

Investigating evaluation and effects of partnered rehabilitation  
research: a mixed methods approach

by

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## Abstract

### Background

Findings from rehabilitation research may be under-utilized in part because of how they are produced, which may impact health outcomes or the economic costs of the healthcare system. An approach which could enhance the use of rehabilitation evidence is for researchers to partner with knowledge users (e.g., clinicians, policymakers, or decision makers) throughout the research process. This approach, known as partnered rehabilitation research, has potential to increase the uptake of rehabilitation research by aligning research designs and processes with knowledge users' priorities and values. Studies on partnered rehabilitation research have reported on characteristics of the partnerships, strategies, and methods to involve knowledge users, when to involve knowledge users, factors affecting the partnerships, impacts, and outcomes. However, little is known about how partnered rehabilitation research was evaluated and its effects on knowledge use. Evaluation is important to confirm short, medium, or long-term effects of partnerships, ensure integrity of the partnering process, confirm assumptions of this approach, and assess how partners work together. Considering the importance of evaluation and knowledge gaps about the effects of partnering, my overarching research question was, "how has partnered rehabilitation research been evaluated and what are its effects on the research process and outcomes?"

### Methods

I used an explanatory sequential mixed method design, underpinned by a pragmatic lens, to conduct a cross-sectional online survey followed by interviews. Individuals were eligible for either study if they were researchers or knowledge users who had experience in partnered rehabilitation research. I used non-probability convenience and snowball sampling to recruit participants to the survey. The survey was conducted in July 2023. I analyzed and reported survey findings descriptively. I situated the interviews in a qualitative descriptive study and used purposive and snowball sampling to recruit participants. The interviews were completed early 2024. I analyzed the findings inductively and deductively and reported results thematically. I kept field notes and used member checking and thick description to enhance trustworthiness. I integrated results from the survey and interviews via narrative weaving and presented them in a stand-alone chapter.

## Results

Participants from the survey (n = 14) and interviews (n = 13) were predominantly female (n = 24, 89%) and white (n = 21, 78%). No survey respondents were knowledge users, but six (46%) interview participants were. Many survey respondents indicated the partnership will be/ had been evaluated (n = 8, 56%). However, no interview participants evaluated the partnerships. Most survey respondents (n = 10, 71%) perceived partnering significantly influenced the research questions, and interview participants discussed how partnering resulted in clinically applicable research questions. Many survey respondents (n = 9, 64%) believed the partnership significantly influenced research outcomes such as the production of useful research findings or evidence-informed clinical decision making (n = 8, 57%). However, interview participants offered few insights and examples of how and when partnering enhanced evidence uptake in clinical decision making.

## Conclusion

Findings from the survey and interviews suggest that partnering influences the research process and research outcomes. However, there was discordance specific to findings about evaluation of partnered rehabilitation research. Many survey respondents evaluated the partnering process, but no interview participants did. Findings from this mixed methods study confirm some assumptions about partnered rehabilitation research, however; more research is needed to substantiate the effects of partnering and extent of evaluation in partnered rehabilitation research.

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## List of Abbreviations

CHERRIES	Checklist for Reporting Results of Internet E-Surveys
CBPR	Community-based participatory research
IAP2	International Association of Public Participation Spectrum
IKT	Integrated knowledge translation
IKTRN	Integrated Knowledge Translation Research Network
KT	Knowledge translation
WHO	World Health Organization

## Chapter one: Introduction

Chapter one is an overview of my thesis. I begin with a brief explanation of the lack of evidence uptake in rehabilitation, propose an approach to addressing the lack of evidence uptake, and summarize some literature specific to partnered rehabilitation research. I introduce and define some key concepts (rehabilitation, researcher, knowledge users, evaluation, effects) for my thesis. The chapter concludes with the purpose of my thesis and my positionality statement.

Rehabilitation is a process consisting of the delivery of tailored, person-centred interventions for individuals with health conditions, which aim to enhance function; optimize quality of life, independence, and social integration; minimize disability; and maximize the ability to adapt to changes in an individual's environment.<sup>1-4</sup> Rehabilitation interventions should be evidence informed to maximize health outcomes and improve the efficiency and effectiveness of rehabilitation care.<sup>5,6</sup> There is a gap between rehabilitation evidence and its uptake, i.e., use or adoption, in rehabilitation practice.<sup>7-10</sup> This gap between evidence and practice may stem in part from researcher-driven approaches in which researchers predominantly develop research questions and agendas, design and conduct research, and disseminate the results, without the involvement of the intended users of research.<sup>11,12</sup> A researcher is someone who conducts investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory.<sup>13</sup> For my thesis, I defined researcher as an individual who carries out thoughtful inquiry or examination of a topic.<sup>13</sup> Research is usually conducted by people in designated roles for this purpose, and they are often intended users of the research findings, but not the only intended users. Researcher-driven approaches develop research findings that, at times, have been perceived as irrelevant by the intended users, thus resulting in the under-utilization of these findings in healthcare practice.<sup>14-16</sup> Studies have reported that when evidence is used to inform practice it can improve health outcomes in patients and minimize the economic costs of healthcare.<sup>6,17-19</sup> Some healthcare and rehabilitation researchers are making efforts to move away from researcher-driven approaches to enhance the uptake of evidence in practice.<sup>20,21</sup>

An approach to increase the uptake of rehabilitation evidence is for researchers to partner with the intended users of research.<sup>22</sup> These intended users may be referred to as knowledge users,<sup>15,16</sup> stakeholders,<sup>21</sup> or research users.<sup>23</sup> For my research I used the term knowledge user because it is the term used within the Canadian health research context consistent with intended research user.<sup>24</sup> However, at times I referred to stakeholders, research users, or consumers when I discussed specific studies because it reflected the language used by the authors. Research conducted with the involvement of knowledge users may contribute to the enhanced uptake of its findings if critical components of the research process (e.g., setting priorities, establishing research questions, choosing methods, collecting, and analyzing data) address relevant priorities or incorporate knowledge user perspectives and experiences.<sup>25,26</sup> Reported benefits of research conducted with knowledge users include enhanced capacity, knowledge and skills of both researchers and knowledge users; improved community services; community empowerment; and system changes by influencing policy.<sup>27</sup>

Evidence syntheses of partnered rehabilitation research has contributed some understanding of certain aspects of partnerships such as the characteristics, e.g., unique aspects of partnerships including partner roles and supporting knowledge users, who is involved with partnerships, strategies and methods to involve knowledge users, when to involve knowledge users as research partners, and barriers and facilitators of partnerships.<sup>21,28,29</sup> This literature represents some phases of the research partnership process, i.e., preparation, planning, and execution.<sup>21,28,29</sup> However, there is little published research on evaluation and effects of partnered rehabilitation research. For my research I defined evaluation as assessing or measuring the value of the research partnership.<sup>30</sup> Evaluating partnered rehabilitation research is important to accurately identify the effects of the partnering process and ensure integrity, i.e., concepts related to involving knowledge users in the research process, are upheld.<sup>31-33</sup> I used the term “effects” in my research to represent the short, medium, and long-term intended or unintended consequences of partnered rehabilitation research that can be evaluated, measured, or assessed from the perspectives of researchers and knowledge users.<sup>28,34,35</sup> There are times I used impacts or outcomes when referring to the effects of partnered research. Considering the gaps in literature about the evaluation and effects of partnered rehabilitation

research, research should be conducted to develop a deeper understanding of what the effects of partnerships are, how these effects are measured, and how evaluation can be improved.

The purpose of my thesis was to investigate the evaluation and effects of partnered rehabilitation research on the research process and outcomes. The overall aim was to advance the use of partnered rehabilitation research.

My overarching research question had two parts, “how has partnered rehabilitation research been evaluated to date” and “what are its effects on the research process and outcomes?” I investigated this question through a pragmatic theoretical perspective using an explanatory sequential mixed-methods design.<sup>36</sup> The quantitative phase included a survey which examined the features, evaluation, and perceived effects of partnered rehabilitation research through an online survey. Following the surveys, the qualitative phase used interviews to explore the evaluation and effects of partnered rehabilitation research through the perspectives of researchers and knowledge users via interviews with particular attention to the strategies used to evaluate the effects, the perceived effects, and how partnering contributed to the effects. I integrated data in different ways. Firstly, findings from the survey informed the sampling and interview questions. After I collected and analyzed data from both studies, I wove findings from the survey and interviews together and shared the integrated results in chapter six.

I identify as a white, female settler, who lives a middle-class lifestyle. I hold bachelor’s degrees specific to exercise science and physiotherapy, and a master’s degree in science. Additionally, I worked as a physiotherapist in multiple Canadian jurisdictions for nearly thirteen years in both the public and private practice sectors. During this time, I focused on offering individually tailored assessment and treatment for individuals with orthopedic and musculoskeletal injuries based on their goals, needs, and expectations. To me, this was consistent with practicing patient-centred care.

I currently work in the physiotherapy department at the Health Sciences Centre (HSC), a tertiary care hospital in Winnipeg, MB, Canada. I am employed in a non-clinical role as an embedded researcher. My role aims to enhance the uptake of physiotherapy evidence to inform practice, program planning, and program evaluation, which may improve patient outcomes or how the

healthcare system functions. To achieve this aim, I work together and in partnership with physiotherapy employees supporting research projects that meet their needs and/or priorities. However, I also collaborate with other rehabilitation and allied health professionals employed at HSC and the Winnipeg Regional Health Authority (WRHA) on research. Not only am I researching partnered rehabilitation research as part of my thesis, but I also hold an insider view on partnered research because of my role at HSC. My position studying partnered rehabilitation research and working in collaboration with physiotherapy employees on research contributed to how I interpreted the results from my studies.

Based on my experiences as a physiotherapist, PhD candidate and embedded researcher, I assume it is necessary to include knowledge users in the research process to enhance the uptake of evidence. I believe knowledge users experiences and perspectives are necessary in all phases of the research process, but especially the early phases, i.e., priority or agenda setting, because this can ensure that research questions are addressing their needs and priorities. I theorize that research which meets the needs of knowledge users will produce findings that are used in practice and will ultimately enhance health outcomes and/or how the healthcare system functions. I am hopeful findings from my research will have implications for partnered rehabilitation research and health research partnerships, and I am confident they will have implications for my how I partner with physiotherapy, rehabilitation, or allied health professionals on research projects within my role at HSC.

I acknowledge as a privileged, white female researcher, licensed physiotherapist, and individual involved in partnered rehabilitation research in a public healthcare setting, aspects of my research including establishing the questions, developing methods, and analyzing the data, have been influenced by my experiences in these roles.

## Chapter two: Background

Chapter two includes details about concepts, i.e., knowledge translation, health research partnerships, rehabilitation, and partnered rehabilitation research, which underpin my thesis. I conclude chapter two by introducing the conceptual framework that informed my thesis.

### Knowledge translation

The Canadian Institutes of Health Research (CIHR) defines knowledge translation (KT) as, “the synthesis, dissemination, implementation, and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system.”<sup>24</sup> This definition acknowledges that KT is a complex process, which could span conceptualization of research to implementation of research findings.<sup>37</sup> Knowledge translation aims to optimize the development of KT interventions and relevant research to promote the dissemination, and implementation of research findings in healthcare.<sup>24</sup> By doing so, KT ultimately strives to improve health outcomes, and the efficiency and effectiveness of the healthcare system.<sup>38</sup>

Knowledge translation is the term that is traditionally used in Canada to capture efforts aimed at moving research findings into healthcare practice.<sup>37</sup> However, it is important to note there are several terms that can be used to describe this process.<sup>39,40</sup> For instance, in their commentary published in 2006, Graham et al<sup>39</sup> defined nine different terms that can be used to capture knowledge translation: 1) knowledge translation, 2) knowledge transfer, 3) knowledge exchange, 4) research utilization, 5) implementation, 6) dissemination, 7) diffusion, 8) continuing education, and 9) continuing professional development. Furthermore, in 2010 McKibbin et al<sup>41</sup> published findings from their cross-sectional study that identified 100 individual terms closely related to KT that were used across of various literature sources.

Despite assumptions KT’s ability to improve health outcomes and the efficiency and effectiveness of the healthcare system, systematic and scoping reviews have reported inconclusive and/or inconsistent findings regarding the effectiveness of KT interventions.<sup>42,43</sup> For example, findings from a systematic review conducted by Cahill et al<sup>44</sup> to investigate implementation interventions to enhance the use of evidence-based practice in stroke

rehabilitation were published in 2020. The systematic review included twelve randomized and non-randomized trials, interrupted time series studies, and controlled before after studies that compared an implementation intervention to no intervention or to another implementation approach in stroke rehabilitation.<sup>44</sup> Some of the outcomes Cahill et al<sup>44</sup> included were healthcare professional adherence to recommended treatment and patient health status and well-being. Cahill et al<sup>44</sup> were uncertain whether implementation interventions improved adherence to evidence-based practice in stroke rehabilitation. Furthermore, the authors found low-certainty evidence that implementation interventions improved patient psychological well-being and moderate-certainty evidence that implementation interventions resulted in little or no difference in patient quality of life and activities of daily living.<sup>44</sup>

In 2015, Yost et al<sup>43</sup> published findings from their systematic review and meta-analysis which aimed to determine if KT interventions targeted towards nurses in tertiary care were effective for promoting evidence-informed decision-making behaviors, healthcare practice, and improving client outcomes. Study designs included systematic reviews, RCTs, cluster RCTs, non-randomized trials, cluster non-randomized trials, interrupted time series, prospective cohort studies, all qualitative designs (e.g. descriptive, phenomenology, grounded theory), and mixed methods.<sup>43</sup> Yost et al<sup>43</sup> included 30 studies for data analysis, the majority of which were quantitative studies (n= 18). There was no positive effect of KT interventions on evidence-informed decision-making behaviors of nurses.<sup>43</sup> However, Yost et al<sup>43</sup> reported small to large effect sizes of KT interventions that promoted the use of research evidence for practice change. As well, the authors reported a positive effect on client outcomes, i.e., pain intensity, but these results were mixed.<sup>43</sup> Yost et al<sup>43</sup> speculated reasons for the inconsistent results could have been related to the study designs or outcomes. Yost et al<sup>43</sup> also reported that several contextual factors could affect the success of KT interventions on evidence-informed decision making, practice behaviors, and client outcomes. For instance, organizational factors, i.e., leadership; individual and interpersonal factors; and characteristics of the intervention may have contributed to the effectiveness of KT interventions targeted to nurses.<sup>43</sup>

While the findings from Cahill et al<sup>44</sup> and Yost et al<sup>43</sup> demonstrate uncertainty, low certainty, or inconsistencies regarding the influence of implementation or KT interventions to enhance

evidence uptake, a scoping review conducted by Flynn et al<sup>45</sup> and published in 2022 found KT strategies have positive benefits on the sustainability of evidence-based practice in healthcare settings. Specifically, the authors identified benefits on health outcomes and the healthcare system. Eighty-two studies were included in the scoping review conducted by Flynn et al.<sup>45</sup> There were no limits on the study type included in the review other than excluding commentaries, editorials, and opinion pieces. Flynn et al<sup>45</sup> identified 22 studies that reported benefits of evidence-based practice for patients, staff, and the healthcare setting. For example, sustained evidence-based practice resulted in decreased hospital admissions and length of stay for patients with asthma. As well, the sustainability of evidence-based practice also led to maintenance of new hospital policies and procedures specific to the management of health conditions, like gastroenteritis in children. The results from the scoping review conducted by Flynn et al<sup>45</sup> are encouraging, however the findings are limited because of the lack of meta-analysis to demonstrate quantifiable effects of the KT strategies.

Considering findings from research about the effectiveness of KT to enhance the use of evidence to inform clinical practice and subsequently health outcomes and the efficiency of the healthcare system is variable, additional approaches to enhance evidence uptake may help to minimize the gap between evidence and practice. One of those approaches consists of researchers collaborating with knowledge users during the research process to produce findings that meet the priorities and needs of the knowledge users. I opted to focus my PhD research on researchers and knowledge users partnering on research because of my past experiences working as a physiotherapist in clinical practice, my current experience working in a physiotherapy department in the public healthcare system, and my beliefs about the value of incorporating knowledge user perspectives into the research process.

### Health research partnerships

Defining health research partnerships

Research partnerships is an umbrella term that captures collaborative approaches to research that actively involves individuals, groups, or organizations in any part of the research process.<sup>15,34,46</sup> Research partnerships involve at least one academically affiliated researcher, and a stakeholder such as (but not limited to), charities, community agency, clinicians, patient,

caregiver, policy and/or decision maker.<sup>15,34,46</sup> Health research partnerships are situated in the healthcare domain and aim to develop relevant and meaningful evidence for the stakeholders.<sup>12</sup> Specific types of research partnerships include, but are not limited to integrated knowledge translation (IKT), engaged scholarship or community-based participatory research (CBPR),<sup>47,48</sup> with CBPR as the most frequent type of partnership captured in a review of reviews of health research partnerships.<sup>49</sup> While each of these types of research partnerships have some differences (e.g., language, purpose, motivation, or theoretical underpinnings), they are rooted in collaborative approaches to knowledge development that actively involve the intended users of the research in any part of the research process.<sup>34,46,48</sup> Research recent has compared different types of research partnerships.<sup>47,48</sup>

In 2020, Nguyen et al<sup>48</sup> published a qualitative descriptive study that aimed to identify the differences and similarities between IKT, engaged scholarship, mode 2 research, co-production, and participatory research. They conducted 17 interviews with researchers to gain an understanding of their perspectives and experiences with the different types of research partnerships.<sup>48</sup> They reported the results in two main themes: 1) differences between perspectives, and 2) similarities between perspectives.<sup>48</sup> The differences that Nguyen et al<sup>48</sup> captured included (but were not limited to): scope, original purpose/intent, epistemological stance, theoretical underpinnings, unique features, roles of the partners, and power-sharing. A summary of differences between some of the types of research partnerships are shown in Table 1, which is adapted from Nguyen et al.<sup>48</sup> The table is meant to articulate some differences

Table 1. A comparison of differences between types of health research partnerships. Adapted from Nguyen et al.<sup>48</sup>

	<b>Participatory research</b>	<b>Integrated knowledge translation (IKT)</b>	<b>Engaged scholarship</b>
<b>Purpose/ Intent</b>	Research is collaborative, consultative, democratic, reflective, reflexive, dialogical and improvement-oriented, it builds capacity and creates actionable, ownership of research findings	Gather perspectives of key stakeholders and study complex problems, increase the chances that research findings will be applicable to those under study	Create knowledge that advances science and practice, and is more penetrating and insightful than that which is done in isolation
<b>Primary motivation</b>	Reducing or eliminating healthcare injustices and inequities, emancipate underserved and vulnerable participants leading to social and environmental transformation and justice	Increase knowledge use and impact	Connecting academia with societal needs, education for democracy, civic responsibility/ engagement and public scholarship
<b>Theoretical or historical underpinnings</b>	Kurt Lewin and action research	Planned action/ change theory, two communities theory <sup>50</sup>	Engaged scholarship model
<b>Unique features</b>	Developed in social sciences and education, explicit focus on social justice, power, emancipation, research humility, capacity building is an intentional outcome	Roots in health research, situated in a funder driven model, i.e., CIHR, develop in health and implementation research, term, “knowledge users” is unique to IKT	Developed in academic settings, explicit involvement of student partners, intersects teaching, scholarship, and service, research, and teaching scholarship
<b>Role of partners</b>	Experts with lived experiences work with researchers to solve a given problem or issue throughout the research process	Use knowledge to impact change in healthcare systems, throughout research process	Partners contribute expertise throughout research process
<b>Power sharing</b>	Equal or equitable, empowerment or emancipation of communities/ community members	Negotiated, equitable throughout role of knowledge users in research process	Leverage expertise

between the types of partnerships, but it is not meant to comprehensively report on all the differences, across all the types of partnerships, as identified by Nguyen et al.<sup>48</sup>

The similarities that Nguyen et al<sup>48</sup> captured between the types of research partnerships that were reported as themes included: true partnerships rather than simple engagement, a focus on essential components and process rather than labels, collaborative research orientations rather than research methods, core values and principles, and extensive time and financial investment. Regardless of the type of research partnership, they all strive to develop deep relationships between the partners, which focus on core values, principles, team interactions and dynamics.<sup>48</sup> Furthermore, Nguyen et al<sup>48</sup> reported that participants emphasized there were more similarities between the perspectives as opposed to differences. As well, participants stressed the way partnerships were applied was contextual, and the different approaches have evolved over-time.<sup>48</sup>

Evidence specific to health research partnerships

Several studies have examined aspects of health research partnerships such as initiating partnerships; principles, strategies, and/or methods to involve intended users of research; knowledge user engagement; theories, models, and frameworks specific to partnerships; outcomes of partnering; and barriers and facilitators of partnerships.<sup>15,23,49,51,52</sup> These studies have included a meta-narrative review,<sup>23</sup> review of reviews,<sup>49</sup> scoping review,<sup>52</sup> other review,<sup>15</sup> and qualitative inquiry.<sup>51</sup> The meta-narrative review included systematic reviews or meta-analyses only.<sup>23</sup> The review of reviews included literature overviews and reviews, and any study that systematically searched the literature.<sup>34</sup> The methodological quality assessments conducted as part the meta-narrative and review of reviews indicated that the quality of the included studies in those reviews was poor.<sup>23,49</sup> While it is important to consider the methodological quality of studies, knowledge syntheses approaches such as reviews, can still be an important step in the development of new knowledge because they can map research activity and consolidate existing knowledge.<sup>53</sup>

### *Initiating health research partnerships*

In 2020, Zych et al<sup>23</sup> published a meta-narrative review of partnership initiation with the aims of capturing the processes, outcomes, barriers, and enablers underlying initiation. They suggested that it is necessary to focus research on partnership initiation because it maybe associated with immediate outcomes.<sup>23</sup> Seventeen reviews were included in the meta-narrative review conducted by the authors.<sup>23</sup> Zych et al<sup>23</sup> found that the reviews were situated across various types of research partnerships such as integrated knowledge translation, action research, stakeholder engagement, knowledge transfer, team initiation, and shared mental models.<sup>23</sup> Furthermore, Zych et al<sup>23</sup> developed a conceptual framework of partnership initiation. This framework could be use as a guide by researchers or research users to operationalize aspects of the initiation of research partnerships, including planning partnerships, anticipating partnership challenges, or identifying relevant outcomes.<sup>23</sup>

### *Principles, strategies, or methods to involve intended users of research*

Hoekstra et al<sup>49</sup> published a review of 86 reviews of health research partnership literature in 2020 with one aim to identify the principles and strategies applied in health research partnerships. Their synthesis identified seventeen over-arching principles of research partnerships and eleven over-arching strategies of research partnerships. The principles and strategies also included several associated sub-categories. The principles Hoekstra et al<sup>34</sup> identified reflected a norm or rule that was desirable. For example, principles were related to the relationship between researchers and stakeholders (e.g., relationships built on trust), co-production of knowledge (e.g., all members have ownership of data), meaningful stakeholder engagement (e.g., research is relevant to stakeholders), capacity building, support, and resources (e.g., bidirectional exchange of skills), communication between researchers and stakeholders is open, and ethical issues of collaborative research are addressed. See Table 2 for more information on the principles Hoekstra et al<sup>49</sup> identified.

On the other hand, the strategies Hoekstra et al identified reflected an action to achieve a specific outcome.<sup>34</sup> Strategies were specific to the relationships between the researcher and

stakeholders (e.g., the partnership can be initiated by researchers or stakeholders), capacity building, support and resources (e.g., provide training for all team members), communication between researchers and stakeholders (e.g., use a variety of communication methods), stakeholder engagement in the planning of research (e.g., identifying research questions), stakeholder engagement conducting research, (e.g., data collection), and stakeholder engagement in dissemination and application of research (e.g., writing manuscripts). See Table 3 for more information on the strategies of health research partnerships.

