partnership approaches (Jull, Giles, & Graham, 2017; Nguyen et al., 2020). Due to its' long-standing history as a research approach aimed at promoting social justice, enhancing KU skills and capacity, and use of specific methods common among CBPR methodology (e. g., digital storytelling, photovoice, focus groups and interviews), it is possible that research traditions underlying CBPR have perhaps been historically more fitting for research partnerships in child health. Furthermore, CBPR focuses on conducting research in partnership with historically vulnerable or disenfranchised communities (Olshansky & Zender, 2008). Alternatively, approaches such as iKT that focus on increasing knowledge use and impact do not explicitly focus on capacity building and attention to power relations (Jull et al., 2017), aspects important when engaging children and youth in particular, where power relations are heightened (Bradbury-Jones et al., 2017).

Given the complexity of health systems, Jull and colleagues (2017) argue that achieving conceptual clarity of various collaborative research approaches will allow research partnership teams to better leverage and use knowledge based on what they hope to achieve. Furthermore, due to their successes and unique strengths they urge consideration of various research partnership approaches and processes when designing and conducting collaborative research (Jull et al., 2017). We encourage researchers to be clearer and more intentional in their use of research partnership approaches to avoid epistemological and ontological slippage. We also found that 74.6% of studies engaged with multiple KU groups, often at varying levels of engagement, suggesting that a range of individuals are involved in child health research partnerships. For example, Anang et al. (2019) first initiated discussion and relationship building with the local health committee and council in 2015, leading to the initial study planning and engagement with an Elder and school representatives. Subsequently, they engaged youth, who co-facilitated focus groups and assisted in interpretation in 2017. In this study, adult KUs took an oversight

role and contributed largely to project initiation. Alternatively, Crudington et al. (2020) concurrently consulted both parents and children to obtain feedback in developing patient-oriented outcome measures (PROMs) for childhood epilepsy. This suggests varying relational, time and resource intensive strategies may be required to undertake research partnerships in child health, depending on project aims. The presence of adult KU groups alongside studies engaging children and youth also suggests that additional protective and safeguard strategies may be used, or required, in the context of child health. However, studies did not consistently differentiate which strategies were used with which KU group, nor was intensity of engagement by KU group clearly reported, suggesting a need for enhanced clarity in reporting.

While KUs were engaged at varying levels of intensity, 74.6% of studies engaged at levels of involve or collaborate, suggesting moderate to high levels of engagement. Several studies suggested need for flexible levels of engagement among KUs within teams. For example, Funk et al. (2012) noted that although their team climbed Hart's ladder of participation (i.e., a model of participation contextualized to young people's participation; Hart, 1992) as the project progressed, not all youth climbed at similar speeds or participated at similar levels based on their interest, strengths and abilities. Similarly, van Staa et al. (2010) suggested that level of participation in the research process should be negotiated as equitable rather than equal, negotiated based on preferences and interests of KUs. This corresponds to the practicality principle of proportional involvement, as outlined by Liabo et al. (2020) which involves balancing involvement throughout the research process based on individual demands and project resources and supports.

Like existing reviews, reporting of barriers and facilitators and effects were variable, reported in 53.8% and 62.5% of studies respectively. Similarly, reporting of effects were largely anecdotal, based on perceived subjective accounts of authors. This adds to the growing body of evidence suggesting a need for more systematic evaluation and measurement of effects in research partnerships in child health

(Vaughn et al., 2013; Freire et al., 2022; Rouncefield-Swales et al., 2021; Bradbury-Jones et al., 2017). Most notably, reporting was heavily weighted towards the positive aspects of engaging, suggesting biased reporting and limiting our ability to constructively learn from the challenges faced by research teams engaging in research partnerships. Van Staa et al. (2010) noted that although not all partnerships lead to tangible or positive effects, challenges are not typically reported. Hoekstra et al. (2020) also noted this predominant reporting of beneficial effects of research partnerships. However, as highlighted by Kothari (2012), the process itself is often more beneficial than the outcomes (van Staa et al., 2010). It is important to note that researchers are not likely to have reported on a comprehensive list of effects depending on study purpose. However, it can be hypothesized that those reported reflect those most prominently experienced, or of those aspects agreed upon for reporting within the partnership engagement process itself. Leveraging prominent facilitators identified in this review may serve to mitigate challenges encountered by research teams.

### ***Limitations***

Our review was limited to studies published in 2007 and later for feasibility and relevant studies dating back to 2000 were minimal. Limiting our review to studies published in English may bias results to developed countries. Electronic literature searches to identify research partnerships often lack precision and require considerable time and resources. Emerging methods such as semi-automated text mining for title and abstract screening could be explored to facilitate this process (Pham et al., 2021). We identified that use of terminology does not necessarily reflect a true partnership and that there may be varying degrees of conceptual understanding across fields. Others have noted a similar trend, with terms sometimes used erroneously to indicate research that is merely conducted *on* people versus *with* people (Vaughn et al., 2013). Due to variable reporting of engagement characteristics within studies and challenges in clearly delineating which strategies were used with which KUs, we were unable to examine differences by KU group. There is potential that relevant articles were excluded in title and abstract

screening if they did not make reference of a research partnerships in the abstract. However, we minimized the risk of missing papers as much as possible by advancing any paper that was unclear regarding eligibility in the abstract screening phase for full text screen. Finally, for similar feasibility reasons, we also chose to exclude studies which may have indirect effects on child health (e.g., academic performance).

### ***Implications***

Although the co-existence of multiple research partnership approaches is well-recognized, these approaches have remained largely disconnected in the literature. This hampers learning across approaches in designing, conducting, assessing and determining effects of research partnerships. Due to broad vocabulary used to describe health research partnerships and variable levels of reporting across approaches, there remains a need to provide reporting guidance to facilitate ongoing efforts (Boland et al., 2020). However, there are limitations in partnership-based reporting. For example, while conversations regarding challenges encountered may occur internally, they are not necessarily shared externally in peer-reviewed publications for a multitude of reasons.

By leveraging common search strategies and terminology outlined by a multi-coordinated team (Hoekstra et al., 2018), this study begins to optimize research quality and consistency across reviews and provides a baseline view of research partnerships conducted in child health. Researchers looking for reporting guidance may look to Hoekstra et al. (2020) to improve consistency. Further, pre-emptive evaluation planning can serve to enhance our understanding of partnership effects.

The findings of this review have practice implications for a broad audience. This review provides insight for both researchers and KUs conducting research in a partnered way in the child health sphere by outlining when and how various KUs may be engaged in the research process, and with what effect.

#### 4.6 Conclusion

This review is unique in scope as we synthesized literature in child health across partnership approaches and KU groups. We note exponential growth in research partnerships in child health, particularly since 2019, and predominance of CBPR as a research partnership approach in child health. Findings highlight variable levels of reporting of engagement characteristics, barriers and facilitators, and effects within the published literature, suggesting need for guidance to support evaluation and consistent reporting. Further, engagement of multiple KU groups at varying intensities within studies introduces challenges in differentiating engagement characteristics within and between studies, and it is not always evident how KUs are engaged in the research process or if there are approaches unique to child health. However, this review begins to outline diverse research partnership literature in child health, providing a starting point to enhance our understanding of practices used within child health. Further research is needed to better understand principles and relational aspects that may render child health a unique context for research partnerships.

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### Preface to Chapter 5

Objective 1 offered a comprehensive description of the published literature on research partnerships in child health, however, there are limitations to what is published and reported. Additionally, focusing only on predetermined indicators of research partnership may overlook the nuanced and diverse nature of engagement. Through individual semi-structured interviews informed by an interpretive description approach, this study explores the experiences and lived perspectives of researchers and knowledge users engaged in partnered child health research. This study facilitated a deeper understanding of the multifaceted dimensions of partnering including experiential, motivational, and relational aspects, and their implications for partnership practice. Specifically, this objective aimed to unravel the *how* and *why* of partnering, factors contributing to partnership successes, and challenges.

I was solely responsible for all aspects of this study, including conceptualization, development of the interview guide, participant recruitment, conducting interviews, analyzing and interpreting data, and writing findings. Throughout this process, Drs. Kathryn Sibley, Shannon Scott, and Michelle Driedger offered invaluable guidance, contributing to the refinement of study conceptualization and providing ongoing feedback on the data analysis and thematic development.

## **Chapter 5: Exploring the experiences, motivations, and dynamics of engaging in partnered child health research: an interpretive description study**

### **5.1 Introduction**

Research partnerships that involve knowledge users alongside academic researchers are increasingly recognized for their potential to optimize research outcomes by fostering collaboration and integrating diverse perspectives (Rycroft-Malone et al., 2022). In the domain of child health research partnerships, where the well-being of children and families is at the forefront, such collaborations hold significant importance. This is because the unique vulnerabilities and developmental aspects of children require research that is both relevant and applicable to real-world settings (Mulvey et al., 2020). Additionally, child health inherently involves a dual focus on both the child and the family, acknowledging their interconnected well-being (Barratt et al., 2023) and often demands coordination across various sectors (Jayaratne et al., 2020; Rungan et al., 2024). Involving knowledge users – such as parents, educators, healthcare providers, and policy makers – helps to ensure that research addresses practical concerns, aligns with the lived experiences of those directly impacted, and promotes the uptake of research findings and/or interventions (Graham et al., 2018). Described by Langley and colleagues as a “way of being” and a process of “working with,” partnerships center on common processes such as dialogue and iteration, supported by principles such as power sharing and reciprocity (Langley et al., 2022). Research partnerships operate in various ways, from forming research questions to applying findings in practice (Kothari & Wathen, 2017), and are intentionally flexible to suit different contexts and needs (McPhee et al., 2023). However, despite their potential benefits, research partnerships face challenges, including managing partnerships, navigating diverse agendas, and reconciling differing perspectives (Kothari & Wathen, 2017; Sibley et al., 2022). Moreover, research partnerships operate in larger systems, such as academic structures, that may unintentionally

perpetuate exclusion (Plamondon et al., 2024), underscoring the need for deeper exploration into their complexities.

The scoping review I conducted for objective 1 provided valuable insights into child health partnership structures and processes reported in peer-reviewed publications. However, it predominantly offered descriptive accounts of partnership characteristics, practices, and effects, constrained by limited reporting of partnership details, as echoed in the literature (Hoekstra et al., 2020; Mrklas et al., 2022). Primary studies on research partnerships suffer from a shortage of comprehensive data that transcends individual projects or funding networks (Kislov et al., 2018; Roberge-Dao et al., 2019). These limitations impede our ability to understand how practices evolve based on lessons learned, the maturation of partnership research theory and support structures, and broader shifts in partnership practice (Sibley et al., 2023). A collection of learnings from diverse partnership experiences can help us further understand common challenges, successful strategies, and evolving trends in partnership dynamics.

There is a need to further explore partnership experiences to glean pragmatic insights into the dynamics of partnerships that may elude traditional study conditions (Dunn et al., 2023). Previous research has revealed differing perceptions of the partnership process between researchers and knowledge users, highlighting the need to further understand factors supporting partnership processes, partnership quality, and effects (Sibbald et al., 2014; Sibbald et al., 2019; Mackenzie et al., 2024). Additionally, evidence on how partnerships operate in practice and the mechanisms driving both the process and their effects is lacking (Camden et al., 2015; Gagliardi et al., 2016; Lawrence et al., 2019; Hoekstra et al., 2020). Understanding the motivations and experiences underpinning researchers' and knowledge users' engagement in research partnerships is important, as motivations influence attitudes, behaviours, and expectations within partnerships. In contrast, experiences offer critical insights into partnership dynamics and inform our understanding of partnership work. Additionally, limited attention

has been paid to understanding how partnership teams navigate power dynamics and collaborative structures (Wallerstein et al., 2019), which may be heightened in partnered child health research by diverse partner roles, enhanced ethical considerations, interdisciplinary demands, and the imperative to translate research into tangible benefits for children and families. Unpacking individual experiences of working in partnership can provide valuable insights, generating commonly experienced perspectives on the realities of navigating partnership work.

### ***Research Aims and Questions***

This study aimed to understand the experiences and lived perspectives of researchers and knowledge users who engage in partnered child health research. My use of lived perspectives intentionally emphasizes not only the experiences but also the unique perspectives and insights gained from those experiences, highlighting the subjective nature of individuals' engagement in research partnerships. To achieve this, I explored the following research questions:

1. What motivates individuals to undertake partnered child health research? How does this motivation influence the process and effects of partnering?
2. How do researchers and knowledge users navigate the partnered health research process, and what factors contribute to successful collaboration or challenges encountered?

By investigating these questions, I aimed to comprehensively understand the multifaceted nature of partnered child health research across experiential, motivational, and relational dimensions and their implications for research partnership practice.

## **5.2 Methods**

### ***Study design***

This study used an exploratory approach informed by interpretive description to provide in-depth insights into research partnership experiences. Interpretive description goes beyond description to understand the underlying meanings and contexts shaping individual experiences (Thorne, 2016).

Interpretive descriptions' emphasis on interpretation and understanding aligned with the objectives of this study. It is a flexible approach that incorporates methodological components, including sampling and data collection from grounded theory, ethnography and phenomenology (Berterö, 2015) but distinguishes itself by recognizing the evolving nature of practice-based insights (Thorne, 2016). While this study does not examine practice-based insights in the traditional sense, such as those seen in clinical disciplines, it does address the dynamic nature of insights derived from practical experiences in research partnerships. This approach enabled me to capture not only the surface-level dynamics of these partnerships but also the deeper complexities that influence their effects. Moreover, interpretive description recognizes the active role of the researcher in the research process, emphasizing their background as valuable assets in the data analysis process (Thompson Burdine et al., 2020). In this study, my experience in KT and child health equipped me to provide meaningful insights into participants' experiences.

### ***Conceptual framework***

Jull et al.'s (2019) conceptual framework of knowledge user engagement informed key aspects of the study. I selected this framework for its emphasis on the diverse ways knowledge users may be engaged in health research, recognizing the importance of using frameworks to explore and understand the processes and impact of their involvement (Jull et al., 2019). I used the framework primarily in developing the interview guide. For example, the interview guide incorporated questions to address the concepts of *ethical principles and values* and *relational processes*.

### ***Study Population & Sampling Frame***

The study population included researchers and knowledge users of Canadian partnered child health research projects funded between 2011 and 2019 who previously completed a cross-sectional questionnaire and indicated an interest in being contacted for a follow-up interview (Sibley et al. under review). I identified potential participants by reviewing the project title and abstract among survey

respondents, which I confirmed through discussion with my advisor (KMS) and independent review by members of the survey research team (MK, DP).

### ***Recruitment***

Initially, I aimed to employ purposive sampling to align with my methodological approach (Thorne, 2016), focusing on recruiting participants who would provide rich, relevant insights into my research topic. However, due to recruitment challenges, I ultimately shifted to convenience sampling to ensure adequate participation. The recruitment process was conducted in three phases:

1. **Maximum variation sampling (July to October 2021):** I began by recruiting participants through a maximum variation sampling approach. This method aimed to capture a wide range of perspectives by including all completed projects and knowledge users identified via survey responses (n=17).
2. **Targeted sampling (October 2021):** To address diversity considerations, including gender, career stage, topic area, and CIHR research pillar, I then used targeted sampling to recruit a more diverse group of participants (n=8).
3. **Convenience sampling (late October 2021):** Upon exhausting these pools, I used convenience sampling to invite all remaining eligible individuals to participate. This phase aimed to fill any gaps and ensure sufficient participant numbers (n=19).

This revised approach allowed for flexible recruitment and a representative sample. Participants were contacted using the email address provided in the survey. Before the interview, participants were emailed a consent form outlining the study's purpose, procedures, and any potential risks associated with participation. Before beginning the interview, participants had the opportunity to ask any questions, and they provided consent to proceed.

### ***Data collection procedures***

I developed a semi-structured interview guide to explore the research questions (Appendix A). The interview guide was pilot tested with one researcher and one knowledge user for clarity and content; no changes were suggested. I conducted the interviews through the Zoom videoconferencing platform or telephone, based on participant preferences. All were audio recorded. No repeat interviews were conducted. Throughout the interview process, I kept a reflective journal to document observations and thoughts that arose during and immediately after the interviews. This served as an additional data source to aid analysis and interpretation.

### ***Data Analysis***

Data collection and analysis were carried out concurrently, adhering to interpretive description that emphasizes ongoing engagement with the data to confirm, explore, and expand on conceptualizations that begin during data collection (Thorne, 2016). For example, interviews were immediately transcribed and reviewed to start the process of data familiarization. Interviews were transcribed verbatim by an independent company (Transcript Heroes) and analyzed using NVivo12. I reviewed the transcripts against the audio file to ensure accuracy. Data were de-identified during this review by removing identifying information such as names, locations, and institutions and assigning pseudonyms to ensure confidentiality.

Data analysis followed an iterative approach consistent with the principles of interpretive description (Thorne, 2016). This involved multiple steps aimed at immersing myself in the data, inductive and structured coding, identifying patterns, and developing meaningful interpretations.

Initially, I engaged in data familiarization and immersion, reviewing transcripts multiple times, including immediately upon transcription, to gain a deep understanding of the participants' experiences. This process included highlighting important text segments and engaging in discussions with my advisor to explore potential coding approaches. Next, I reviewed transcripts in NVIVO and assigned preliminary

codes. These initial codes captured surface-level content described by participants. I assigned codes inductively (i.e., with no preconceived theory or guidebook to guide the process). That said, the interviews were structured according to the research questions. Therefore, I acknowledge an element of preliminary categorization guiding the initial coding process.

To ensure coherence and consistency in the analysis, I then developed a codebook (Appendix C) to define each code and refine those with similar conceptualizations. This served as a reference guide throughout the analysis process, promoting consistency and clarity in coding and categorization. Continual refinement of the codebook, guided by ongoing discussions with my advisor, ensured that the coding process remained responsive to the evolving data.

To further enhance the credibility and depth of the findings, I then involved a patient partner (KL) who expressed interest in this project. KL individually reviewed two transcripts, and we met to discuss important text segments, providing context and interpretation from a knowledge user perspective. KL provided valuable contextual insights drawn from personal experiences in the healthcare system and health research, offering a knowledge user perspective that deepened my understanding and interpretation of participants' experiences.

Fourth, I synthesized and interpreted codes and relevant text segments to identify overarching patterns and relationships within the data. This helped me to explore deeper meaning and insights, which formed the foundation of potential themes. Throughout the process, I maintained a reflexive stance, continually revisiting refining interpretations based on new insights and findings through constant comparison. This involved querying the data to discern patterns and variations in how participants discussed interpretive and thematic ideas, comparing data segments and groupings across cases and by participant attributes. I also kept reflective memos to capture emerging insights and potential alternative explanations for initial interpretations. This approach helped to build confidence in the themes and interpretations presented, enabling the identification of similarities, differences, and

patterns within the data. By refining and organizing codes and categories through constant comparison, I was able to weave different codes and categories into coherent and meaningful narratives. This iterative refinement process, which extended to written drafts, allowed for the continuous integration of new insights, enhancing the depth and richness of the analysis and contributing to the trustworthiness of the preliminary themes and interpretations. Furthermore, I solicited feedback from my committee and incorporated their insights through a Zoom presentation and multiple iterations of written drafts. This iterative refinement process strengthened the interpretations and contributed to a deeper understanding of the findings.

I maintained an audit trail documenting codes, code definitions, and text excerpts to track the evolution of themes and ensure analytic rigour and transparency throughout the process.

### ***Ethics approval***

This study was approved by the University of Manitoba Health Research Ethics Board (HS24838/H2021:224) and adhered to all ethical guidelines. Participants were offered a \$25 Visa gift card for participating.

## **5.3 Results**

### ***Participants***

Invitations to participate in the study were sent to 44 individuals (n=39 researchers and 5 knowledge users). Seventeen interviews were scheduled, and fifteen were conducted, lasting on average 40 minutes (range: 25 – 59 minutes). Two invitees cancelled scheduled interviews and rescheduled, but ultimately did not occur. Three invitees declined due to workload, 3 requested follow-up after a specific date but did not participate, and the remainder did not respond. Most interviews were conducted via Zoom (n=14), while one was conducted by telephone. Twelve researchers and 3 knowledge users participated. Table 5.1 describes the interview participant characteristics. Most interview participants identified as women (n=12, 80.0%). Participants worked in many areas of child

health, the most frequent being health systems and services (n=6, 40.0%). Participants resided in multiple provinces, the most common being Alberta (n=4, 29.0%). Among researchers, there was an equal split between mid (n=6, 50.0%) and senior career (n=6, 50.0%) phases. Two (67%) of the knowledge users had 8-11 years of experience in that role, while 1 (33%) reported 0-3 years of experience.

Table 5.1 Participant characteristics

<b>Characteristic</b>	<b>n (%)</b>
<b><u>Research partnership role</u></b>	
Researcher	12 (80.0)
Knowledge user	3 (20.0)
<b><u>Province</u></b>	
Alberta	4 (26.6)
Manitoba	3 (20.0)
Ontario	3 (20.0)
British Columbia	3 (20.0)
Quebec	1 (6.7)
Nova Scotia	1 (6.7)
<b><u>Research pillar</u></b>	
Health systems and services	6 (40.0)
Social, cultural, environmental and population health	4 (26.7)
Clinical	3 (20.0)
Biomedical	0 (0.0)
N/A	2 (13.3)
<b><u>Gender</u></b>	
Female	12 (80.0)
Male	3 (20.0)
<b><u>Self-identifies as a visible minority</u></b>	
Yes	1 (6.7)
No	14 (92.3)
<b><u>Self-identifies as Indigenous</u></b>	
Yes	1 (6.7)
No	14 (92.3)
<b><u>Researchers (n=12)</u></b>	
<b><u>Career stage</u></b>	
Early-career	0 (0.0)
Mid-career	6 (50.0)
Senior-career	6 (50.0)
<b><u>Discipline</u></b>	
Rehabilitation	3 (25.0)
Population and public health	3 (25.0)
Nursing	3 (25.0)
Social work	1 (8.3)

Sociology and criminology	1 (8.3)
Psychiatry	1 (8.3)
<b>Knowledge users (n=3)</b>	
<b><u>Years of experience as a knowledge user</u></b>	
0-3 years	1 (33.3)
4-7 years	0 (0.0)
8-11 years	2 (66.7)
12+ years	0 (0.0)

### ***Interview themes***

I identified three overarching themes woven throughout researcher and knowledge user experiences in child health research partnerships. First, *Diverse Drivers: Role-Based Motivations* underscores how motivations are influenced by the roles and experiences of those involved. This role-based dynamic shapes the impetus for engaging in partnerships and perceptions regarding their significance and value. Second, *Navigating Evolutions and Tensions* highlights the balance required to uphold research partnership practices within academic systems and structures that are not always conducive to collaboration, particularly among researchers. Third, *It's All About the Relationships* underscores the central role of relational quality in navigating both the successes and challenges of research partnerships. These themes illuminate the multifaceted nature of research partnerships, highlighting the interplay of motivations, dynamics, and relational intricacies that shape them.

### **Theme 1. Diverse drivers: role-based motivation**

There were clear distinctions in motivations for working in partnership that varied according to the participants' role in child health partnerships. Research partnerships offered both instrumental and broader social benefits, extending research into the 'real world' beyond academic silos. Role-based distinctions were also reflected in the perceived effects of engaging in research partnerships, aligning with participants' motivation.

#### ***Among Researchers: The Desire for Relevant, Impactful Research***

Researchers were motivated primarily to produce relevant, meaningful, and impactful research. This motivation was shaped by a blend of personal experiences and broader contextual influences, reflecting the diverse backgrounds of researchers. Often, pivotal experiences shaped this motivation. For instance, one researcher recounted their early experience working in government, where they recognized a disconnect between science and practice:

I think how I ended up where I am is that I worked in government for many years, and I realized that the science that I was focused on wasn't the problem. The problem was that we weren't giving adequate voice to the people who were concerned about what was happening in their communities and enabling them to engage better with what we know. There was just a real disconnect there (R09).

Their diverse personal and disciplinary backgrounds imbued researchers with unique insights and priorities, shaping their motivations to conduct research that directly addresses real-world challenges. Exposure and availability of funding initiatives with partnership requirements like the Strategy for Patient-Oriented Research (SPOR) further fueled researchers' interest in partnership-based approaches. Recounting their journey, one participant shared: *"So that sort of got me more and more interested because I saw how it really can change research in ways that enable it to be more impactful or more likely to be taken up and used"* (R03). Over time, researchers noted an evolution in their approach,

recognizing partnerships as crucial to their work. Researchers expressed a strong desire for their research to have a real-world impact and a commitment to ensuring accessibility to various stakeholders. While external mandates supported partnership approaches, the commitment to collaboration stemmed from a genuine belief in its capacity for meaningful change.

***Seeing tangible impact.*** Researchers found engaging in research partnerships to be personally enriching, expanding their worldview and contributing to their personal growth, *“It’s also involved with me, at least, a much greater and in-depth understanding of different ways of looking at research and looking at the world” (R10)*. Researchers also noted that feeling more accountable to end-users led to intentional research practices and a willingness to embrace diverse perspectives. However, the most significant value was seeing their research have a tangible impact in the real world:

For me some of the most meaningful impact is meeting people that used our product, in like, the weirdest places. Like, watching hockey games and talking to a complete stranger and then them figuring out, "oh my god, I've actually used something you've developed. It was really helpful." Stories like that. And it's happened, actually, so many times. For them to share that, to remember that they've used it, that speaks to me. - R02

***Among knowledge users: Enhanced Advocacy and Credibility***

In contrast, knowledge users were motivated by advocacy, cross-learning and the pursuit of credibility. One participant shared their journey, driven by a commitment to changing the stigma surrounding mental health:

After I went through that first episode, I essentially vowed that I would do whatever I could to basically change the stigma that was surrounding mental health because back in 2012 no one was really talking about mental health at all (KU04).

Knowledge users also saw research partnerships as a means to enhance credibility and reinforce their advocacy work, *“it gives us credibility also being able to say what we- or cite what we say, whatever that*

*expression is. But being able to cite what we're advocating for and not just relying on research done by others" (KU01).* This highlights the reciprocal benefits of research partnerships for knowledge users, presenting opportunities for them to contribute their insights and strengthen their positions and influence through evidence-based advocacy. This aspect may be crucial for knowledge users, especially those advocating for underserved communities or underrepresented perspectives. Engaging in research partnerships may bolster their credibility and authority in advocating for policy changes, resource allocation, or community interventions. Moreover, being directly involved in the research process allows knowledge users to ensure that the research adequately addresses their concerns and reflects the lived experiences of those they represent.

***"It just makes things more human"***. Knowledge users recognized the instrumental value of research partnerships, noting accelerated processes of change, enhanced advocacy abilities, and a humanization of the research process. As illustrated by one knowledge user,

Having patient partners at the table just brings a very unique voice. It makes things just more like human. It's not like, "Oh we're just doing this to win a grant," like, "We're doing this because we actually want to change people's lives" and to me, I think that that's incredibly amazing. - KU04

### ***Having a foot in both worlds***

Although I initially categorized participants as either researchers or knowledge users, a third perspective was evident: approximately half of the researchers interviewed also had relevant health professional training, work experience, and/or lived experience, which allowed them to straddle academic and healthcare environments. These individuals held characteristics and responsibilities of both a researcher and a knowledge user, and I referred to them as "duals". These individuals merged the analytical skills and perspectives of a researcher with the practical, applied approach of a knowledge user. Their active involvement in both realms often blurred the lines between research and practice

during our interview, making it necessary to clarify their contributions to research partnerships. For instance, one dual explained, *“I think probably a bit of both, because my clinical background helps what I contributed to the work, as well as my research background. So, there was a bit of both going on, I would say”* (D06).

Dual identities were advantageous for many aspects of partnered child health research. For instance, the dual identity could offer an important advantage in forming research teams: *“For somebody that’s a PhD who maybe hasn’t worked in the clinical area, well how you go about building a team I think is more challenging”* (D06).

### ***Among Duals: Enhancing Practical Relevance and Improving Health Outcomes***

Enhancing practical relevance and improving health outcomes was central to the motivation behind research partnerships for duals. Engaging in research partnerships was not only ingrained and inherent but also a practical necessity.

All duals emphasized the importance of incorporating diverse perspectives in research, recognizing that teamwork enriches dialogue and enhances the overall quality of research projects. Furthermore, duals recognized that each perspective influences the other, contributing to a more comprehensive understanding and better outcomes.

I don’t know that I’d want to do research without a partnership anymore. I think that no one person in any role can know everything. So, I can bring my perspective as a mom or a [healthcare provider] or a researcher but I can’t represent any of those uniquely. I bring all my hats. So any one of those perspectives is affected by the other and so the more people you can have with the different perspectives around the team I think it's just the richer project you’re going to have (D13).

While many duals felt they had always approached research through a partnership lens, the evolution of these practices has bolstered their legitimacy and acceptance, minimizing the need to defend their use.

Similarly, exposure over time and the gaining prominence of research partnership approaches have legitimized their use within the research context. As one dual noted, these practices are standard in clinical practice but have become increasingly prominent in research.

I mean, before that, I would listen to my patients and listen to my participants in my studies, but I wouldn't do it formally. It would be more informal consultation. So, it came out of my clinical work, where if you listen to your patients, that's how you figure out what to do. I only do applied projects – that's all I've ever done. (D08)

Participants perceived this enhanced legitimization of research partnerships as fostering a cultural shift towards collaboration within academia, encouraging interdisciplinary teamwork, recognizing diverse forms of knowledge, and promoting transparency and accountability.

***A unique blend.*** Duals experienced a unique blend of role-based partnership effects. Like researchers, duals experienced personal growth and enrichment through their involvement in research partnerships, expanding their understanding of communities and health issues. Duals also highlighted tangible effects, such as reducing child apprehension rates and demonstrating cost-effectiveness. Like knowledge users, engaging in research partnerships promoted advocacy and accountability, facilitating more responsive research practices and humanizing the research process.

Their emphasis on sustained impact beyond project completion was unique to duals, ensuring long-term relevance and applicability of research findings. Duals exuded a deep commitment to their communities, often extending beyond traditional research roles. Demonstrating a distinct perspective and understanding of the complexities of bridging research and practice, they actively addressed practical challenges, developing tailored solutions accessible and relevant to their communities. As noted by one dual, *“I think this has been really important because there are some who do this work kind of intuitively, and then sometimes they can't label it, and they just get it done”* (D11). This practical

approach addressed immediate project goals and ensured long-term impact, extending benefits into everyday practice and fostering examples of positive change.

## **Theme 2. Navigating evolutions and tensions in research partnerships**

Participants unanimously recognized the evolving nature of systemic and structural conditions in research partnerships, facilitating advancements in the field and introducing tensions. This principally involved the academic system; while the academic landscape has adapted to accommodate research partnerships to some extent, participants highlighted the mismatch between academic structures, funding expectations, and the foundational principles of research partnerships. This incongruity often acts as a double-edged sword, generating challenges for conducting research partnerships.

### ***Evolution of Research Partnerships***

Participants noted a shift in academic culture towards acknowledging and embracing research partnerships. This evolution reflects a growing acceptance and integration of partnership work into academic research practices. However, it has required adjustments for researchers, as noted by one participant's remark that *"funders really had to pull some academics to get onside with that"* (R02). While this acknowledgment represents progress in integrating partnership work into academia, it also underscores the ongoing challenges and adjustments required to embrace collaborative research endeavours fully.

Additionally, participants emphasized advancements in the practice of partnering, with knowledge users playing increasingly significant roles. As one knowledge user reflected, *"I think the rules of engagement have changed substantially. Knowledge users are more involved in research themselves and as part of the projects. And so we're not just partners on paper anymore (KU01)."* This formalization and standardization of engaging knowledge users in the research process, coupled with increased funding opportunities and changes in funding requirements, have incentivized collaboration. One participant observed that *"Requirements have changed in terms of what governing bodies or funding*

*bodies have requested, so that maybe enforced certain collaborations more than would have happened before” (KU03).*

### ***Tensions Between Academic Structures and Partnership Processes***

Despite progress, significant tensions persist, posing challenges for researchers and duals. These tensions stem from an ongoing mismatch between traditional academic structures, funding expectations, and the principles that underpin effective research partnerships. One of the most pressing challenges highlighted by researchers was the lack of recognition for research partnerships within existing tenure and promotion systems. As one participant lamented,

What’s interesting is that it’s something in our world of academia that’s basically of no value right now, like in the tenure system and stuff. No one seems to care – but I think a lot of people that are good applied researchers have a different value system. But if you’re good at doing applied research, you also tend to have a pretty good CV, so I think it doesn’t matter (R09).

This discrepancy often leads to academic researchers feeling undervalued for their partnership efforts, which are not adequately rewarded in the current academic evaluation criteria. As another researcher expressed, *“So it’s been an uphill battle. I mean the timelines and metrics of doing partnership research with communities are going to be different. And that’s a good thing not a bad thing. But often the academics themselves are penalized for it” (R10).*

This tension necessitates a delicate balance between meeting academic standards and fulfilling responsibilities to knowledge users. As expressed by another participant, *“So it’s like who’s at the forefront, who’s getting the accolades because of this? Communities typically do not need first authored publications in a journal but that’s what we’re after” (D04).* This balancing act is particularly challenging given the time and resource-intensive nature of research partnerships compared to traditional research paradigms.

Moreover, systemic obstacles within academic institutions further impede effective research partnerships. Participants recounted instances where they were met with bureaucratic hurdles in reimbursing partners and navigating research ethics processes. For example, one participant recounted an incident where they took a parent to a conference and struggled to convince the university to reimburse their costs, emphasizing the need for institutions to evolve their policies to better support partnership activities. Another participant noted that research ethics processes within academic institutions can be challenging to navigate, indicating a need for greater clarity and understanding among research ethics boards.

So those are some of the hurdles that you know sometimes institutionally our ethics and well-intentioned ways of doing things the right way, end up not making sense. Somebody wasn't thinking you know, in both cases (R10).

Some participants shared strategies for addressing these tensions, such as adjusting research agreements to uphold partnership integrity and leveraging existing resources for support. However, these strategies often required significant effort and negotiation, further complicating the partnership process. As one participant reflected,

And to me that was just inconceivable that they would think that I should have to do that, so we had huge fights. I ended up having to get letters from the community telling them this is the right way to do things, and pointing to TCPS 2 Chapter 9 that says that our priority was to do things that worked with Indigenous communities, you know, not against them; and stuff like that (R10).

Additionally, participants acknowledged tensions related to funding mechanisms and the need to strike a balance. One participant reflected on the cyclical nature of funding dynamics, noting the need for symbiotic components to do partnership research. Participants cautioned against including partner names on grants without genuine engagement, highlighting the need for funders to consider the

implications of their funding strategies on research partnerships. Furthermore, participants suggested that funding structures may not always align with the principles of genuine partnerships, sometimes leading to compromises in partnership integrity.

I think it's more advice for funders; the funders are putting us in these compromising positions of ultimately – like the funding agencies are really defining everything. And if we are researchers and we're wanting to get grants and get tenure promotion, we play that game. But they're really putting – and I have experience put us in compromising positions. So the funders I think as well as the institutions and just the policies that we have in place. (D04)

### **Theme 3. It's all about the relationships**

When describing partnerships that participants felt worked remarkably well, it was evident that success hinged on more than the technical aspects of collaboration. It was fundamentally about the quality of relationships fostered among partnership teams. These relationships not only facilitated effective communication and teamwork but also served as normative principles shaping the partnership's dynamics, sustainability, and ability to navigate challenges.

#### ***“There has to be some chemistry there”***

Successful research partnerships were anchored in a foundational set of principles that emphasized establishing and maintaining relational quality. Enacting these principles required leveraging a set of often overlooked and undervalued skills – not typically part of formal research training – that participants had to navigate, fumble through, and cultivate over time through practical experience and learning from past interactions. Participants recognized the critical role of cultivating trusting relationships and dedicating time to connect, foster understanding, and value all contributions. Beyond trust, participants emphasized the need for a deeper, intuitive connection between partners, emphasizing the centrality of relational quality. Additionally, participants stressed the need to value the contributions of all partners, suggesting that there should be no hierarchy among collaborators based on

their backgrounds or roles: *“so they respect my position, I respect their position. But you can’t think one trumps the other”* (D08). Flexibility, openness, and commitment to continuous learning further strengthened research partnerships. Adapting to changing circumstances and acknowledging mistakes required confidence to pivot and humility, described metaphorically as *“parking your ego”* (D11). Lastly, partnership sustainability requires mutual support and reciprocity, where both parties contribute and support each other’s work.

In essence, these principles that participants consistently described when recounting successful research partnerships collectively underscore the significance of relationality in research partnerships. Relationships were not incidental but required ongoing and deliberate effort that shaped partnerships' perceived success or failure.

#### ***Unpacking power dynamics: navigating principle and reality***

Appreciating the intricacies of power-sharing was important for fostering relational quality within research partnerships. As collaborations evolved, participants observed a shift towards more authentic and equitable interactions. Initially, challenges arose due to technical language and acronyms, which hindered open communication and excluded certain voices. Reflecting on this, a knowledge user remarked on the discomfort experienced when faced with these barriers, highlighting the need for a more inclusive approach: *“I would often think to myself like what if I didn’t have that, would I even feel comfortable sitting at the table. And I think the answer would be no. I think a lot of people would get intimidated by that. But now I see that things are becoming a little bit more formalized”* (KU04).

Similarly, researchers noted instances where knowledge users, particularly parents, felt intimidated and hesitant to voice their opinions.