Table 2. Over-arching principles of health research partnerships. Adapted from Hoekstra et al.<sup>49</sup>

<b>Over-arching principles of health research partnerships</b>	<b>Subcategory</b>
Partners build and maintain relationships based on trust, credibility, respect, dignity, and transparency*	Relationship between researchers and stakeholders
Partners acknowledge, reward and value the diverse expertise of the partnership and its members	
Partners share in decision-making and leadership of different research activities	
The partnership addresses power dynamics within the team and aim to promote equity, self-determination and/or social justice	
The partnership ensures representation and/or inclusivity and addresses disciplinary and sectoral issues	
Partners co-produce knowledge and meaningfully engage stakeholders at different phases of the research process*	Co-production of knowledge
Partners ensure that all members of the partnership have ownership over the data and resulting knowledge products	
Partners strive to balance the need for scientific rigor alongside the practical need for actionable knowledge	
Partners ensure the long-term implementation of the findings in real world settings and systems	
Partners carefully plan and regularly reflect on their strategic approach to collaboration	Meaningful stakeholder engagement
Partners are flexible and creative in the collaborative research activities and tailor the approach*	
Researchers and stakeholders benefit from the partnership	
The partnership identifies the stakeholder's needs and makes sure that the research is relevant for the stakeholders	
Partners build capacity among all members of the partnership	Capacity building, support, and resources
Partners ensure bidirectional exchange of skills, knowledge, and capacity between members of the partnership	
The partnership fosters regular, open, clear, and honest communication between its members	Communication between researchers and stakeholders
Partners address ethical issues related to the collaborative research activities	Ethical issues of collaborative research activities

\*= most frequently identified principles related to the over-arching principles

Table 3. Over-arching strategies of health research partnerships. Adapted from Hoekstra et al.<sup>49</sup>

Strategies of health research partnerships	Sub-categories
Initiate partnership and identify the team members; the partnership can be initiated by researchers or stakeholders; researchers can use targeted or open strategies to identify the stakeholders	Relationship between researchers and stakeholders
Monitor, experiment with and evaluate the collaborative research activities on an ongoing basis	
Work together to develop and define norms, rules, and expectations in terms of timelines and tasks; this includes defining the level of stakeholders' engagement, roles, and commitment	
Use a variety of activities to foster collaboration, communication, and respect amongst the team members; strategies can include, but are not limited to, creating a common language, negotiating, and addressing conflict, tailoring meets to the needs of the team, and providing opportunities to socialize	
Provide opportunities to educate and train all team members, this strategy may include training that supports capacity for collaboration or research methods	Capacity-building, support, and resources
Provide time, resources, and funding to support the collaborative research activities, stakeholders may be paid for engagement in the research process	
Provide practical and emotional support to stakeholders to help overcome barriers to engagement	
Use a variety of methods to facilitate communication amongst team members, strategies include, but are not limited to, verbal methods (e.g., structured meetings, brainstorm sessions), written methods (e.g., email discussions, surveys) and visual methods (e.g., photovoice); this communication can be done in-person or via mediated methods (e.g., teleconference, online) *	Communication between researchers and stakeholders
Strategies include, but are not limited to, stakeholder engagement in identifying or refining the 'research questions', stakeholder engagement in development the 'research protocol', stakeholder engagement developing or refining 'research instruments' (e.g., questionnaires, interview guides) and stakeholder engagement in development of participant 'information material' (e.g., informed consent) *	Stakeholder engagement in the planning of the research
Strategies include, but are not limited to, stakeholder engagement in 'data collection' (e.g., recruitment of participants, study outcomes, conducting interviews, conducting literature review), stakeholder engagement in data analysis, and interpretation of findings) *	Stakeholder engagement in conducting the research

<p>Strategies include, but are not limited to, stakeholder engagement in 'writing reports or scientific papers' (e.g., stakeholder is co-author on a scientific paper), stakeholder engagement in 'presenting findings' to academic and community audiences, stakeholder engagement in a 'developing and implementation action plan' to ensure findings are used, and stakeholders use the findings to create change</p>	<p>Stakeholder engagement in dissemination and application of the research</p>
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\*= top three most frequently identified strategies related to the over-arching strategies

### *Knowledge user engagement*

In 2019, Jull et al<sup>15</sup> published research that used a consensus building design involving an international group of researchers and knowledge users to identify and synthesize 54 frameworks and fifteen concepts of knowledge user engagement in research. The authors conceptualized engagement as involving a diverse group of individuals who influence, administer, or were active users of healthcare systems (i.e., knowledge users) in the research process to produce knowledge that is relevant or significant for knowledge users.<sup>15</sup> The authors included articles that either reported on frameworks that described how the research was done, or frameworks that suggested how research with knowledge users should be conducted.<sup>15</sup> The authors identified 15 concepts of knowledge user engagement: 1) researcher: prepare/support, 2) knowledge user: prepare/support, 3) relational process, 4) research agenda, 5) ethics: principles/values, 6) research questions, 7) resources, 8) ethics: policy/rules, 9) methodology, 10) methods, 11) collect data, 12) analysis, 13) disseminate, 14) evaluate, and 15) sustain (Table 4).<sup>15</sup> The concepts provided insight on when and how knowledge users were involved in the research process or should be involved, i.e., developing research agendas, research questions and policy/ rules (preparation); deciding on methodology and methods (preparation); collecting and analyzing data (conducting); dissemination (apply); and evaluating and sustaining project benefits (apply).<sup>15</sup> The authors proposed that these concepts were fluid and could help researchers and knowledge users operationalize the partnering process and optimize how individuals worked together during the research process.<sup>15</sup>

Table 4: Concepts of knowledge user engagement, as identified by Jull et al.<sup>15</sup>

<b>Concept</b>	<b>Description of collaborative research process</b>
<b>Researcher: prepare, support</b>	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).
<b>Knowledge user: prepare, support</b>	Initiate/support knowledge user/community organizational capacity/behaviour for power sharing, expertise, engagement (e.g., develop resource manual, provide training in research methods).
<b>Relational process</b>	Initiate and/or sustain a relational process (relationship building) between knowledge user-researcher to promote respect, reciprocity, trust, and partnership synergy.
<b>Research agenda</b>	Engage in a process to define study agenda: scope, priorities, objective(s).
<b>Ethics: principles/values</b>	Conduct knowledge user-researcher partnership work in an ethical way demonstrated by reflection on ethical concepts, and/or concern with 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.
<b>Research questions</b>	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?).
<b>Resources</b>	Develop funding applications/grant proposals for and/or to obtain resources (e.g., funding, time) to support knowledge user-researcher engagement.
<b>Ethics: policy/rules</b>	Conduct knowledge user-research partnership work in an ethical way demonstrated by participation in an ethical application development (e.g., writing consent forms et cetera), 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).
<b>Methodology</b>	Decide on the research methodology (approach) or report process to justify the use of the proposed methodology.
<b>Methods</b>	Decide upon research methods and a justification for the use of the proposed methods; selection of outcome measures.
<b>Collect data</b>	Collect data and includes tool development.
<b>Analysis</b>	Decide about the analysis and interpretation of data (e.g., what form of analysis and how will be conducted).
<b>Disseminate</b>	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).

<b>Evaluate</b>	Evaluate the research study processes.
<b>Sustain</b>	Maintain study benefits at a certain rate, level (i.e., make deliberate efforts to sustain study intervention(s)).

*Theories, models, and frameworks of health research partnerships*

In 2022, I led and published<sup>52</sup> a scoping review which identified and described the characteristics of theories, models, frameworks (TMFs) of partnered health research, and the concepts of knowledge user engagement in each TMF. I identified the need for this synthesis because there was limited published evidence specific to TMFs that could be used to facilitate partnered health research. Research about TMFs of partnered research is needed to explain why partnered research succeeds or fails, clarify assumptions about partnerships, provide insight into contexts for partnering, partnering dynamics and effects of partnering, and to help understand at what point and the ways to engage with knowledge users.<sup>15,54,55</sup> Furthermore, the use of TMFs may help minimize some barriers, e.g., a lack of role clarification, associated with partnered research.<sup>56</sup>

I searched for research published between January 2005 and June 2021. Articles were included in my scoping review if they were specific to partnered health research, included the use of a TMF to inform the partnership, explained how knowledge users were involved in the development of the TMF, and were published in the English language.<sup>52</sup> I identified 39 models or frameworks, herein referred to as MFs, but no theory.<sup>52</sup> This is problematic because theory can describe, explain, and predict a phenomenon.<sup>57,58</sup> Without theory specific to partnered health research, it may be difficult to explain why partnerships succeed or fail, or how to predict successful research partnerships.

I also analyzed the content of the models and frameworks by coding them against the concepts of knowledge user engagement Jull et al identified.<sup>15</sup> The median of the total number of concepts represented in the 39 MFs was seven.<sup>52</sup> As well, ethics: principles/values was the predominant concept represented in the identified MFs, followed by relational process, and knowledge user: prepare, support.<sup>52</sup> In contrast, methodology was the least represented concept of knowledge user engagement.<sup>52</sup>

While fourteen of the identified MFs could be used to guide the partnering process, six MFs indicated their purpose was evaluating partnering.<sup>52</sup> Of these six MFs, two articles referred to the same conceptual model, i.e., the Community-Based Participatory Research (CBPR) model which was developed by Wallerstein et al<sup>59</sup> to understand the effects of partnerships and how

they could enhance health outcomes and community capacity.<sup>55</sup> Because the CBPR model is underpinned by the socio-ecological theory, used multiple methods to develop and revise the model, includes a graphical depiction of intersecting concepts informing outcomes of partnered research, has undergone some examination to validate its conceptual underpinnings, and can be used across various phases of the research process, I thought it was an appropriate model to inform aspects of my thesis.<sup>55,59</sup>

The CBPR model consists of four domains: context (socio-economic characteristics, historical contributions, university and community capacities, and health issue being studied); partnership dynamics (partnership structures, members, and relationships); research/intervention, and outcomes (systems, capacities, health, and social justice).<sup>55,59</sup> Research conducted by Belone et al<sup>55</sup> found that many partnered research outcomes were related to contextual factors via a dynamic feedback loop occurring within the partnered research process. Essentially, the authors suggest that outcomes related to partnering, may influence contextual or partnership dynamics which will in turn influence the partnering process and subsequent outcomes.<sup>55</sup> Since its initial conceptualization, the Wallerstein CBPR model has been validated by subsequent studies as a model that can be used to address knowledge gaps in partnered research literature,<sup>55,60</sup> such as identifying and describing effects of partnered rehabilitation research. I explain which concepts of knowledge user engagement and the Wallerstein CBPR model informed methods in my thesis in more detail in chapters four and five.

#### *Barriers and facilitators of health research partnerships*

In 2014, Sibblad, Tetroe, and Graham<sup>51</sup> published findings from their qualitative inquiry using semi-structured interviews in which one aim was to explore the perceived factors that influenced collaborative research partnerships between researchers and knowledge users. Twenty-four researchers and twenty-five knowledge users were interviewed for their study.<sup>51</sup> Through iterative thematic analysis, Sibbald, Tetroe, and Graham<sup>51</sup> described the barriers to collaborative research partnerships in the theme, “Challenges to Partnerships”. This theme identified three common sub-themes including role clarity and expectations, organization change, and cultural differences.<sup>51</sup> Budget was mentioned as a barrier but not consistently among the interviewees, so it was not included as a sub-theme.<sup>51</sup> Facilitators were described in

the theme, “Facilitators of Successful Partnerships” and included the sub-themes of alignment of goals and objectives, skilled researchers, and regular communication which included multi-modal strategies to keep the knowledge users informed.<sup>51</sup>

*Outcomes of health research partnerships*

Hoekstra et al,<sup>49</sup> Zych et al<sup>23</sup> and Sibbald, Tetroe, and Graham<sup>51</sup> reported on the outcomes of research partnerships in their studies (Table 5). It appears some outcomes were related to research, i.e., increased capacity, knowledge skills, understanding and value of research; enhanced trust in research; and high-quality research.<sup>23,49,51</sup> Other outcomes appeared to be related to specific phases of the research process, i.e., establishing research agenda, and facilitated dissemination and implementation.<sup>23</sup> Further outcomes seemed to be related to the relational aspects of partnerships, i.e., increased trust and respect between partners, strengthened partnerships and goodwill, and enhanced feelings of confidence and being valued.<sup>23,49</sup> Lastly, outcomes were related to the healthcare system and policy, and communities.<sup>49,51</sup> Somewhat surprisingly, there were few explicit similarities in the outcomes between the studies, however this could be because Zych et al<sup>23</sup> focused specifically on partnership initiation or because Sibbald, Tetroe, and Graham<sup>51</sup> conducted a qualitative study that included thematic analysis.

Despite evidence that has synthesized the positive outcomes of health research partnerships, several studies have highlighted the ongoing challenges regarding the evaluation of health research partnerships.<sup>15,61-64</sup> More specifically, there are a lack of standard measures for evaluating partnerships,<sup>65</sup> poorly described methods of evaluation,<sup>65</sup> lack of comprehensive evaluation measures, that are often not validated,<sup>63</sup> and of the standardized evaluations that exist, they do not thoroughly evaluate all aspects of the partnership.<sup>63</sup> Without validated, standard measures to evaluate all aspects of research partnerships, it may be difficult to fully capture the outcomes of partnerships.

Table 4. Outcomes of health research partnerships

Outcomes of health research partnerships			
Hoekstra et al <sup>49</sup>		Zych et al <sup>23</sup>	Sibbald, Tetroe, and Graham <sup>51</sup>
<i>Positive</i>	<i>Negative</i>		
Increased capacity, knowledge, and skills for research; more positive attitudes towards research	Stakeholder personal challenges including not feeling listened to, not feeling empowered, not taken seriously	Increased understanding of research value	Cultural change: bridge between academia and the real world
High quality research	Research personal challenges including power sharing, additional time needed, and financial burden	Facilitated dissemination and implementation	Improved relevancy of research
Enhanced feelings of confidence and being valued	Conflicts between stakeholders and researchers	Increased trust and respect between partners	Research uptake: ownership of the research
System changes by influencing policy	Feeling overwhelmed with responsibilities, tasks, or the financial burden of research partnerships	Strengthened relationships and goodwill	Partnership sustainability
Improved community services	Biased data or tokenism	Reduced anxiety about research findings	
Improving community health-related outcomes	Stigmatization of community organizations	Empowerment of research users	
Created capacity to sustain the projects		Clear understanding of the different expectations of partners	
Enhanced motivation for research projects		Enhanced understanding of process	
Community empowerment		Jointly develop research agenda	

Improved acceptability and trust of research		Enhanced strengths and resources in the community	
Increased accessibility to healthcare information		Increased compliance and compatibility	

## Rehabilitation

### Defining rehabilitation

I defined rehabilitation as a process consisting of the delivery of tailored, person-centred interventions for individuals with health conditions, which aim to enhance function; optimize quality of life, independence and social integration; minimize disability; and maximize the ability to adapt to changes in an individual's circumstances.<sup>1,2</sup> Rehabilitation enhances an individual's ability to live, work, socialize, and learn to their fullest potential.<sup>1,2</sup> Person-centred means rehabilitation considers an individual's situation, priorities, needs, wishes, values, and goals.<sup>1,2</sup> According to the World Health Organization (WHO), health conditions refer to an acute or chronic disease, disorder, disability, injury or trauma,<sup>1</sup> but may not be limited to them. The environment individuals live, work, socialize or learn in should be considered when delivering rehabilitation and rehabilitation can be delivered at any stage of a health condition.<sup>1,2</sup>

My definition of rehabilitation was based on a 2020 literature review of definitions of rehabilitation in peer-reviewed publications,<sup>4</sup> and a terminology analysis which examined the underlying concepts of existing rehabilitation definitions.<sup>3</sup> Both studies identified numerous published definitions of rehabilitation, highlighting a person-centred process and concepts related to disability and function.<sup>3,4</sup> Consequently, I chose two definitions of rehabilitation that described it as a person-centred process which focused on function, to inform my definition of rehabilitation for my research. Firstly, I used the definition of rehabilitation from the WHO<sup>1</sup> which states rehabilitation is "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment."<sup>p.1</sup> This definition included the concept of function within it; however, it does not highlight how rehabilitation is a process and person-centred. Secondly, I used the definition of rehabilitation from Wade<sup>2</sup> because it described rehabilitation as a tailored, person-centred process, highlighted several goals of rehabilitation beyond optimizing function, and was a clear, comprehensive, and evidence-based description of rehabilitation. Missing from the two definitions of rehabilitation that I used was reference to care that needs to be equitable.<sup>1,2</sup> Health equity means that every individual has access to fair and just healthcare, which is achieved when obstacles to health care are removed.<sup>66</sup> However, because my definition

describes rehabilitation as tailored and person-centred rehabilitation it may provide the opportunity to deliver equitable rehabilitation. Tailored, person-centred is important because it includes individuals in decision-making for their care, ensure care meets their needs, and results suggest it may also affect health behaviors, subsequently improving health outcomes.<sup>67</sup> For more details about the concepts from WHO<sup>1</sup> and Wade<sup>2</sup> that informed my rehabilitation definition, see Table 6.

Table 6. Components from rehabilitation definitions/ descriptions that are consistent with my definition (bolded)

Definitions of rehabilitation		
My definition of rehabilitation <sup>1,2</sup>	WHO <sup>1</sup>	Wade <sup>2</sup>
<p>A process consisting of the delivery of tailored, person-centered interventions for individuals with health conditions, which aim to enhance function; optimize quality of life, independence, and social integration; minimize disability; and maximize the ability to adapt to changes in an individual's circumstances.</p>	<p>Rehabilitation is a set of <b>interventions</b> designed to <b>optimize functioning</b> and <b>reduce disability in individuals with health conditions in interaction with their environment</b>. Health condition <b>refers to disease (acute or chronic), disorder, injury, or trauma</b>.</p>	<p><b>The goal:</b> To <b>optimize</b> a patient's self-rated <b>quality of life and degree of social integration</b> through <b>optimizing independence</b> in activities, minimizing pain and distress, and optimizing the <b>ability to adapt</b> and respond <b>to changes in circumstances</b>.  <b>Patients and places:</b> Rehabilitation may benefit anyone with a long-term disabling <b>illness at any stage of that illness; Be delivered in any setting</b>.  <b>The content:</b></p> <ul style="list-style-type: none"> <li>• Rehabilitation is a problem-solving <b>process</b>, framed in the context of the holistic biopsychosocial model of illness, delivered in a <b>person-centered</b> way, and requiring: An expert, multidisciplinary team, setting collaborative team-based goals; A formulation of the situation, covering all domains of the biopsychosocial model; Close, collaborative working across all boundaries, professional, organizational, and geographic; Ongoing monitoring of change and effects of interventions.</li> <li>• Will almost always use the following general approaches to management: Repeated practice of functional activities; General exercise that increases cardio-respiratory work; Education with an emphasis upon self-management; Psycho-social support (not well defined yet)</li> <li>• and always involves many specific actions <b>tailored</b> to the patient's priorities and specific <b>needs and goals</b>, covering (if necessary) all domains of the biopsychosocial model of illness; being evaluated regularly for their benefits and harms, to determine whether they should be continued, changed, or abandoned.</li> </ul>

Rehabilitation as a focus of research

Rehabilitation has several features that make it a unique context for research. Firstly, rehabilitation situates itself within the biopsychosocial model of illness, potentially distinguishing itself from other medical professions.<sup>2</sup> This model was first described by Engle<sup>68</sup> in 1977 in response to the biomedical model of illness, a traditionally analytic approach which attributed illness to a single cause related to biology, physiology or anatomy of the human body. In contrast, the biopsychosocial model of illness is an integrated model which considers the impact of the biological, psychological, and social dimensions on health and illness thus offering a more comprehensive understanding of them.<sup>68</sup> Furthermore, the biopsychosocial model of illness positions the individual at the centre of their healthcare thus ensuring the goals of the patient are considered and prioritized.<sup>68,69</sup> Because rehabilitation is situated within the biopsychosocial model of illness, it is specifically tailored to meet the needs and expectations of the individual.<sup>2</sup> As such, no two individuals will respond to rehabilitation in the same manner.<sup>2</sup>

Secondly, rehabilitation interventions may be complex in nature, often consisting of several interacting components.<sup>2,70</sup> Complex healthcare interventions are characterised by the extent and difficulty of behaviors needed by those delivering the intervention, groups or organizational levels the intervention targets, the variability of outcomes, and the extent to which interventions can be tailored.<sup>71</sup> For example, rehabilitation interventions can be delivered across diverse settings within the healthcare spectrum such as a hospital, primary care centre, school, or private practice clinic.<sup>1,2</sup> In addition, rehabilitation interventions may be delivered by a variety of different healthcare professionals, such as physiotherapists, occupational therapists, or speech-language pathologists, who possess expertise, i.e., knowledge and skills, specific to their discipline.<sup>2,72,73</sup> People with health conditions, disease or injury may have various physical, cognitive, or developmental impairments which can affect mobility, social interaction, function, or activities of daily living.<sup>73</sup> As such, it is not unusual for people obtaining rehabilitation interventions to have them delivered by different healthcare professionals situated within the context of rehabilitation.

Thirdly, for rehabilitation to be successful, an individual must be an active participant in the rehabilitation process, beyond goal setting.<sup>74</sup> As well, individuals' complete rehabilitation

interventions in contexts that are most relevant to them.<sup>74</sup> Lastly, feedback is provided to the individuals by the rehabilitation therapist which is used to improve performance of the activities targeted by the intervention.<sup>74</sup> By promoting active participation in rehabilitation and the opportunity to receive feedback, individuals are provided the opportunity to learn and improve their performance.<sup>74</sup> Consequently, this may optimize independence, participation in life events, and reduce disability thus enhancing their quality of life.

Unique contexts such as rehabilitation are important to research because findings may inform the prevention, treatment, and delivery of interventions through a biopsychosocial perspective with the aim of improving health, wellness, function, and quality of life of individuals in their individual environments.<sup>74,75</sup> Furthermore, findings from rehabilitation research could offer solutions into the optimal setting, approaches, and professionals who should be delivering rehabilitation which can provide insights about how to maximize the outcomes of rehabilitation.<sup>74</sup> As well, because rehabilitation interventions often include multiple components, research may help identify the optimal “mixing” of components to maximize health outcomes.

Research situated in medicine may not provide findings that are transferrable to rehabilitation contexts because medicine is situated in a medical model of illness that primarily aims to diagnose the presence or absence of disease and typically does not consider how social and psychological dimensions influence health conditions, disease, or injury.<sup>68,76</sup> Furthermore, medical research often examines the effects of one intervention, usually consisting of one component, i.e., medicine, surgery, etc., on disease.<sup>77</sup> This is very different from rehabilitation interventions which, as stated earlier, typically consist of multiple components. Additionally, rehabilitation interventions are not focused on eliminating disease, but rather, rehabilitation interventions aim to optimize how individuals with disease, health conditions, or injuries, can function within their environment.<sup>75</sup> Considering findings from medical research may not be appropriate to inform rehabilitation, the unique context and complexity of rehabilitation interventions, the role individuals themselves play as active participants in rehabilitation, rehabilitation is therefore an important focus for research.

The gap between rehabilitation research and practice  
Several studies have found that rehabilitation evidence has not consistently informed clinical practice.<sup>7-10</sup> For example, a mixed methods study published in 2014 investigated use of evidence to inform practice and its barriers in rural rehabilitation settings in India.<sup>7</sup> Participants were physiotherapists who kept a logbook to track their practice and completed interviews after tracking their clinical practice for four weeks.<sup>7</sup> According to the logbooks, clinical practice was informed by rehabilitation evidence only 53% of the time.<sup>7</sup> During the interviews, participants stated that they thought the outcomes used in rehabilitation research were not like outcomes they used in practice and did not reflect their patient's goals.<sup>7</sup> As such, they had difficulty applying research findings in rehabilitation treatments.<sup>7</sup> Another study conducted in Norway and published in 2018 used survey methodology to investigate the use of rehabilitation research evidence in hospitals within South-Eastern Norway.<sup>9</sup> The study compared perceptions from rehabilitation clinicians about the use of evidence to inform rehabilitation interventions within a hospital site (locally) or across several hospitals (regionally).<sup>9</sup> The findings from this survey indicated that 75% of respondents agreed that interventions informed by evidence were used in similar ways in local settings.<sup>9</sup> However, only 39% of respondents agreed that the same interventions were used in similar ways in regional settings;<sup>9</sup> perhaps indicating barriers exist in in regional rehabilitation settings which influence the use of rehabilitation evidence in practice. Lastly, another cross-sectional survey conducted in 2016 in Ontario and Quebec investigated the implementation of recommendations from clinical practice guidelines for people with traumatic brain injury.<sup>10</sup> Participants included individuals working in rehabilitation facilities treating people with traumatic brain injuries.<sup>10</sup> The study found that up to 34% of recommendations from clinical practice guidelines were not implemented despite being perceived as priorities and feasible by respondents.<sup>10</sup>

It is problematic that a gap exists between rehabilitation evidence and practice because it can have impacts on health outcomes and economic costs of healthcare. Systematic reviews and economic analysis published between 2016 and 2020 have reported positive effects on patient outcomes and rehabilitation costs when the rehabilitation evidence to practice gap is reduced or eliminated.<sup>6,17-19</sup> For instance, when rehabilitation practice specific to musculoskeletal,

stroke, or cardiac care was informed by evidence there was an increased likelihood of improving functional mobility and reducing disability, burden of disease, and economic costs, such as those related to inpatient hospital stays.<sup>17-19</sup> To enhance the uptake of rehabilitation research and minimize the gap between evidence and practice, researchers could partner with knowledge users during the research process. This approach to research may be referred to as research partnerships.