As partnerships matured, participants observed improvements in power-sharing dynamics through trial and error, facilitated by deliberate efforts to diversify and expand the composition of collaborative teams. For instance, by including a broader range of knowledge users, projects could more

equitably balance voices at the table, supporting knowledge users in feeling more comfortable. This restructuring allowed for a more democratic decision-making process, where parents felt empowered to contribute their insights without the intimidation of formalities. However, participants also acknowledged power dynamics' fluid and nuanced nature within partnerships. Individual preferences and professional backgrounds influenced the degree of involvement and control exerted by each member, leading to variations in decision-making processes.

Despite progress, tensions between the principle of sharing power and the realities of enacting power-sharing in practice was an issue that participants grappled with. As one participant expressed, *“So it’s really hard. Right? Particularly when you’re bringing in, say, like high level decision makers or high level researchers and the partnership is bringing in patient partners or youth or whomever. It’s really hard to avoid a natural hierarchy that develops in those conversations”* (D05). Some participants, particularly senior researchers and knowledge users with more experience, noted their role in disrupting these imbalances. The hierarchical nature of academia and factors like tenure and promotion occasionally posed challenges to achieving true equity in decision-making processes. Concerns were raised regarding the unequal access to resources and the inherent advantages held by researchers, prompting reflection on the true meaning of sharing power within research partnerships.

Yes, I think we have to be so careful about this, right, the sharing power piece. Ultimately we’re – in reality I have the money typically, ... And what does that really mean, like how do we define that? So we can’t say that we don’t hold more power because we do as the researchers (D04). Participants emphasized proactive measures to address these challenges, including setting clear guiding principles, creating safe spaces for dialogue, and valuing and utilizing input from all members. Despite the time and effort required, these strategies are essential for fostering genuine collaboration and ensuring that all voices are heard and respected in the partnership process. As one participant remarked when discussing ways to facilitate shared decision-making, *“the quickest way to do it is not the easiest*

*way to do it, but I think in the long run it's worth it"* (D05), underscoring the importance of investing early in the process of power-sharing for the long-term success and sustainability of research partnerships.

### ***Productive Tensions: Adapting to Adversity***

Navigating challenges was acknowledged as a natural aspect of research partnerships. Participants, particularly duals, emphasized the importance of authenticity and trust-building in addressing difficulties head-on. Open dialogue and problem-solving efforts were seen as catalysts for strengthening relationships, even in the face of adversity. Participants underscored the significance of trust, noting that lack thereof could hinder problem-solving efforts and lead to withdrawal. Despite setbacks, productive tensions provided valuable learning opportunities, fostering resilience and strengthening relational quality.

In some ways it brought us closer. That sounds funny. But because we – in talking over how to deal with that difficult situation it made us talk about a whole bunch of other things that probably should have been talked about before but haven't. And we all ended up kind of banding together in adversity (R10).

### ***Adopting a long-term perspective***

Researchers stressed the importance of adopting a long-term perspective when engaging in research partnerships, viewing their career trajectory as an ongoing engagement cycle. Rather than solely focusing on individual projects, some researchers highlighted the importance of nurturing enduring relationships that transcend the constraints of project-based funding. Reflecting on past experiences, one participant highlighted the shift from forming advisory panels for each grant to adopting a more sustainable approach.

*I look at when I became an independent investigator in 2008, so while I had all these great relationships and collaborations, I was developing advisory panels for every grant I was writing. And I quickly realized how that was not sustainable moving forward (R02).*

This realization underscores the need for a paradigm shift towards cultivating long-term, reciprocal relationships that endure beyond the confines of project-based funding, thereby introducing tension within current funding systems. Participants emphasized the significance of reciprocity in sustaining enduring partnerships and stressed the need to move beyond project-specific needs. Instead, they advocated for a holistic approach where cultivating relationships becomes integral to their professional journey. This reciprocity fostered a two-way exchange where researchers not only drew on the expertise of their partners but also actively contributed to the partnership's growth and sustainability.

*So the purview can't be - "oh for this project we're going to need to work with these people." We just need to think of, "oh, in my career I need to have contact and relationships with these organizations and find a way to foster that." It's a two-way street. We just can't be taking (R02).*

Moreover, participants emphasized the importance of starting small and allowing partnerships to evolve, mirroring the gradual progression of a research program. This incremental approach enables researchers to build upon past successes, gradually expanding their networks and partnerships in alignment with evolving research priorities.

*I really think mine fell into a program of research where one project built on the other, and so I kept adding people as appropriate. So to think about a program of research I guess, start small with your team, but then build as appropriate on future ones and get them a little bit bigger (D06).*

#### **5.4 Discussion**

This study aimed to understand the experiences, motivations and dynamics of researchers and knowledge users who engage in partnered child health research. The findings provide insights across

three key themes. First, the findings advance our understanding of role-based distinctions in research partnerships, highlighting diverse motivations and effects that vary by role. Second, this study reaffirms the ongoing challenges of navigating research partnership processes within academic systems, emphasizing the need to adapt to evolving landscapes. Third, the critical role of relationships permeated participants' narratives, influencing how partners work together, share power, and solve problems. By exploring the experiences and lived perspectives of researchers and knowledge users, this study enhances our understanding of partnership dynamics, offering insights for research partnership practice in child health.

### ***Understanding motivations and role dynamics in research partnerships***

This study deepens our understanding of role-based dynamics in research partnerships, highlighting distinct motivations that vary by role. I found that diverse motivations drive engagement in research partnerships, ranging from a desire for impactful research to enhanced advocacy and credibility. While research suggests that researchers and knowledge users are highly motivated to partner (Shwed et al., 2023), the literature lacks exploration of the specific drivers behind this motivation, particularly as they relate to different roles within the partnership. Understanding these distinctions provides insights into the factors influencing partnership dynamics and effectiveness.

A previous qualitative study by Sibbald et al. (2014) highlighted varying perceptions of partnership barriers among researchers and knowledge users involved in funder-required research partnerships (Sibbald et al., 2014). Notably, it identified mixed perceptions of role clarity and clearly defined expectations as barriers hindering effective collaboration. Researchers often assumed more operational responsibilities while positioning knowledge users in advisory roles, leading to a perceived power imbalance. Conversely, knowledge users sometimes felt marginalized in reactive roles, further exacerbating the lack of clarity and expectations. Additionally, frustrations arose when there was a lack of transparency regarding agendas, particularly when researchers' and knowledge users' goals were

misaligned (Sibbald et al., 2014). This indicates the need for consistent communication and clearly defined expectations and roles from the outset. While Sibbald et al.'s (2014) study provided insights into these challenges, my findings offer a deeper exploration of the underlying mechanisms. Understanding what motivates individuals to engage in research partnerships can inform strategies to enhance capacity-building and support (Hoekstra et al., 2022). Recognizing role-based distinctions is crucial for fostering effective collaboration, communication, and decision-making within partnerships, thereby contributing to their long-term sustainability. The alignment of participants' motivations with the perceived value of research partnerships further underscores the intricate interplay between individual motivations and partnership goals.

This study's participants exhibited strong intrinsic motivation to engage in research partnerships. For example, researchers and knowledge users expressed belief in the transformative potential of research partnerships for the betterment of society. This intrinsic motivation, rooted in personal satisfaction, professional growth, and a genuine interest in the moral dimensions of their work, played a pivotal role in nurturing meaningful partnership practices. Participants revealed that they were highly motivated, committed to continuous learning, and reflective about how they worked alongside partners. This suggests that extrinsic motivators like mandated partnerships or reward systems, while necessary for supporting partnerships, are unlikely to foster meaningful partnerships alone (Hoekstra et al., 2022). This aligns with existing research indicating that while external factors such as funding are considered necessary resources, they are not the primary drivers of researcher's work (Suominen et al., 2021). My findings support previous analyses suggesting that cultivating intrinsic motivation may be crucial for supporting sustained engagement in research partnerships (Suominen et al., 2021).

While distinct, the motivations among partnership roles were synergistic, creating a fertile ground for collaboration, innovation and impact. For example, while each role may have different motivations, their collective aim ideally converges toward a common objective. Furthermore, each role

contributes unique expertise and perspectives to the partnership, enabling the utilization of these complementary strengths. For example, impactful research findings enhance knowledge users' credibility and advocacy efforts, while practical implementation and improved health outcomes contribute to the relevance and impact of research. This mutual reinforcement can promote collaboration, strengthen partnerships, and enhance their effects. By aligning and leveraging these diverse motivations, partnership teams can maximize the impact of research partnerships. Therefore, understanding role-based distinctions in motivation provides valuable insights into the dynamics of research partnerships and enhances our understanding of pathways to effects.

### ***The opportunity of the dual role***

Approximately half of the researchers interviewed in this study embodied dual experiences, integrating academic responsibilities with a knowledge user's experiential knowledge, making them more sensitive to and aware of the broader context. This unique perspective enabled them to bridge academic and healthcare environments, yielding advantages such as fostering team development, enhancing practical relevance, and improving health outcomes. For these participants, their involvement in research partnerships was inherent and deemed a practical necessity. While the phenomenon of dual roles has been acknowledged in the research partnership literature, described using terms like boundary spanners (Dunn et al., 2023), intermediaries (Bornbaum et al., 2015), embedded researchers (Eljiz et al., 2020), and pracademics (Fowler et al., 2023), it has not garnered significant traction, warranting further attention. Boundary spanners have been acknowledged as key facilitators of early-stage iKT (Zych et al., 2019), critical enablers of successful research partnerships. Gagliardi and Dobrow (2016) have also highlighted the criticality of multiple roles, including opinion leaders, dedicated facilitators, and local champions, in enabling partnership functioning. Interestingly, these roles also serve as implementation strategies (Flynn et al., 2023), suggesting that leveraging the dual role may promote translating research findings into real-world impact, bridging the fields of implementation science and research partnerships.

The findings from this study suggest that individuals with dual identities may hold promise for facilitating research partnership practices and outcomes, demonstrating a distinct affinity and drive for conducting practical research, along with nuanced motivations and effects. Their potential is supported by global investments to produce and support embedded researchers in governments and health systems to promote sustained collaborations between sectors (Eljiz et al., 2020; Sim et al., 2019; Yin et al., 2017). Further exploring this role may be important for advancing collaborative research efforts.

### ***The central role of relationships in partnership dynamics***

My findings underscore the central role of relationships in shaping the dynamics and effects of research partnerships. While not explicitly probed, participants consistently emphasized the importance of fostering and nurturing high-quality relationships within and across partnerships, characterized by trust, respect, flexibility, reciprocity, and power-sharing. These principles are not just theoretical but are fundamental when working together, reflecting basic social values often learned early in life yet sometimes overlooked in professional settings. Furthermore, these principles have deep roots in Indigenous scholarship, where community, interconnectedness, and relationality have long been emphasized (Wildcat & Voth, 2023; Wilson, 2008). Indigenous approaches to knowledge creation and sharing are grounded in relational accountability, mutual respect, relevance, and shared responsibility (Brant et al., 2023; Gerlach, 2018; McGregor, 2019; Wildcat & Voth, 2023), illustrating that these concepts are well-established and foundational in some fields. This connection highlights that the focus on relational quality in partnerships, though gaining more recognition in mainstream health research, is not new. While the evolution of research partnerships reflects a growing acceptance and integration of partnership work into academic research practices, tensions persist due to discrepancies between academic structures, funding expectations, and the foundational principles of effective partnerships. However, participants expressed a commitment to promoting more equitable partnership practices,

recognizing that relational quality is critical in navigating and fostering sustainable, mutually beneficial partnerships.

This study reaffirmed the importance and challenges of sharing power in research partnerships. While participants demonstrated increasing capabilities to enable and support higher levels of engagement over time, challenges such as power imbalances and discrepancies between partnership expectations and traditional academic success metrics persisted. These findings resonate with the evolving discourse on power-sharing in research partnerships, indicating a growing recognition of the need for transformative changes in research systems and practices (Plamondon et al., 2024). In this study, partnerships were not necessarily explicitly conducted to reduce inequities, reflecting perhaps project-specific aims and underlying philosophical traditions. Notably, it is unrealistic to expect all partnerships to share power equally, as knowledge users may not always desire or have the capacity for extensive involvement. Jull et al. (2019) distinguish between equitable rather than equal engagement, underscoring the variability in desired levels of engagement both within and across projects. This underscores the importance of building relationships to facilitate ongoing dialogue and iteration throughout partnerships, ensuring alignment with the evolving needs and expectations of all team members (Langley et al., 2022). Participants' commitment to inclusion and reflexivity demonstrates a willingness to address power imbalances and promote more equitable partnership practices, though ongoing efforts are necessary to overcome structural barriers and foster genuine collective efforts.

Furthermore, participants were proactive in addressing challenges within research partnerships, emphasizing the importance of transparency, learning and continuous improvement. The openness to acknowledging challenges contrasts with the tendency in the research partnership literature to focus solely on successes (Hoekstra et al., 2020; Meibner et al., 2021). This approach fosters a more balanced understanding of partnership dynamics and enables the development of robust strategies for overcoming obstacles and building resilient partnerships. While known barriers to research

partnerships, such as time constraints and resource limitations (Gagliardi et al., 2016; Lawrence et al., 2019) were not frequently discussed, participants emphasized overcoming challenges and fostering productive dialogue. This reinforces the central role of relational quality, suggesting that partnerships founded on established, trusting relationships may be better equipped to manage conflict and navigate tensions effectively (Sibbald et al., 2014). By prioritizing relationship-building and emphasizing mutual understanding and trust, partnerships can better navigate tensions and achieve their goals more effectively.

### ***Study limitations***

Despite including early-career researchers in recruitment, my sample was restricted to mid and late-career researchers. Given the timeframe for which research partnership approaches grew in popularity in Canada, this may mean that many of these researchers adopted a partnership approach while already established in their careers. This experience may differ from an early career researcher who may have received training or mentorship within a partnership paradigm, resulting in potentially different motivations and experiences. Mid and late-career researchers may have established networks and experiences that differ from those at earlier career stages. This could lead to a limited understanding of the challenges and opportunities faced by early career researchers. However, hearing from mid to late-career researchers was also a strength, as it provided insights into the complexities of research partnerships, informed by their extensive experience, institutional knowledge, longitudinal perspective, established networks and/or programs of research, and mentorship roles. All participants witnessed the evolution of partnered research, allowing reflection on trends, shifts, and emerging best practices, providing valuable context for understanding current challenges and opportunities. Their insights into research partnerships are often informed by years of navigating academic environments, collaborating with diverse stakeholders, and managing complex projects. Coupled with a familiarity of

institutional structures, policies, and cultures that influence research partnerships, this provided unique insights into the practical considerations and constraints that shape partnership dynamics.

Similarly, only three knowledge users agreed to participate in the study. However, this represents a greater response rate (60%) than the eligible researchers (31%). This may not adequately capture the diversity of perspectives and experiences in the knowledge user community, limiting the depth of understanding about how research partnerships impact different groups. Hearing from a broader range of knowledge users could provide richer insights into how research partnerships are perceived and experienced across various sectors and communities. Future studies could examine the experiences of children and youth engaged in research partnerships.

#### **5.4 Conclusion**

This study advances the understanding of role-based variation in research partnerships by unpacking the diverse but synergistic motivation and effects among researchers, knowledge users and duals. These findings further reaffirm the central role of relationships in navigating and sustaining research partnerships and highlight the ongoing need to address mismatches between academic structures and research partnership processes to support their practice. Additional study is needed to explore what may render the child health context unique and further understand the dual role's contribution to research partnerships.

### Preface to Chapter 6

Persistent measurement challenges exist in the research partnership literature, including non-standard terminology, inconsistent reporting and use of term definitions, and a lack of quantitative measurement of effects. As a result, there is a lack of comprehensive primary data on research partnership dynamics, processes and effects. More specifically, there has been limited to no exploration of what may differentiate child health in the context of research partnerships. While the previous two studies examined the characteristics, dynamics, processes and effects of partnered child health research, I was limited to what was published and reported and limited to the in-depth experiences of a small sample. This study seeks to further enhance my understanding of these partnership components leveraging a large cross-sectional data set and individual interviews to explore perceptions. Specifically, this objective focused on the role of the *research context* in understanding partnership dynamics, processes and effects.

This work describes the establishment of a child health cohort derived from a cross-sectional survey of Canadian partnered research projects funded from 2011 to 2019. In this study, I describe the characteristics of partnered child health research in Canada, explore researcher and knowledge user perceptions of the differences and considerations when partnering to conduct child health research, and compare perceived effects and individual determinants to work in partnership between child and general health cohorts. Findings are integrated in the discussion to provide a more wholesome understanding of partnered child health research.

#### **Contribution of authors**

Although the quantitative data in this chapter are secondary in nature, I played a role in the conceptualization and design of the questionnaire, led by Dr. Kathryn Sibley (the nominated principal investigator of CIHR project grant PJT #156372). I was solely responsible for creating the child health cohort, writing this paper and conducting all analyses. For the qualitative portion of the study, I was

solely responsible for participant recruitment, data collection, and analysis. Drs. Kathryn Sibley, Shannon Scott, and Michelle Driedger informed this project's research design and conceptual considerations and provided valuable feedback during theme generation. Mr. Kent Cadogan Loftsgard was involved in data interpretation from the lens of a person with lived experience of childhood health management and health system navigation.

This study is being prepared for submission to an academic journal and was presented in poster format at the 2024 Knowledge Utilization colloquium in Uppsala, Sweden.

**Accepted Conference Abstract:**

Crockett LK, Scott SD, Driedger SM, Sibley KM. (2024, June 24-26). *Is child health a unique context for research partnerships? A mixed-methods study to understand partnership experiences and effects.*

Knowledge Utilization Colloquium, Uppsala, Sweden.

## **Chapter 6: Unpacking context: a mixed-methods exploration of Canadian researchers' and knowledge users' perceived distinctions in partnered child health research**

### **6.1 Introduction**

Partnerships with knowledge users in child health research, like all partnered health research, are recommended to enhance the relevance and uptake of health research findings (Gagliardi et al., 2016). However, child health research and healthcare are distinct from other populations, owing to factors such as children's unique epidemiological profile and specialized needs, strict regulatory requirements, and heightened ethical considerations with minors (Sammy et al., 2023; Tyack, 2023; Zylke et al., 2012). Consequently, partnered child health research may also possess distinct features from research partnerships in other areas of health, such as the need to navigate diverse family structures and various life stage commitments (Taylor et al., 2018), incorporate multiple societal perspectives (Tyack, 2023), and employ suitable engagement strategies for different age groups.

However, we lack basic data on the extent of partnered child health research in the research landscape. Existing reviews of partnered child health research, while valuable, are limited to data shared in publications (Crockett et al., 2024; Vanderhout et al., 2023). There are no reporting requirements for partnered research and not all study teams may report on the partnership in the primary study or identify as partnered research. Additionally, primary evaluations of partnered health research often aggregate findings across diverse populations (Sibbald et al., 2019), making it challenging to understand specific effects in a distinct population group such as child health.