### Partnered rehabilitation research

Defining partnered rehabilitation research

The term research partnership may describe the relationship between researchers and knowledge users, research programs, and/or specific research projects.<sup>78</sup> However, when focusing on the outcomes, i.e., effects resulting from a partnered approach to conducting research, “partnered research” may be a more suitable term to reflect the process of partnering during research. Because I am investigating the effects of the partnering process in rehabilitation research, as opposed to undertaking a rehabilitation research partnership to conduct research, I decided to use the term “partnered rehabilitation research” for my research. For the purposes of my thesis, I included researchers involved in partnered rehabilitation research who were not necessarily academically affiliated. Removing this qualifier allowed this research to include researchers working in private or public healthcare sectors, as well as graduate students.

Partnered rehabilitation research evidence

The research that has been conducted to date about partnered rehabilitation research includes two reviews<sup>21,29</sup> and a mixed methods study.<sup>28</sup> These studies explicitly investigated partnered research in rehabilitation. Specifically, they investigated the characteristics and scope of the partnerships, the impacts and outcomes of partnerships, and the experiences of researchers and knowledge users as partners in the research process.<sup>21,28,29</sup>

In 2015 Camden et al<sup>21</sup> published a scoping review to identify knowledge users engaged as partners in rehabilitation research, strategies for engaging knowledge users, factors that may influence engaging knowledge users in rehabilitation research, and the impacts of their engagement. Using studies conducted up to 2013, Camden et al<sup>21</sup> reported that knowledge

users most frequently engaged were individuals with disabilities and their families, rehabilitation clinicians, and individuals representing community organizations or groups. Furthermore, they found that the knowledge users were engaged in most steps of the research process, except for manuscript writing.<sup>21</sup> Camden et al<sup>21</sup> also reported that strategies to engage knowledge users included targeted or open recruiting, establishing committees with specific roles for knowledge users through-out the research project, and supporting knowledge users with informal and formal research training. Of significance, Camden et al<sup>21</sup> reported that only six of the nineteen studies, approximately 32%, evaluated partnerships to identify the impacts. The methods of evaluation were not standardized and included focus groups, interviews, debriefing sessions, and questionnaires.<sup>21</sup> Of the studies that evaluated partnerships, the impacts of engaging knowledge users included establishing partnerships and value, empowerment of knowledge users, knowledge that was more accessible, and facilitating the research process, i.e., identifying relevant questions and dissemination of results.<sup>21</sup>

In 2019 Roberge-Dao et al<sup>28</sup> published a mixed methods study consisting of a document review, survey, and focus groups, which recruited a sample from 37 research partnerships between rehabilitation clinicians and university-affiliated rehabilitation researchers within a specific funding model, i.e., integrated knowledge translation funding model. The funding model was a partnership between the School of Physical and Occupational Therapy at a research-intensive university in Quebec, Canada and the Richard and Edith Strauss Canada Foundation.<sup>28</sup> Roberge-Dao et al<sup>28</sup> aimed to describe the research process and study outcomes of the individual research projects within this funding model. They reported that most partnerships involved healthcare system practitioners, were predominantly conducted in rehabilitation settings, and used the Knowledge-to-Action Framework.<sup>28</sup> Additionally, only four studies (11%) evaluated long-term study outcomes, e.g., intervention sustainability or intervention impact.<sup>28</sup> When the study outcomes were evaluated, a standardized measure was used only three times; questionnaires, focus groups and interviews were the predominant methods of evaluation.<sup>28</sup> No information on which standardized measures used were reported. The most common primary study outcomes measured were specific to the clinician, i.e., practice behavior, knowledge, and attitudes towards research, which may not be surprising considering the

partnership was between research and clinicians.<sup>28</sup> Furthermore, the participants in the study could not provide concrete evidence of enhanced clinical or healthcare system outcomes, which could be reflective of the fact that most partnerships did not use standard measures for evaluation.<sup>28</sup>

Roberge-Dao et al<sup>28</sup> reported the results from the interviews with the researchers and clinicians thematically (Appendix 1). The themes and sub-themes that were described by Roberge-Dao et al<sup>28</sup> were different between the researcher and clinicians focus groups, perhaps reflecting the different perspectives, experiences, or positionality that each group brought to a research partnership. As one example, researchers noted a disconnect in the feasibility of completing research projects with the clinicians, specifically what clinicians wanted to get out of the project and what could be achieved in the research context.<sup>28</sup> The researchers interviewed perceived that clinicians aimed to get more out of the research projects that could be realistically achieved in the research context.<sup>28</sup> Furthermore, the clinicians posed research questions that were not always practical.<sup>28</sup> As another example, clinicians discussed that researcher proximity facilitated partnerships.<sup>28</sup> The clinicians indicated that being close to the researchers was a motivating factor to collaborating with researchers and believed that frequent and casual in-person meetings optimized the partnership.<sup>28</sup> This finding regarding the proximity to researchers as a facilitator of research partnerships, was new not only to partnered rehabilitation research, but also, partnered health research. <sup>23,51</sup>

In 2021 Cox et al<sup>29</sup> published a scoping review on the status of consumer engagement in occupational therapy related research published in the Australian Occupational Therapy Journal between 2014-2019. Cox et al<sup>29</sup> defined consumer engagement as, “research that is carried out with or by consumers, rather than to, about or for them.”<sup>p.181</sup> Forty-eight papers were included for data analysis;<sup>29</sup> of those, 52% used a qualitative methodology.<sup>29</sup> Cox et al<sup>29</sup> found that less than half of included studies involved consumer engagement. Furthermore, only two studies reported consumer engagement throughout the lifespan of the research project.<sup>29</sup> These are concerning findings as the search included a more recent timeframe than that of Camden et al,<sup>21</sup> and may suggest a partnered approach is not being adopted. There were some new findings in the review conducted by Cox et al.<sup>29</sup> Firstly, they reported that most papers (62.5%)

only involved consumers in one phase of the research process, i.e., research execution.<sup>29</sup> As well, Cox et al<sup>29</sup> reported that consumers were likely to be involved in research to enhance rigour of the study.

Evaluation of partnered rehabilitation research

While published literature on partnered rehabilitation research has reported on similar concepts such as what types of knowledge users were involved in the partnerships, when they were involved, and some impacts and outcomes of the partnering process, it is evident from the studies conducted by Camden et al<sup>21</sup> and Roberge-Dao et al<sup>28</sup> that partnered rehabilitation research was not consistently evaluated. Furthermore, when the partnering process was evaluated, standardized measures were not always used.<sup>21</sup> But even when standardized measures were used, information on the measures was not reported.<sup>21</sup> These findings are consistent with those from studies on the evaluation of health research partnerships. For instance, a review of reviews published in 2020 by Hoekstra et al<sup>27</sup> found few studies evaluated partnered health research. Furthermore, when studies evaluated the partnering process, they predominantly focused on perceived and/or self-reported outcomes.<sup>27</sup>

There may be many reasons why partnered research is not evaluated using standardized measures.<sup>33,63</sup> For instance, a systematic review published in 2018 found that evaluation tools were not consistently informed by literature reviews, the tools often lacked scientific rigor, were not grounded in theoretical concepts or conceptual frameworks, and lacked reliability testing.<sup>33</sup> Furthermore, of the standardized evaluations that exist, they do not thoroughly evaluate all aspects of the partnership.<sup>63</sup> Considering these findings, standard measures for evaluating the partnering process require further development to enhance their scientific rigour and reliability. Without validated, standard measures to evaluate all aspects of partnered research, it may be difficult to accurately identify the effects of partnerships and ensure the integrity of the partnering process.<sup>33</sup> While the use of standard measures to evaluate partnering reflects a post-positivistic stance, the effects of partnering identified with standard measures may compliment findings identified through other stances, i.e., interpretivism or constructivism. Having both objective and subjective data about the effects of partnering may be extremely valuable to rehabilitation managers, directors, or funders who make decisions

about partnered research. Information gathered from a variety of sources may help inform decisions they make about promoting, providing funding, or granting protected time to rehabilitation clinicians to engage in partnered research. The limitations of existing standardized measures could also be a reason they are not used more to evaluate partnerships. However, this is a theory only and it would be beneficial to investigate behaviors specific to tool use in more depth.

Evaluation is an embedded component of the research landscape,<sup>79</sup> and occurs during many phases of the research cycle. For example, research proposals are evaluated at the funding stage to determine the originality, relevance, and feasibility of proposed studies. Research ethics boards evaluate the risks and harms of proposed studies and how they will be mitigated during a study. As well, manuscripts are typically peer-reviewed prior to publication to evaluate methodological rigor of the study so readers can be confident in the findings and interpretations of them. Considering how widespread research evaluation is, it should come as no surprise there have been increased calls for evaluation of partnered research to build its evidence base.<sup>79,80</sup>

Evaluating partnered rehabilitation research is necessary to accurately identify the short, medium, and long-term effects related to the partnering process instead of relying on anecdotal evidence which can be biased.<sup>31,32</sup> By accurately identifying the effects of partnered rehabilitation research, we will also deepen our understanding of the effects on partners, patients, or organizations.<sup>81</sup> For instance, it is possible that partnering may influence the economic costs associated with rehabilitation, an effect that may not be identified until long after the partnerships concludes. Information on economic considerations specific to healthcare, like rehabilitation, is important to support the decisions that healthcare organizations make to ensure that services provided are good value for their money.<sup>82</sup> Identifying the range of effects of partnering can also have the added benefit of demonstrating the value of this approach, which may justify investments by researchers, knowledge users, or research funders into it. Additionally, by identifying the effects we can confirm assumptions of this research approach, such as its ability to promote the uptake of evidence and the subsequent improvement in health outcomes. Confirming assumptions about partnered

rehabilitation research is necessary to ensure individuals are not misled about its potential, which could lead to irresponsible use of research resources or funding. Furthermore, evaluating the partnering process can ensure the integrity, i.e., concepts related to involving knowledge users in the research process are upheld.<sup>33</sup> Lastly, evaluating the partnering process can deepen our understanding about how these partnerships work which may lead to improvements in how researchers and knowledge users' partner.

Because there is a paucity of data on effects of partnered rehabilitation research, it is necessary to conduct further studies to understand if partnered rehabilitation research is being evaluated, what measures are used to evaluate the partnerships, and the effects of the partnering process in a variety of contexts other than what has been reported. This research could advance the evaluation of partnered rehabilitation research, such as how it can be improved or lead to the development of measures to evaluate partnering. As well, further research can identify more effects of the partnerships, specifically medium or long-term impacts, which can be used to confirm the value, the economic impacts, or assumptions about partnered research. Lastly, findings from additional research on partnered rehabilitation research can be used to help individuals make decisions about partnering on research and promote a partnered approach to research.

### Conceptual framework

A conceptual framework is a model consisting of multiple components that highlight the importance and relevancy of the phenomena that will be studied.<sup>83,84</sup> Furthermore, a conceptual framework can be used to guide the development of the research questions, inform the methodology, and establish methods.<sup>84</sup> The conceptual framework that underpinned my thesis is presented in Figure 1. Overall, my conceptual framework includes the key concepts and assumptions I discussed in this chapter about partnered rehabilitation research. These concepts represent the foundation and justification for my research. For example, the conceptual framework includes the problem of the evidence to practice gap that exists in rehabilitation. Furthermore, my conceptual framework includes the assumption that a partnered approach to research will increase the uptake of rehabilitation evidence, which may subsequently enhance patient outcomes or how the healthcare system functions. Some arrows in my conceptual

framework are depicted as broken lines because they represent assumptions that are not well supported by existing literature. However, my research may result in findings that substantiate these assumptions of partnered rehabilitation research.

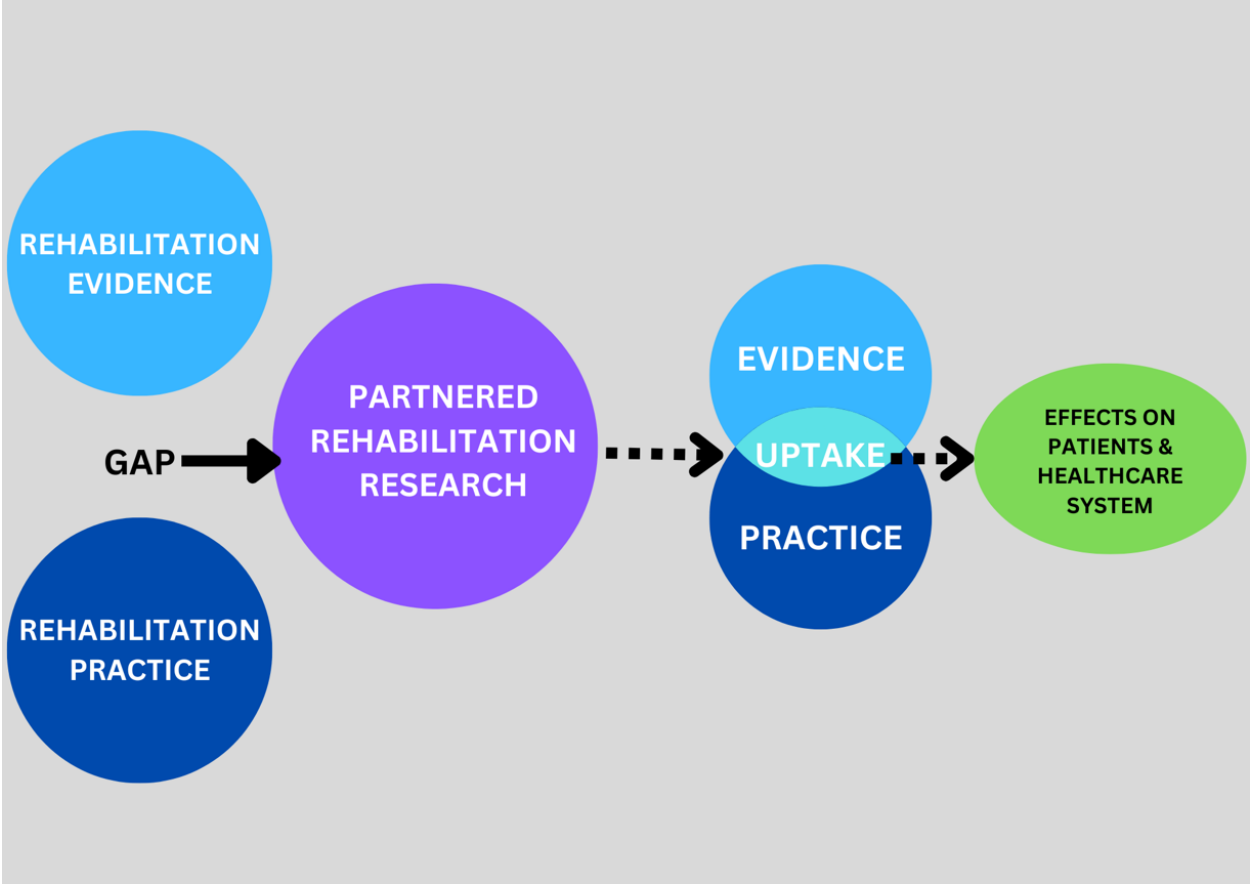


Figure 1. Conceptual framework for my research

## Chapter three: Methodology

I begin chapter three with an explanation about my view of the world and how it informed the theoretical perspective (pragmatism) for my research. I discuss why I chose pragmatism and how it aligns with studying and undertaking partnered rehabilitation research. I continue with an over-arching explanation of the methods (explanatory sequential mixed methods) that I used for my thesis, why I chose it, and how it aligns with pragmatism. Furthermore, I outline plans for integration of the results.

### Theoretical Perspective

I primarily hold a pragmatic view of the world meaning that I do not believe there is one ideal approach to creating or discovering truth and knowledge. Rather, I believe truth and knowledge can be created or discovered by a variety of ways. I think the challenge is to choose the most appropriate approach to create or discover knowledge for a situation. Furthermore, I believe there are many truths and knowledge existing in the world. Lastly, I believe in practical solutions to the real-world problems that knowledge users face in their day-to-day jobs, which also underpins a pragmatic view of the world.

Considering my views of the world, I believed pragmatism aligned with them best and decided to use it as the paradigm for my research. Pragmatism is a philosophical orientation that acknowledges truth is what works at the time, but it cannot be truly uncovered.<sup>36,85</sup>

Ontologically, many different truths and realities exist, they are influenced by different contexts, are not absolute entities, and are interpreted differently between people.<sup>36,86,87</sup> From an epistemological standpoint, knowledge is relative to the current situation, is unique to everyone, can be both constructed and based on the experiences individuals have in the world, and recognizes knowledge can change over time.<sup>86,87</sup>

A defining feature of pragmatism is that it will use whichever methodologies are most suited to explore phenomenon, cultural ideas, experiences, or values.<sup>36</sup> For instance, researchers who view the world through a pragmatic lens do not situate themselves solely within either quantitative or qualitative methodology. Rather, researchers will pick the methodology that will allow them to best access truth, reality, or knowledge about a research problem at that

time.<sup>36,85</sup> As such, it is not unusual that research conducted within a pragmatic paradigm uses more than one method to access truth, reality, or knowledge.<sup>36</sup> Lastly, pragmatism is an explicitly value-laden approach to research that is influenced by cultural values, particularly democracy, freedom, equality and progress.<sup>86</sup> Because pragmatism is value-laden, researchers using a pragmatic lens may believe that research should benefit all people.<sup>85</sup>

Pragmatism allowed me to examine and explore the evaluation and effects of partnered rehabilitation research in a practical manner, using pluralistic approaches to do so.<sup>86,88</sup> As well, because I am attempting to address an established real-world problem, i.e., the lack of evidence uptake in rehabilitation, a pragmatic lens was a suitable paradigm to use.<sup>87</sup>

Furthermore, the intersection of pragmatism and partnered research aligned well. For instance, pragmatism considers the value of diverse real-world experiences when seeking truth, reality, or knowledge.<sup>87</sup> Pragmatism also recognizes that a variety of realities, truths and ways of knowing that exist.<sup>87</sup> Similarly, partnered research is fundamentally rooted in values and principles that privilege the multiple experiences and unique knowledges of diverse groups of people, including clinicians, policymakers, or decision makers.<sup>48</sup> Pragmatism also recognizes that knowledge is never absolute but rather changes over-time.<sup>36</sup> This assumption aligns itself well with partnered research because in collaborative research, knowledge may be continually adapted to improve practice and the delivery of healthcare services.<sup>87</sup> Therefore, informing my studies through a pragmatic lens was appropriate because both pragmatism and research partnerships possess similar attitudes towards the existence of multiple truths, realities, knowledge and diverse experiences that individuals within their unique realities have. Lastly, both pragmatism and rehabilitation acknowledge the significance of context, whether when viewing research or during the delivery of rehabilitation and effectiveness of rehabilitation interventions. For instance, pragmatism acknowledges the role of context in the search for truth, reality, and knowledge.<sup>36,87</sup> Likewise, rehabilitation acknowledges it is highly contextual, and that the environment in which rehabilitation occurs affects the delivery of rehabilitation interventions.<sup>89</sup> Furthermore, context influences the effectiveness of the complex rehabilitation interventions.<sup>70,90</sup> Because both pragmatism and rehabilitation acknowledge the importance of

context, it was imperative to use a paradigm that explicitly recognizes the impact context would have on my research.

## Methods

### Design

I used an explanatory sequential mixed methods design. This design involves the intentional use of both quantitative and qualitative methods during the research process, with quantitative data collection and analysis preceding qualitative data collection and analysis.<sup>36</sup> I chose an explanatory sequential mixed methods design because it is an inclusive and pluralistic scientific approach to research that can investigate a research problem more comprehensively than either quantitative or qualitative methods alone.<sup>36,86,91</sup>

Mixed methods approaches are well aligned with pragmatism because it strives to solve research problems in practical ways using logical approaches that rely on a combination of methodologies and methods; it considers real-world problems, diverse truths, realities, and knowledge; and aims to provide solutions which can be applied in real-world settings.<sup>86,87,91-93</sup>

Mixed methods attempt to maximize the strengths and compensate for the limitations of either quantitative or qualitative methods.<sup>86,93</sup>

The distinguishing feature of mixed methods is the integration of quantitative and qualitative data. For my research, integration occurred during design (mixed methods), methods (sampling and interview questions), reporting, and interpretation.<sup>94,95</sup> Specific to reporting and interpretation, I integrated survey and interview findings through narrative description in which the survey and interview results were woven together.<sup>95</sup> Findings from the interviews validated and expanded survey results. Narrative weaving also allowed me to explore and describe the linkages between the survey and interview findings in depth.<sup>96</sup> I chose to present the integrated results in a stand-alone chapter (six) to highlight the original nature of the findings and to propose a conceptual framework for evaluation of partnered rehabilitation research.<sup>67</sup>

### Data storage and management

I retained data from my research on a shared drive (s:) within the Department of Community Health Sciences/Centres for Healthcare Innovation/Knowledge Translation laboratory folder. Permission must be granted to access this folder. The shared drive is password protected, and a

FIPPA-compliant database housed on the Faculty of Health Sciences (i.e., MEDIT) network. Only Dr. Sibley and I had access to this folder.

I kept back-ups of all study data on a University of Manitoba protected SharePoint site. The Rady Faculty of Health Sciences provides SharePoint 2013 on a Windows server for use by students and faculty. SharePoint is a cloud-based service that Microsoft hosts but Information Services and Technology (IST) at the University of Manitoba is the service provider to the university community. When in SharePoint, data is encrypted at rest and in transit, using several strong encryption protocols, and technologies. Access to SharePoint is centrally controlled via Microsoft Active Directory, which requires an account vetted by the University of Manitoba and a password. The server and storage all reside behind university firewalls and are regularly updated. I created a private group on SharePoint to house the study data in individual study folders. In addition to needing a University of Manitoba vetted account and password to access SharePoint, access to the folders in the private group is only available by invitation from myself. I will retain study data for a maximum of five years on the shared drive, after which it will be deleted from the shared as per UM IST data destruction guidelines.

Process for integrating findings

I integrated findings from the survey and interviews based on Lewis et al.<sup>96</sup> The integration process involved four main phases: drafting an outline for the integrated chapter, identifying the key findings from each study for discussion points, determining supporting arguments for the discussion points, and writing the findings.<sup>96</sup> I briefly describe each of these phases below.

The initial outline I developed for the integrated chapter included five main sections: 1) introduction to the chapter, 2) summary of the purpose and study results, 3) main integrated findings theme-by-theme (evaluation and effects of partnering), 4) strengths and limitations of my research, and 5) conclusion. These sections were consistent with the recommendations by Lewis et al.<sup>96</sup> As I proceeded with integrating the survey and interview findings, my outline evolved to include a section for discussion about my conceptual framework for evaluation of partnered rehabilitation research.

Identifying the key findings from each study for discussion, determining the supporting arguments for the findings, and integrating the findings theme-by-theme, was not a linear process. Rather, it was iterative cycle between all three phases. I established key findings by reviewing the overarching research questions underpinning my thesis. I identified findings from the survey and interviews which provided answers on the extent of evaluation of partnered rehabilitation research, or the effects of the partnering process. Once I identified the key findings, I looked for data from the survey and interviews to substantiate or refute the findings. I often circled back to my overarching research questions to ensure the information I found to substantiate my key findings, would answer these questions. As all of this was going on, I was writing my findings in a draft integrated chapter. I organized the findings by themes and wove the results from the surveys and interviews together to describe each theme in depth. I revisited my overarching research questions and the key findings and data to support these findings several times before finally settling on the final integrated results. I also shared my integrated results with my advisor and further revised the results as necessary. I discuss the integrated results in chapter six which includes the introduction of a conceptual framework for the evaluation of partnered rehabilitation research.

## Chapter Four: A cross-sectional survey of partnered rehabilitation research features, evaluation, and perceived effects

Chapter four begins with an outline of the rationale, aims, and objectives of my first study. Following this, I explain the methods I used. I then share the results from the survey. I conclude chapter four by discussing how these results compare to existing literature and what some implications of the results may be for partnered rehabilitation research.

### Rationale

As discussed in chapter one, rehabilitation evidence may be under-utilized in part because of how it is produced, particularly if it does not address the priorities and include the knowledge users in its design, conduct, and interpretation. Partnered rehabilitation research may increase the uptake of rehabilitation evidence because it includes knowledge users in important aspects of the research process, like establishing research priorities or questions. However, there is limited evidence on the extent to which and how partnered rehabilitation research achieves this key objective, and much of the existing evidence is older, limited to high-income countries, and restricted to narrow or poorly defined concepts of partnership. For example, the scoping review by Camden et al<sup>21</sup> searched databases until August 2013; and considering over ten years have passed, their findings may not be reflective of the current state of partnered rehabilitation research. Furthermore, studies included in syntheses of partnered rehabilitation research were predominantly conducted in high-income countries such as Australia, the United States, and the United Kingdom.<sup>21,29</sup> Lastly, the research by Roberge-Dao et al<sup>28</sup> was carried out within a very specific funding context between the School of Physical and Occupational Therapy at a university in Quebec, Canada and the Richard and Edith Strauss Canada Foundation.

Understanding features of partnered rehabilitation research is important to confirm who is engaging in these partnerships, how are partners engaged, and to what extent knowledge users are involved in the partnership. This information could help us understand if and how partnered rehabilitation research has evolved over time. Evaluating the effects of partnered rehabilitation research on the research process, outcomes, or individuals can contribute valuable evidence about the benefits of partnering. This evaluation can validate the assumptions of partnering, such as its potential to improve evidence uptake and health

outcomes, while also ensuring meaningful engagement with knowledge users. In addition, it can help identify how partners work together, providing insights to improve the partnering process and determine whether this approach yields economic benefits. Furthermore, evidence with an international focus could enhance our understanding of partnered rehabilitation research and identify the various contexts, e.g., low- and middle-income countries, these partnerships occur in which are not well represented in the literature to date.<sup>97,98</sup>

### Aim

The overall aim of this study was to examine the features, evaluation, and perceived effects of partnered rehabilitation research on the research process and outcomes within an international context.

### Objectives

1. Identify and describe features of partnered rehabilitation research such as (but not limited to) partners role in the partnership, length of partnerships, level of knowledge user engagement, or type of knowledge user involved.
2. Identify and describe if and how partnered rehabilitation research is evaluated.
3. Identify the perceived effects of partnered rehabilitation research on the research process and research outcomes.
4. Determine if there is a relationship between the perceived effects of the research process and perceived effects of research outcomes.
5. Determine if there is a relationship between evaluation of partnered rehabilitation research and perceived effects on research outcomes.
6. Compare perceptions of the effects of partnered rehabilitation research between researchers and knowledge users.

### Methods

#### Design

I conducted a cross-sectional survey. I chose this approach because a survey can identify the extent of a phenomenon, compare characteristics of a population sampled, and are relatively inexpensive and easy to conduct.<sup>97,99</sup> Furthermore, a survey is a quantitative data collection

method, and using it was consistent with the explanatory sequential mixed method that underpinned my research.<sup>36</sup>

#### Ethical considerations

My study was approved by the Health Research Ethics Board at the University of Manitoba (HS25974 (H2023:132)). All participants were presented with the survey consent disclosure statement before accessing the survey. Participants who proceeded to the survey after reading the disclosure statement were considered to have consented to participate in our survey. See Appendix 2 for the disclosure statement form.

#### Participants and eligibility

Participants were eligible if they could understand, read, and write in English; and were involved in partnered rehabilitation research as either a researcher or a knowledge user. I defined partnered rehabilitation research as a collaboration between researchers and knowledge users during the rehabilitation research process. I defined researcher as an individual who carries out thoughtful inquiry or examination of a topic.<sup>13</sup> This included investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory.<sup>13</sup> A researcher could be, but did not necessarily need to be, affiliated with an academic institution. As well, the researcher could be a graduate student. I defined knowledge user as any person who could use the knowledge resulting from research to make informed in clinical or healthcare policy decisions. Knowledge users could include (but were not limited to): health professionals, patients, and decision and policy makers.

#### Sampling and sample size

I used non-probability convenience sampling, which means the probability of selection of the sample was unknown and chance alone did not dictate who was selected for the sample.<sup>100</sup> I chose this sampling approach because I intended to liaise with international rehabilitation organizations for recruitment and I would not know how many people received the study information. In non-probabilistic convenience sampling, it is not possible to determine the exact number of people that will be potentially sampled.<sup>100</sup> As such, I was not able to establish a sample frame, i.e., list of potentially eligible participants, based on the organizations I liaised with.<sup>100</sup> However, it is possible to estimate sample size based on findings from previously

published research in which the research questions and sample may be similar.<sup>101</sup> In 2019, a cross-sectional study was conducted by Sibbald, Kang, and Graham<sup>102</sup> using survey methodology investigated how researcher-knowledge user partnerships were perceived, barriers and facilitators of partnering, and impact of partnering on research uptake was published. The sample included researchers and knowledge users involved in partnered health research who obtained grants from the Canadian Institutes of Health Research between 2005-2009.<sup>102</sup> A total of 216 individuals (141 researchers and 75 knowledge users) completed the survey.<sup>102</sup> Even though this survey was situated in a Canadian context only, it was similar in scope to mine. As such, I decided to use the number of respondents from it to estimate a sample size for my survey. Using an online sample size calculator (<https://www.calculator.net/sample-size-calculator.html?type=1&cl=95&ci=5&pp=50&ps=75&x=Calculate>), a confidence interval of 95% and a 5% margin of error, I estimated I would need a sample of n= 167 (104 researchers and 63 knowledge users) to ensure the Spearman rank correlation and Mann Whitney tests were adequately powered.

#### Participant recruitment

In conversation with my advisory committee, I developed criteria that would inform which organizations I contacted to share my survey. We decided together that I would email organizations to request their assistance with recruitment only if they met the following criteria, 1) aligned with my conceptualization and definition of rehabilitation, 2) were located on various continents, and 3) included researchers and/or knowledge users in their membership or had potential networks with researchers or knowledge users. While it was not necessary for the organizations to promote partnered research, I tried to locate ones that did. After establishing the criteria, I systematically searched the internet for potential organizations beginning with North America and progressing through all continents. I identified twenty organizations from several different countries that met my criteria. I emailed these organizations between January and June 2023, and I explained who I was, the survey I was conducting, and requested their assistance in helping recruit eligible participants. Three organizations were able to tell me how many members my study information could reach.

These organizations had a combined total of 255 members: European Academy of Rehabilitation Medicine (n = 45), the Integrated Knowledge Translation Network (n = 133), and the International Centre for Disability and Rehabilitation (n = 77). Based on the membership numbers of these three organizations and conservatively estimating that the remaining four organizations would have similar membership sizes, I anticipated that approximately 500 people could receive my survey information, potentially increasing the likelihood I achieve the necessary sample size.

Lastly, I asked individuals who received my survey invitation to forward that information to other people they thought may be interested or eligible in participating (snowball sampling). Lastly, some members of my PhD committee and I shared links to the survey via their social media platforms, i.e., LinkedIn, X (Twitter).

#### Survey instrument and data collection

I developed and refined the survey questions through an evidence-informed and iterative process based on research my advisor had conducted on partnered research and published research specific to partnered health research.<sup>34,103</sup> Firstly, I used a questionnaire developed by my advisor that examined partnered health research characteristics in a Canadian funding context to help identify questions for my survey specific to features of the partnerships, effects on the research process and outcomes, and characteristics of the respondents. I chose this study to inform aspects of my survey because it specifically investigated funded research in which knowledge users were involved collaboratively in the research process. Furthermore, it included questions specific to the characteristics of partnerships, evaluation, and effects. I reviewed the survey questions developed by my advisor and chose questions that could offer insights into my study objectives. I compared the research questions and objectives for my study to the questions I picked from my advisor's survey to determine if they were appropriate. I shared the questions I had chosen with my committee to ensure they agreed the questions were relevant to my study.

As I mentioned in chapter two, concepts from knowledge user engagement identified by Jull et al<sup>15</sup> and the Wallerstein CBPR model<sup>55</sup> informed aspects of my survey. For example, survey questions were informed by the following concepts of knowledge user engagement from Jull et

al<sup>15</sup>: research agenda; ethics: policy/ rules; research questions; methodology; methods; collect data; analysis; dissemination; evaluate; and sustain. I used the Wallerstein CBPR model to inform survey questions specific to measuring the effects of partnered rehabilitation research, such as, policy, empowerment, cultural reinforcement, individual capacity, research productivity, and health outcomes.<sup>55,59</sup>

Thirdly, I used the Spectrum of Public Participation developed by the International Association of Public Participation (IAP2),<sup>104</sup> to inform the survey question identifying the extent of knowledge user involvement in the partnering process (feature of the partnership). I chose the IAP2 spectrum because it includes published definitions specific to the level of involvement an individual may have in any public participation process.<sup>104</sup> The IAP2 Spectrum consists of five levels of public participation: inform, consult, involve, collaborate, and empower; with “inform” representing the lowest level of engagement and “empower” representing the highest.<sup>104</sup> Lastly, as mentioned in chapter three, I developed survey questions focused on the effects on the research process and outcomes by drawing on partnered health research literature that examined knowledge user engagement and the outcomes of research partnerships.<sup>15,55,59,60</sup>

After developing the survey questions, I asked a group of individuals, i.e., researchers and knowledge users with experience in partnered rehabilitation research, or rehabilitation, to review the survey questions. The group examined the survey questions to assess their face and content validity. As well, I conducted cognitive interviews with three individuals who I recruited through my research networks at the University of Manitoba to increase survey validity<sup>105</sup> and minimize response errors.<sup>106,107</sup> Two individuals were rehabilitation researchers and one individual was a knowledge user. All three individuals had knowledge and experience in partnered rehabilitation research. I revised the survey based on feedback received throughout the survey development process.

Following the survey development process, the final survey consisted of a total of 42, primarily closed ended questions, grouped in six sections with 1-27 questions per section. See Table 7 for information specific to the survey sections and variables that data was extracted on. Survey questions can be found in Appendix 3.

Lastly, several pilot testers who were either rehabilitation researchers with experience in partnered research, or knowledge users with experience in rehabilitation research or partnered research, completed the survey using various interfaces, i.e., laptop or mobile phone. The pilot testers provided feedback on the time to complete the survey, skip logic, and/ or survey layout. Once development of the survey was completed, I used Survey Monkey (<https://www.surveymonkey.com/>) to collect data for six weeks between July and September 2023.

Table 7. Description of data extraction variables

Variable	Variable Details (type of variable, survey response options)	Reference
<b>INTRODUCTION AND CONSENT</b>		
Consent	Dichotomous, 1= Yes, 2= No	
<b>ELIGIBILITY AND ROLE</b>		
Involvement partnered research	Dichotomous, 1= Yes, 2= No	
Rehabilitation research	Dichotomous, 1= Yes, 2= No	
Role	Nominal 1= Researcher, 2= Knowledge user, 3= research and knowledge user	Sibley et al <sup>108</sup>
<b>PARTNERSHIP FEATURES</b>		
Current involvement	Dichotomous, 1= Ongoing, 2= Completed	
Length of partnership	Nominal, years 1= 0-2, 2-4, 5-7, 8-10	
Type of knowledge user the researcher partnered with	Nominal (check all that apply) 1= Health professional 2= Person with lived experience of a health condition, either directly ( <i>i.e.</i> , "patient") or indirectly ( <i>i.e.</i> , family member, friend, or caregiver) 3= Healthcare manager or administrator 4= Health system decision or policy maker 5= Community organization representative 6= Health research funding organization representative 7= Health professional organization representative 8= Industry representative 9= Community member 10= Other, please specify: 11= Unsure	Sibley et al <sup>108</sup>

Type of knowledge user	Nominal (check all that apply) 1= Health professional 2= Person with lived experience of a health condition, either directly ( <i>i.e.</i> , " <i>patient</i> ") or indirectly ( <i>i.e.</i> , <i>family member, friend, or caregiver</i> ) 3= Healthcare manager or administrator 4= Health system decision or policy maker 5= Community organization representative 6= Health research funding organization representative 7= Health professional organization representative 8= Industry representative 9= Community member 10= Other, please specify: 11= Unsure	Sibley et al <sup>108</sup>
Years as a (researcher or knowledge user)	Nominal, years 1= 0-3, 2= 4-7, 3= 8-11, 4= 12 years or more	Sibley et al <sup>108</sup>
Number of partnerships involved in as a (researcher or knowledge user)	Nominal 1= 1-5, 2= 6-10, 3= 11-15, 4= ≥ 16, 5= Ongoing partnered rehabilitation research program, 6= Other, please specify	Sibley et al <sup>108</sup>
Knowledge user involvement	Nominal 0= I don't know, 1= Inform, 2= Consult, 3= Involve, 4= Collaborate, 5= Empower	IAP2 <sup>2104</sup>
<b>EVALUATION</b>		
Partnership evaluation	Nominal 0= I don't know, 1= Yes, 2= No	Sibley et al <sup>108</sup>
Timing of evaluation	Dichotomous, 1= Selected, 2= Not selected Pre-study, During the study, Post-study, Other, I don't know	Jull et al <sup>47</sup> Sibley et al <sup>108</sup>
Type of evaluation	Dichotomous, 1= Selected, 2= Not selected Informal (for internal use only), Formal research study (obtained ethics approval, findings may be published), Other, I don't know	Sibley et al <sup>108</sup>
Methodologies evaluation	Dichotomous, 1= Selected, 2= Not selected Quantitative, Qualitative, Mixed Methods, Other, I don't know	Sibley et al <sup>108</sup>

Methods evaluation	Dichotomous, 1= Selected, 2= Not selected Tool or Instrument, Interview, Focus group, Other, I don't know	Hoekstra et al <sup>34</sup> Mrklas et al <sup>103</sup> Sibley et al <sup>108</sup>
<b>PERCEIVED EFFECTS</b>		
Influence of partnership on overall project	Ordinal 1= No influence, 2= A little influence, 3= Moderate influence, 4= Significant influence	Sibley et al <sup>108</sup>
Extent of partnership influence on research process	Ordinal 1= No influence, 2= A little influence, 3= Moderate influence, 4= Significant influence, 5= not applicable  Setting the project's research priorities (Jull et al concept = research agenda) Choosing research questions (Jull et al concept = research questions) Development of study design/ methods (Jull et al concept = methodology and methods) Choosing study outcomes (Jull et al concept = research agenda) Development of research ethics documents (e.g., consent forms), (Jull et al concept = ethics: policy/rules) Participant recruitment (Jull et al concept = methods) Data collection (Jull et al concept = collect data) Data analysis and interpretation (Jull et al concept = analysis) Dissemination (sharing) of research findings to non-academic audiences (Jull et al concept = disseminate) Dissemination (sharing) of research findings to academic audiences (Jull et al concept = disseminate) Sustainability of interventions (Jull et al concept = sustain)	Sibley et al <sup>108</sup>  Jull et al <sup>47</sup>
Extent of partnership influence research outcomes	Ordinal 1= No influence, 2= A little influence, 3= Moderate influence, 4= Significant influence, 5= Unsure	Sibley et al, <sup>108</sup> Belone et al, <sup>55</sup> Wallerstein et

	Health policy system changes (Wallerstein/ Belone CBPR model) Sustainable partnerships Knowledge user empowerment Shared power relations (Wallerstein/ Belone CBPR model) Cultural revitalization (Wallerstein/ Belone CBPR model) Knowledge about research process Knowledge user research skill (Wallerstein/ Belone CBPR model) Researcher's capacity for partnership Health disparities (Wallerstein/ Belone CBPR model) Produce useful research findings Evidence-informed decision making	al, <sup>59</sup> Oetzel et al <sup>60</sup>
Comments on partnered research	Open ended	Sibley et al <sup>108</sup>
<b>RESPONDENT CHARACTERISTICS</b>		
Profession	Nominal 1= Nurse 2= Occupational Therapist 3= Orthotist 4= Prosthetist 5= Physician 6= Physiotherapist/ Physical therapist 7= Rehabilitation counsellor 8= Social worker 9= Speech Language Pathologist 10= Other, please specify	
Country of residence	Open ended	
Gender	Nominal 0= Prefer not to answer, 1= Female, 2= Male, 3= Prefer to self-describe	Sibley et al <sup>108</sup>

IAP2= International Association of Public Participation, CBPR= Community Based Participatory Research

Data analysis and reporting

Survey Monkey data were exported to Microsoft Excel for data analysis. Data from the questionnaires were entered into a password protected Microsoft Excel database. Only data from completed questionnaires (defined as those who answer 80% of questions, n = 33) were analyzed. I knew from previous experience conducting studies using survey methodology it was likely that respondents would not complete the entire questionnaire. I decided that respondents would need to complete a minimum number of questions, as opposed to the entire questionnaire, to be included in data analysis as I did not want to risk excluding respondents who answered the questions about partnered rehabilitation research. I chose 80% as the cutoff for question completion because I thought this would ensure a high proportion of completed questions answered would be specific to partnered rehabilitation research. I cleaned the data to prepare for analysis by removing the respondents who did not complete the survey. I used descriptive statistics, i.e., counts, and/or percentages, to describe survey participants (*objective 1*), report on if and how effects were evaluated (*objective 2*), and the effects on research processes and outcomes (*objective 3*).

For objective four, I intended to use Spearman rank correlation to calculate whether there was a relationship between perceived effects of the research process (independent variable) and research outcome (dependent variable). The independent variables I planned to compare were setting research priorities, choosing research questions, development of study design and methods, choosing study outcomes, development of research ethics documents, participant recruitment, data collection, data analysis and interpretation, dissemination of research findings to academic and non-academic audiences, and sustainability of interventions. The dependent variables were health system policy changes, sustainability of partnerships, knowledge user empowerment shared power relations, i.e., equity in decision making related to research and knowledge sharing, cultural revitalization, i.e., regaining cultural identity, languages or reviving traditions and customs, knowledge users' knowledge about the research process, knowledge users' research skills, researchers capacity for partnered research, reduction of health disparities, production of useful research findings for the knowledge, and evidence-informed clinical decision making by knowledge users. As well, I intended to use

Spearman rank correlation for *objective five* to assess the relationship between the evaluation (dependent variable) of partnered rehabilitation research and research outcomes (independent variable). Lastly, I intended to compare the perceptions of the effects of partnered rehabilitation researchers between researchers and knowledge using Mann Whitney tests (*objective 6*). P-values greater than 0.05 would be statistically significant.

In the event I did not obtain a sample with sufficient researchers or knowledge users to conduct Spearman rank correlation and/or Mann Whitney tests I would report on *objectives 1-3* only using descriptive analysis. I reported findings consistent with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES).<sup>109,110</sup>

### Results

Of the twenty organizations I contacted, ten responded and agreed to share a link to my survey or survey details with their members via their website, email, newsletters, and/or social media between July and August 2023. However, only seven organizations confirmed they shared study information on my behalf. The organizations who assisted with recruitment included: the Canadian-International HIV-Rehabilitation Research Collaborative (North America), Cochrane Rehabilitation (Europe), European Academy of Rehabilitation Medicine (Europe), Centre on Knowledge Translation for Disability and Rehabilitation Research (North America), Rehabilitation Center for Children (North America), Integrated Knowledge Translation Network (North America), and the International Centre for Disability and Rehabilitation (North America).

#### Characteristics of participants

Thirty individuals responded to my survey. Eleven respondents (36.7%) were ineligible [not involved in partnered research (n = 7, 63.6%), did not know if they were involved in partnered research (n = 3, 27.3%), their research was not specific to rehabilitation (n = 1, 9.1%)]. Five respondents (26.3%) were excluded from data analysis because they only answered the consent question (n = 4, 80%) or answered less than 80% of the questions (n = 1, 20%). Data from fourteen respondents (47%) were included in data analysis.<sup>110</sup> Because of the low number of respondents, I was unable to conduct correlation analysis to identify relationships between the perceived effects of the research process and perceived effects of research outcomes and the evaluation of partnered rehabilitation research and research outcomes. Furthermore, I was

unable to compare the perceptions of the effects of partnered rehabilitation research between researchers and knowledge users because I was unable to recruit any individuals who identified only as knowledge users.

Most respondents were physiotherapists/ physical therapists (n = 5, 36%). Respondents predominantly resided in Canada (n = 9, 64%). Most respondents identified as white (n = 9, 64%). Nearly all respondents identified as woman (n = 12, 86%). Ten respondents (71%) were researchers, while the remaining four respondents (29%) identified as researchers/ knowledge users. See Table 8 for more details on the characteristics of the respondents.

Table 8. Characteristics of the partnered rehabilitation survey respondents (n = 14)

<b>Profession</b>	n (%)
Physiotherapist/ physical therapist	5 (36)
Speech and language pathologist	2 (14)
Audiologist	1 (7)
Nurse	1 (7)
Occupational therapist	1 (7)
Physician	1 (7)
Post-doctoral fellow	1 (7)
Researcher/ knowledge translation specialist	1 (7)
Researcher	1 (7)
<b>Country of residence</b>	
Canada	9 (64)
United States	3 (21)
Bangladesh	1 (7)
India	1 (7)
<b>Ethnicity</b>	
White	9 (64)
South Asian	3 (21)
White and visible multiple minorities	1 (7)
Black	1 (7)
<b>Gender</b>	
Women	12 (86)
Men	2 (14)
<b>Role in partnered rehabilitation research</b>	
Researcher	10 (71)
Researcher/ knowledge user	4 (29)
Knowledge user	0

<b>Number of years as a researcher</b>	<b>n = 14</b>
0-3	0
4-7	3 (21)
8-11	3 (21)
≥ 12	8 (57)
<b>Involvement in partnered research</b>	<b>n = 14</b>
Ongoing	10 (71)
Completed	4 (29)

#### Features of partnered rehabilitation research

Four respondents (40%) reported being involved in partnerships that had been on-going for 8-10 years. Five respondents (36%) indicated they had been involved in 1-5 partnerships. All respondents (n = 14, 100%) indicated they partnered with health professionals, followed by people with lived experience of a health condition (n = 12, 86%). Respondents indicated that knowledge users were predominantly involved at the 'collaborate' level of involvement (n= 8, 57%). More information on the features of partnered rehabilitation research, including characteristics of researchers who identified as knowledge users, can be found in Table 9.

Table 9. Features of partnered rehabilitation research

	n (%)
<b>Length of ongoing partnerships</b>	<b>n = 10</b>
0- 2 years	1 (10)
2- 4 years	2 (20)
5-7 years	2 (20)
8-10 years	4 (40)
≥11 years	1 (10)
<b>Number of partnerships that researchers have been involved with</b>	<b>n = 14</b>
1-5	5 (36)
6-10	4 (29)
11-15	0
≥ 16	3 (21)
Ongoing partnered rehabilitation research programs	2 (14)
<b>Type of knowledge user researchers partnered with*</b>	<b>n = 14</b>
Health professional	14 (100)
Person with lived experience of a health condition, either directly or indirectly	12 (86)
Healthcare manager or administrator	10 (71)
Health system decision or policy maker	7 (50)
Community organization representative (i.e., representative from a non-profit organization)	7 (50)
Health research funding organization representative	3 (21)
Health professional organization representative	4 (29)
Industry representative (i.e., business or company)	3 (21)
Community member	3 (21)
<b>Level of involvement of knowledge users in partnerships (as per IAP2)<sup>104</sup></b>	<b>n = 14</b>
Inform	0
Consult	1(7)
Involve	4 (29)
Collaborate	8 (57)
Empower	1 (7)

<b>Type of knowledge user researchers identified as*</b>	<b>n = 4</b>
Health professional	4 (100)
Healthcare manager or administrator	2 (50)
<b>Number of years researcher identified as a knowledge user</b>	<b>n = 4</b>
4-7	2 (14)
8-11	0
≥ 12	2 (14)
<b>Number of partnerships researchers have been involved in as a knowledge user</b>	<b>n = 4</b>
1-5	4 (100)

\*Respondents could select more than one option

#### Evaluation of partnered rehabilitation research

Eight respondents (57%) indicated the partnership was evaluated or was going to be evaluated. Three respondents (38%) stated the evaluation occurred pre-study and seven respondents (88%) indicated they would conduct a formal evaluation. A tool or instrument such as a survey, measure, assessment, inventory, checklist, list of factors, or subscales, were the most common methods of evaluating partnerships (n = 6, 75%) and these tools were predominantly designed by the research teams (n = 4, 67%). See Table 10 for more details on the evaluation of partnered rehabilitation research.