Fortunately, these questions can be readily examined through ongoing work and existing data sources. Sibley et al. (in review) aimed to advance our understanding of partnered health research through a cross-sectional survey of self-reported practices and perceptions of involving knowledge users in Canadian partnered health research projects funded between 2011 and 2019. This comprehensive survey, completed by 589 respondents from 456 projects across all domains of health research, provides

a unique opportunity to identify a subset of projects focused on child health. This allows for describing partnered child health project characteristics and comparison across research contexts. The dataset includes many concepts influencing partnered research that may vary in child health contexts, including the perceived effects of involving research users in specific research projects and partnership dynamics (e.g., trust, dialogue, conflict management, power sharing). Partnership dynamics are influenced by both individual and structural determinants of partnering (Wallerstein et al., 2018; Ortiz et al., 2020). For instance, behavioural theory posits that individuals must have the capability (e.g., knowledge, skills), opportunity (e.g., resources, supports), and motivation (e.g., intrinsic and extrinsic drive) to engage in partnered research (Michie et al., 2011). These individual determinants can contribute to various effects of partnered research while understanding these determinants can help to identify barriers and facilitators to optimal partnering. Additionally, understanding and comparing partnership dynamics and effects between child and general health contexts can elucidate variations and identify best practices.

While the survey offers valuable descriptive and comparative insights, its design may overlook specific challenges and considerations specific to partnered child health research. Qualitative methods can provide insight into the experiences and perceptions of individuals involved in partnered child health research, offering the contextual depth to understand how partnerships function fully. Additionally, qualitative methods can identify relevant factors, challenges, and unique considerations specific to partnered child health research that may not be apparent in structured survey responses. Combining quantitative and qualitative methods offers several key advantages, including enhanced reliability of results and a deeper understanding of the mechanisms behind observed patterns and trends, which is particularly important in understanding the dynamics and effects of partnered child health research. Furthermore, qualitative data can help explain the “why” and “how” behind the “what” found in quantitative results, leading to richer interpretations and more actionable insights. Therefore,

integration provides more holistic insights that address both the breadth and depth of research questions, allowing for examining different dimensions of partnered health research.

Through this complementary mixed-methods approach, this study seeks to identify convergent and divergent aspects of partnering across health research contexts. These findings may provide insight for partnership teams looking to draw transferrable lessons and contextual insights to inform the design, practice, and evaluation of partnered child health research.

## **6.2 Methods**

### ***Context and conceptual guidance***

This study adopted a pragmatic research paradigm, prioritizing research findings to address practical, real-world problems and emphasizing research questions over a specific philosophical standpoint (Kaushik & Walsh, 2019; Morgan, 2014). It rests on conceptual guidance developed for a set of research projects to understand current practices in Canadian-partnered health research and develop practice recommendations (CIHR project grant PJT #156372). The development of research questions and data collection were guided by the Jull concepts for knowledge user engagement (Jull et al., 2019).

### ***Study design***

A concurrent exploratory mixed-methods design was used, integrating sequential sampling components. The quantitative phase involved a secondary analysis of a cross-sectional survey of Canadian partnered health research projects, while the qualitative phase included semi-structured interviews with a subset of child health survey respondents. Survey data used in this study were collected between August and October 2020, preceding qualitative data collection. Quantitative and qualitative components were analyzed simultaneously (QUANT + QUAL), integrating findings into the discussion (Creswell & Plano Clark, 2018). The integration of qualitative and quantitative findings allowed for a comprehensive understanding, with qualitative insights providing context to quantitative

results and quantitative data offering a broader scope to qualitative findings, equally highlighting areas of convergence and divergence.

### **6.2.1 Quantitative component**

Comprehensive details of the survey, including the sampling frame (Sibley et al., 2023), design, and questionnaire, are outlined elsewhere (Sibley et al. in review). In summary, the survey aimed to collect project-specific information on project characteristics, partnership practices, perceived effects of working in partnership with knowledge users, and team cohesion, capability, opportunity, and motivation for working in partnership. Eligibility for participation in the survey was contingent upon individuals meeting the following criteria: 1) inclusion as a project team member approved for funding by a Canadian federal or provincial health research funding organization through a peer-reviewed competition, ii) funding received between 2011 and 2019, and iii) explicit inclusion of at least one non-academic knowledge user as a principal or co-investigator on the funding application. Branching logic (Dillman et al., 2014) was used to customize questions by project role, project status, research components included in the project, knowledge user involvement in included components of the research process, and perceived effects of knowledge user involvement. The survey was available in both English and French. The survey achieved a response rate of 34%, with 589 individuals completing the survey, representing 456 unique projects. Due to the occurrence of multiple respondents for some projects (n=89 projects representing n=222 respondents) which violates the assumption of data independence required for statistical comparisons, I was unable to analyze and compare project-level variables, such as partnership practices (e.g., knowledge users engaged, engagement activities). The original survey dataset underwent data cleaning and quality checks, including multiple sensitivity analyses based on respondent type and level of completion, indicating no significant differences (Sibley et al., in review).

### ***Data Procedures and Analysis***

As per Sibley et al. (in review), I included full and partial responders in the analysis (n=589), defined as those responding past a specified cut-off question (question 4.3). Missing data were addressed using pairwise deletion to retain as many meaningful responses as possible, ensuring that partial responses contributed where applicable (Newman, 2014; Mirzaei et al., 2022). It has been argued that when construct-level missingness is minimal (<10%), imputations offer no significant advantages over pairwise or listwise deletion (Newman, 2014). Project title and abstracts included in the final data set (n=589) were screened in duplicate to create a subset of projects meeting our defined criteria of child health, herein referred to as the child health cohort. Those coded as unsure were discussed with my advisor (KMS) until a consensus was reached. Several conceptualizations of child health were considered. Child was defined as studies focusing on populations from birth to 18 years of age (World Health Organization, 2007), unless otherwise specified (e.g., mental health, and Indigenous health, where age cut-offs are often expanded), while health was defined according to the World Health Organization conceptualization of health as “a state of complete physical and mental well-being and not merely the absence of disease or infirmity, including prevention components and mental health” (Grad, 2002). Projects that did not explicitly specify child health outcomes (e.g., focus on maternal experiences, interventions, or outcomes during pregnancy) and those with a focus on the general population where the target population was unclear (e.g., fetal alcohol syndrome disorder across the lifespan) were excluded. Those that focused on transitions in care (e.g., youth onset diabetes), multiple populations (e.g., youth and young adult psychosis), and maternal child health with a focus on at least one child health-focused outcome, were included in the child health cohort.

Statistical analyses were performed using SPSS version 28.0. Consistent with Sibley et al (in review), data were collapsed or re-categorized where appropriate. Descriptive statistics were computed for all variables, and between-group differences were examined using chi-square testing. Post hoc

analyses were conducted for categorical variables where appropriate to identify specific cells driving the observed difference (Sharpe, 2015). To mitigate the risk of type 1 error associated with multiple statistical tests, I used a Bonferroni-adjusted statistical significance level of  $p < 0.001$  (Armstrong, 2014).

## **6.2.2 Qualitative component**

### ***Methodology***

The qualitative phase used a subset of interview data collected for and described in Chapter 5 and was informed by a qualitative description approach. This methodology aims to provide a comprehensive summary of experiences, prioritizing participants' perspectives while minimizing theoretical imposition (Bradshaw et al., 2017). The qualitative description focuses on factually describing participants' views and experiences with low inference interpretations that remain 'data-near' (Doyle et al., 2020; Sandelowski, 2010). This approach is particularly suitable for areas with limited existing knowledge (Sandelowski, 2010), providing straightforward descriptions while acknowledging subjectivity and varied participant experiences (Bradshaw et al., 2017). Although some interpretation is inherent, qualitative description stays close to the data, ensuring findings are practical and directly applicable to practice (Neergaard et al., 2009). It aligns with pragmatism and is often used in mixed-methods studies to inform, confirm, or enhance quantitative data (Neergaard et al., 2009; Doyle et al., 2020).

### ***Participants and Recruitment***

As outlined in the preceding chapter, a convenience sampling approach was used to recruit individuals with experience in partnered child health research. Although I initially aimed to purposefully recruit participants using maximum variation sampling in alignment with my methodological stance (Neergaard et al., 2009), I ultimately extended invitations to all eligible participants due to low response rates. The sample was drawn from child health survey respondents who expressed willingness to be contacted for a follow-up interview. Potential participants were invited by email from July 2020 to October 2020.

### ***Procedure and Data Collection***

Data for this study focused on the latter part of the interview (refer to Appendix D, question 6), contextualized by earlier sections of the interview. Specifically, the final segment of the interview explored experiences partnering in child health compared to other populations, including discussions on perceived differences, interactions with various knowledge users in child health, and unique considerations specific to the child health focus. Unlike the surveys, the interviews examined individuals' overall experiences rather than a single project, with a particular emphasis on their experiences in child health. Interviews were conducted via Zoom or telephone based on the interviewee's preference and were audio-recorded and transcribed by an independent company (Transcript Heroes).

### ***Data Analysis***

I used an inductive thematic approach to explore patterns and themes in participant descriptions (Braun & Clark, 2022). Audio files were professionally transcribed and reviewed for accuracy. Transcripts were de-identified, with all identifying information replaced by pseudonyms. Data collection and analysis occurred concurrently. The analysis followed an iterative six-stage process which included: i) becoming familiar with the data, ii) conducting open-coding in NVIVO, iii) establishing a codebook, iv) conducting rounds of coding, sorting, and refining, v) organizing codes into preliminary categories, and vi) drafting and refining themes. To ensure the trustworthiness of the analysis, a sample of transcripts was independently reviewed by two members of the research team (KMS [advisor] and KL [patient partner]), followed by discussions to exchange initial impressions. Regular meetings with KMS facilitated ongoing discussion and refinement throughout the analysis process. Additionally, a detailed audit trail was maintained, documenting the progression from text excerpts to codes, data categorization, and themes. Themes were further refined through written drafts and ongoing committee feedback.

### ***Integration of quantitative survey and qualitative interviews***

The integration of findings occurred during interpretation and reporting (Fetters, Curry, & Creswell, 2013). The survey provided a quantitative analysis of cohort characteristics and differences in perceptions within the participant sample, focusing on project-specific metrics such as individual determinants for partnering and perceived effects. In contrast, the qualitative interviews offered rich, non-project-specific insights into individual experiences and perspectives, capturing the nuanced and contextual aspects of partnered child health research. During the discussion phase, I compared the quantitative and qualitative findings to identify areas of convergence and divergence, reinforcing the credibility of convergent findings, expanding insights, and exploring reasons behind any discrepancies (Fetters, Curry, & Creswell, 2013). For example, if the survey showed high levels of opportunity to partner, I examined whether interview participants similarly highlighted factors influencing opportunities in their experiences. I also explored discrepancies between survey and interview findings to uncover underlying contextual factors. For example, if the survey indicated high perceived effects while interviews revealed mixed experiences, I investigated potential reasons for these differences such as varying project contexts or personal interpretations. This triangulation process allowed me to combine the breadth of quantitative data with the depth of qualitative insights, facilitating a comprehensive understanding of the factors influencing partnered child health research. By integrating both perceived differences and measurable differences in perceptions, I was able to provide a richer interpretation and enhance the overall validity and depth of the findings.

### ***Ethics approvals***

This study was approved by the University of Manitoba Health Research Ethics Board (Survey: HS24238/H2020:399 and Interviews: HS24838/H2021:224) and adhered to all ethical guidelines. Interview participants were offered a \$25 Visa gift card for participating.

## 6.3 Results

### 6.3.1 Characteristics of funded Canadian Partnered Child Health Research, 2011-2019

Of the 589 completed surveys, 104 (17.7%) were classified as child health, representing 78 unique projects. Select respondent and project characteristics are presented in Table 6.1. Most child health respondents identified as female (n=64, 61.5%), 10 identified (9.6%) as a member of a visible minority, and 4 (3.8%) identified as Indigenous. Most child health respondents identified as researchers who held the role of team researcher (n=49, 47.1%) or nominated principal investigator (n=45, 43.3%). Ten child health respondents identified as knowledge users (9.6%), representing diverse roles. Role breakdown is not displayed due to low cell-counts. Most child health researcher respondents identified as mid (n=37, 39.4%) to late (n=32, 34.0%) career researchers and nearly half (46.2%) had been involved in 7 or more partnerships at the time of project funding. There were no differences in distribution of respondent characteristics between child health and general cohorts.

Child health respondents represented 79 unique projects. Most child health projects were federally funded (n=61, 77.2%), had a funder required partnership (n=63, 79.7%), and were funded during the 2014-2016 funding block (n=32, 40.5%). Among federally funded projects with available research pillar data, the highest frequency for the child health cohort was in social, population, and cultural health (n=31, 42.5%). There were no differences between cohorts in funding amount, project length, or project team size.

Table 6.1 Cohort characteristics

	N (%) or Mean (SD)			p-value
	Full sample (n=589)	Cohort		
		Child health (n=104)	General health (n=485)	
<b>Respondent Characteristics</b>				
<b>Project role</b>				
Nominated Principal Investigator	248 (42.1)	45 (43.3)	203 (41.9)	0.03
Team researcher	233 (39.6)	49 (47.1)	184 (37.8)	
Knowledge user	108 (18.3)	10 (9.6)	98 (20.2)	

<b>Gender</b>				
Woman	328 (55.7)	64 (61.5)	265 (54.6)	0.24
Man	169 (28.7)	26 (25.0)	143 (29.5)	
Fluid	1 (0.2)	0 (0.0)	1 (0.2)	
Prefer not to answer	31 (5.3)	7 (6.7)	24 (4.9)	
Missing	59 (10.0)	7 (6.7)	52 (10.7)	
<b>Member of a visible minority in Canada</b>				
Yes	59 (10.0)	10 (9.6)	49 (10.1)	0.54
No	452 (76.7)	83 (79.8)	369 (76.1)	
Prefer not to answer	23 (3.9)	5 (4.8)	18 (3.7)	
Missing	55 (9.3)	6 (5.8)	49 (10.1)	
<b>Indigenous</b>				
Yes	23 (3.9)	4 (3.8)	19 (3.9)	0.52
No	496 (84.2)	90 (86.5)	406 (83.7)	
Prefer not to answer	16 (2.7)	4 (3.8)	12 (2.5)	
Missing	54 (9.2)	6 (5.8)	48 (9.9)	
<b>Career stage: researchers (n=481)</b>				
Early career researcher (<5 years)	118 (24.5)	18 (19.1)	100 (25.8)	0.02
Mid-career researcher (5-15 years)	174 (36.2)	37 (39.4)	137 (35.4)	
Late career researcher (>15 years)	144 (29.9)	32 (34.0)	112 (28.9)	
Missing	45 (9.4)	7 (7.4)	38 (9.8)	
<b>Research partnership experience</b>				
1 – 3 partnerships	95 (16.1)	19 (18.3)	76 (15.7)	0.34
4 – 6 partnerships	139 (23.6)	30 (28.8)	109 (22.5)	
7+ partnerships	299 (50.8)	48 (46.2)	251 (51.8)	
Missing	56 (9.5)	7 (6.7)	49 (10.1)	
<b>Project Characteristics (n=456)</b>				
<b>Funding type</b>				
Federal	346 (76.3)	61 (77.2)	287 (76.1)	0.84
Provincial	108 (23.7)	18 (22.8)	90 (23.9)	
<b>Funding year block</b>				
2011 – 2013	157 (34.4)	27 (34.2)	130 (34.5)	0.53
2014 – 2016	163 (35.7)	32 (40.5)	131 (34.4)	
2017 – 2019	136 (29.8)	20 (25.3)	116 (30.8)	
<b>Research Pillar (CIHR funded)</b>				
Health systems and Services	199 (45.5)	27 (37.0)	172 (47.3)	0.05
Social, cultural, and population health	130 (29.8)	31 (42.5)	99 (27.2)	
Clinical	66 (15.1)	12 (16.4)	54 (14.8)	
Biomedical	11 (2.5)	0 (0.0)	11 (3.0)	
Not available	31 (7.1)	3 (4.1)	28 (7.7)	
<b>Funder required partnership</b>	361 (79.2)	63 (79.7)	298 (79.0)	0.89
<b>Number of named investigators</b>	10.8 (12.0, 1-137)	9.4 (6.3, 1-31)	11.1 (12.9, 1-137)	0.25
<b>Project length (months)</b>	28.5 (18.3, 4-84)	27.3 (18.4, 12-60)	28.7 (18.3, 4-84)	0.53

<b>Funding amount (CAD)</b>	446 288	375 610	461 404	0.39
	(782 650)	(702 267)	(798 920)	

### 6.3.2 Perspectives on Partnered Child Health Research: Differences and Considerations

#### *Interview Participant Demographics*

As discussed in chapter 5, I interviewed 12 researchers (80%) and 3 knowledge users (20%) between July and November 2021. A detailed account of participants' demographics is available in Chapter 5 (Table 5.2). The participants represented diverse research disciplines, ranging from rehabilitation to psychiatry. Geographically, participants were dispersed across five Canadian provinces, and most were female (n=12, 80%). All researcher participants identified as mid to late-career researchers, while two-thirds of knowledge users reported having 8-11 years of experience in a knowledge user role.

#### *Interview themes*

Analysis of researcher and knowledge user perceptions of partnered child health research highlighted three themes: 1) common principles, unique challenges, 2) distinct considerations, processes and effects when engaging children and youth, and 3) the child health community facilitates partnership work.

#### **Theme 1: Common principles, unique challenges**

Participants universally recognized that the core principles of research partnerships, such as respect and full involvement, apply universally across different contexts. For example, one researcher stated: *"Well I don't know that there are major differences. I think the principles of respect and full involvement and engagement and all the things we've talked about apply equally."* (R05)

Like partnerships in other research contexts, building strong, enduring relationships was deemed essential for meaningful engagement in child health research. Trust, familiarity, and strategic relationship-building were emphasized as core components in fostering collaboration and ensuring that

diverse stakeholders felt valued and heard. As mentioned by one participant: *“The strategy that I often use is that connection is really important in child health. So if they’re a new partner, providing the context of well this is how I got to know them, or so-and-so introduced me [spending time to get to know each other and how things came to be]. The relational piece I can’t overstate enough”* (R02). Participants noted the iterative and time-consuming nature of this process, stressing the need for patience, persistence, and ongoing investment to build enduring partnerships, expanding teams as partnerships mature. Similarly, foundational principles such as valuing all expertise and navigating power dynamics were emphasized.

Despite these commonalities, most participants also highlighted the need to navigate additional logistical and practical challenges that they perceived as unique to the child health context.

#### ***Facing additional logistical and practical challenges***

Participants discussed several logistical challenges encountered in child health research partnerships, including navigating institutional processes, addressing age-related consent issues, and maintaining consistent engagement with children and youth. As one participant explained: *“Just different rules, restrictions and comfort levels around how and when and if you can work with and involve different individuals based on permissions and privacy, and who gets to make that decision”* (D13). Common frustrations were expressed regarding institutional processes, characterized by inflexibility and a lack of clarity regarding approvals for engagement. For example, one respondent recounted prolonged struggles with ethics boards, which imposed impractical restrictions that contradicted the community-oriented nature of their research. Additionally, participants highlighted the complexities of consent when working with underage children. Maintaining a consistent cohort was also noted as a challenge, particularly as youth transition into adulthood, presenting logistical hurdles in partnership continuity.

Participants also identified practical challenges related to partnership composition in child health research partnerships. There were mixed perceptions of the utility and feasibility of directly engaging children and youth in research partnerships. Some expressed uncertainty due to age and capability, proposing alternative methods to capture children's perspectives. As one researcher reflected:

Because children are – if you're looking at a particular group, they're often not necessarily old enough to participate themselves or may have certain challenges that limit their participation. So, what is unique is that very often the patient partners are the parents, and often the mothers – so I think that is unusual. And it probably is like that, say, with elderly populations where it's often the caregiver, so that, to me, would be the greatest parallel. (R03)

Conversely, others recognized the value of directly involving children and youth, emphasizing the importance of affording voice and agency in decisions that affect them. This perspective came from experience and familiarity with the child health context, with participants emphasizing a duty to engage them and noting the invaluable insights gained from their unique perspectives.

#### *Engaging proxies as a common approach*

Given the complexities of directly engaging children and youth, a more common strategy involved engaging proxies such as parents or caregivers. Participants emphasized the importance of carefully considering who should be involved in the partnership and addressing their diverse needs: *"Yeah, there are various factors to consider. But the first things that come to mind are: are you partnering with parents or are you partnering with children and youth, or both, or all?"* (R13) This approach often resulted in a network of individuals, including a multidisciplinary team and various knowledge users to represent the interests of children and youth.

Participants highlighted the intricate dynamics involved in partnering, often involving multiple individuals due to children's inherent dependency:

I would say often in child health, you're dealing with more than one person. I mean, you can't argue that. I'm just thinking of when I worked with adult patients. The family is incredibly important too, but you could work with one adult patient, right? As opposed to pediatrics, there will always be others, whether it's a grandparent, guardian, parent, or other family member who is part of that. (KU03)

Participants recognized the responsibilities of engaging through proxies (e.g., parents and caregivers). Additionally, they emphasized the impact of child health issues on their surrounding networks, highlighting the importance of adopting a holistic approach to address the multifaceted needs of children and their families.

Depending on the nature of the project, participants also noted the challenges of navigating various sectors beyond health. For example, conducting research in schools involved obtaining additional permissions from school boards and interacting with multiple stakeholders who indirectly influenced the research process. Engaging with other sectors, such as child and family services, introduced further practical challenges, including differing rules, restrictions, and comfort levels regarding permissions and privacy. These additional stakeholders were thought to add layers of complexity to partnership dynamics and processes, highlighting the importance of considering the broader network of individuals involved in child health research partnerships.

## **Theme 2: Distinct considerations, processes and effects when engaging children and youth**

When discussing specific considerations for partnering in child health research, some participants highlighted the importance of context when conceptualizing, navigating, and evaluating research partnerships. These perceptions were particularly prominent in experiences engaging children and youth, highlighting the need to understand and adapt to project-specific dynamics.

### ***Understanding and addressing contextual nuances***

Participants described the need to understand and address various factors, such as safeguarding vulnerable populations and recognizing generational differences, to effectively build rapport and conduct meaningful research partnerships in child health.

#### *Safeguarding Vulnerable Populations*

Participants articulated the complexities of safeguarding vulnerable populations within research partnerships, highlighting the need to navigate ethical dilemmas and power dynamics. They discussed the importance of recognizing the vulnerabilities of children, youth, and mothers, and the ethical imperative to protect their rights and well-being. Furthermore, several participants noted that research involving youth necessitates a heightened sensitivity to their vulnerabilities.

Adults are vulnerable too, but in some ways, you sometimes have to be more attuned to whether they're aware of their own rights. I think with youth, you just have to be much, much more sensitive to issues like that. Like you're in a relationship where they're fragile. (R01)

Participants highlighted the ethical challenges of maintaining researcher neutrality while providing emotional support to youth. In situations where youths' sense of justice is challenged, researchers must navigate the delicate balance between supporting the youth and maintaining professional boundaries. One participant shared an example of this challenge in a courtroom setting: *"Youth have a strong sense of justice and right and wrong. But he said, 'I don't think he had the right to say that.' The tricky thing is as a researcher, you want to agree but you're not supposed to interfere. It's a delicate balance"* (R01).

#### *Understanding Generational Dynamics*

Participants underscored the importance of acknowledging and embracing the perspectives of younger generations, which may diverge from more traditional viewpoints. For instance, one participant highlighted the challenge of engaging different generations, stating, *"So it's being open to our older ways of understanding things to be totally flipped upside down"* (D04). Recognizing these generational

differences was deemed crucial for establishing rapport, trust, and relatability when engaging children and youth. Strategies to promote this understanding included hiring staff who could authentically relate to and understand the communities being served, considering factors such as age and cultural background. However, it was noted that successful engagement with youth populations goes beyond surface-level similarities, requiring a deep understanding of the community's unique needs, concerns, and communication styles to ensure that youth perspectives are effectively integrated into research projects.

### ***Adapting engagement strategies to developmental contexts***

Child health was described as a dynamic context of growth and change, distinct from the more static nature of adulthood. This dynamic nature presented unique challenges and opportunities for research and intervention, requiring engagement strategies that are both developmentally appropriate and adaptable to these evolving needs. For instance, this participant highlights the challenges posed by children's ongoing development:

But here is a child who is growing and developing, so it's a very unique phase because the background has changed. So it's not the same thing over time, so there will always be new challenges. So I think that's the other thing about child health, is their context is development, so it's not a static thing. (R03)

Participants noted the importance of engaging children and youth at their specific developmental stages, moving beyond a one-size-fits-all approach based solely on age. Instead, they advocated for meeting individuals where they are, creating environments conducive to their growth and active participation: *"because you know kids are so variable in how they get to various stages. But meet them where they're at, get down on the floor with them"* (R05).

While participants recognized that some engagement strategies may apply to both children and adults, others require modifications. This involved tailoring interactions to be meaningful and relatable,

incorporating active and enjoyable activities to enhance engagement. Additionally, participants acknowledged the agency and leadership potential of children and youth within research activities, describing instances where young participants directed research projects and contributed their unique perspectives.

### ***Distinct effects in partnerships engaging children and youth***

Partnerships that involved children and youth produced distinct and diverse effects, showcasing their transformative potential. Participants predominantly emphasized effects on individuals. Engagement not only bolstered confidence but also facilitated skill acquisition and nurtured a sense of agency among children and youth. Research partnerships helped cultivate the interests and passions of young people, often leading to personal and professional pursuits. Furthermore, partnerships fostered intergenerational connections, promoting a sense of belonging and shared identity within the community. One participant expressed pride in witnessing the transformative journey of participants, stating:

I mean honestly, what we try to do is make them believe in themselves, to have confidence in themselves to know that they have opportunities if they choose to do that. I mean I'm just so proud of the fact that so many of our kids have gone on to do – to take further training or to work in jobs that were really related to things they found their passion for in our research project. (R10)

Partnerships engaging children and youth also had broader societal effects. Participants recounted instances where projects led by children and youth catalyzed tangible effects, such as accelerating municipal decision-making processes and challenging societal stigmas. Reflecting on these experiences, one participant emphasized the importance of meeting youth on their terms and empowering them to effect change. These partnerships also provided a platform for amplifying youth voices and challenging prevailing narratives. Participants highlighted how these projects empowered

youth to advocate for themselves and redefine societal perceptions, ultimately fostering a more inclusive and representative discourse.

### **Theme 3: The child health community facilitates partnership work**

The nature of the community was identified as a defining feature influencing partnered child health research, offering both challenges and advantages. There was a collective appreciation for the tightly knit nature of the child health community in Canada. This cohesion was seen as a strategic advantage for partnered research, attributed to its interconnectedness and familiarity with interdisciplinary collaboration. One participant underscored the benefits of this interconnectedness, stating:

I think one of the real benefits of working in child health is how connected the community is, like, in Canada. And I think that's an advantage to doing iKT work. The community is smaller, it's well-connected. We're used to working interdisciplinary, which is an advantage, I think, to doing iKT work. (R02)

This interconnectedness was thought to foster an environment conducive to interdisciplinary and cross-sectoral engagement, facilitating effective partnership efforts.

However, participants also acknowledged the strains placed on specific organizations and groups due to this interconnected nature, with knowledge users expressing feelings of being inundated by partnership requests. Additionally, one participant lamented the lack of robust advocacy structures for youth, highlighting this as a key distinction in partnering in child health relative to other areas. Despite these challenges, some participants recognized the importance of established pediatric healthcare practices, such as family-centered care, in guiding research partnership approaches. By acknowledging the central role of parents or caregivers in child health, they emphasized the broader implications of family-centered care principles in fostering meaningful engagement and partnership development. As articulated by a knowledge user, *"I think maybe child health is further ahead in terms*

*of recognizing family-centred care, and just by nature, the parents or caregivers are typically there with the child and involved” (KU03). This alignment with family-centred care principles aligns with the community’s ethos and encourages a more comprehensive understanding of children’s needs within their familial and healthcare contexts.*

### **7.3.3 Cohort Comparisons of Individual Determinants and Perceived Effects**

#### ***Capability, opportunity, and motivation for working in partnership***

Child health respondents held high levels of agreement for their capability and motivation for working in partnership, with moderately lower ratings for perceived opportunity. Child health respondents had the highest agreement on the value of engaging (100%), confidence in their ability to engage (97.0%), having the knowledge and skills to engage (96.0%), and their responsibility to engage (96.0%). Ratings were lowest in the opportunity domain, with 67.3% of child health respondents agreeing with the statement “I have the resources to engage.” There were no statistically significant differences between cohorts (Table 6.2).

#### ***Research Partnership Effects***

Perceived effects of involving knowledge users on project outcomes and on specific components of the research process are reported in Table 6.3. There were no significant differences in perceived effects by cohort. Fifty-eight percent of child health respondents rated the overall influence of knowledge user involvement in the project as significant. Ratings of a significant influence of knowledge user involvement in child health project outcomes ranged between 13.3% (impact on health system policies) and 42.2% (production of useful findings). 40% of child health respondents reported involvement as having a significant influence on the promotion of evidence-informed decision-making in health care or the health care system compared to 28.4% in the general health cohort, though this difference was not significant. Ratings of significant influence of knowledge user involvement in child

health project outcomes ranged between 28.6% (data analysis and interpretation) and 66.1% (participant recruitment).

Table 6.2 Capability, opportunity, and motivation for working in partnership by cohort

		Significant influence of research user involvement, n (%)			<i>p</i> -value
		Full sample (n=589)	Cohort		
			Child health (n=104)	General health (n=485)	
<b>Capability</b>					
I have the knowledge and skills to engage (n=537)	Agree	515 (95.9)	95 (96.0)	420 (95.9)	0.02
	Neutral	17 (3.2)	1 (1.0)	16 (3.7)	
	Disagree	5 (0.9)	3 (3.0) <sup>b</sup>	2 (0.5)	
<b>Opportunity</b>					
I have the resources to engage (n=537)	Agree	308 (57.5)	66 (67.3) <sup>b</sup>	242 (55.3)	0.07
	Neutral	134 (25.0)	21 (21.4)	113 (25.8)	
	Disagree	94 (17.5)	11 (11.2)	83 (18.9)	
I have the support from others to engage (n=537)	Agree	413 (76.9)	83 (83.8)	330 (75.3)	0.11
	Neutral	93 (17.3)	14 (14.1)	79 (18.0)	
	Disagree	31 (5.8)	2 (2.0)	29 (6.6)	
I feel pressure to engage (n=536)	Agree	156 (29.1)	26 (26.3)	130 (29.7)	0.29
	Neutral	136 (25.4)	21 (21.2)	115 (26.3)	
	Disagree	244 (25.5)	52 (52.5)	192 (43.9)	
<b>Motivation</b>					
I am confident in my ability to engage (n=537)	Agree	501 (93.3)	96 (97.0)	405 (92.5)	0.06
	Neutral	30 (5.6)	1 (1.0)	29 (6.6) <sup>b</sup>	
	Disagree	6 (1.1)	2 (2.0)	4 (0.9)	
There is value in engaging (n=535)	Agree	520 (97.2)	98 (100.0)	422 (96.6)	0.18
	Neutral	14 (2.6)	0 (0.0)	14 (3.2)	
	Disagree	1 (0.2)	0 (0.0)	1 (0.2)	
It is my responsibility to engage (n=536)	Agree	486 (90.7)	95 (96.0)	391 (89.5) <sup>b</sup>	0.11
	Neutral	43 (8.0)	4 (4.0)	39 (8.9)	
	Disagree	7 (1.3)	0 (0.0)	7 (1.6)	

I intend to engage in the future (n=535)	Agree	491 (91.8)	89 (90.8)	402 (92.0)	0.58
	Neutral	34 (6.4)	8 (8.2)	26 (5.9)	
	Disagree	10 (1.9)	1 (1.0)	9 (2.1)	
The decision to engage is beyond my control (n=537)	Agree	48 (8.9)	9 (9.1)	39 (8.9)	0.99
	Neutral	106 (19.7)	20 (20.2)	86 (19.6)	
	Disagree	383 (71.3)	70 (70.7)	313 (71.5)	
It is useful to engage in research partnerships (n=537)	Agree	509 (94.8)	98 (99.0) <sup>b</sup>	411 (93.8)	0.11
	Neutral	24 (4.5)	1 (1.0)	23 (5.3)	
	Disagree	4 (0.7)	0 (0.0)	4 (0.9)	

*b* – denotes within-case significance at the .05 level in post-hoc analyses

Table 6.3 Perceived significant influence of knowledge user involvement by cohort

	Significant influence of research user involvement, n (%)			<i>p-value</i>
	Full sample (n=589)	Cohort		
		Child health (n=104)	General health (n=485)	
Overall influence (n=548)	313 (57.1)	58 (58.6)	255 (56.8)	0.74
<b>Influence on the research process</b>				
Participant recruitment (n=290)	183 (63.1)	37 (66.1)	146 (62.4)	0.61
Data collection (n=241)	123 (51.0)	23 (53.5)	100 (50.5)	0.73
Setting research project' priorities (n=428)	208 (48.6)	38 (49.4)	170 (48.4)	0.88
Choosing the research questions (n=386)	170 (44.0)	32 (45.7)	138 (43.7)	0.76
Disseminating findings to non-academic audiences (n=342)	171 (50.0)	26 (44.8)	145 (51.1)	0.39
Developing research ethics documents (n=179)	63 (35.2)	17 (37.0)	46 (34.6)	0.77
Choosing study outcomes (n=360)	140 (38.9)	26 (36.6)	114 (39.4)	0.66
Disseminating findings to academic audiences (n=274)	89 (32.5)	14 (35.0)	75 (32.1)	0.71
Developing study design and methods (n=349)	118 (33.8)	21 (31.8)	97 (34.3)	0.70
Data analysis and interpretation (n=289)	102 (35.3)	14 (28.6)	88 (36.7)	0.28
<b>Influence on project outcomes</b>				
Production of useful research findings (n=267)	125 (46.8)	19 (42.2)	106 (47.7)	0.50
Promotion of evidence-informed decision-making in healthcare or the health system (n=267)	81 (30.3)	18 (40.0)	63 (28.4)	0.12
The projects' impact on healthcare professional practices (n=264)	61 (23.1)	12 (27.3)	49 (22.3)	0.47
The projects' impact on health system policies (n=266)	33 (12.4)	6 (13.3)	27 (12.2)	0.84

## 6.4 Discussion

This study advances our understanding of partnered child health research by assembling the largest cohort of partnered child health research projects to date, identifying perceived differences and considerations for partnering from the perspectives of child health researchers and knowledge users, and by comparing individual determinants and perceived effects of partnering between survey respondents working in child health and the remaining sample. This study is the first to compare cohorts in partnered health research, providing a unique contribution to the literature. Survey responses revealed no significant differences between child and general health cohorts, indicating shared perceptions of partnership dynamics and effects. Interviews confirmed key similarities to core principles such as trust and power sharing. However, interviews also highlighted unique challenges in child health research partnerships, including logistical and practical challenges, and the need for tailored approaches when engaging children and youth. These insights are valuable for informing future research and practice in child health by advancing our understanding of partnership dynamics (e.g., capability, opportunity, motivation, navigating heightened vulnerability), processes (e.g., engaging proxies, adapting engagement strategies) and effects.

### ***Research partnership dynamics and processes***

The integration of survey data and interview findings reveal both convergence and divergence in partnership dynamics and processes; mainly because each method was examining slightly different but interrelated concepts. Survey results indicated consistent perceptions of capability, opportunity, and motivation for working in research partnerships across cohorts. In contrast, interviews emphasized unique challenges specific to child health research partnerships, particularly regarding partnership processes. These challenges included navigating institutional procedures and maintaining sustained engagement with children and youth over time, necessitating resources and support to navigate. Like previous research specific to the spinal cord injury community (Shwed et al., 2023), respondents in this

study reported the lowest agreement rates in the opportunity domain, particularly regarding having the resources to engage (67.3%). This aligns with existing literature, which highlights the significant time, resources and support needed to manage and sustain partnerships (Sibbald et al., 2014; Sibbald et al., 2019). Additionally, participants emphasized the importance of tailoring engagement strategies to the unique developmental stages and characteristics of children and youth involved in research partnerships. Despite these challenges, child health respondents reported high levels of motivation and confidence in their ability to collaborate effectively. The survey and interview findings collectively support the notion that a supportive research environment can facilitate effective partnership processes.

Interview findings illuminated adaptive strategies for fostering collaboration within diverse research teams (e.g., engaging proxies) and recognized the need to incorporate diverse perspectives into partnered child health research. These findings align with the scoping review findings (chapter 4) and corroborate existing literature (Flynn et al., 2019; Freire et al., 2022; MacFarlane et al., 2024) indicating that partnerships in child health often involve multiple stakeholders due to the dependency of children, highlighting the need for comprehensive engagement strategies. However, there remains an ongoing gap in understanding the range of knowledge users engaged in partnered child health research and the practicalities of navigating this dynamic, highlighting an area for future research.

Even among child health researchers, there were mixed perceptions regarding the utility and feasibility of engaging children and youth in research partnerships. While some emphasized the duty to involve children and youth in decision-making, practical challenges and feasibility concerns were acknowledged. If engaging children and youth, interview participants highlighted the need to safeguard vulnerable populations, understand generational dynamics, and tailor engagement strategies. Researchers were conscious of who best to engage, often involving proxies or finding alternative methods to include young perspectives. Collectively, this aligns with the survey findings, which indicated

high levels of perceived responsibility (96.0%) to work in partnerships among child health respondents. As child and youth engagement in research partnerships is accelerating (Freire et al., 2022; Rouncefield-Swales et al., 2021), ongoing support is needed to address practical, conceptual and feasibility challenges associated with their involvement.