Table 10. Evaluation of partnered rehabilitation research

	n (%)
<b>Partnership evaluation</b>	<b>n = 14</b>
Yes	8 (57)
No	5 (36)
I don't know	1 (7)
<b>Timing of evaluation*</b>	<b>n = 8</b>
Pre-study	3 (38)
During study	6 (75)
Post-study	6 (75)
<b>Type of evaluation conducted*</b>	<b>n = 8</b>
Informal	5 (63)
Formal	7 (88)
<b>Methodologies used to evaluate partnership*</b>	<b>n = 8</b>
Qualitative	3 (38)
Quantitative	1 (13)
Mixed Methods	6 (75)
<b>Methods used to evaluate partnership*</b>	<b>n = 8</b>
Tool or instrument such as a survey, measure, assessment, inventory, checklist, list of factors, or subscales	6 (75)
Interview	4 (50)
Focus group	3 (38)
Other (dialogue)	1 (13)
<b>Name of tool or instrument**</b>	<b>n = 6</b>
No formal name (internally designed)	4 (67)
No formal name (informed by WHO)	1 (17)
Implementation Leadership Scale	1 (17)
Organizational Readiness for Change	1 (17)
Unknown	1 (17)

WHO= World Health Organization, \*respondents could select more than one option, \*\* open-ended, respondents could include multiple responses

Perceived effects of partnered rehabilitation research on the research process  
Eleven respondents (79%) indicated they perceived that partnered rehabilitation research had a significant influence on the overall research project (Figure 2).

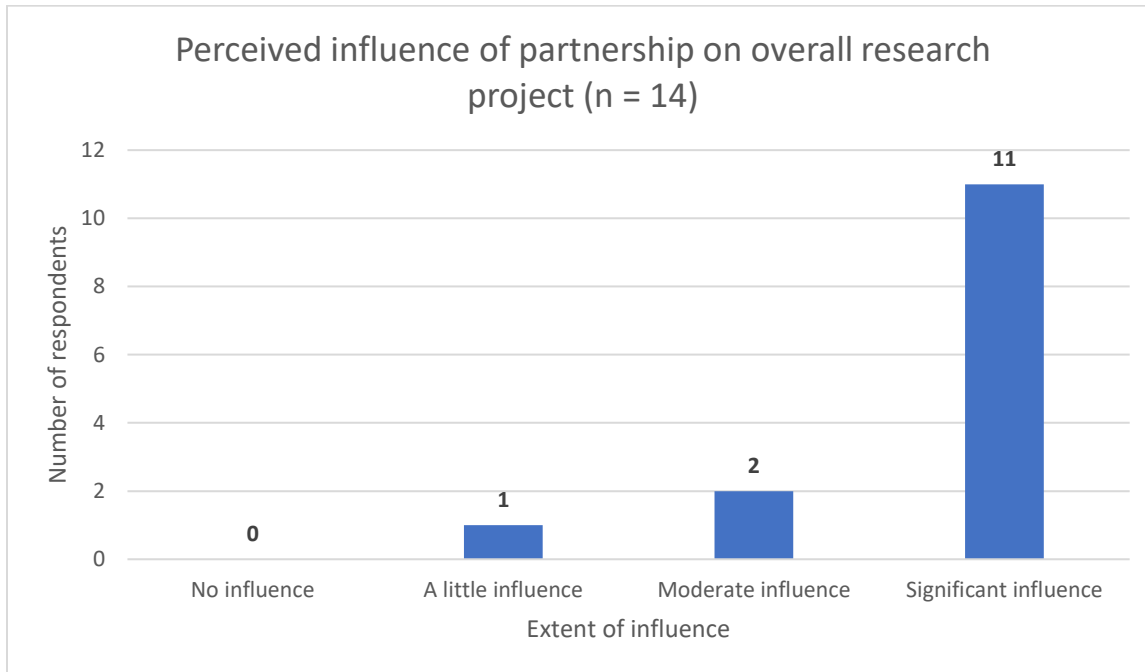


Figure 2. Perceived influence of partnered rehabilitation research on the overall research project

Specific to the phases of the research process, most respondents perceived partnering had a significant effect on setting research project priorities (n = 8, 57%) and choosing the research questions (n= 10, 71%). As well, eight respondents (57%) indicated partnering had a significant effect on disseminating findings to non-academic audiences. Lastly, some respondents perceived partnering had little (n = 4, 29%) or no (n = 2, 14%) effect on developing research ethics documents. Table 11 provides details on the effects of partnered rehabilitation research on the research process.

Table 11. Perceived effects of partnered rehabilitation research on the research process (n= 14)

Component of research process	Perceived effect of partnership [n (%)]					
	None	A little	Moderate	Significant	Not applicable	Missing
Setting research project's priorities	0	3 (21)	3 (21)	8 (57)	0	0
Choosing the research questions	0	3 (21)	1 (7)	10 (71)	0	0
Developing study design and methods	1 (7)	5 (36)	1 (7)	7 (50)	0	0
Choosing study outcomes	2 (14)	3 (21)	3 (21)	6 (43)	0	0
Developing research ethics documents	2 (14)	4 (29)	1 (7)	4 (29)	3 (21)	0
Participant recruitment	0	3 (21)	3 (21)	6 (43)	2 (14)	0
Data collection	0	3 (21)	4 (29)	7 (50)	0	0
Data analysis and interpretation	2 (14)	2 (14)	5 (36)	5 (36)	0	0
Disseminating findings to non-academic audiences	0	1 (7)	5 (36)	8 (57)	0	0
Disseminating findings to academic audiences	1 (7)	2 (14)	3 (21)	7 (50)	0	1 (7)
Sustainability of interventions	1 (7)	2 (14)	3 (21)	7 (50)	1 (7)	0

#### Perceived effects of partnered rehabilitation research on research outcomes

Most respondents (n = 10, 71%) perceived that partnering had significant effects on knowledge users' knowledge about the research process and on the production of useful research findings for the knowledge users involved in the partnership (n = 9, 64%). Furthermore, respondents also perceived partnering had a significant (n= 7, 50%) or moderate (n = 7, 50%) effect on researchers' capacity for partnered research. However, some respondents perceived that the partnership had little (n = 3, 21%) or no (n = 4, 29%) effect on health system policy changes. For more information about the perceived effects of partnered rehabilitation research on research outcomes, see Table 12.

Table 12. Perceived effects of partnered rehabilitation research on research outcomes (n = 14)

	Perceived effect of partnership [n (%)]					
	None	A little	Moderate	Significant	Not applicable	Missing
Health system policy changes	4 (29)	3 (21)	2 (14)	3 (21)	1 (7)	1 (7)
Sustainability of partnerships	1 (7)	2 (14)	2 (14)	9 (64)	0	0
Knowledge user empowerment	0	1 (14)	5 (36)	8 (57)	0	0
Shared power relations, i.e., equity in decision making related to research and knowledge sharing	1 (7)	2 (14)	8 (57)	3 (21)	0	0
Cultural revitalization, i.e., regaining cultural identity, languages or reviving traditions and customs	5 (36)	1 (7)	4 (29)	4 (29)	0	0
Knowledge users' knowledge about the research process	0	2 (14)	2 (14)	10 (71)	0	0
Knowledge users' research skills	1 (7)	3 (21)	5 (36)	5 (36)	0	0
Researchers' capacity for partnered research	0	0	7 (50)	7 (50)	0	0
Reduction of health disparities	2 (14)	4 (29)	4 (29)	3 (21)	1 (7)	0
Production of useful research findings for the knowledge users involved in the partnership	0	0	5 (36)	9 (64)	0	0
Evidence-informed clinical decision making in healthcare by knowledge users	0	2 (14)	3 (21)	8 (57)	1 (7)	0

## Discussion

I conducted an online survey to examine the features, evaluation, and perceived effects of partnered rehabilitation research on the research process and outcomes within an international context. Seven of the 20 organizations I contacted shared recruitment materials. Thirty individuals responded to my survey invitation and of those, fourteen responses were included in data analysis. While I could only conservatively guess how many people would potentially receive information about my survey, considering only thirty people responded, it is possible my survey reached far less people than I anticipated. Likewise, of the eligible people it did reach, perhaps many were not interested or did not have the capacity to complete the survey. Regardless, I did not obtain the estimated sample size I would need for Spearman rank correlation and Mann Whitney tests. Therefore, the findings are reported consistent with my contingency data analysis plan, i.e., report results specific to objectives 1-3 descriptively. As well, because of the small sample size, results must be interpreted with caution.

Over half of the respondents in the survey stated they had or were going to evaluate the partnership. This is an encouraging finding because it suggests that the partnering process is being evaluated in partnered rehabilitation research. However, my study findings contrast with Camden et al's<sup>21</sup> synthesis of partnered rehabilitation research, where they found fewer than half of the studies collected data to evaluate the effects of partnering. Camden et al<sup>21</sup> scoped literature between 2003- 2013 and the difference between their and my findings may be related to evolving attitudes and beliefs from partners who recognize the value of evaluation. Like my study findings, Camden et al<sup>21</sup> found that questionnaires, interviews, or focus groups were the predominant methods used to evaluate partnering. Respondents from my survey indicated that when they used tools or instruments, they were predominantly internally developed, i.e., created by the research team. This is consistent with reported findings,<sup>103</sup> and a known issue in implementation research where projects and settings are highly contextualized. However, use of internally designed tools for a specific partnership may be problematic as these tools could lack scientific rigor, conceptual or theoretical underpinnings, reliability testing, and appropriate literature to inform their design.<sup>33</sup> This may impact the ability to accurately capture the effects of the partnering process, which could lead to individuals in

partnered research under or over emphasizing the potential effects of this approach. Furthermore, instruments or measures that lack theoretical underpinnings may not be able to provide insights on how effects are achieved through the partnering process. Lastly, developing tools or instruments for each partnership may be time consuming and use research resources that are better suited for building, strengthening, or sustaining partnerships. A systematic review by Mrklas et al,<sup>103</sup> synthesized the literature up to June 2021, identified 58 tools for assessing partnered health research. Most of these tools were in English, targeted multiple partner groups, and were surveys, questionnaires, or scales.<sup>103</sup> Some of the tools identified in the review by Mrklas et al<sup>103</sup> could be useful for evaluating partnered rehabilitation research.

Other encouraging findings from my survey were the high proportion of respondents who perceived that partnering influenced the production of useful research findings (n = 9, 64%) and evidence-informed clinical decision making for knowledge users (n = 8, 57%). Neither of these findings have been reported in existing partnered rehabilitation research, however the production of useful research findings was an effect of partnered health research as reported by in the review by Hoekstra et al.<sup>27</sup> Survey respondents who perceived that partnering led to useful research is important because partnered rehabilitation research states that one of the benefits of this approach is that it develops findings that are more useful for knowledge users compared to researcher-driven approaches. As such, findings from the survey provide some evidence to substantiate this assumption.

The finding that partnering influences evidence-informed decision-making is encouraging as well because it suggests that another assumption of partnering, i.e., enhanced uptake of evidence and a reduced evidence-practice gap, may be an effect of this approach. This finding appears to be consistent with the results from the interviews Roberge-Dao et al<sup>28</sup> conducted with knowledge users in their mixed methods study. Roberge-Dao et al<sup>28</sup> reported that evidence-informed clinical decision making was an effect of partnering. Furthermore, knowledge users confirmed their own clinical practice had changed because of partnering on rehabilitation research.<sup>28</sup> However, participants in the study by Roberge-Dao et al<sup>28</sup> did not explain how their practice changed, whether evidence informed their new practice and clinical decisions, and could not provide examples of a new clinical practice being informed by

evidence.<sup>28</sup> I did not examine this concept in depth in the survey either. Therefore, future research could explore concrete examples of how partnering contributes to evidence-informed clinical decision making.

Another interesting finding from my survey was that most respondents indicated partnerships had little to no effect on health system policy changes. This is a new finding specific to partnered rehabilitation research and it is somewhat different to other published studies.<sup>27,55</sup> For instance, Belone et al<sup>55</sup> reported when government officials were involved in partnered health research, new policies were developed, or existing policies were transformed. Additionally, the review by Hoekstra et al<sup>27</sup> found that partnering resulted in system changes by influencing policy. This review included any partnered health research and was not limited in scope to rehabilitation.<sup>27</sup> My survey did not include policymakers, decision-makers, or government officials, which may explain why it did not find that rehabilitation research partnerships had any influence on health system policy changes. Furthermore, eligibility for my study was restricted to individuals involved in rehabilitation only and was not as broad as the search strategy employed by Hoekstra et al.<sup>27</sup> Considering there are multiple studies demonstrating that partnered research influences policy changes, it may be beneficial to investigate this more thoroughly in partnered rehabilitation research. This may be done using alternate methods to a survey, such as interviews or focus groups, with knowledge users who identify as policy or decision-makers.

As mentioned in chapter two, published literature about partnered rehabilitation research has been conducted in high-income countries, with little research on these partnerships in low- and middle- income countries.<sup>21</sup> Recognizing this gap in the literature, I decided to situate my survey within an international context. Despite using a systematic and methodological approach to recruit participants, my survey had few respondents from outside of North America. Even though I had little success in gaining perspectives from individuals involved in partnered rehabilitation research from low- and middle-income countries, there is still merit in examining and exploring the evaluation and effects of partnerships in these countries. Different barriers and facilitators to partnered rehabilitation research may exist in low- and middle-income countries, and the evaluation or effects of the partnerships may be influenced by them.

If investigators aim to include the perspectives of individuals from low- and middle-income countries, they should consider partnering with researchers or knowledge users from these countries to ensure evaluation and effects of partnered rehabilitation research is a research priority. If studies investigating partnered rehabilitation research are not a research priority in these countries, it may be difficult to recruit individuals to the studies.

#### Strengths

One strength of my study was that I used many strategies to enhance rigor in the survey development. For instance, I used published evidence on partnered health research, concepts of knowledge user engagement, and partnered health research outcomes to inform the survey questions. Furthermore, survey development was an iterative process in that I engaged my advisory committee and group of individuals with experience in rehabilitation and/or partnered research to ensure validity of the survey. I conducted cognitive interviews to also ensure survey validity and minimize response errors. Lastly, I completed several rounds of pilot testing to ensure the survey was easy to read, understandable, and not overly burdensome to potential participants.

#### Limitations

There are a few limitations to the survey. Despite using a systematic approach to identifying rehabilitation organizations situated throughout several continents who could share study information with their members, my recruitment strategy retrieved a small sample. As such, results must be interpreted with caution. I was not able to conduct correlational analysis and compare differences in perceptions of the effects of partnered rehabilitation research between researchers and knowledge users. However, lessons learned from my recruitment approach may inform future recruitment efforts when investigating partnered rehabilitation research. Studies on partnered rehabilitation research that aim to include a variety of perspectives from rehabilitation professionals should consider recruiting potential participants through their professional associations, i.e., physiotherapy or occupational therapy associations. This strategy may reach rehabilitation professionals who are involved in partnered research because they are more likely to be members of their specific professional associations than a rehabilitation organization.

Despite not obtaining a sample needed for some statistical analysis I planned; I did have a contingency plan for this situation and was able to still examine some predefined research objectives. Lastly, it is also important to remember the survey findings reflect the perspectives of researchers only. The findings may not be consistent with those of knowledge users. Future research needs to ensure the experiences, and thus perspectives of knowledge users, are considered when investigating the effects of partnering.

### Conclusion

Partnered rehabilitation research was evaluated by most survey respondents using tools and/or instruments, which were predominantly internally developed. However, more information is necessary to understand exactly what aspects of the partnership these tools and instruments evaluate. Future studies should continue to examine evaluation of partnered rehabilitation research but they need to use robust recruitment strategies to obtain a sufficient sample for rigorous analysis. According to the survey findings, partnered rehabilitation research affects the research process and outcomes, including the production of useful research findings and evidence-informed decision making. More research is needed to understand how these findings lead to health outcomes.

## Chapter five: Exploring evaluation and perceived effects of partnered rehabilitation research in a Canadian context

I begin chapter five by explaining why I chose interviews for my second study. I then review key findings from the survey, explain how these findings informed study design in line with my sequential mixed methods approach, and outline the aim and objectives. Following this, I discuss the methods I used and report the findings. I conclude chapter five by discussing how these findings compare to existing research and offer insights on implications of the findings.

### Rationale

As mentioned in chapter three, I used an explanatory mixed methods approach for my thesis, which began with a quantitative component (survey) and followed with qualitative inquiry via interviews. The interviews I conducted explored researchers and knowledge users' perceptions of evaluation and effects of partnered rehabilitation research based on their experiences. I suspected these insights may substantiate or provide greater detail on the survey findings which could enhance understanding of the survey results or highlight issues not addressed in the survey.

Key findings from the survey indicated most respondents had evaluated or were going to evaluate the partnering process using an internally developed tool or instrument, i.e., created by the research team, and most respondents perceived partnering influenced many phases of the research process, and several research outcomes, including (but not limited to) production of useful research findings for knowledge users and evidence-informed clinical decision making by knowledge users. Consistent with integration, which is a fundamental element of mixed methods, I used the key findings from the survey to inform aspects of my second study, including the sample and interview questions. For example, due to the challenges I had recruiting participants outside of Canada for my survey, I opted to situate the interview study in a Canadian context which would allow me to undertake a targeted and systematic recruitment approach to optimize my efforts and ensure a sufficient sample. Furthermore, I believed that targeting recruitment to Canada would allow me to contribute new insights about partnered rehabilitation research that would build onto findings reported by Roberge-Dao et al<sup>28</sup> who conducted their research in a single Canadian province. As well, I developed interview

questions that would explore the types of tools used for evaluation how they were internally developed. I also developed interview questions that would probe the effects of partnering on the research process and outcomes. Lastly, recognizing that I did not investigate how survey respondents perceived the influence of partnering on the effects, I decided to explore this more comprehensively in the interviews. I hoped these questions would encourage participants to think about what factors and in what ways these factors affected how partners worked together.

### Aim

My aim was to explore researchers' and knowledge users' perspectives on evaluation of partnered rehabilitation research, the effects of partnering on the research process and outcomes and how partnering contributed to the effects.

### Objectives

1. Explore perceptions of evaluation in partnered research among researchers and knowledge users working in partnered rehabilitation research in a Canadian context.
2. Explore perceptions of the effects of partnering on the research process and outcomes by researchers and knowledge users situated in a Canadian context.
3. Explore perceptions on how partnering in rehabilitation research in a Canadian context contributed to effects on the research process and outcomes.

### Methods

#### Design

I used a qualitative descriptive design<sup>111</sup> because it is an appropriate design when the phenomenon of study, like evaluation and effects of partnered rehabilitation research, is not well understood.<sup>112,113</sup> As well, it is a design that can be employed to provide practical answers to real-world problems, which is consistent with the pragmatic perspective I used for my research.<sup>112,113</sup> Studies using a qualitative descriptive design attempt to accurately describe the phenomena under study in concrete terms without too much interpretation or straying too far from the data.<sup>113</sup> As someone with limited experience analyzing interview data, I wanted to situate my interviews in a design that I felt confident carrying out and would not risk the

confidence others may have in my study. I believed a qualitative descriptive design would ensure that.

#### Ethical considerations

I obtained ethics approval from the University of Manitoba Health Research Ethics Board (HS6260 (H2024:008)).

#### Participants and eligibility

To be eligible for the interviews, participants had to reside in Canada, understand and speak English and be a researcher or knowledge user who was involved or had been involved in partnered rehabilitation research. I used definitions of key concepts consistent with those from my survey to inform eligibility for the interviews. For example, I defined partnered rehabilitation research as a collaboration between researchers and knowledge users during the rehabilitation research process. Furthermore, I defined a researcher as an individual who carried out thoughtful inquiry or examination of a topic and could be but did not necessarily need to be affiliated with an academic institution. A researcher could be a graduate student as well. I defined knowledge user as any person who could use the knowledge resulting from research to make informed decisions. All participants were emailed the consent form to read, review, and sign before the interviews (Appendix 4). Furthermore, I confirmed participant consent prior to beginning the interviews.

#### Sample and sample size

I used two sampling approaches for recruitment: purposive and snowball. My primary sampling approach was purposive, which is a sampling method that allowed me to intentionally choose the individuals I wanted to include in this study.<sup>84,114</sup> I recruited researchers and knowledge users who were geographically spread throughout Canada and who had been involved in partnered rehabilitation research. I strived to identify researchers and knowledge users with a variety of experiences in partnered rehabilitation research across rehabilitation specialities, i.e., physiotherapy, occupational therapy, speech-language pathology. This purposive approach to sampling ensured I would achieve a maximum variation sample, i.e., a wide range of participants with diverse experiences and thus perspectives in the sample.<sup>84</sup>

Secondly, I used snowball sampling to help identify eligible participants as well. Snowball sampling is a strategy to enhance the recruitment of participants to a study, when it is particularly hard to recruit participants.<sup>84</sup> Snowball sampling involved asking my PhD advisor and study participants to share information about my study with relevant contacts who may be interested in participating.<sup>84</sup>

Based on research regarding meaning saturation and partnered rehabilitation research that used interviews for data collection, I suspected I would need a sample of approximately 15-19 individuals.<sup>28,115</sup> Meaning saturation is a concept coined by Hennink, Kaiser and Marconi<sup>115</sup> that can be used when attempting to identify sufficient sample sizes in qualitative research. Meaning saturation reflects the point when qualitative researchers fully understand the phenomenon under study.<sup>116</sup> It occurs when no new dimensions, impressions, concepts, or insights about the study issues are found.<sup>116</sup> Meaning saturation may produce a richly textured understanding of the phenomenon under study.<sup>116</sup> Research has found that meaning saturation often occurs between 19-24 individual interviews.<sup>115,116</sup> However, when determining a sufficient sample size for meaning saturation, qualitative researchers should also consider the study purpose, nature of the study topic, study population, sampling strategy, data quality, the goal and focus of saturation, and the codebook.<sup>116,117</sup>

#### Recruitment

I used multiple strategies for recruitment. Firstly, I asked the Canadian Physiotherapy Association, the Canadian Association of Occupational Therapists, the Canadian Association of Physical Medicine & Rehabilitation, Speech-Language and Audiology Canada, and Orthotists Prosthetics Canada if they would be willing to assist with recruitment. Members belonging to these organizations could include individuals who were involved in partnered rehabilitation research as researchers and/or knowledge users. Secondly, I emailed respondents from our e-survey who agreed to be contacted for future research on partnered rehabilitation research and invited them to participate in our study. Thirdly, I identified primary authors of published research articles in Canadian rehabilitation specialty journals including The Canadian Journal of Occupational Therapy, Canadian Journal of Speech-Language Pathology and Audiology, Canadian Prosthetics & Orthotics Journal, and Physiotherapy Canada. I reviewed the table of

contents of these journals on public facing websites for the primary authors of articles published between January 2022 and early 2024. After identifying the primary authors and determining they were Canadian based on their contact information, I emailed them an invitation to participate in the study. Lastly, I asked my study participants and my PhD advisor to share my study information with their partnered rehabilitation research networks. Once I received an expression of interest to participate in my study from the snowball sampling, I emailed the study information to the potential participant.

#### Data collection

I chose interviews for my second study because they would allow me to explore the perspectives of researchers and knowledge users based on their experiences being involved in partnered rehabilitation research in depth. As well, interviews are a flexible method of data collection that can be conducted virtually and could accommodate participation from a sample who I was recruiting from across Canada. Lastly, according to Sandelowski,<sup>113</sup> interviews are a data collection method that are consistent with a qualitative descriptive design.

I developed a semi-structured interview guide (Appendix 5). It included primary questions, follow up questions, and associated probes about the evaluation and effects of partnered rehabilitation research, and how partnering contributed to the effects. The interview questions were open ended and informed by existing partnership literature<sup>15,28,55,59</sup> and insights from the survey findings. For example, I asked participants to explain in detail the effects of partnering on specific aspects of the research process, e.g., agenda setting, research questions, data collection, analysis, and interpretation, and dissemination, all concepts of knowledge user engagement identified by Jull et al.<sup>15</sup> Furthermore, the Wallerstein CBPR model,<sup>55,59</sup> in part, informed the interview questions. For example, I encouraged participants to think about and explain how they perceived partnering contributed to effects on the research process and outcomes. I asked participants to consider what aspects of how partners worked together or interacted contributed to effects. I sometimes gave examples of specific behaviors, e.g., show respect, or strategies implemented, e.g., a framework to guide the partnership, to help participants. These questions and probing are reflective of the concepts in the CBPR which act as mediators influencing the effects of partnering.<sup>55,59</sup> Following my analysis of the survey

responses, I decided to explore why certain tools were chosen or internally developed, how tools were internally developed, and what aspects of the partnerships the tools evaluated. The interview guide was pilot tested for clarity and relevance. Data from pilot testing was not included in analysis.