### ***Research partnership effects***

Quantifying partnership effects across a large sample of Canadian partnership teams fills a critical gap in the literature amid persistent measurement challenges in the field (Hoekstra et al., 2020; Mrklas et al., 2022). Understanding these effects is key to determining whether the proposed benefits of engagement are being realized and how researchers and knowledge users can best work together. A recent scoping review of studies reporting the effects of patient and family engagement in child health research revealed the rarity of measurement and reporting in child health research, identifying only 25 publications over time (Vanderhout et al., 2023). Of these, only 2 used quantitative measures, reporting increased study participation and adoption rates following patient and family engagement, and none used a comprehensive evaluation tool (Vanderhout et al., 2023). Furthermore, while several reviews have summarized partnership effects in adult health research, reviews in child health are fewer and have not addressed the breadth of potential effects (Bailey et al., 2015; Rouncefield-Swales et al., 2021; Vanderhout et al., 2023).

This analysis enriches the literature by comprehensively examining the perceived effects of partnering across different phases of the research process, various project outcomes, and diverse partnership projects. Unlike existing evaluations that are project-specific or confined to small or specific funding networks, this study employed a comprehensive sampling strategy of all funded partnered health research projects over nearly a decade in Canada (Sibley et al., 2023), providing more robust findings. This study demonstrates that perceptions of partnership effects remain consistent across different research contexts by comparing perceived effects between child and general health cohorts.

Most child health respondents (58.6%) perceived the overall influence of involving knowledge users in the research process as significant. These findings are more conservative than a previous Canadian evaluation, which reported rates exceeding 80% for the anticipated impact of partnered research (Sibbald et al., 2019). Respondents were more reserved about the specific effects of involving knowledge users in components of the research process, suggesting varied perceptions of knowledge user utility and influence within the research process. The effects on specific project outcomes, such as influence on health system policies, were even less pronounced, likely due to the diverse goals of individual projects and the long timeframes required to achieve such effects. For example, engagement is just one of many factors driving policy decisions, which are also contingent on timing and the presence of windows of opportunity for policy change (Danis, 2019; Thurston et al., 2004). As Kothari and Wathen (2013) suggest, partnered research generates something “more” than tangible end-products. A deeper understanding of partnership dynamics, such as measuring partnership synergy over time, can provide insights into intermediate effects that may be more attainable within individual partnerships (Loban et al., 2021).

While the survey findings advance our understanding of specific child health project outcomes, the interview findings provide a deeper understanding of the distinct effects observed in research partnerships directly engaging children and youth. Interview findings underscored the transformative effects observed in partnerships directly engaging children and youth in research. Participants highlighted enhanced empowerment, skill development, and community building among youth, emphasizing their role in amplifying voices, challenging prevailing narratives, and fostering inclusive discourse within child health research. These findings align with a recent scoping review highlighting significant benefits among child and youth partners, such as boosting self-confidence and independence, fostering peer relationships, and acquiring new skills to succeed personally and professionally, providing added value beyond their research project involvement (Vanderhout et al., 2023). Such effects are

particularly crucial in addressing equity issues among underserved populations and contribute to partnership sustainability through skill development and empowerment (Rodriguez Espinosa et al., 2020). Although the survey did not specifically explore child and youth involvement in partnered research, the qualitative data emphasized the perceived value of their engagement. These insights provide crucial considerations for partnership teams when conceptualizing, navigating and evaluating research partnerships involving children and youth.

### ***Study implications***

Partnerships in child health exhibit fundamental similarities to those in other health domains. Still, they are uniquely challenged by context-specific factors related to processes, particularly when engaging specific populations or varied team compositions. These challenges may manifest in logistical complexities, practical considerations, and nuanced conceptual dynamics that vary across research contexts. Despite these varied challenges, this study indicates that these contextual differences did not significantly impact the perceived effects of partnerships. This finding suggests that positive perceptions of capability, opportunity, and motivation to work in partnerships may mitigate the impact of contextual challenges on partnership outcomes.

The absence of significant group differences in this study prompts a crucial discussion regarding the implications for future research and practice. While these findings may suggest that specific partnership groups do not exhibit substantial differences in the variables under investigation, this does not necessarily imply that studying these groups lacks relevance. Understanding why certain groups show similarities can be equally informative, shedding light on commonalities in experiences or processes across diverse partnership contexts. Moreover, these findings underscore the need for nuanced research design and interpretation approaches. Exploring factors contributing to similarities among partnership groups – such as shared challenges, contextual influences, or structural determinants – can provide valuable insights into effective strategies for fostering collaboration and

achieving desired outcomes in diverse partnership settings. Rather than dismissing the study of specific partnership groups, my results advocate for a more thorough exploration beyond surface-level comparisons. Future research could focus on identifying underlying mechanisms contributing to similarities across groups, thereby enhancing our understanding of partnership dynamics and informing strategies to accommodate diverse partnership needs. Additionally, future research specific to child health could explore the practicalities and challenges of engaging children and youth, examine dynamics among multiple knowledge users within projects, and focus on a specific subset of the child population due to their heterogeneous nature.

### ***Study strengths and limitations***

The primary strength of the study lies in its integration of quantitative and qualitative findings, which offer a nuanced understanding of the dynamics, processes and perceived effects of child health research partnerships. However, the study is not without its limitations. First, I could not examine variables related to research partnership practices due to challenges associated with multiple respondents per project, limiting the depth of exploration and integration. Nonetheless, the study explored various aspects of team functioning, including capability, opportunity, and motivation to engage in research partnerships. Complemented by interview findings, this provided valuable insights into research partnership dynamics and processes. Second, the survey used in this study was not designed specifically for child health, limiting the depth of understanding within this research context. Future adaptations of the survey could enable a more thorough exploration of the child health landscape, including a detailed examination of knowledge users engaged, practice modifications, and distinct effects. Third, like ongoing challenges in the field related to measuring research partnerships (Hoekstra et al., 2020; Mrklas et al., 2022), this study was confined to self-report and relied on indirect assessment of effects. Additionally, the survey sample was restricted to a selection of Canadian-partnered health research projects that received competitive funding, potentially limiting its

generalizability to other jurisdictions. Despite a thorough recruitment strategy (Sibley et al., 2023), the perspectives captured in this study predominantly represent those of academics, with only a small proportion of child health respondents identifying as knowledge users. Similarly, the interview cohort mainly comprised mid to late-career female researchers, limiting the diversity of perspectives.

## **6.5 Conclusion**

In conclusion, this study contributes to understanding the dynamics, processes and challenges encountered in child health research partnerships. It suggests that partnerships in child health exhibit similarities and differences to partnerships in other health domains, drawing on fundamental partnership principles while navigating additional challenges. Integrating quantitative and qualitative findings underscores the challenges (e.g., logistical and practical) and strengths (e.g., the interconnectedness of the child health community, positively perceived capabilities, motivation and team dynamics, and comparable project effects) of partnered child health research. Integrating study findings underscores the importance of considering context when conceptualizing, conducting, and evaluating child health research partnerships to maximize effectiveness. By incorporating these insights into future research and practice, partnership teams can better navigate complexities and foster inclusive and impactful partnerships in child health research to advance the well-being of children, youth, and their families.

## Chapter 7: Discussion

In this dissertation, I set out to answer the question: Is child health a unique context for research partnerships? My answer to this question is: it depends – in some ways, yes; in other ways, no. While this question served as a clear focal point for investigation, I have come to understand that its simplicity belies the multifaceted nature of the topic, making it challenging to unpack. Instead, the answer requires understanding the distinct features of partnered child health research while also acknowledging the common elements that transcend research contexts.

Child health encompasses a wide range of populations, each with their unique needs influenced by their specific circumstances. This diversity affects how research partnerships operate and highlights the inherent difficulty of understanding and characterizing them as a uniform whole. While these partnerships share common elements and challenges with other areas of research, such as the importance of relationship building and challenges navigating academic systems, they require different qualities and commitments. Research partnerships in child health involve distinct considerations that demand heightened sensitivity, creativity, and empathy. Partnership dynamics and processes can be more complex, often involving proxies (e.g., parents and families) and requiring tailored processes to navigate various developmental stages when engaging children and youth. Therefore, while child health research partnerships are not entirely unique, they do require a thoughtful, context-specific approach to address the unique needs of children and their families, and one that is dependent on the partnership characteristics.

### 7.2 Summary of key findings

This dissertation explored child health as a context for research partnerships, focusing on their characteristics, dynamics, processes, and effects. The findings, summarized across three main objectives, offer valuable insights into child health research partnerships' distinct and shared elements.

***Objective 1: Characterizing Child Health Research Partnerships***

In objective 1, I used scoping review methodology to characterize published child health research partnerships, encompassing partnership traditions and knowledge user groups. The review revealed a notable increase in publications on child health research partnerships over time, particularly since 2019. Partnerships frequently engaged multiple knowledge user groups, with children, healthcare professionals, and parents being the most common. Engagement levels in child health research partnerships were generally moderate to high, with 75% of studies engaging at levels of involvement or collaboration. Studies reported engagement across all stages of the research process, particularly in conducting (82%) and planning (75%) research, using multiple engagement strategies. Variations in reporting barriers, facilitators, and partnership effects underscored the need for more comprehensive documentation and evaluation of partnership practices. This study contributes to the literature by bridging previously siloed research partnership approaches and considering the multiple knowledge user groups involved in child health research, thus enhancing our understanding of the global landscape of child health research partnerships.

***Objective 2: Exploring the experiences, motivations and dynamics of child health research partnerships***

In objective 2, I conducted semi-structured interviews to explore the experiences and lived perspectives of Canadian researchers and knowledge users who engage in partnered child health research informed by an interpretive description approach. I revealed three key themes that underscore the complexities of research partnerships in child health. First, I identified diverse motivations for working in partnership that varied by role: researchers aspired for impactful research, knowledge users sought enhanced advocacy and credibility, and duals sought practical relevance and improved health outcomes. This understanding underscores the importance of recognizing and addressing role-specific dynamics to foster effective collaboration. Second, despite evolutions that support partnership practice, the study reaffirmed the ongoing challenges of navigating research partnership processes within

academic systems. This highlights the importance of fostering an environment that supports partnership practices within academic settings. While institutions play a crucial role, individual researchers in academia are key agents in supporting this cultural shift. Those committed to partnership approaches have a responsibility to position the value and relevance of their partnership work, thereby contributing to this transformation. Third, the critical role of relationships permeated participants' narratives, influencing how they work together, share power, and overcome challenges. This underscores the importance of prioritizing relational dynamics in fostering successful and enduring research partnerships. This study contributes to the literature by extending the project-focused approach to understanding research partnerships, highlighting role-based variation in research partnerships by unpacking the diverse but synergistic motivation and effects among researchers, knowledge users and duals. This study enhances our understanding of partnership dynamics, offering insights for research partnership practice in child health.

***Objective 3: Unpacking context: exploring distinctions in partnered child health research***

In objective 3, I conducted a concurrent mixed-methods study to explore perceptions and perceived differences in considerations influencing individual determinants and perceived effects of partnered child health research relative to other health research contexts in Canada. This study assembled the largest cohort of partnered child health research to date, describing respondent and project level descriptives of Canadian partnered child health research projects funded between 2011-2019. Interview participants emphasized alignment with core elements of partnering (e.g., building relationships, valuing expertise) but highlighted additional engagement complexities in child health research partnerships across logistical (e.g., navigating institutional procedures), practical (e.g., engaging proxies) and conceptual domains (e.g., understanding generational differences), particularly when engaging children and youth. The interconnected nature of the child health community was seen as a strategic advantage for partnership work. While interviewees articulated perceived distinctions in

partnered child health research, there were no significant differences between child and general health cohorts across survey variables. Child health respondents exhibited positive perceptions of their capability, opportunity, and motivation for working in partnership and mixed perceptions of partnership effects. This study adds to the literature by enhancing our understanding of both shared and distinct aspects of research partnerships in child health.

### **7.3 Integrated discussion**

This research highlights that while some aspects of research partnerships are consistent across research contexts, child health research requires a contextually informed and conceptually enriched approach. Child health research partnerships have unique characteristics and challenges specific to their context, which necessitate considerations beyond generalized approaches. Factors such as the dynamics of proxy representation and the need to adapt processes when engaging children and youth emphasize the need for a comprehensive understanding tailored to their specific nature. Moreover, universal principles – such as trust and reciprocity – are foundational, but their application varies depending on the partnership and knowledge users involved. Recognizing these nuances is crucial for advancing child health through research partnerships.

In this section, I will synthesize the key findings from my research, focusing on characterizing child health research partnerships and examining their distinctive and universal features.

#### **Adoption and Evolution of Research Partnership Approaches in Child Health Research**

Across the studies conducted in this dissertation, I observed a discernible upward trend in the use of research partnership approaches within child health, transcending geographical regions and disciplinary boundaries (Objective 1). Notably, partnerships were predominant in contexts where active incentivization and support exist, such as North America, Australia, and the United Kingdom. Certain approaches, such as CBPR and PE, were more commonly used in child health research, aligning with the focus of existing child health reviews (Chapter 2). However, despite the promotion of iKT in Canada, its

uptake in child health research remains limited, potentially reflecting underlying motivations other than uptake and application (Nguyen et al., 2020). In objectives 1 and 2, I extend this understanding by highlighting the increased formalization and evolution of partnership research in Canadian academic health research, reflecting a shift towards more inclusive and participatory child health research practices. This trend underscores the importance of research partnerships in child health, aligning with broader shifts in health research (Bowen et al., 2019; Sibley et al., 2023) and emphasizing their significance in contemporary research practice.

Documenting this trend is important for understanding the evolving landscape of child health research partnerships and providing insights into their operational mechanisms. Despite challenges such as limited advocacy groups, the interconnected nature of the child health community, coupled with favourable perceptions of capability, opportunity, and motivation for working in partnership (objective 3), emerged as a notable asset. Additionally, the rise in partnerships involving children and youth signals an evolving landscape in child health research. As these practices continue to develop, the distinctiveness and commonalities of child health research partnerships may become more apparent. This ongoing evolution underscores the need to document and adapt partnership practices to meet the evolving needs of child health research.

### ***Distinctive characteristics of child health research partnerships***

**Considering Child Health Research Partnerships in Relational Webs.** Throughout this dissertation, I observed that child health research partnerships often operate within relational webs. This insight emerged from observing features such as the engagement of multiple knowledge user groups, including adults, in partnership processes. The concept of a relational web in partnered child health research emphasizes the interconnectedness of individuals within and beyond the partnership ecosystem, with the child at its core (Doane & Varcoe, 2005; Yarwood, 2008). It acknowledges the diverse range of individuals who may be directly or indirectly involved, including families, policymakers,

and various service sectors such as healthcare and education. Additionally, it recognizes that partnerships in child health may span generations, which adds layers of complexity to the partnership process. I propose that this relational web may be one of the defining features of child health research partnerships, warranting further attention and exploration.

The concept of a relational web remains largely unexplored in the current discourse on research partnerships. While this idea draws on feminist political economy (Rocheleau & Roth, 2007) and nursing literature (Doane & Varcoe, 2005), where scholars have emphasized the interconnectedness of individuals, families, communities, and systems (Rocheleau & Roth, 2007; Doane & Varcoe, 2005; Frosch, Schoppe-Sullivan, & O'Banum, 2021), it is crucial to acknowledge that Indigenous scholarship views this interconnectedness as relationality (Wilson, 2016). Indigenous worldviews on relationality emphasize the interconnectedness and interdependence of all beings as foundational to knowing and being, often approaching partnerships with a focus on familial and community ties through a generational or kinship mindset (Gerlach et al., 2018; Tynan, 2021). This perspective aligns with the functioning of child health partnerships, which must engage children and youth as they evolve and involve and/or consider caregivers and other generational ties. These perspectives underscore the need for an approach that acknowledges the relational dynamics specific to partnered child health research, where the range of knowledge users may be expanded for practical or protective reasons and where outcomes impact not only children but also their relations (Gerlach et al., 2018).

The notion of a relational web within child health research partnerships is subtly yet consistently woven throughout my dissertation's findings. For example, objective 1 revealed that a 75% of child health partnerships engaged multiple knowledge user groups, illustrating the network of individuals involved. Partnerships that included children and youth often expanded to include various adult knowledge user groups, though details on the purpose of this expanded scope or management of these dynamics were scarce. This network surrounding the child was further highlighted in objective 3, where

engaging children, parents, or both was underscored as a fundamental initial consideration that had downstream implications for partnership dynamics, processes and effects.

The unique dynamics among individual actors within and outside the partnership add complexity but also depth to the partnering process. Understanding and navigating these dynamics requires adaptable approaches to address the multifaceted needs of children and their families. For instance, research suggests that this may involve negotiating with “gatekeepers” (such as parents, guardians, communities, elders), navigating enhanced ethical procedures, balancing child privacy rights with parental protection, and navigating inherent power dynamics across generations (Huang et al., 2014). Viewing child health research partnerships through a relational web offers a holistic framework, emphasizing the need to consider not only the immediate network surrounding the child but also generational influences when conceptualizing, conducting, and evaluating research partnerships.

**Implications:** Recognizing the relational web in child health research partnerships underscores the need for an interconnected, flexible, and contextually informed approach. This perspective is crucial for effectively engaging the diverse individuals involved in child health research. My findings extend the focus on relationships in research partnerships by highlighting the importance of recognizing the relational context in optimizing and navigating partnership dynamics and processes.

**Tailoring Processes When Engaging Children and Youth.** Child health research partnerships, particularly those directly involving children and youth, present unique challenges and opportunities (objective 3). These observations suggest that partnerships engaging proxies may adhere to more generalizable aspects of research partnerships. However, there remains a significant gap in our understanding of the dynamics and processes of engaging children, parents, and other indirect stakeholders together. Being attuned to the additional logistical, practical, and conceptual challenges that may arise in child health research partnerships provides information to help teams effectively navigate engagement processes. Adaptable, flexible approaches to collaboration are important

(objective 2), along with tailored guidance and support for research teams to navigate challenges specific to the child health context.

**Implications:** Adaptable approaches and tailored engagement strategies are necessary for effectively engaging children and youth in health research partnerships. Research partnership teams must consider logistical, practical, and conceptual challenges specific to child health research partnerships, particularly when engaging children and youth.

### ***Universal (but nuanced) aspects***

**Common Principles and Challenges.** While unique in their focus and scope, child health research partnerships share universal principles to partnerships in other health research contexts, including trust, power-sharing, and reciprocity (objectives 2 and 3). Reviews have identified numerous principles for research partnerships that emphasize building and maintaining relationships between researchers and knowledge users (Hoekstra et al., 2020; Hoekstra et al., 2022). A review specific to the spinal cord injury community found alignment with principles applicable to general partnerships, suggesting broad applicability across research areas, populations, and partnership types (Hoekstra et al., 2022). Collectively, these commonly promoted research partnership principles underscore the importance of achieving relational quality – a product of trust, commitment, and reciprocity – that is distinct from the mere action of collaboration (Warsen, 2023). Understanding this distinction sheds light on the underlying dynamics of research partnerships, emphasizing that successful partnerships hinge not only on action but also on the quality of relationships among partners.