#### Data analysis

I led data analysis; however, it was a collaborative process involving my advisory committee as a research team. It was informed by the following stages of reflexive thematic analysis: 1) transcription, 2) reading of and familiarization with the data, 3) coding, 4) generating themes, 5) reviewing themes and producing a thematic map, 6) defining and naming themes, and 7) writing and finalizing analysis in a descriptive fashion suited for the intended audiences (Appendix 6).<sup>114,118</sup> Data collection and analysis were an iterative process that occurred simultaneously at times, meaning I began preliminary data analysis while I was still conducting interviews.<sup>118,119</sup> After completing two interviews, I listened to them separately while reviewing the transcripts to revise any errors. After this, I began familiarizing myself with the data by reading and re-reading the transcribed interviews. I made some preliminary notes, including initial impressions, concepts, or ideas. I paused reading and familiarizing myself with the data to conduct more interviews, and repeated the process of listening to the interview, reviewing the transcription for errors, and reading and familiarizing myself with the transcriptions. After I completed several interviews, I reviewed my fieldnotes from the earlier interviews. I used some of the insights from the field notes to inform the remaining interviews, e.g., ensure that I was clear and concise with my interview questions, or avoid “rambling” when asking participants questions. I also began coding, i.e., looking for groups or chunks of interview data that related to my research questions, after I completed several interviews.<sup>114,118</sup> After completing coding, I started to look for patterns in the codes which would lead to preliminary themes, i.e., central concepts that would contribute a meaningful answer to my research questions.<sup>114,118</sup> I began identifying and drafting themes during this phase while I was still conducting interviews. Once I concluded data collection, I reviewed draft themes to ensure they were consistent with the meaning of the data and considered how they answered my research questions. I reviewed my field notes again to read some of my initial impressions of the interviews and the information

that participants shared about evaluation and effects. I reflected whether those initial impressions were captured in any of the preliminary themes. I also considered how my initial impressions may have demonstrated my bias about partnered rehabilitation research and whether this influenced the preliminary themes I was developing. I met with my advisory committee to discuss the draft themes. Based on our discussions, I revised the themes and met with my primary advisor for further discussion and, following additional discussions, I continued to revise the themes. I then named and defined the final themes before sharing the findings with my entire advisory committee and writing the results of this analytic process. Throughout these phases of data analysis, my advisory committee and I discussed the analysis process, codes, and themes until consensus was reached.<sup>114,118</sup>

I completed data analysis inductively, i.e., from the data, and deductively, i.e., from another source.<sup>84</sup> For example, I analyzed the effects of the partnership on the research process and outcomes inductively because there is not a lot of published information about either. As well, I was open to discovering new insights and understanding the effects of partnering without preconceived notions. For the inductive analysis, I generated codes directly from the participant reflections. However, I analyzed how partnering contributed to effects deductively because I could use the Wallerstein CBPR model to inform my analysis, thus strengthening trustworthiness of my analysis.<sup>55,59</sup> As I discussed in chapter two, the CBPR model consists of four domains: 1) context, 2) group dynamics, 3) research/ intervention, and 4) outcomes.<sup>55</sup> Contextual factors include socio-economic characteristics, historical contributions, and/or university and community capacities.<sup>55</sup> Group dynamics include the individual (e.g., core values and beliefs), structural (e.g., formal agreements, diversity), and relational (e.g., power dynamics) factors that may influence partnering. Research has shown that many partnered research outcomes, i.e., effects, were related to contextual factors and group dynamics.<sup>55</sup> I used context, individual, structural, and relational factors as codes to deductively analyze some participant data regarding their perceptions of how partnering influences effect. As I analyzed the results on how participants perceived partnering influenced effects, I grouped data as contextual, individual, structural, or relational factors. Findings were reported consisted with the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist.<sup>120</sup>

I took several measures to ensure trustworthiness of the interview data and analysis. For example, I employed member checking by asking every interview participant if they would like to review their transcript to ensure it reflected their perspectives accurately. I also kept fieldnotes while I conducted interviews to capture my own thoughts, insights, or challenges I experienced during this period, and used thick description to describe the study participants and their experiences of partnered rehabilitation research.

As mentioned in chapter one, I am a privileged, white female researcher, licensed physiotherapist, and hold an insider-outside view of partnered rehabilitation research, both operationalizing it in my job and researching it for my doctoral studies. I assume partnered rehabilitation research is necessary to enhance the uptake of rehabilitation evidence. I have a positive attitude towards partnered research having witnessed its effects first-hand. I think it is important to acknowledge these intersections again as they likely affected my analysis and interpretation of the results, particularly my tendency to view the results as having more positive than negative effects.

## Results

The Canadian Physiotherapy Association shared study information in a March 2024 e-newsletter and the Canadian Association of Occupational Therapists shared study information on their website from mid-March to mid-April 2024. Orthotists Prosthetics Canada shared my study information on their website beginning in mid-March 2024. The Canadian Association of Physical Medicine & Rehabilitation indicated they had received several requests to share study information with members for free, and my request was not shared before the recruitment period ended. They did inform me I could pay for an advertisement at a cost of \$400 that would be sent directly to all members. Speech-Language and Audiology Canada did not respond to requests to support recruitment.

Twenty-five individuals contacted me about participating in the study. Of the 25, I contacted 18 people to arrange an interview. One individual was ineligible because they had not been involved in partnered research. Another individual was not available for an interview until the end of April 2024. Three individuals did not respond to my emails confirming eligibility,

requesting they sign a consent form, or attempting to set-up an interview date and time. In the end, I conducted thirteen interviews between January and April 2024. My advisory committee and I decided to stop data collection primarily based on meaning saturation. We discussed how the interviews were progressing, and the ideas, concepts, impressions, and insights I had about the data. As well, we discussed whether I perceived repetition in what participants were sharing with me during the interviews. Based on these conversations, my advisory committee and I determined that no new information was emerging from the interviews, and I had achieved meaning saturation. However, we also spoke about how recruitment was proceeding. These discussions focused on ensuring consistency with recruitment strategies, responses to the study advertisements, and whether we perceived I had exhausted approaches to boost recruitment. It was through all these discussions that the committee and I decided to end data collection.

#### Characteristics of participants

Most participants identified as women (n = 12, 92%) and white (n = 12, 92%). Participants resided in western, central, and eastern Canada. Seven participants were researchers affiliated with an academic setting whose research included children, adults, and older adults. Research topics included (but were not limited to) motor disabilities, homecare, falls rehabilitation, aging and dementia, neurological conditions such as spinal cord injuries, use of power mobility, health professional education, and reflective practice. Most researchers (n = 6, 86%) were trained as rehabilitation therapists. Researchers had experience partnering with a variety of knowledge users, including those who had lived experience of a health condition, policy makers, and rehabilitation clinicians. As well, researchers had a substantial range of years of experience in partnered rehabilitation research. For instance, some researchers had been engaging in partnered rehabilitation for several years, even decades, whereas other researchers were just beginning to delve into it. Not all researchers were involved in partnered rehabilitation research at the time of the interview, but confirmed they did have experience in participating in this research approach.

The other six participants were knowledge users with a variety of experience in partnered rehabilitation research. The knowledge users ranged from those with lived experience of a

health condition to one individual involved in policy development in the Canadian public healthcare system. One knowledge user with a health condition had been living with the condition since the mid 1990's, whereas the other two knowledge users had been living with their conditions more recently. Most knowledge users had been involved in research partnerships for five years. Lastly, the knowledge users were either currently involved in a partnership at the time of their interview or had recently finished being involved in one. See Table 13 for information on interview participants.

Table 13. Characteristics of interview participants (n = 13)

<b>Characteristics</b>	<b>N, (%)</b>
<b>Gender</b>	<b>n = 13</b>
Female	12 (92)
Male	1 (8)
<b>Race, Ethnicity, or Indigeneity</b>	<b>n = 13</b>
White	12 (92)
Chinese	1 (8)
<b>Province of residence</b>	<b>n = 13</b>
British Columbia	4
Alberta	1
Manitoba	2
Ontario	5
Quebec	1
<b>Type of partner</b>	<b>n = 13</b>
Researcher	7 (54)
Knowledge user	6 (46)
<b>Type of rehabilitation therapist (researcher only)</b>	<b>n = 6</b>
Physiotherapist	3 (50)
Occupational therapist	2 (33)
Speech-language pathologist	1 (17)
<b>Type of knowledge user</b>	<b>n = 6</b>
Lived experience with a stroke	2 (33)
Lived experience with osteoporosis	1 (17)
Speech language pathologist	1 (1.7)
Prosthetist	1 (1.7)
Leadership/ policy development public healthcare system	1 (1.7)

Evaluation of partnered rehabilitation research

No interview participants evaluated the partnering process. When probed, both researchers and knowledge users recognized the value of conducting an evaluation. Some participants acknowledged evaluation may help to understand partnerships in more depth or enhance and optimize how partners collaborated during the rehabilitation research process. One knowledge user (Participant 11) perceived that evaluation was beneficial because it could determine if knowledge users were involved in the partnership in a meaningful way and this was important because “... *ensuring the patient perspective is included in research produces higher quality and better research.*” As well, evaluation was viewed as a means of improving the partnerships and could help everyone, “*Get better at doing research together.*” (Participant 8, knowledge user).

I asked researchers why they did not complete evaluation of the partnering process. I specifically asked only researchers this question because of their typical role in leading research. Some researchers described what they perceived as challenges to evaluation. For instance, researchers were cognisant of not wanting to over burden partners with another task. One researcher (Participant 2) who has been involved in partnered rehabilitation research for many years stated, “*Um, I think that I'm always worried about the burden of participation. So, I try not to add layers, right.*” Additionally, researchers felt that the time it would take to complete an evaluation of the partnership would be a challenge. As one researcher (Participant 4) commented, “*.... but it is realistic or practical? I don't think so. It's just endless, the list of partners, right.*” Furthermore, there was inconsistency in knowledge about the availability of existing tools for evaluation. For example, some researchers were unsure if tools existed, whereas other researchers were aware of tools to evaluate partnerships.

Even though no formal evaluations were conducted, researchers explained that they “checked-in” informally with knowledge users during the partnership to ask how things were going, and how they were feeling about their involvement in the partnership and research process. As one researcher (Participant 4) explained, “*I'm checking in with the partners that I'm engaged with, about how this [partnership] is going for them. Is there anything that's kind of a barrier, is there anything that we can do to make things easier?*” One knowledge user (Participant 8) commented that even though the researchers did not evaluate the partnering process, they

(knowledge user) conducted their own “informal” assessment of the partnership. In this case, the knowledge user provided feedback to the research project team leaders, but unfortunately, *“the team leader was not always open to the feedback.”*

Overarching theme: The Effects are Extensive

Despite the lack of formal evaluations, all participants described effects of partnering on research process and outcomes, and how they believed the partnership contributed to these effects. My analysis of the perceived effects of partnering in rehabilitation research generated one overarching theme, “The Effects are Extensive” (Figure 3). This overarching theme captured participants’ perceptions that the effects covered a wide range of possibilities, including effects on the research process, outcomes, or individuals involved in partnering. To capture specific effects of the partnership, I constructed two sub-themes, “Beginning, Middle, and End”, and “Opportunity for Learning.” I generated a third sub-theme, “How Partnering Influences Effects,” which described participants perceptions on various factors related to partnering, e.g., contextual, structural, individual, or relational, that contributed to effects.

## The Effects are Extensive

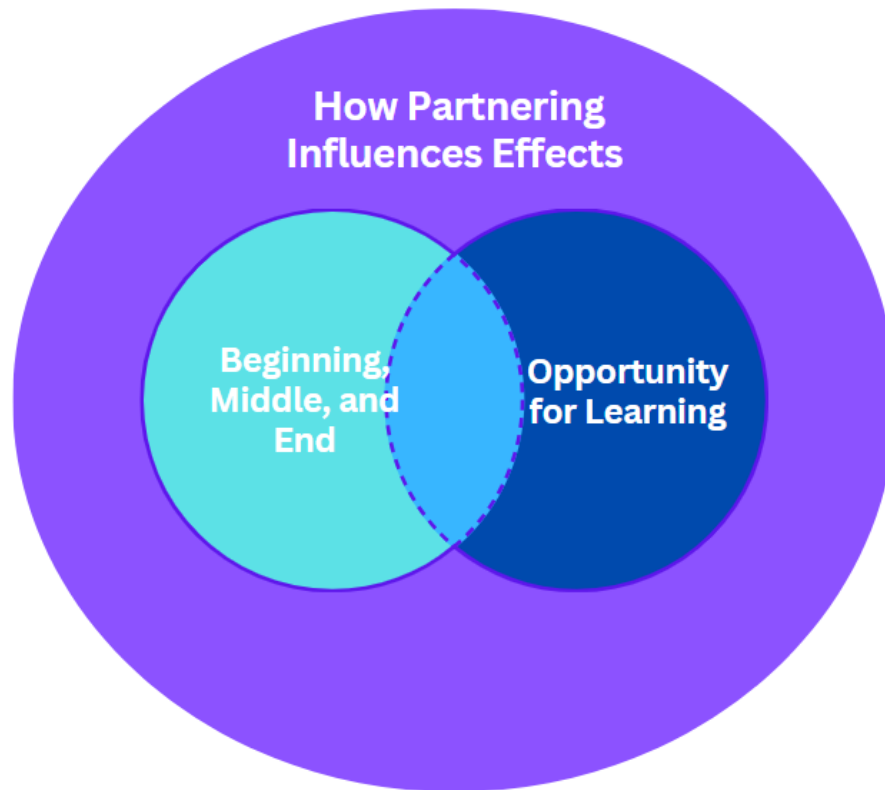


Figure 3. Themes and sub-themes about the effects of partnered rehabilitation research

*Sub-theme: Beginning, Middle, and End*

This sub-theme reflects participants' perceptions that partnering was associated with effects on the research process that occurred throughout the life of a project, as well as effects on research outcomes, i.e., research findings, that would be apparent after finishing a project, as well as their application. One knowledge user (Participant 9) perceived that because their workplace was involved in partnering on rehabilitation research, it created, "... a legacy for our centre" and more employees became engaged in research.

Both researchers and knowledge users recognized that including a variety of perspectives in study preparation and planning helped people to look at research problems in different ways and ensured all solutions to a problem were considered. Furthermore, participants commented on how working together affected the development of the research questions. Researchers

acknowledged that when they collaborated with knowledge users on identifying research questions, the questions were more clinically applicable than if the researchers defined them on their own because they included perspectives from knowledge users regarding what was happening in real-world practice. As participant 6 (researcher) stated, “...[the] questions are much more targeted to what is clinically useful.” Furthermore, clinically applicable questions resulted in research that, “...was more relevant for them [knowledge users].” (Participant 2, researcher). Participants also noted that during study preparation and planning, a partnership that included different types of expertise strengthened the research design. As one researcher (Participant 2) stated, “the study design is richer because you have broader and different types of expertise that are consulting on it.”

There were also perceived effects of partnering on the middle phases of the research process, such as recruitment, data collection, or analysis/ interpretation. Both researchers and knowledge users explained that partnering influenced the design of study advertisements to make them attractive to potential participants. As one knowledge user (Participant 11) explained, they advised the research team to refine a study advertisement looking for people who survived a stroke, and suggested the researchers needed to, “...take off their “application writing skills” and talk in a lay language.” Furthermore, researchers perceived that partnering led to data collection methods that were more feasible because knowledge users were able to provide insight on the clinical environment to ensure data collection is convenient. Both researchers and knowledge users believed that during data analysis, knowledge users helped interpret data and think about how the results were applicable and useful. Participant 5 (researcher) explained that when looking at findings together, it helped partners to think about, “...how could this [finding] be useful to people? How can it actually be used in practice?”

Participants described how partnering in rehabilitation research influenced the end phases of the research process, i.e., dissemination of research outcomes. The effects of partnering on dissemination included how to write research findings in a way that creates an impactful message. As well, several knowledge users were involved in manuscript writing which they perceived as important because they could ensure the correct language was being used for the audience of the publication. Partnering also influenced dissemination at conferences. One

researcher (Participant 4) spoke about when knowledge users attended research conferences with them, during workshops or panel discussions they [knowledge users], *“bring a perspective that researchers cannot. And so, and so it does help immensely with the effectiveness of the delivery or sharing or dissemination.”*

Specific to research outcomes, one knowledge user spoke about how partnering affected the production of useful research findings and the effect of this. This knowledge user was involved in a partnership in which they developed the research questions and methods for a study that investigated if and how often in-patients with a prosthesis wore their prosthesis when not doing rehabilitation. The findings showed that in-patients wore their prosthesis very little when not participating in rehabilitation and this finding resulted in development of recommendations to guide in-patients when to wear prostheses throughout the day. The recommendations were implemented by the knowledge users and other rehabilitation clinicians. As the knowledge user (Participant 13) said about the findings, *“... they were immediately used to change clinical practice.”*

Participants perceived the partnering process as the vehicle for establishing, strengthening, and sustaining relationships amongst researchers and knowledge users, and was key to, *“laying the foundation for partnerships that last overtime.”* (Participant 3, researcher). Furthermore, knowledge users perceived that being involved in the partnership connected them to published research in their area of practice because of the opportunity to conduct literature searches. Lastly, one knowledge user perceived partnering benefitted their organization because it strengthened and increased the organization’s involvement in research including the publication of their research.

#### *Sub-theme: Opportunity for Learning*

This sub-theme highlights that both researchers’ and knowledge users’ experiences within the partnership led to individual effects including learning opportunities that arose through partner interactions and active involvement in the research process. Participants described their learning as an individualized experience as a result of partnering. For instance, many researchers spoke about how they perceived the research partnership as an opportunity to learn from the knowledge users and especially enhance their own partnering skills. Many

researchers believed this could ultimately, “... *make me a better partnership partner [and] researcher.*” (Participant 7, researcher).

Both researchers and knowledge users recognized that being involved in the partnership expanded their own research capacity, i.e., personal research knowledge and skills, such as learning about different research methodologies, different ways of thinking about research, developing research questions and how to answer those questions, and writing for manuscripts. As one knowledge user (Participant 9) explained, the partnership helped to teach them “...*what are good questions to ask. And how to go about [answering] that.*” Partnering was also an opportunity for knowledge users to learn how to think critically about research. One knowledge user (Participant 10), who was just beginning to gain experience in partnered rehabilitation research stated,

*“But I think also going through it ourselves was also helpful in understanding the limitations as well. You know both the good and the bad of research, right”*

Researchers also commented how partnering increased their chance to learn about the healthcare system. As Participant 1 (researcher) explained, “*I think that these partnerships are the kind of the vehicle that we're able to use to create understanding of the breadth of the healthcare system.*” Furthermore, the partnership was an opportunity to learn how services, like rehabilitation and homecare, were organized and delivered within the healthcare system. One researcher (Participant 7) discussed how they gained new insight into how speech and language pathology services were provided in clinical settings, like hospitals. Furthermore, this participant learned which questionnaires were being used to assess speech and language difficulties in clinical practice. The knowledge gained about the state of the clinical field influenced their teaching at the university. Additionally, by partnering with rehabilitation clinicians on research in a hospital setting, the same researcher developed a better understanding of the research that was being conducted within the healthcare facility, the types of internal funding resources that were available to clinicians to conduct research, and the support that managers could provide to front-line speech and language pathologists to participate in rehabilitation research.

Lastly, partnered rehabilitation research was an opportunity for students involved in research partnerships to learn from knowledge users as well. One researcher (Participant 4) commented that knowledge users they partnered with were willing to engage with students and trainees, and how that enriched learning opportunities. *“They're very happy to share and provide feedback, so they will often attend presentations or look at the script that a student may have written for them to narrate in these products that we develop and they, uh will often stop us and say, look, this is not going to be very useful. The language is too difficult to understand. Your student is speaking too fast.”*

*Sub-theme: How Partnering Influences Effects on the Research Process, Outcomes, and Individuals*

This sub-theme reflects how researchers and knowledge users perceived contextual, structural, relational, and individual factors of partnered rehabilitation research influenced effects on the research process, outcomes, or individuals.

Contextual factors

Some knowledge users highlighted how contextual factors such as support from departmental or organizational leaders contributed to positive effects of the partnership. One knowledge user who was employed in a private healthcare setting and partnered with researchers from an academic institution shared how the leadership at their workplace appreciated, prioritized, and supported evidence-based practice and research. This organization wanted to be a centre of excellence and believed that partnering with an academic institution to work together on rehabilitation research was one way to achieve this goal. As this knowledge user (Participant 9) stated, *“But I think it was easier [to partner] because of having that support and not having to fight for it, right?”*

However, this sub-theme also reflects researchers perceived several contextual factors beyond their control that influenced the effects of partnering. For instance, researchers spoke about the challenges with obtaining funding to support partnerships because often funding is only for the research process. One researcher described how they often self-funded for partnering activities, at least until they received grant money. As well, researchers shared that it was often a challenge convincing ethics boards that the compensation they wanted to provide knowledge

users was reflective of the expertise the knowledge users brought to the partnership, and not coercion. Another researcher (Participant 2) perceived that funding agencies required knowledge users to, *“jump through hoops to be on a grant”* and relayed that knowledge users had a lot of paperwork and training to complete. Lastly, researchers admitted that COVID also impacted their partnered rehabilitation research, *“Losing five of the six partners during COVID, they just couldn't handle it because they barely were operating themselves, right.”* Participant 4 (researcher).

As well, both researchers and knowledge users acknowledged engaging in a partnered approach to research was time-consuming and took a lot of work. Researchers also perceived that knowledge users didn't always understand components of the research process and the time it takes to conduct research well. However, researchers also acknowledged that they may not understand the barriers from clinical practice that influenced the partnership process.

*“Because I think you know the realities of clinical practice and the time constraints and the competing demands. Researchers don't always understand those things because they're not in that environment.”* Participant 3 (researcher).

#### Structural factors

Many participants commented on how they perceived structural factors related to partnering promoted positive effects. For instance, one researcher (Participant 4) explained that their partnerships had a point of contact who was, *“An individual [that] just coordinates and makes sure that everyone is doing what they should be doing.”* Furthermore, many of the researchers commented that they created terms of reference materials, research agreements, or charters. While the researchers did not explicitly define what these were in the interviews, one researcher described their research agreement as a guide that would keep all the partners on the right track while they were collaborating on a research project. Another researcher described the charter they use as,

*“... a document that says like this is what our objective is. This is how often this is how we're gonna meet. This is the authorship rules. These are your options for communicating all these, like we'll do that kind of stuff.”* Participant 2 (researcher).

## Relational factors

Relational factors, that is how the partners behaved and interacted amongst each other during the partnership, was another component of partnering that contributed to the effects identified by interview participants. Many different aspects of relationship dynamics were mentioned as factors influencing the effects of the partnership including trust, reliability and accountability, role definition and clarity, showing an interest in partners, respect, recognition, acknowledgement, and showing partners were valued.

*“I think also it was really nice knowing that as an academic, she respected what we saw as a research question, right. So that was the other thing is that there was this, it wasn't lesser than or you know just because it was coming from a clinical place.”* Participant 9 (Knowledge user).

When asked to elaborate on how respect was shown to them by researchers, one knowledge user (Participant 10) explained, *“It meant feeling my voice was heard. It meant open, transparent information sharing.”*

One additional relational factor that influenced the partnership was minimizing power imbalances or differentials. Many participants spoke about how all partners should be on equal footing and the partnership must develop a level playing field for everyone. When pressed further to explain how power imbalances were prevented or reduced, one researcher spoke about how they presented themselves and interacted with knowledge users.

*“I only use my first name. I don't wear a lab coat. I use a co-leadership model. Having the space and time to listen, to engage and get to know people. Taking the time to hear their [knowledge users] thoughts.”* (Participant 5).

However, some knowledge users highlighted relational factors that negatively influenced partnering. For instance, they spoke about not being given the opportunity to provide feedback to researchers on research applications, not being listened to in a partnership, and the predominance of white, female voices being represented in partnerships. As participant 8 said, *“Only one voice is being represented, that is a white, middle-class person.”* The same knowledge user also commented that they were invited to be involved in a partnership and had several

years of lived experience with a health condition but felt like a token during their experience, *“I felt like a token; not being heard, listened too, and understood. I felt like a voice on the margin.”*

#### Individual factors

Both researchers and knowledge users stated that individual factors such as interest, curiosity, and enthusiasm; being open-minded, adaptable, and motivated; and collaborating on the research problem also contributed to positive effects of partnering. As Participant 10 (knowledge user) explained, *“We cheerfully would take on problem solving together.”*

Researcher humility, that is acknowledging the limits of one’s knowledge, was another individual factor that participants felt contributed to positive effects of partnering. As one researcher (Participant 3) stated,

*“You have to acknowledge that what you see as a researcher is one tiny slice and you really have to be reliant on others to guide you.”*

#### Discussion

The aims of this qualitative descriptive study situated in a Canadian context were to explore evaluation, perceived effects of partnered rehabilitation research on the research process and research outcomes and how partnering contributed to the effects. I found that participants did not evaluate the partnerships they were involved in. However, researchers explained that “informal check-ins” took place during the partnership to ask knowledge users about their level of satisfaction with the partnerships. Camden et al<sup>21</sup> also reported informal check-ins were a common strategy to touch-base with knowledge users. Camden et al<sup>21</sup> referred to this approach as “debriefing,” which only occurred after the partnership ended. While informal check-ins were helpful to determine if changes needed to be made to the partnering process, using standardized tools or instruments to evaluate the partnering process may accurately capture effects without relying solely on researchers’ or knowledge users’ perceptions. The use of high-quality standardized tools or instruments to evaluate partnerships may be particularly helpful to identify medium or long-term effects of the partnering process on health outcomes or the healthcare system, evidence which is currently lacking. Future studies could investigate why the evaluation tools identified by Mrklas et al<sup>121</sup> are not used to evaluate rehabilitation

partnerships, and whether these tools are acceptable, appropriate, and feasible of the tools identified for use by individuals in partnered rehabilitation research.

Even though participants did not evaluate the partnering process, they perceived evaluation was valuable, which is a new finding that is important because it demonstrates a positive attitude towards it. However, in my study, acknowledging the value of evaluation did not translate into evaluating partnerships. When questioned why evaluation was not completed, researchers described perceived challenges with evaluation. Understanding existing barriers is helpful as these results may guide interventions which could facilitate evaluation of the partnering process. My study did not aim to explore the barriers of evaluation in depth and may have not identified all of them. As well, I did not explore ways to facilitate evaluation, which is another important topic to investigate. As such, future research that examines the barriers and facilitators to evaluation of partnered rehabilitation research could be a valuable next step in understanding why partners do not evaluate partnered rehabilitation research. Findings from this research could be used to inform strategies, approaches, or interventions which could facilitate evaluation of the partnering process. I elaborate on future research opportunities for evaluation in chapter six, and comment on using a model of behavior change, the COM-B model, for this research.<sup>122</sup>

Findings from my interview confirm our understanding of the individual effects of partnering. For instance, Camden et al<sup>21</sup> found that knowledge users involved in partnered rehabilitation research experienced individual effects such as empowerment and increased confidence because of learning how to access resources, social supports, and belonging to a group. Similar to my study findings, Camden et al<sup>21</sup> also found that power sharing, a relational factor, was essential for partnered research because it established a common ground for partners and helped to promote an environment which allowed for negotiation of study agendas, resolved conflicts, and supported meaningful engagement, teamwork, and collaboration. Rycroft-Malone et al<sup>123</sup> highlight that partnered approaches to research should be equity-driven and ensure they include processes for power sharing. However, imbalances in power-sharing within partnered health research continue and create hierarchies between researchers and knowledge users.<sup>124</sup> These hierarchies perpetuate unconscious biases, and patient partners report that they

perceive that their lived experiences are given less credit and respect compared by researchers.<sup>124</sup> Consequently, patient partners have reported feeling less important, not as smart as other team members, “lesser” than other partners, and not worth the time, effort, or resources to be engaged.<sup>124</sup> Rycroft-Malone et al<sup>123</sup> acknowledge relinquishing power and influence in partnered research can be a challenge but argue researchers must adapt to an equitable way of conducting research with knowledge users. To do so, creates a space where differences in knowledge, perspectives, and viewpoints are equally embraced and have the capacity to contribute valuable insights into health research.<sup>123</sup>

Studies specific to partnered health research have previously reported on individual effects of partnering such as increased knowledge, capacity, and skills for research, confidence, self-efficacy, enhanced health behaviors, feeling valued, and building trust.<sup>23,27,121</sup> As well, findings from partnered health research have identified and described several principles and strategies that can be used to plan and conduct partnered research thus potentially enhancing the optimization of these partnerships, leading to positive effects.<sup>27</sup> Many of the participants from my interviews identified factors that were consistent with these principles and strategies including respect, minimizing power differentials, role clarity and definition, the use of terms of reference or charters, and engaging with knowledge users in various phases of the research process.<sup>121</sup> I discuss the implications of the similarities in findings between partnered rehabilitation and partnered health research in chapter six.

The findings regarding the effects on the research process may confirm the integrity of partnering was upheld. As I discussed in chapter two, Jull et al<sup>15</sup> identified 15 concepts of knowledge user engagement that can be used to guide how researchers and knowledge users’ partner throughout the research process. The concepts identified by Jull et al<sup>15</sup> included: 1) researcher: prepare/support, 2) knowledge user: prepare/support, 3) relational process, 4) research agenda, 5) ethics: principles/values, 6) research questions, 7) resources, 8) ethics: policy/rules, 9) methodology, 10) methods, 11) collect data, 12) analysis, 13) disseminate, 14) evaluate, and 15) sustain. Table 2 provides more details on the 15 concepts. Interview participants discussed and shared examples of how partnering was upheld across all the

concepts except for evaluation. This is an encouraging finding as suggests that the integrity of the partnering process was upheld.

Despite assumptions that partnered rehabilitation research can enhance effects on the uptake of evidence thus minimizing the evidence to practice gap, most participants in my interviews did not really provide insights into this. Only one knowledge user described a concrete example of how the partnering process enhanced the use of evidence in clinical practice and changed practice recommendations. It was surprising that more participants in my study didn't provide examples of uptake of evidence in practice. Its concerning that partnered research presents itself as a solution to the gap between evidence and practice considering the evidence to substantiate this assumption is limited. However, only two knowledge users in my study were rehabilitation clinicians and if I had interviewed more of these knowledge users, from a variety of clinical settings, I may have heard more examples of how partnering enhanced evidence uptake. Furthermore, I should have asked participants for explicit examples of when they perceived the partnership enhanced the uptake of evidence. Probing participants on this specific assumption of partnered rehabilitation research, may have generated more examples. However, speaking to one of my earlier points, I wonder if this is a situation where standardized tools or instruments could be more accurate in identifying evidence uptake, an effect that may not be experienced in the lifetime of a research partnership, compared to interviews.

#### Strengths

I used several different strategies to enhance trustworthiness of my study including member checking, field notes, and thick description. Member checking can ensure accuracy of interview transcripts. I asked all participants if they would like to review their transcript and one interview participant agreed to. They reported the transcript was accurate, as such, I did not make any changes to it. The field notes I kept informed the interview process. For instance, I used insights from the field notes to remind myself to keep the interview questions clear and concise, and not over explain the questions to the interview participants. Furthermore, as I was analyzing the results, I compared my initial impressions about evaluation and effects I kept in my field notes to the preliminary themes I was developing. This ensured I was reflecting on my positionality and how it may have influenced analysis and interpretation. For instance, my initial

impressions of partnered rehabilitation research tended to be very positive, and I thought about how those impressions could have been influenced by my experiences and perspectives with partnering. By using thick description, I was able to provide a deeper understanding of contextual factors that influenced participant experiences in partnered rehabilitation research. Using thick description could also enhance the transferability of my findings to other individuals involved in partnered rehabilitation research in Canada. Lastly, I used a sampling approach and recruitment strategies to ensure my sample included a wide range of perspectives from individuals who were engaged in partnered rehabilitation research in various contexts in Canada and was able to recruit several knowledge users to my study.

#### Limitations

There are a couple limitations of my study. It is important to acknowledge that despite using an intentional and systematic recruitment approach to ensure maximum variation sampling, my sample primarily identified as female and white. I was only able to recruit one male to my study and none of the study participants identified as Black, Indigenous, or People of Colour (BIPOC). These findings are consistent with some published research that has described the socio-demographics characteristics of individuals engaged in partnered research.<sup>125</sup> For instance, researchers and knowledge users in Canada involved in patient-oriented research are more likely to be women and white.<sup>125</sup> In this regard, my sample is consistent with who is typically represented in partnered research which may enhance the transferability of results. However, the fact that perspectives of BIPOC researchers and knowledge users were not included in my study, is problematic. I theorize it likely represents a much larger systemic issue regarding lack of representation of these individuals in academia, specifically rehabilitation research and rehabilitation educational training programs. As well, the under-representation of BIPOC knowledge users may reflect their personal experiences with the healthcare system. BIPOC people are more likely to experience racism in healthcare,<sup>126,127</sup> and this may influence their interest in being involved in partnered rehabilitation research. However, investigating why BIPOC people are under-represented in partnered rehabilitation research could be a topic for future research.

Furthermore, individuals had to understand and speak English to be eligible for the interviews because that is my only language. However, this restriction may have inadvertently dissuaded individuals from participating, especially those who speak English as a second language because they may have not felt comfortable conversing in English. As such, the experiences and thus perspectives of individuals whose first language is not English and who are involved in partnered rehabilitation research, may have been overlooked. Lastly, involvement in the study was voluntary and may reflect the perspectives of individuals with a vested interest in partnered rehabilitation research.

Lastly, the intersection of being a white female researcher and licensed physiotherapist who is involved in partnered rehabilitation research, likely influenced data analysis and interpretation. However, I took several steps to mitigate the impact of these influences. As mentioned, in the strengths section, I used member checking and kept field notes to monitor and minimize biases. Furthermore, I engaged in frequent dialogue with my committee to discuss the coding process and themes and reflect on how my positionality may have influenced them.

### Conclusion

Partnered rehabilitation research was not evaluated by participants in the interviews. Despite the lack of evaluation, participants perceived there were many effects of partnering on the research process, outcomes, and individuals. Furthermore, participants perceived that there were many contextual, individual, structural, and relational factors which influenced partnering and effects. Unfortunately, there were almost no insights on whether partnering enhanced evidence uptake, despite the assumptions this approach does do so. Future research could investigate why partnered rehabilitation research is not evaluated or why brown, black, and Indigenous people are not involved in partnered rehabilitation research.

## Chapter six: Integration of research findings

I begin chapter six by restating the purpose of my thesis and summarizing the key findings from my survey and interview studies. Following this, I present a high-level summary of the integrated results and present a revised conceptual framework for evaluation of partnered rehabilitation research on a theme-by-theme basis. Within each theme, survey and interview results are woven together to explain the theme in depth. Lastly, I conclude chapter six by discussing the strengths and limitations of my overall approach to my thesis.

### Purpose and summary of research findings

The purpose of my thesis was to investigate the evaluation and effects of partnered rehabilitation research on the research process and outcomes through a pragmatic lens using an explanatory sequential mixed methods design. My first study was an observational, cross-sectional online survey situated in an international context that examined the features, evaluation, and perceived effects of partnered rehabilitation research. The key findings were over half of respondents (mostly white female, researchers, living in Canada) reported evaluating, or that they were going to evaluate their partnerships. These respondents reported using or intending to use a mixed methods approach that included internally developed tools or instruments, i.e., created by the research team, such as (but not limited to) surveys, questionnaires, or checklists, focus groups, or interviews. Furthermore, respondents indicated partnerships had significant effects on most phases of the research process including (but not limited to) setting research priorities and questions and disseminating results to non-academic audiences. Respondents indicated partnerships had a significant effect on research outcomes including knowledge user empowerment, knowledge users' knowledge about the research process, production of useful research findings for the knowledge users involved in the partnership, and evidence-informed clinical decision making in healthcare by knowledge users. However, results need to be interpreted with caution because data from only fourteen participants were included in analysis.

My second study was a qualitative descriptive study that used interviews to explore the perspectives of researchers' and knowledge users' experience of evaluation and effects of partnered rehabilitation research in more depth. Situated in a Canadian context, this study

aimed to learn more about evaluation, such as but not limited to, tools or instruments used to evaluate the partnering process, perceived effects of the partnerships on the research process and outcomes, and perceptions about how partnering contributed to the effects. I interviewed thirteen individuals: seven researchers and six knowledge users. One key finding was none of the respondents reported evaluating the partnerships they were or had been involved in. However, researchers described informally checking in with study partners during the partnerships to ask how the research process was going. Another key finding was that the effects of the partnership were more extensive than just on the research process or outcomes. For instance, respondents spoke about individual effects they experienced, such as enhancing their research capacity. Participants identified several contextual (support), individual (humility), or relational factors (respect, trust) specific to the partnering process that contributed to the effects. However, many participants spoke about factors beyond their control that affected partnering such as expectations from funding organizations or ethics committees.

#### Conceptual framework for evaluation of partnered rehabilitation research

My research set out to answer two overarching questions, “how has partnered rehabilitation research been evaluated”, and “what are the effects on the research process and outcomes.” I propose a revised conceptual framework, “Conceptual framework for evaluation of partnered rehabilitation research,” herein afterward referred to as the conceptual framework for evaluation, based on findings from my studies that answer my overarching research questions. This framework illustrates how evaluation of partnered rehabilitation research could contribute to our understanding of the effects of partnering on the research process, outcomes, and individuals. I present this conceptual framework below in Figure 4.

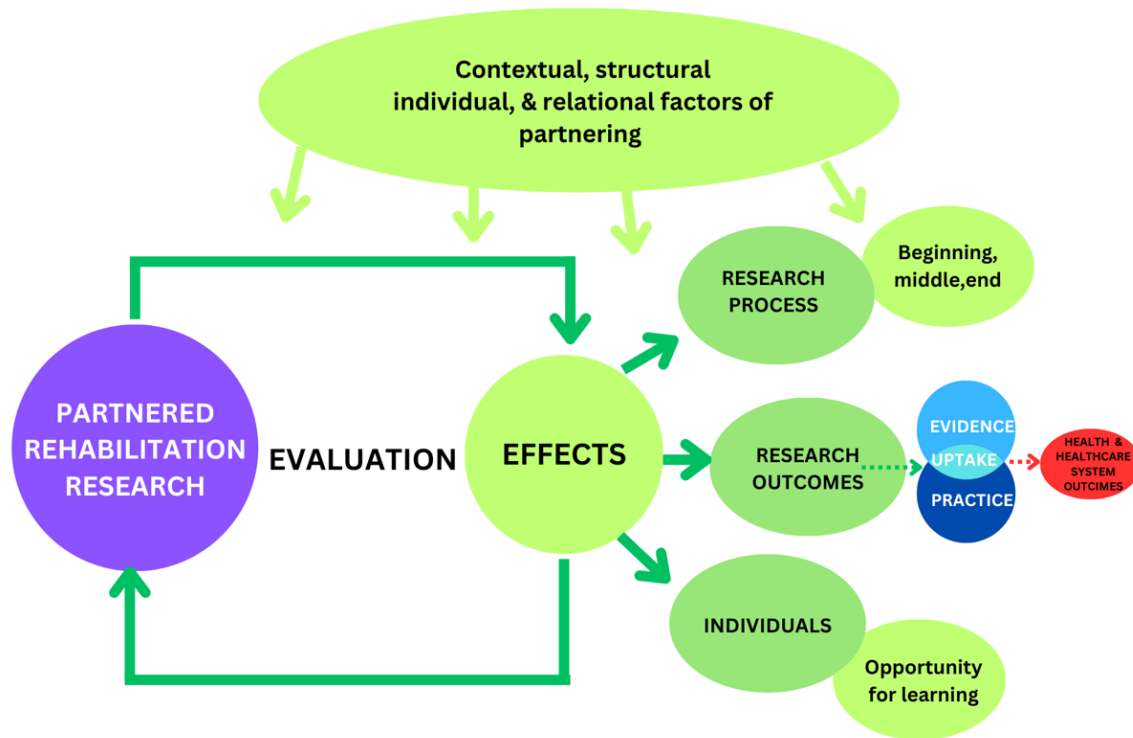


Figure 4. Conceptual framework for evaluation of partnered rehabilitation research

#### High-level summary

The conceptual framework for evaluation of partnered rehabilitation research is an evolution of the conceptual framework I proposed at the onset of my thesis based on findings from my studies. The first difference in the conceptual framework for evaluation is that it includes the concept of *evaluation*, which was not a part of the original framework for my thesis. I added this because it represents the “ideal” behavior, and I wanted to explicitly highlight its potential value in identifying effects of the partnering process. Furthermore, the conceptual framework for evaluation differentiates the perceived effects of partnered rehabilitation research into effects on the *research process*, *research outcomes*, and *individuals*, which is reflective of the findings from my studies. Like the initial framework, the conceptual framework for evaluation includes the assumption that partnered rehabilitation research can enhance evidence uptake thus influencing health outcomes and the healthcare system. However, as I discuss below, assumptions about how partnered rehabilitation research affects health outcomes and the healthcare system, remain unclear. Unfortunately, the findings from either study did not

provide much insight on effects beyond the research process, outcomes, or individuals. I convey this uncertainty as a dotted line. Lastly, the conceptual framework for evaluation includes how effects of partnering influences partnered rehabilitation research. I expand on the conceptual framework for evaluation of partnered rehabilitation research below by examining the concepts in the framework theme-by-theme.

#### Evaluation

There was discordance between the data sources with regards to the extent to which partnered rehabilitation research is evaluated. The significant disparity between the survey and interview participants on evaluation, may be a novel finding. Many survey respondents, but not all, indicated they had or were going to evaluate the partnership. This is not a new finding. Furthermore, my findings were consistent with existing research that identified tools, questionnaires, and instruments were used to evaluate partnerships.<sup>21,28</sup> I viewed the interviews as an opportunity to learn more about evaluation, including the tools or instruments used to evaluate partnering. In contrast to the survey respondents, no interview participants evaluated the partnering process. I was surprised by this unexpected finding considering many survey respondents indicated they had or were going to evaluate the partnering process. However, interview participants perceived evaluating the partnership could be valuable which is an important new finding as it may suggest positive attitudes towards evaluation. Unfortunately, I am unable to provide deeper insight on evaluation, or the tools or instruments used to evaluate partnerships such as how they were developed, what informed them, and precisely what aspects of partnering they evaluated. Overall, findings from the survey and interviews offer a couple of new insights but mostly confirm what we already knew about evaluation of partnered rehabilitation research. Despite several years passed since studies on evaluation of partnered rehabilitation research were first published, my findings suggest that progress in this area has been limited, and significant challenges remain. My study results highlight that difficulties specific to evaluating the partnering process currently exist.

As mentioned, I included evaluation in the revised conceptual framework because it represents the ideal behavior, even though there was discordance between my two data sources.

Theoretically, evaluation plays a role in identifying the effects of partnering, and while my

research may provide some insight into understanding the causal mechanisms of partnering, that is how partnering contributes to effects, future research could further confirm these mechanisms. As such, there is potential for the relationship between partnering and effects to be more deeply understood than it currently is. A valuable starting point for future studies could be to understand barriers and facilitators that influence evaluation of partnered rehabilitation research. For instance, research could investigate evaluation in more depth using an existing model like the COM-B model.<sup>122</sup> The COM-B is a behavior change model that theorizes for any behavior to occur three interconnected components are necessary: capability (C), i.e., knowledge, skills, and ability; opportunity (O), i.e., external factors influencing behavior; and motivation (M), i.e., internal cognitive processes that influence decision-making and behavior.<sup>122</sup> As such, the COM-B can be used to understand why evaluation of partnered rehabilitation research, does or does not occur.<sup>122</sup> The COM-B may be an appropriate model to use for investigating evaluation of partnered rehabilitation research because evidence indicates it has the ability to explain behavior,<sup>128</sup> it has been used successfully in a variety of contexts, including rehabilitation,<sup>129</sup> and it can be used in conjunction with the Behavior Change Wheel (BCW), a framework to identify intervention functions and policy categories to develop interventions that may lead to behavior change.<sup>122</sup> The COM-B can be used to identify barriers or facilitators specific to capability, opportunity, and motivation that influence evaluation of partnered rehabilitation research. Based on those findings, the BCW can be used to inform interventions to enhance evaluation of partnered research.

#### Effects of partnered rehabilitation research

The conceptual framework for evaluation includes the effects of partnered rehabilitation research that were confirmed and described in my studies (research process, outcomes, and individuals). The relationship between partnering and effects is shown as a solid green line on the framework because findings from the survey and interviews found that partnering resulted in effects.

#### *Effects on the research process*

Survey respondents perceived partnerships influenced all phases of the research process, from beginning to end. For example, many survey respondents perceived partnering significantly

influenced developing research questions. From the interviews, participants provided insights on how the partnerships affected this early phase in the research process. Interview participants explained that partnerships contributed to developing questions that were more clinically relevant for knowledge users by incorporating their perspectives on the phenomenon under study. Furthermore, during the interviews researchers spoke about learning to listen and give space to knowledge users to share their perspectives thus providing valuable insights to the early phases of the research process like developing research questions. This is important because research questions aligned with the priorities and needs of knowledge users may facilitate the use of research findings to inform clinical practice, improve rehabilitation delivery, and guide the development of rehabilitation policies.

My studies confirmed insights on the middle phases of the research process. For instance, most survey respondents perceived that partnering significantly influenced recruitment, data collection, analysis, or interpretation. During the interviews, participants provided more details and specific examples of how partnering affected this phase. Participants described how partnering contributed to better recruitment methods and practical data collection approaches. These are important because knowledge user insight into participant recruitment may increase study participation, combatting the difficulty in recruiting study participants. Knowledge users' perspectives on data collection may ensure proposed methods are feasible or realistic. Partnering also enhanced data analysis and interpretation of study findings which is important because researchers and knowledge users may have different perspectives on what research findings mean. Ensuring research findings are interpreted through a knowledge user lens may enhance which findings are used to inform rehabilitation and how.

Lastly, findings from my studies also deepen our knowledge about how the partnerships affected the end stages of a study, such as dissemination. Nearly all survey respondents perceived the partnerships had a significant effect on dissemination to non-academic audiences. During the interviews, participants explained the value of knowledge users partnering in dissemination activities, such as writing manuscripts or attending conferences, because it improved the effectiveness of sharing research findings with target audiences. This is a novel finding about partnered rehabilitation research and is valuable because it provides

insights onto how researchers and knowledge users can collaborate during dissemination to potentially optimize knowledge sharing. Furthermore, these results may highlight the value of including knowledge users in manuscript writing and research conferences. As well, disseminating findings via partnering with knowledge users could influence how acceptable the findings are to other individuals, especially knowledge users.

#### *Effects on research outcomes*

The conceptual framework for evaluation includes the effect of partnering on research outcomes. Most individuals who responded to the survey perceived that partnering significantly influenced sustainability of the partnerships, which is a new finding specific to partnered rehabilitation research. During the interviews, both researchers and knowledge users explained that partnering on research ultimately strengthened the relationships between researchers and knowledge users. Subsequently, this could result in partnerships that were maintained over time, even when research was not going on. In the conceptual framework for evaluation, I created a feedback loop from effects to partnered rehabilitation research to indicate effects influence the partnership. This is depicted as a solid green line because findings from my research substantiate this.

Survey findings also indicated a high proportion of respondents perceived the partnership resulted in significant or moderate effects on evidence-informed clinical decision making in healthcare by knowledge users and the production of useful research findings for knowledge users. In the interviews, knowledge users discussed how the partnership gave them the chance to use best practices in clinical settings. One knowledge user explained that findings from partnered rehabilitation research were used to change and improve practice. These are new findings specific to partnered rehabilitation research are encouraging because they advance our understanding of effects on research outcomes and offer insight into the value of partnered rehabilitation research beyond the research process. As well, the results may confirm that partnered rehabilitation research enhances the uptake of research findings. Evidence uptake in rehabilitation remains a challenge. Knowing that partnerships can facilitate this process may encourage knowledge users in healthcare settings to engage in partnered rehabilitation research, especially if they aim to strengthen evidence-informed decision-making. Furthermore,

these findings can support advocacy for the involvement of knowledge users in partnered research and for dedicating time or resources to facilitate their involvement, targeting supervisors, managers, or directors of rehabilitation departments, clinics, or organizations.

While findings from my studies show that partnering influenced the uptake of evidence, neither the survey results or interviews provided conclusive evidence of how the uptake of evidence influenced health outcomes or how the healthcare system functions. This lack of evidence is problematic because partnered rehabilitation research explicitly positions itself as an approach to improve health outcomes, as well as the efficiency and effectiveness of the healthcare system. Despite the results, I kept health outcomes, and the healthcare system effects in the framework. The red dotted line between uptake and health outcomes and the healthcare system indicates they were not supported by my research and remain an assumption of this approach. However, depicting this relationship as a dotted line also suggests there is potential for a partnered approach to research to affect health outcomes and the healthcare system. Further evidence is needed to substantiate these claims.