However, the unique characteristics of child health partnerships introduce nuances that enrich these core principles. Trust, for instance, takes on a distinct dimension when engaging children and youth compared to other partners. Establishing trust with children involves creating a safe and supportive environment where they feel heard and respected (Totzeck et al., 2024; Woodgate & Edwards, 2010), often requiring additional time, tailored communication and engagement strategies

(Bradbury-Jones et al., 2018; Smith et al., 2019). Moreover, trust in child health research extends to encompass a broader network, involving not only the dyadic relationship between the child and research team but also parents and caregivers who facilitate child engagement in research (Woodgate & Edwards, 2010).

Caregivers and families acting as proxy partners bring unique responsibilities and perspectives to the partnership equation. Research indicates significant differences between a child's perception and that of adult proxies (Khanna et al., 2022; Soderback et al., 2011), highlighting children's distinct knowledge and perspectives (Bird et al., 2013). In child health research, caregivers offer essential insights into the child's health, preferences, and well-being, balancing protecting the child's interests while fostering their developing autonomy. This role is similar but differs from proxies in aging research, who often base decision on the older adult's previously expressed wishes, behaviours and values, accommodating diminished capacity due to cognitive decline or other health issues (Bogaerts et al., 2023; Dunn et al., 2013; Shepherd et al., 2018). When acting as knowledge users, proxies contribute their lived perspective and understanding of the child's needs and context into the research process. While enhancing relevance and applicability, this involvement also necessitates managing potential conflicts of interest, differing viewpoints, and power dynamics (Flynn et al., 2019; Martin et al., 2023; Shen et al., 2017), adding complexity to partnership dynamics.

These dynamics underscore the importance of conceptualizing partnership principles to address the specific vulnerabilities and needs of children and youth. Effective child health research partnerships must transcend universal principles to operationalize them within the unique child health context. This approach ensures that trust, commitment, and reciprocity are not only preserved but also adapted to meet the developmental stages and familial contexts of young people. Thus, while participants identified common values regardless of research context, a more thorough reflection on how these may be operationalized is warranted. Nguyen et al. (2022) found that while child health research

partnerships shared common values, such as transparency, inclusivity, and respect, the approach to implementing these values varied across different project teams. This variation highlights the need for flexible processes that can be adapted to the specific circumstances of each partnership, considering the diverse ways in which team operationalize these foundational principles.

**Implications:** Child health research partnerships benefit from the shared understanding and application of foundational principles observed across various domains. Given the unique considerations in child health, such as ethical and protective factors, enacting these principles may assume heightened significance and be conceptually nuanced. By reflecting on these unique aspects, child health research partnerships can move beyond generic applications, enriching core principles to create a more supportive and effective research environment.

**Reconceptualizing Partnership Effects.** The perceived effects of child health research partnerships varied across studies. While the survey indicated no significant differences in perceived effects across cohorts (objective 3), suggesting uniformity regardless of context, interviews highlighted variations in perceived value by role (objective 2). Distinct effects also emerged in partnerships directly engaging with children and youth (objective 3), emphasizing the importance of context and project-specific evaluation.

Despite the importance of determining partnership effects, challenges persist in their measurement and reporting (objective 1), aligning with broader trends in the field (Hoekstra et al., 2020; Mrklas et al., 2022). There is a need for methods capable of capturing both tangible and intangible effects alongside guidance and support for partnership evaluation. Given the diversity of project aims and compositions, coupled with the ideal for long-term collaboration (objectives 2 and 3), it is not surprising that a comprehensive understanding of partnership effects remains limited. Instead, reconsidering how we value partnerships, particularly considering evolving paradigms, is crucial. The current emphasis on measuring partnership effects may stem from the dominance of biomedical models

in health research, prompting a fundamental re-evaluation of success criteria. For example, Smith et al. (2022) argue that the emphasis on experimental research to justify its value ignores the democratic rationale for partnered research.

Nonetheless, understanding partnership effects provides valuable insights into partnership effectiveness, promotes accountability and support for research partnerships, and supports continuous improvement in partnership science and practice (Mrklas et al., 2022). The secondary positioning and incidental nature of research partnership effects preclude the ability to conduct cross-partnership comparison (Mrklas et al., 2022). Criteria for evaluating child health research partnerships may differ from traditional metrics. Currently, no evaluation tools are designed explicitly for assessing partnership effects in child health (Vanderhout et al., 2023). It remains unclear whether partnership effects in child health are inherently unique or share universal similarities, highlighting the need for additional investigation to develop customized evaluation criteria that address the specific challenges and opportunities within child health research partnerships.

### ***Summary***

Integrating findings from three key objectives, this research underscores the nuanced nature of child health research partnerships, revealing both unique and shared characteristics with research partnerships in other health research contexts. While child health research partnerships exhibit distinct features shaped by the characteristics of child health, they also adhere to universal principles of effective collaboration, such as trust, reciprocity, and power sharing, though how these are operationalized require nuanced reflection. Additionally, this discussion emphasizes the importance of context and adaptability within these partnerships, underscoring the need to tailor approaches to specific circumstances.

#### **7.4 Reflection on positionality**

Throughout this dissertation, I have continuously tried to reflect on my positionality and its impact on my research stance, design, and interpretation of findings. This reflective process has revealed how my background and perspectives have influenced the language I used, the methodologies I embraced, and the overarching trajectory of my study.

At the outset, my positionality was rooted in a predominantly biomedical and evidence-based medicine (EBM) paradigm, mirroring prevailing trends within the iKT field at that time. My research approach was characterized by a focus on measurable outcomes and favored established methodologies reflective of this paradigm. However, as the research progressed and my understanding deepened, particularly as I wrote this dissertation, I began to recognize how this lens implicitly shaped my thinking and its limitations in addressing the complex challenges within child health research partnerships.

This evolution in thinking was driven, in part, by my growing understanding of the diversity of research partnership approaches and their underlying philosophical traditions. I encountered challenges in navigating the subtle yet important differences between various partnership approaches, each grounded in its unique epistemological and ontological foundations. The tension between well-entrenched outcome measures (e.g., evidence-informed decision-making) rooted in EBM thinking and the broader principles of collaborative inquiry inherent in research partnerships exemplify this complexity. Additionally, I became increasingly aware of my linguistic choices, such as using terms like 'shift,' 'increase,' and 'adoption.' This made me reflect that I was comparing it to something, to some baseline, highlighting the underlying assumptions and biases embedded within my language and thought processes.

The comments and insights received during this process spurred deeper reflection, prompting me to move beyond surface-level observations. Initially, I tended to take participant's comments at face value. However, delving deeper, I recognized the nuances in how various principles and practices may

be operationalized in child health contexts. This critical reflection prompted me to question the assumptions and lens underlying my initial interpretations. For example, exploring the Indigenous scholarship literature highlighted the importance of relationality and kinship, contrasting with the more individualistic paradigms I initially adopted. Comments from my committee encouraged me to explore how the enactment of universally valued principles like trust and reciprocity might be nuanced in child health. This process of critical engagement and deeper reflection enriched my understanding, allowing me to appreciate the complexity and diversity inherent in partnered child health research.

As I conclude this dissertation, I am mindful of the ongoing evolution of my positionality and the dynamic nature of the research landscape. My journey has underscored the importance of reflexivity and continual self-examination in conducting meaningful research. Moving forward, I am committed to embracing the plurality of perspectives and methodologies within child health research partnerships with a renewed appreciation for the voices and experiences that shape our collective understanding.

## **7.5 Strengths and limitations**

### ***Strengths***

The main strength of this dissertation is its comprehensive scope, encompassing various research partnership approaches and diverse knowledge user groups. This inclusivity enhanced the richness and depth of my research findings, providing a holistic understanding of child health research partnerships. This approach aligns with ongoing trends in the field to adopt a broader research partnership approach (Hoekstra et al., 2020; Mrklas et al., 2022; Mrklas et al., 2023; Sibley et al., 2023) and facilitates cross-learning and formal cross-talk between disciplines. Second, the pragmatic mixed-methods approach employed in this study enhances its robustness by leveraging the strengths of both qualitative and quantitative methodologies. This methodological diversity allowed for data triangulation, providing multiple perspectives and insights into child health research partnerships.

### ***Limitations***

As previously discussed, framing the overarching dissertation question, “Is child health a unique context for research partnerships?” may be considered reductionist, oversimplifying the complex nature of child health research partnerships. However, it served as a useful starting point and stimulated critical inquiry into the dynamics of child health research partnerships. Second, I acknowledge the missed opportunity for more extensive partnership in this work. Balancing the tension between effective engagement within trainee work, particularly amidst COVID-19 (Medeiros et al., 2022), proved challenging. If I were to go back, I would prioritize greater engagement with knowledge users from the outset, particularly in study conceptualization. While still mindful of the need to balance engagement with the imperative to complete the thesis within the allocated timeframe, I believe that a more concerted effort towards involving knowledge users early on would have been feasible within the scope of doctoral work (Cassidy et al., 2021). This would have ensured a more robust and relevant research design, better reflecting the needs and priorities of those involved in child health research partnerships. Third, while the broad focus of the dissertation enables exploration across various dimensions of child health research partnerships, it may also be considered a limitation. A narrower focus could lead to deeper exploration and more focused insights into specific aspects of the topic. The expansive scope of the study may have resulted in some areas receiving less detailed examination than others, potentially overlooking nuances within the field and limiting its practical implications. However, given the absence of evidence on child health research partnerships from this broad lens, a more expansive approach was necessary to establish a foundational understanding before delving into more specific areas. This broader perspective provides a basis for future research endeavours to explore facets of child health research partnerships in greater depth.

## 7.6 Study implications

Collectively, this study provides an enhanced understanding of child health research partnerships spanning previously siloed partnership approaches. While child health research partnerships exhibit distinct features, they are also characterized by diversity, reflecting the multifaceted nature of child health. Additionally, due to universal aspects across research partnership domains, child health shares ongoing challenges with the field of research partnerships broadly. Therefore, the implications of this study extend across several dimensions, including informing practice and contributing to research partnership science.

### *Informing practice*

Findings from this dissertation may provide insights for institutions, funders, researchers and knowledge users involved in research partnerships:

1) Tensions between academic structures and research partnership processes:

By understanding the unique characteristics and challenges associated with partnering in child health, these findings provide insights to funders and institutions to support research partnerships more effectively. This study reaffirms ongoing tensions in research partnerships, such as mismatches between academic structures and partnership processes (Oliver, Kothari, & Mays, 2019; Smith et al., 2022). However, it highlights additional logistical and practical challenges (e.g., navigating ethics procedures) within child health, reaffirming the need to promote ongoing understanding of partnerships within institutions. These challenges are not unique to child health.

2) Supporting long-term partnerships: This study underscores the importance of fostering long-term partnerships over project-based relationships, highlighting the need for time, support, and a cultural shift. This reaffirms that it takes resources to build and sustain partnerships over time (McPhee et al., 2023) but may result in enhanced relational quality, leading to improved effects.

This study identified leadership and infrastructure support as crucial factors for successfully upholding partnership principles and navigating partnership dynamics.

### ***Implications for research partnership science***

This study has implications for the science of research partnerships specific to child health:

- 1) Inclusive engagement:** By acknowledging the diversity of knowledge user groups involved in child health research partnerships, including children and youth, the study advocates for inclusive collaboration. By acknowledging the relational web surrounding the child, research partnership teams can better anticipate and navigate the range of stakeholders both directly and indirectly involved in child health partnerships. Adopting a more holistic approach may promote long-term partnerships, enduring relationships across research projects, and sustained commitment to child health research.
- 2) Navigating complexity:** By examining research partnership dynamics and processes (e.g., relational dynamics and systemic structures), the findings can help guide partnership teams to understand and navigate these complexities more effectively. Understanding the additional challenges encountered in child health can help research partnership teams navigate barriers to engagement.
- 3) Informing best practices:** The study provides a foundation for developing best practice guidelines for research partnerships in child health, leveraging the generalizable principles and unique contextual factors to enhance research quality and impact. Given the differences observed in partnerships involving children and youth, tailored guidelines may be particularly suitable for this demographic.

### **7.7 Building on this work**

Reflecting on completing my doctoral work and transitioning to a Banting postdoctoral fellowship, I recognize the invaluable lessons gained through my research journey. Central to my

learnings is recognizing the complexities and value of adopting a partnership approach. Takeaways for future research include the value of engaging where possible, planning for evaluation upfront, initiating early and transparent engagement processes, and diligently documenting and sharing these engagement experiences to help advance the field of research partnerships. Additionally, I have also learnt valuable lessons related to my own research processes (e.g., project conceptualization, writing practices) that I will continue to develop moving forward.

Under the mentorship of Dr. Terry Klassen, my upcoming fellowship provides an opportunity to apply and refine these insights within a specific child health context. By evaluating an intervention targeting pediatric readiness in Manitoba's general emergency departments, I am positioned to further examine the processes and effects of engagement with healthcare providers – a critical yet underexplored knowledge user group within child health research partnerships. Leveraging the randomized controlled trial design of the intervention offers a unique chance to examine both intervention and engagement effects, aiming to unravel the dynamics shaping partnership effects and contributing insights into implementation effectiveness. Additionally, recognizing the inherent value of mixed-methods research, I intend to undertake a qualitative study to explore variations in pediatric readiness scores post-intervention, aiming to enrich our understanding of the multifaceted variables influencing intervention effectiveness in healthcare contexts. As I move on to this next phase, the skills and knowledge gained during my doctoral studies provide a robust foundation for my future research endeavours. The broad perspective gained on research partnerships in child health has left me with numerous questions for future inquiry. I eagerly anticipate this next step, fueled by curiosity and a commitment to advancing child health research and outcomes.

## **7.8 Conclusion**

With the growing emphasis for research partnership approaches in health and healthcare settings, these findings are timely and important as they represent the first attempt to characterize the

dynamics, processes and perceived effects of child health research partnerships across multiple partnership domains. While child health research partnerships possess distinct characteristics, they also share fundamental principles and processes with research partnerships across research contexts. Despite encountering additional engagement hurdles, these challenges are often project and context-specific. Therefore, a flexible and adaptable approach, grounded in foundational principles that promote relational quality, is essential for navigating these complexities. This refined understanding has the potential to improve child health research partnership practices while also creating a foundation for future research.

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## Appendix A

### Search Strategy – Scoping Review

Database: "Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)"	
Line	Search terms
1	("community partners" adj2 (research* or engage*)).ab,ti
2	("as partners" adj4 research).ab,ti
3	("community engagement" AND research).ab,ti
4	("community involvement" AND research).ab,ti
5	("community participation" adj3 research).ab,ti
6	("knowledge users" adj3 research).ab,ti
7	("service user" AND (involvement OR engagement)).ab,ti
8	((clinical or health) adj4 partnership*).ab,ti
9	(collaborat* adj3 (partner* or research*)).ab,ti
10	((engag* or participation) adj2 stakeholder?).ab,ti
11	((involvement or engagement) adj4 research).ab,ti
12	(partnership* adj4 research*).ab,ti
13	(action research).ab,ti
14	(coalition? adj3 health).ab,ti
15	(cocreation).ab,ti
16	(co-creation).ab,ti
17	(community coalition?).ab,ti
18	(community-based research).ab,ti
19	(community-engaged research).ab,ti
20	(consumer involvement).ab,ti
21	(coproduction AND research).ab,ti
22	(co-production AND research).ab,ti
23	(coresearch*).ab,ti
24	(co-research*).ab,ti
25	(disseminat* research).ab,ti
26	(emancipatory research).ab,ti
27	(engage* adj3 research*).ab,ti
28	(engaged scholarship).ab,ti
29	(inclusive adj2 research).ab,ti
30	("knowledge transfer and exchange").ab,ti
31	(knowledge translation).ab,ti
32	(participatory design).ab,ti
33	(participatory evaluation).ab,ti
34	(participatory intervention?).ab,ti
35	(participatory research).ab,ti

36	("patient and public involvement").ab,ti
37	(patient-centered adj2 research).ab,ti
38	(peer research).ab,ti
39	(research adj2 translation).ab,ti
40	(("mode 2" or "mode two" or "mode II") adj3 (knowledge or research)).ab,ti
41	("linkage and exchange").ab,ti
42	(research and ("peer led" or "public led" or "patient led" or "stakeholder led")).ab,ti
43	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42
44	(community-based participatory research).kw,kf
45	(participatory research).kw,kf
46	(integrated knowledge translation).kw,kf
47	(action research).kw,kf
48	(community involvement).kw,kf
49	(participatory action research).kw,kf
50	("patient and public involvement").kw,kf
51	(cocreation).kw,kf
52	(co-creation).kw,kf
53	(Collaborative research).kw,kf
54	(Community engagement).kw,kf
55	(community-academic partnership).kw,kf
56	(community-based research).kw,kf
57	(coproduction).kw,kf
58	(co-production).kw,kf
59	(Inclusive research).kw,kf
60	(knowledge exchange).kw,kf
61	(participatory research partnership?).kw,kf
62	(partnership research).kw,kf
63	(Patient participation).kw,kf
64	(researcher-stakeholder collaboration).kw,kf
65	44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64
66	43 or 65
82	65 and 81

## Appendix B

### PRISMA checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4-5
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	6
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	N/A
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	6-7
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Table 1
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A

Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	7
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	7
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	7-9
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	7-9
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	7-9
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	10-14
Limitations	20	Discuss the limitations of the scoping review process.	14-15
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	15-16
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	16

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: 10.7326/M18-0850.

## Appendix C

### Definitions of research partnership effects used in scoping review

Data extraction variables: Effects (Hoekstra et al., 2020)		
Subcategory	Beneficial Effects	Challenging Effects
Individual level		
Effects on researchers conducting partnership research	Researchers have experienced increased <b>'capacity, knowledge and skills'</b> related to planning, conducting and disseminating research in partnership with KUs; this may include a better understanding of the area under study and/or an increased awareness of community issues	Researchers have experienced <b>'personal challenges'</b> when working in a research partnership such as uncomfortable feelings when sharing power over the research and/or the additional time and financial burden associated with the research partnership.
	Researchers have experienced <b>'personal benefits'</b> from working in a research partnership such as enhanced motivation for the research project and/or lightening of the workload	
Effects on KUs involved in research partnerships	KUs have experienced increased <b>'capacity, knowledge and skills'</b> related to research processes; this may include a better understanding of the area under study and/or an increased awareness to the application of the research	KUs have experienced <b>'personal challenges'</b> when working in a research partnership, such as feelings of not being listened to, not being empowered, not being taken seriously, frustrated and/or dissatisfied about the research processes
	KUs have experienced a more <b>'positive attitude'</b> towards research and researchers	KUs have experienced <b>'feeling overburdened'</b> by tasks and responsibilities
	KUs have reported <b>better access to information</b> relevant for them such as information on treatments or management of specific diseases or illnesses	
	KUs have experienced <b>'personal benefits'</b> from working in a research partnership; examples include but are not limited to, feeling empowered, feeling valued, increased confidence, increased sense of accomplishment, extended social and support network, and/or increased chances on future employment	
Partnership level		
Effects on the relationship between researchers and KUs (partnership level)	Partners have reported that the research partnership can <b>'have positive outcomes/impacts on the relationship'</b> between researchers and KUs; examples include, but are not limited to, greater partnership synergy, mutual respect, mutual understanding of work style, language,	Partners have reported that the research partnership may result in <b>'conflicts'</b> between researchers and KUs

	needs and constraints, and/or can create sustainable partnerships	
Community or society level		
Effects on the community or society	Partners have reported that the research partnership can <b>'create system changes or action'</b> by influencing policy-making, improving community services, improving health-related outcomes for community, and/or creating capacity to sustain the projects	Partners have reported that research partnership may create <b>'challenging outcomes or impacts on the community'</b> such as increased time and financial burden on the community organizations, further stigmatization of the group and/or negative research findings
	Partners have reported that the research partnership can <b>'increase capacity'</b> in the community by creating better understanding of research in the community and/or increased awareness and knowledge of the study topic	
	Partners have reported that the research partnership can increase <b>'community empowerment'</b>	
	Partners have reported that the research partnership can <b>'create community ownership'</b> of the research	
	Partners have reported that the research partnership can increase the <b>'acceptability and trust of the research'</b> in the community	
Research process level		
Effects on the research process	Partners have reported that the research partnership can create <b>'relevant and useful research findings'</b>	Partners have reported that the research partnership may lead to negative outcomes or impacts, including <b>biased data or tokenism.</b>
	Partners have reported that the research partnership can create <b>'high quality research'</b> by generating credible and valid data, developing effective interventions, and/or unearthing new information; the partnership can also generate new and other projects	
	Partners have reported that the research partnership can create <b>'increased capacity'</b> to conduct and disseminate the research	

## Appendix D

### Interview guide

Thank you for agreeing to participate in this study and for your time today. I am a PhD student from the University of Manitoba's Department of Community Health Sciences studying integrated KT and other related health research partnerships in child health. As I mentioned in my email, you were contacted because you responded to a survey in summer 2020 regarding your experiences with "X" project grant and indicated you'd be willing to be contacted for a follow-up interview. Today I'm going to be asking you some more information about your experiences with engaging not only in that partnership, but your experiences overall. This study has been approved by the University of Manitoba Health Research Ethics board. Please note that your responses will be kept confidential and that you don't have to answer any questions that you don't want to. Given that you also responded to the survey, your answers today may be linked to the survey for greater understanding.

- *Before I start, do you have any questions?*
  - *I will be audio recording our interview to allow for thorough documentation. All interviews will be de-identified for reporting purposes, kept on a password protected server, and destroyed after 10 years. Do I have your consent to proceed with the interview and audio recording of this interview?*
1. To start, can you first tell me a little bit about yourself? (eg. background, training environment (if applicable), research interests)
  2. What was it about your research journey that led you to be involved in partnership style research?
  3. For how long would you say you have been doing partnership style research? When thinking broadly about all of the different research partnerships you've been involved in over X years, what comes to mind?
  4. For those with lots of experience with research partnerships:
    - Can you reflect on how the various partnerships you have been involved in have worked over time?
    - Which of your experiences in working in partnership do you feel worked best?  
Probes: explore what made it so successful in their view? Can you think of a partnership where maybe that ideal wasn't achieved and why?

For those with few partnership experiences:

- Can you tell me a little bit about your most recent partnership?
- Do you have an experience with a different partnership that was perhaps managed differently?

Additional potential probes:

- *Tell me about your experience working with knowledge users (or for knowledge users, working with researchers)*
- *Who initiated the partnership, how did you become involved?*

- *Why did you get involved? What incentives, if anything, motivated you?*
  - *Where there any strategies that worked well/didn't work well*
  - *Not all people want to be engaged at the same level. How did you navigate that as a team?*
  - *How were decisions made within the team? Were other aspects of power shared within the team? (eg. how project resources were allocated, how priorities for the research were established, etc).*
  - *How do you think the opinions and expertise of various partners have been included in the projects you've been involved in (eg. decision-making, co-production)*
5. When thinking about all of these experiences, what would be an ideal partnership?
    - How does this compare to your actual experience?
    - *Probe: What factors do you attribute to this? What factors or attributes are needed for successful partnership research?*
  6. As I mentioned, I'm studying partnership research in child health for this project. Do you have experience in partnership research focused on other populations (eg. adults)?
    - a. If yes, how do you think the two might have been different based on your experience?
    - b. If no, why have you chosen to focus on child health? Is there anything you've learned over time that you feel has influenced your ability to engage?
    - c. Have you ever engaged with children and youth as partners? How did that go?
    - d. Have you engaged with other knowledge users on behalf of children? How did that go?
    - e. Have there been any special considerations you've had to make because your partnerships was focused on child health?
  7. What value do you feel a partnership approach has brought to the projects you've been involved in?
    - a. Probes: personal, research, health or health policy outcomes
    - b. What was achieved through working in partnership? (probe: what would have been different if a partnership approach was not used?)
    - c. Have there been any challenging or negative outcomes that have come from the projects you've been engaged in?
  8. Moving forward, do you intend to engage in other health research partnerships?
    - a. Why or why not?
  9. Based on the experiences you've shared with me today, do you have any words of advice that you would bring forward into your next partnership?
  10. Summarize general themes from the interview
  11. That's all the questions I have for you today. Based on what we talked about, is there anything I've missed or anything else you'd like to share?

Thank you so much for your time. Your contributions are very much appreciated and will help to enhance our understanding of health research partnerships in child health. If anything else comes to mind after our interview, you have my contact information so please don't hesitate to reach out.

## Appendix E

### Mapping interview components to research questions

Research Questions	Interview Guide Question Examples
What are the experiences of researchers and knowledge users who engage in child health research partnerships and what value do they see this partnership bringing to the research?	<ul style="list-style-type: none"> <li>- For how long would you say you have been doing partnership style research? When thinking broadly about all of the different research partnerships you've been involved in over X years, what comes to mind?</li> <li>- What value do you feel a partnership approach has brought to the projects you've been involved in?</li> </ul>
In what way might beliefs, attitudes and prior experiences shape and/or influence researcher and knowledge users desire to engage in health research partnerships? What drives this motivation and what principles underlie it?	<ul style="list-style-type: none"> <li>- To start, can you first tell me a little bit about you? (eg. background, training environment (if applicable), research interests)</li> <li>- What was it about your research journey that led you to be involved in partnership research?</li> <li>- Moving forward, do you intend to engage in other health research partnerships?</li> </ul>
How are relationships formed, navigated and maintained? How are relational aspects of partnerships such as power sharing and ethical considerations navigated?	<ul style="list-style-type: none"> <li>- Can you reflect on how the various partnerships you have been involved in have worked over time?</li> <li>- Which of your experiences in working in partnership do you feel worked best?</li> <li>- Can you tell me a little bit about your most recent partnership?</li> <li>- When thinking about all of these experiences, what would be an ideal partnership?</li> </ul>
What are the specific nuances and special considerations for engaging in child health research partnerships?	<ul style="list-style-type: none"> <li>- As I mentioned, I'm studying child health research for this project. Do you have experience in research partnerships focused on other populations?</li> <li>- Have there been any special considerations you've had to make because your partnership was focused on child health?</li> </ul>

## Appendix F

### Codebook

Code	Definition
Academic structures	Academic structures refer to the systems and structures in place that either facilitate or create tensions for engaging in partnership research. This can refer to expected timelines, metrics and outputs, and recognition within the academic system.
Ethics	Within academic structures, ethics refers to some of the ethical challenges when engaging research partnerships, such as obtaining approvals, intellectual property when working with communities, naming knowledge users on ethics forms, REB unfamiliarity with research partnerships, and the additional ethical safeguards in place for child health research.
Funding	Within academic structures, funding refers to the role of funding in supporting or hindering partnership activities, logistics around where the funding is held and how it is distributed, and advice and opportunities for funders.
Evolution of the field	Evolution of the field refers to the shifts that researchers and knowledge users have observed in the science and practice of research partnerships over time, reflecting growth in, and support for, research partnerships.
Evolving science and training	Within evolution of the field, this refers to the growth in evidence to support research partnerships, training to engage, mentoring of trainees, and ongoing formalization and standardization of research partnerships.
Evolving with experience	Within evolution of the field, this refers to both a shift in the mindset and skills of researchers and knowledge users with experience and practice.
Funding and structural mechanisms	Within evolution of the field, this refers to the structural mechanisms (e.g., funding, academic expectations, research partnership requirements) that influence research partnerships.
Geographical differences	Within evolution of this field, this refers to geographical differences in research partnerships. In particular, the state of the field in Canada relative to other countries.
Increasing level of engagement	Within evolution of the field, this refers to more meaningful and intensive involvement of knowledge users in the research process over time.
Rules of engagement	Within evolution of the field, this refers to what is expected, and accepted in terms of engaging with, or as, a knowledge user.
Terminology	Within evolution of the field, this refers to the words used to describe research partnership approaches and the shift in its' use over time.

Child health	This overarching category incapsulates all discussion that was focused specifically on research partnerships in child health. Specifically, this refers to whether child health is a unique context for research and research partnerships, specific considerations for engaging, strategies for engaging, and the value and purpose of engaging in research partnerships in child health.
Conducting research	Within child health, conducting research refers to the additional complexities of <i>conducting research</i> in child health, including issues of consent, research design and methods, ethics, and safety.
Partnerships	Within child health, partnerships refers to the additional complexities of <i>engaging in research partnerships</i> that are focused on child health, and whether this context is unique compared to other populations.
Considerations	Within child health, this refers to unique considerations or reflections relating to engaging in research partnerships in child health, including generational differences, age and developmental appropriateness, concepts of development and change, inclusivity and giving voice, and working with proxies and gatekeepers on behalf of children and youth.
Strategies for engaging children & youth	Within child health, this refers to activities/strategies (i.e., observable actions) used to engage children and youth as partners in the research process.
Value & purpose	Within child health, the reasons or motivations for engaging that are specific to child health.
Common conditions needed	Common conditions needed refers to the overarching conditions present or required for research partnerships, such as common goals, high level support, commitment, key intermediaries, resources and compensation, and flexibility. When present, these facilitated what were perceived to be “successful” research partnerships.
Partnership challenges	Partnership challenges refers to experiences that are perceived to be negative (e.g. unethical behaviour, tokenism), non-desirable research partnership outcomes, challenges in balancing research partnership activities, and actions taken (e.g., when intentions were not perceived to be pure). This can also refer to barriers, defined as factors that are negatively associated with or hinder research partnerships and/or its definition, conceptualization, establishment, or conduct, design, assessment, or impact.
Principles	Principles refer to fundamental norms, rules, beliefs or values that represent what is desirable and positive for a person, group, organization, or community and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives and are meant to govern both. These are both explicitly and implicitly stated when discussing research partnerships.
Relationships	Relationships refers to identifying, initiating, establishing and fostering relationships between researchers and knowledge users. Relationships can be defined as a situation in which there is an attempt to build close links between researchers and knowledge users that remain distinct (e.g., two-communication theory), but which choose to work closely together. Relationships can be at varying levels of maturity and operate at varying levels of intensity. Those within the relationship also have varying skills, abilities, needs, requests, and levels of power. They also have different forms of knowledge to contribute.

KU differences	Merged with relationships – referred to the different needs, demands and questions by knowledge user group(s), often broken down into individual, community, provincial and federal.
Sustainability	Sustainability refers to accounts of, or strategies for sustaining relationships, projects, and future partnerships. Factors influencing sustainability includes: barriers - turnover/retirement, funding, political climate; and facilitators – trainees advancing aspects in their future careers, dedicated staff and resources, positive partnership relationships.
Strategies	Strategies refers to observable actions designed to achieve an outcome. With regards to research partnerships, this involves participants describing activities or strategies used to engage knowledge users in the research process.
Value	Value refers to the benefits resulting from engaging in research partnerships, such as partnership benefits (e.g., accountability, relevance, recruitment), outcomes (i.e., change in status as a result of the project, not futuristic) and impacts (i.e., identifiable benefit to, or positive influence on the economy, society, public services, health, the environment, quality of life, or academia).
Why partnership research	‘Why partnership research’ refers to the reasons for engaging in research partnerships and the desire to engage in future research partnerships. This relates to researchers’ backgrounds, attributes, and intrinsic and extrinsic motivations for engaging in research partnerships (i.e., the “why” of engaging). This category intertwines with principles, all of which influence relationships and the relative “success” of research partnerships.

## Sets:

Categories	Definition	Participants
Knowledge user (n=3)	Knowledge users were defined as individuals in a research partnership who are able to use the knowledge generated through research in order to make informed decisions about health policies, programs, and/or practices (CIHR, 2022). In the survey, these individuals were named as collaborators or knowledge-users on a research partnership grant.	KU01, KU03, KU04
Researcher (n=7)	Researchers were defined as individuals who hold an academic appointment, are autonomous regarding their research activities, and are responsible for leading the intellectual direction of a research project (CIHR, 2022). In the survey, these individuals were named as principal investigator or co-investigator and had experience leading, or as a research team member, on a research partnership grant.	R01, R02, R03, R05, R09, R10, R14
Dual (n=5)	Based on their background and interview responses, duals were considered those who have characteristics of both a researcher and knowledge user, and whose role was sometime indistinct when they spoke about research partnerships.	R04, R06, R08, R11, R13

## Appendix G

### Data analysis overview

Research question	Theme	Theme definition	Subthemes	Analysis	Code	Code definition
2	Motivation for research partnerships varies by role	The initial drive, stimulus, or influence for engaging in research partnerships.	<p>Researchers: relevant, impactful research &amp; funder driven initiatives</p> <p>Knowledge Users: learning, advocacy, and credibility</p> <p>Duals: “something we’ve always done”</p>	<p>Cross-case analysis</p> <p>Analytic queries</p>	<p>Background</p> <p>Why partnership research</p>	<p>Participant describes training, disciplinary, career, and/or individual experiences about themselves.</p> <p>Participant describes the impetus for engaging in research partnerships and/or the desire to maintain research partnerships in the future. This relates to researchers’ backgrounds, attributes, and intrinsic and extrinsic motivations for engaging in research partnerships (i.e., the “why” of engaging).</p>
1	Structural processes: academic and funding structures	The role of structural processes, such as those within the academic system and funding institutions, in facilitating or hindering research partnerships.	<p>An evolving field</p> <p>Tensions between academic structures and research partnerships</p> <p>Finding that sweet spot (funding)</p> <p>*sustainability</p>	Cross-case analysis	<p>Evolution of the field</p> <p>Academic structures</p> <p>Funding</p> <p>Sustainability</p>	<p>Participant describes the shifts observed in the science and practice of research partnerships over time.</p> <p>Participant describes systems and structures in place within academic institutions that either facilitate or create tensions for engaging in partnership research. This can refer to expected timelines, ethics, metrics and outputs, and recognition within the academic system.</p> <p>Participant describes the role of funding processes in supporting or hindering partnership activities, logistics around where the funding is held and how it is distributed, and advice and opportunities for funders.</p>

						Participant describes accounts of, or strategies for sustaining relationships, projects, and future partnerships.
3 Partnering processes: relationships and collaborative structures	Exploring partnership dynamics			Cross-case analysis  Analytic queries	Relationships  Power dynamics  KU differences	<p>Participants describe aspects of identifying, initiating, establishing and fostering relationships between researchers and knowledge users. Relationships can be defined as a situation in which there is an attempt to build close links between researchers and knowledge users that remain distinct (e.g., two-communication theory), but which choose to work closely together. Relationships can be at varying levels of maturity and operate at varying levels of intensity. Those within the relationship also have varying skills, abilities, needs, requests, and levels of power. They also have different forms of knowledge to contribute.</p> <p>Participants describe, either directly or indirectly, different levels of control, access, agency, and decision-making authority in research partnerships, and processes and/or efforts to redistribute power.</p> <p>Participants describe differences in the needs, questions and demands of various knowledge user groups who are engaged in research partnerships.</p>
2 Partnering processes: research partnership processes contributing to outcomes	<p>Research partnership processes contributing to outcomes</p> <p>It's all about the relationships</p>		<p>Step in a larger effort (looking down the pipeline)</p> <p>The critical role of dedicated staff, flexibility, and coordination</p> <p>Leadership and boundary spanners</p>	Cross-case analysis  Analytic queries	<p>Common conditions needed</p> <p>Successful partnerships</p> <p>Partnership challenges</p>	<p>Participants describe overarching factors, attributes, or conditions present or required for research partnerships, such as common goals, high level support, commitment, key intermediaries, resources and compensation, and flexibility.</p> <p>Participants describe accounts of experiences that are perceived to be positive. Common conditions needed are precursors or factors from their experiences that may or may not be present in an account of a successful partnership.</p> <p>Participants describe experiences that are perceived to be negative (eg. unethical behaviour, tokenism), non-desirable research partnership outcomes, challenges in balancing research partnership activities, and actions taken (eg., when intentions were not perceived to be pure). This can also refer to barriers, defined as factors that are negatively associated with or hinder</p>

			Partnership challenges  Not for the faint of heart		Principles  Researcher attributes	research partnerships and/or its definition, conceptualization, establishment, or conduct, design, assessment, or impact.  Participants describe fundamental norms, rules, beliefs or values that represent what is desirable and positive for a person, group, organization, or community and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives and are meant to govern both. These are both explicitly and implicitly stated when discussing research partnerships.  Qualities, characters, or characteristics of researchers who engage in research partnerships (eg. tenacious, flexible, caring)
1  Outcomes and impacts: value of research partnerships	Perceived value of research partnerships varies by role and aligns with their motivation		Value added (outcomes, impacts)  Ambiguity around defining success  Differences by KU group  Challenges with sustainability	Cross-case analysis	Value  Sustainability	Participant describes the benefits resulting from engaging in research partnerships, such as partnership benefits (e.g., accountability, relevance, recruitment), outcomes (i.e., change in status as a result of the project, not futuristic) and impacts (i.e., identifiable benefit to, or positive influence on the economy, society, public services, health, the environment, quality of life, or academia).  Participant describes accounts of, or strategies for sustaining relationships, projects, and future partnerships.
4  Context: child health	Common principles, unique challenges	The perceived similarities, differences and considerations for engaging in research partnerships in child health	Similarities  Differences  State of research partnerships in child health relative to other populations	Cross-case analysis	Child health  Unique  Research  Partnerships	Participant makes explicit reference to conducting research partnerships in child health.  Participant describes whether they perceive child health as being a unique context for engaging in research partnerships.  Participant refers to the additional complexities of <i>conducting research</i> in child health, including issues of consent, research design and methods, ethics, and safety.  Participant refers to the additional complexities of <i>engaging in</i>

			Considerations		<p><i>research partnerships</i> that are focused on child health, and whether this context is unique compared to other populations.</p> <p>Participant describes considerations, reflections, or learnings relating to engaging in research partnerships in child health</p> <p>Participant describes activities/strategies (i.e., observable actions) used to engage children and youth as partners in the research process.</p>
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