Future research should investigate the effects of partnering on health outcomes and healthcare system. One way to achieve this may be by using high-quality evaluation tools. As I mentioned in chapter four, a systematic review conducted by Mrklas et al<sup>103</sup> identified several evaluation tools that could be used to evaluate partnered research, including the impacts and outcomes of partnering. To determine the quality of the tools, Mrklas et al<sup>103</sup> developed a checklist that consisted of four domains: Scientific Rigour, Partner Perspective, Comprehensiveness and Usability. Each domain had five items and was scored out of five.<sup>103</sup> The overall tool score was out of 25 and Mrklas et al<sup>103</sup> reported it as a percentage. Approximately 30% (n = 13) tools scored a minimum of 80% on their evaluation. Mrklas et al<sup>103</sup> also identified which tools were theoretically underpinned and had empirical psychometric evidence for validity and/or reliability. While none of the tools identified by Mrklas et al<sup>103</sup> were specific to rehabilitation, they may be applicable in partnered rehabilitation research. If future research confirms that the availability of tools for evaluation of partnered rehabilitation research would facilitate it, additional study could investigate the appropriateness (fit or relevance),<sup>130</sup> acceptability

(agreeability),<sup>130</sup> and the feasibility (successful use)<sup>130</sup> of implementing the high-quality tools identified by Mrklas et al.<sup>103</sup>

#### *Effects on individuals*

I included the effects of partnering on individuals in the revised conceptual framework. This was not something I anticipated in advance, but the data, particularly in the qualitative component, highlighted the importance of these effects. Both survey respondents and interview participants identified or described how partnering affected individuals. For instance, a high proportion of survey respondents perceived that partnering affected capacity for research and partnering. During the interviews, it became evident that partnering provided an opportunity to learn a variety of new things, not only about research and the participants' own capacity for conducting research and partnering, but also about the healthcare system. Many interview participants described what they personally took away from partnered rehabilitation research.

#### *How partnering contributes to effects*

As I analyzed the survey data, I wondered how partnering contributed to the research process and outcomes. I did not examine this in the survey, so I decided to explore this in the interviews. I discussed these results in depth in chapter five (interviews). As a recap, interview participants perceived many different factors of partnered rehabilitation research related to the context (supportive leadership), structure (terms of reference), individual (enthusiasm, interest, curiosity, humility), or how research and knowledge users worked together during research (respect, trust, accountability, minimizing power dynamics), contributed to the effects of partnering. There is virtually no information how partnered rehabilitation research contributes to effects of partnering. While both Camden et al<sup>21</sup> and Roberge-Dao<sup>28</sup> et al reported strategies to enhance partnering, this is different than examining how partnering contributes to identified effects. The interview findings captured new insights about contextual factors of partnering, e.g., ethics boards and COVID, that influence the effects. These findings advance our understanding of factors related to partnering that contribute to effects. Identifying and understanding partnering factors that influence effects is important for both researchers and knowledge users as this information can help inform how individuals work together during the

research process. I included these factors in the conceptual framework and depict them as directly influencing partnered rehabilitation research and thus potentially contributing to effects.<sup>131</sup>

Purpose of conceptual framework for evaluation

The conceptual framework for evaluation of partnered rehabilitation research can be used to inform future research about evaluation, such as confirming how evaluation identifies the effects of partnering. As well, the framework can be used to inform research that examines how a partnered approach affects health outcomes and the healthcare system. Lastly, because the framework includes concepts specific to the effects of partnering, it can be used to justify a partnered approach to research.

### Strengths

One strength of my thesis was the use of mixed methods methodology to help me understand evaluation and effects of partnered rehabilitation research on the research process and outcomes in more depth. Mixed methods are an approach that can provide a thorough understanding of a research problem that has not been fully investigated. There were few published studies on partnered rehabilitation research and a mixed methods approach allowed me to comprehensively investigate this phenomenon and expand on the existing partnered rehabilitation research literature. Furthermore, by using mixed methods, I was able to compensate for the small survey sample and lack of knowledge user respondents by conducting interviews. For instance, because the interviews included the perspectives of six knowledge users, I was able to confirm effects of partnering they experienced such as, enhanced research capacity and skills, evidence uptake, and changes to clinical practice, instead of relying on researcher perspectives only. Furthermore, the data from the interviews provided a deeper understanding of several factors that influenced the partnering process, a topic I did not examine in the survey. Information on factors of partnering which contributed to the effects deepening our understanding of the mechanisms of partnering.

### Limitations

I acknowledge the limitations of my research. Firstly, I developed a new, umbrella term to capture the many approaches that researchers and knowledge users can use when

collaborating on rehabilitation research. However, this term is not well represented in existing literature. As such, using this term for literature searches likely influenced how much available literature there was to inform aspects of my research.

Secondly, one challenge to conducting research in rehabilitation is that rehabilitation is often poorly defined.<sup>3</sup> When rehabilitation is poorly defined, it may lead to uncertainty into what it is, what it is meant to achieve, who it is for, and how it should be evaluated.<sup>2,70,132</sup> Subsequently, this may affect the credibility of rehabilitation,<sup>70</sup> making it susceptible to decreases in resource allocation, such as funding for rehabilitation staff or programs. Furthermore, definitions of rehabilitation are at times not evidence-based either, which can make it challenging to quantify rehabilitation or may even hinder rehabilitation research.<sup>2,70</sup> I developed an evidence-based definition of rehabilitation that was informed by existing literature.<sup>1-4</sup> I discussed the definition of rehabilitation that underpinned my research in chapter two. In retrospect, one concept was missing from my definition that may have affected aspects of my research.

My definition of rehabilitation did not explicitly state that rehabilitation interventions target capacity (ability to execute a task or skill)<sup>133</sup> and performance (execution of a task or skill in an individual's usual environment).<sup>133</sup> This is important because these qualifiers may have provided insight into how I conceptualized rehabilitation and guidance into the healthcare disciplines who were more likely to offer rehabilitation. If my definition explicitly included concepts related to capacity and performance, I believe the sample for my survey may have been better identified and this would have informed my recruitment strategies for reaching eligible participants. For instance, I think I would have reached out to specific organizations representing rehabilitation professionals, e.g., the Canadian Physiotherapy Association, to ask them to share information about my survey with their members, because these organizations include members who are more likely to provide interventions related to capacity and performance. Ultimately, information on my survey could have reached more eligible people and may have increased my survey sample. Based on my experience recruiting participants to the survey, I decided to recruit interview participants through specific rehabilitation organizations. While few individuals were recruited through this approach to the interviews, I

still think this is a better way to recruit rehabilitation professionals when a large sample is needed.

### Summary

Effects of partnering on the research process and research outcomes identified in my survey were substantiated and expanded on by interview participants. Furthermore, findings from the interviews deepened our understanding of how partnering contributes to effects. Based on my research, I developed a conceptual framework for evaluation of partnered rehabilitation research. Key concepts in the conceptual framework that were substantiated include the effects of partnering on the research process, outcomes, and individual, and factors which influence partnering and thus effects. The conceptual framework can be used to inform future research or advocate for a partnered approach. Continued study is needed to understand the knowledge, skills, ability, opportunity, and motivation needed for evaluating partnered rehabilitation research. As well, future research could investigate whether existing evaluation tools are appropriate, acceptable, and feasible for use in rehabilitation. Furthermore, research is necessary to substantiate the assumption that evidence developed through a partnering process impacts health outcomes and the healthcare system.

## Chapter seven: Conclusion

In this chapter, I discuss recommendations for practice, research on partnered approaches, and how I have, and intend to, share my research findings.

### Recommendations: practice

My thesis showed that a partnered approach to rehabilitation research resulted in positive effects on the research process, outcomes, and individuals involved in the partnership. To ensure research findings are used to inform practice, researchers should consider adopting a partnered approach to rehabilitation research. Involving knowledge users in critical components of the research process, such as setting research priorities and developing research questions, can help align the research with priorities, perspectives, and experiences of knowledge users. This will ensure research priorities and questions are clinically applicable and meet the needs of knowledge users. Similarly, knowledge users who would like evidence to inform practice, or rehabilitation program development and evaluation, should consider engaging in partnered rehabilitation research. Their experiences and perspectives can contribute valuable insights on clinically applicable research questions, and aspects of methods, data analysis and interpretation or dissemination that may be relevant, appropriate, or acceptable for end-users of research compared to researcher-driven approaches.

There are several factors specific to partnering that influence effects of a partnered approach to rehabilitation research. My research indicated that when embarking on partnered rehabilitation research, both researchers and knowledge users must be aware that contextual, structural, relational, and individual factors may influence the partnering process.<sup>55,59</sup> For example, support from leadership in an organization is important because it will facilitate the partnering process. Specifically, leadership may provide resources for partnering, i.e., money or people, or ensure knowledge users have time to participate in partnerships. As well, as my thesis found that including point-of- contact people for partners to liaise with, or developing reference guides, charters, or research agreements to keep all partners on the same page during the research and partnering process is valuable. These structural factors may increase the likelihood the partnering process is efficient and effective and that partners remain on the

same page while partnering. This may ensure the partnership meets their research objectives and produces evidence to answer their research questions.

An important finding from my thesis that has not been widely reported specific to partnered rehabilitation research was that both researchers and knowledge users need to acknowledge the relationship they create between each other and how they work together will also influence the effects of their partnership. For instance, trust, reliability, accountability, role definition and clarity, respect, recognition, acknowledgement, and respecting and valuing partners, are all relational dynamics that must be considered. Researchers can show respect to knowledge users by actively listening to their inputs and being transparent throughout the partnering process. Furthermore, researchers and knowledge users must recognize how as individuals, they will also influence the partnering process. For example, partners should be enthusiastic, humble, open-minded, curious, motivated and adaptable.

Minimizing power imbalances was an important aspect of partnered rehabilitation research that both researchers and knowledge users spoke about in the interviews. This finding is consistent with Camden et al,<sup>21</sup> however, my thesis emphasized that creating a space where all partners feel equal is essential when partnering on rehabilitation research. Researchers should reflect on how they present themselves and engage with knowledge users, as these interactions may inadvertently contribute to power imbalances in the partnership. Getting to know knowledge users, creating a space for knowledge users to share their thoughts, giving knowledge users time to share their perspectives and experiences, and referring to each other on a first name basis, are a few simple ways researchers can enhance the power knowledge users feel in the partnership.

#### Recommendations: research

In chapters four, five, and six, I discussed findings from my research specific to the effects of partnered rehabilitation research on the research process, outcomes, and individuals. The findings reinforce what was already known about evaluation of partnered rehabilitation and its effects on the research process and outcomes. For instance, previously published partnered rehabilitation and partnered health research has identified numerous effects of partnering on the research process, outcomes, and individuals, including increased capacity for research and

partnering.<sup>21,23,27,28,121</sup> As well, research has identified several strategies, principles, or approaches that may influence partnering and thus the effects.<sup>27</sup> In view of the similarities between my research and existing evidence on the effects of partnering on the research process, individuals, and factors that may optimize the partnering process, I think it may be necessary to move on from researching these topics. Existing literature articulates both the positive and negative effects of partnering on the research process, contains comprehensive information on factors that optimize partnerships, and has identified numerous approaches or strategies that can be implemented during partnering to ensure.<sup>21,23,27,28,121</sup> I theorize it is unlikely that additional research will uncover any effects on the research process, nor will research uncover any new approaches or strategies to guide how to use this approach to research.

Furthermore, considering the similarity in findings between findings on partnered rehabilitation and partnered health research, there may be generalizable insights between the two approaches. Individuals with a vested interest in partnered research could rely on published findings from either partnered health research or partnered rehabilitation research to inform how to conduct partnered research. This may help expedite the use of a partnered approach to research and individuals interested in partnering because they will not need to rely on evidence specific to their discipline to help guide them in this approach.

#### Dissemination: activities to date and planned

On October 25, 2024, I presented my interview findings at the Prairie Collaborative Rehabilitation Conference in a 10-minute podium presentation. This conference was hosted by the Faculty of Rehabilitation Medicine, University of Alberta, and held in collaboration with the College of Rehabilitation Sciences, Rady Faculty of Health Sciences, University of Manitoba. The virtual conference showcased rehabilitation science research and highlighted the past, present, and future of rehabilitation sciences and research. The audience predominantly included researchers and graduate students (MSc and PhD).

Furthermore, I recently presented findings from my research to Knowledge Translation (KT) Canada, via a 45-minute webinar on October 10, 2024, as part of their seminar series. KT Canada consists of a network of researchers throughout Canada that aim to minimize the gap

between knowledge and practice. The seminar series occur throughout the year and are dedicated to current and emerging topics in KT. To date, research shared via the seminar series builds capacity in topics such as patient-oriented research, integrated knowledge translation, and knowledge synthesis among a range of viewers including researchers, trainees, patients, and members of the public. In addition, it encourages collaboration across Canada and internationally through connections made via the series. My presentation included results from both my survey and interviews. As well, I discussed future partnered rehabilitation research opportunities and the strengths and limitations of my research.

In May 2024, I shared results from my interviews via a 10-minute podium presentation at the University of Manitoba Applied Health Sciences PhD program annual research day. This event was attended by both graduate students in the program, and researchers from the College of Rehabilitation Sciences and Community Health Sciences with an interest in rehabilitation. I also shared results from my survey at the Prairie Rehabilitation Research conference in a 10-minute podium presentation in October 2023. This was an online conference, and it was attended mostly by researchers and graduate students with a focus on rehabilitation research from the University of Saskatchewan, University of Alberta, and the University of Manitoba. During both presentations I shared study findings, discussed the strengths and limitations of the study, and highlighted my plans for future research.

My abstract about my interview results was accepted as an e-poster submission for the World Physiotherapy Congress 2025, occurring in Tokyo Japan May 29-31<sup>st</sup>. The World Physiotherapy Congress is an international event that is held every two years that brings together the physiotherapy profession.

Lastly, I intend to write a manuscript specific to the results from my interviews to submit for publication. While I have not confirmed which journal I will submit to, one option is the Journal of Rehabilitation Medicine which publishes a wide range of rehabilitation topics for an audience that includes rehabilitation specialists such as (but not limited to) physiotherapists, occupational therapists, physical medicine practitioners, or social workers. Another option is Disability and Rehabilitation which publishes on a variety of topics specific to disability and

rehabilitation, including partnered research. The scoping review by Camden et al<sup>21</sup> was published in this journal. The benefit of these two journals is that they specifically target rehabilitation. However, because findings my interviews also discuss the effects on evidence uptake and clinical practice, journals that publish in this scope may be appropriate as well. A few different journals that may be included here are Implementation Science, BioMed Central Health Services Research, and Implementation Research and Practice. These three journals publish research specific to implementation research, i.e., enhancing the uptake of research findings in clinical practice. Furthermore, according to a cross-sectional study published in 2021, these three journals were perceived as the most relevant to implementation science.<sup>134</sup> However, the audiences for these journals may not include rehabilitation researchers, clinicians, or knowledge users.

### Final reflections

Despite the disagreement between survey and interview findings specific to the extent of evaluation in partnered rehabilitation research, my research identified positive effects of partnering on the research process, outcomes, and individuals. These findings may be used to highlight the value and advantages of a partnered approach to rehabilitation research to researchers, knowledge users, or organizations. Furthermore, my research identified several factors which influence partnering thus contributing to the effects. Researchers and knowledge users should pay particular attention to ensuring equity in partnerships and minimize power differentials as able to ensure all partners feel as though they are on equal footing throughout the partnering process. Based on the findings from my research and how they compared to existing evidence, I suggest it may be time to move on from investigating the effects of partnered rehabilitation research and factors of partnering which contribute to the effects. Instead, future research could focus on investigating evaluation of partnered rehabilitation research using an existing framework like the COM-B to identify barriers and facilitators of evaluation. Continued study on existing evaluation tools for partnered research would be helpful to identify tools appropriate for use in partnered rehabilitation research. As well, research is needed to confirm the effects of evidence uptake on health outcomes and the healthcare system. Overall, findings from my thesis advance our understanding on some

aspects of partnered rehabilitation research but also show that continued inquiry on this topic in necessary.

## Appendix 1. Themes and sub-themes about partnered rehabilitation research from focus groups and interviews

As per Roberge-Dao et al<sup>28</sup>

Researchers		Clinicians	
Themes	Sub themes	Themes	Sub-themes
Individual projects are framed within a broad vision of research	A project is a piece of a larger research project	Project Deliverables	Scientific contribution
	KT framework as essential		Training and development
	Planning for sustainability		Increased awareness of best practices
We can't measure everything	Lessons learned by researchers		Step in larger direction
	Project leader as an agent of change		Difficulty measuring clinical changes
	The unknown impact of dissemination strategies		Shared leadership
Ambiguity around defining success	Success	Exploration of partnership dynamics	Researcher as the leader
	Failures		Clinician as the leader
Building partnerships with clinicians and clinical program directors	Clinical context as a significant driver		Facilitators of effective IKT
	Understanding clinician motivation	Being motivated to participate in research	
	Feasibility of projects co-led by clinicians	Institutional support	
		The proximity of researchers	
			Previous research experience

KT = knowledge translation, IKT = Integrated Knowledge Translation

## Appendix 2: Survey questions

### Section 2: Eligibility and role

This section confirms your eligibility for the survey and your role in partnered rehabilitation research. When answering the following questions, please think about your **most recent** involvement in partnered rehabilitation research. Your involvement in the partnership could be **ongoing** or **completed**.

#### 2.1 Are you/ have you been involved in partnered research?

*Partnered research is defined as a collaboration between researchers and knowledge users during the research process. Research involves investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory.*

- a. Yes → skip logic to 2.2
- b. No → skip logic to bring participants to end of survey message
- c. I don't know → skip logic to bring participants to end of survey message

#### 2.2 Is/ was the partnered research specific to rehabilitation?

*Rehabilitation consists of interventions for people with health conditions. It aims to enhance function, quality of life, independence, ability to adapt to changing circumstances, social integration, and minimize disability. Rehabilitation may involve, but is not limited to, physical therapy, occupational therapy, speech and language pathology, audiology, vocational rehabilitation specialists, and physicians or nurses.*

- a. Yes → skip logic to 2.3
- b. No → skip logic to bring participants to end of survey message
- c. I don't know → skip logic to bring participants to end of survey message

#### 2.3 What is/ was your role in the partnered rehabilitation research?

- a. Researcher: an individual who carries out thoughtful inquiry or examination of a topic. This includes investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory. A researcher can be, but does not need to be, affiliated with an academic institution. As well, the researcher may be a graduate student, i.e., Masters or PhD. Yes → skip logic to 3.1, exclude 3.4
- b. Knowledge user: any person who can use the knowledge resulting from research to make informed decisions. May include (but is not limited to): people with lived experience of a health condition, e.g., patients or family members of patients, health

professionals and health system decision and policy makers. Yes → skip logic to 3.1, exclude 3.3

- c. Researcher and knowledge user. Yes → skip logic to 3.1

### Section 3: Features of partnered rehabilitation research

This section asks questions about features of partnered rehabilitation research that you are/ have been involved in. When answering the following questions, please think about your **most recent** involvement in partnered rehabilitation research.

3.1 Which describes your current involvement in partnered rehabilitation research. **Check one.**

- a. Ongoing Yes → skip logic to 3.2
- b. Completed Yes → skip logic to 3.3

3.2 How long has your partnership been going on?

- a. 0-2 years
- b. 2- 4 years
- c. 5-7 years
- d. 8-10 years
- e. ≥ 11 years

3.3 As a researcher, which type (s) of knowledge user (s) are/ have you partnered with? **Check all that apply.**

- a. Health professional
- b. Person with lived experience of a health condition, either directly (*i.e., patient*) or indirectly (*i.e., family member, friend, or caregiver*)
- c. Healthcare manager or administrator
- d. Health system decision or policy maker
- e. Community organization representative (*i.e., representative from a non-profit organization*)
- f. Health research funding organization representative
- g. Health professional organization representative
- h. Industry representative (*i.e., business or company*)
- i. Community member
- j. Other, please specify: \_\_\_\_\_
- k. Unsure

3.4 Which type of knowledge user are/ were you? **Check all that apply.**

- a. Health professional

- b. Person with lived experience of a health condition, either directly (*i.e.*, "patient") or indirectly (*i.e.*, family member, friend, or caregiver)
- c. Healthcare manager or administrator
- d. Health system decision or policy maker
- l. Community organization representative (*i.e.*, representative from a non-profit organization)
- e. Health research funding organization representative
- f. Health professional organization representative
- g. Industry representative (*i.e.*, business or company)
- h. Community member
- i. Other, please specify: \_\_\_\_\_
- j. Unsure

3.5 How many years have you been a (response from 2.1)?

- a. 0-3 years
- b. 4-7 years
- c. 8-11 years
- d. ≥ 12 years

3.6 How many rehabilitation research partnerships have you been involved with as a (response from 2.1)?

- a. 1-5
- b. 6-10
- c. 11-15
- d. ≥ 16
- e. Ongoing partnered rehabilitation research program
- f. Other, please specify: \_\_\_\_\_

3.7 This question is about the levels of involvement in research developed by The International Association for Public Participation <https://www.iap2.org/>.

When thinking about your ***most recent*** involvement in partnered rehabilitation research, what is/ was the highest level of involvement of the knowledge users? **Check all that apply.**

- a. Inform: knowledge users were only kept informed about the research
- b. Consult: knowledge users gave feedback about the research
- c. Involve: knowledge users were involved throughout the research to ensure their concerns or goals were understood or considered
- d. Collaborate: knowledge users were involved in all aspects of decision making about the research
- e. Empower: knowledge users were given final decision making about the research

- f. I don't know

#### Section 4: Evaluation of partnered rehabilitation research

This section asks questions about if and how you evaluated partnered rehabilitation research. When answering the following questions, please think about your ***most recent*** involvement in partnered rehabilitation research.

##### 4.1 Is/ was the research partnership evaluated?

*For this survey, evaluation means to assess or measure the value of the research partnership.*

- a. Yes → Skip logic: 4.2- 4.5
- b. No → Skip logic: 5.1
- c. I don't know → Skip logic: 5.1

##### 4.2 When is/ was the research partnership evaluated? **Check all that apply.**

- a. Pre-study
- b. During the study
- c. Post-study
- d. Other, please specify: \_\_\_\_\_
- d. I don't know

##### 4.3 What type of evaluation of the research partnership is/ was conducted? **Check all that apply.**

- a. Informal evaluation (for internal use only)
- b. Formal research study (obtained ethics approval, findings may be published)
- c. Other, please specify: \_\_\_\_\_
- d. I don't know

##### 4.4 What methodologies are/ were used to evaluate the research partnership? **Check all that apply.**

*Methodology consists of the broad approaches that are applied to research. It states how research questions should be asked and answered. Methodology includes a plan of action and strategies to guide how research should be conducted.*

- a. Qualitative
- b. Quantitative

- c. Mixed methods i.e., intentional use and mixing of both quantitative and qualitative approaches during the design, methods, analysis and/ or reporting phases of the research.
- d. Other, please specify: \_\_\_\_\_
- e. I don't know

4.5 What methods are/ were used to evaluate the research partnership? **Check all that apply.**

*Methods consist of the ways that the partnered rehabilitation research was evaluated.*

- a. Tool or instrument such as a survey, measure, assessment, inventory, checklist, list of factors, or subscales → skip logic: Please specify the instrument that was used for the evaluation of the research partnership: \_\_\_\_\_
- b. Interview
- c. Focus group
- d. Other, please specify: \_\_\_\_\_
- e. I don't know

#### Section 5: Perceived effects of partnered rehabilitation research

This section asks questions about the perceived effects of partnered rehabilitation research.

Effects are short, medium, long-term, or secondary intended or unintended consequences. When answering the following questions, please think about your ***most recent*** involvement in partnered rehabilitation research.

5.1 In your opinion, to what extent does/ did the research partnership influence the overall research project?

- a. No influence
- b. A little influence
- c. Moderate influence
- d. Significant influence
- e. Unsure

5.2 The following questions ask about the influence of the research partnership on research processes. We know research may have different aims, purposes, outcomes etc. Not every question may be applicable to you. Please answer the questions as best you can.

In your opinion, to what extent does/ did the research partnership influence the following specific research processes:

	No influence	A little influence	Moderate influence	Significant influence	Not applicable

O5.3 Setting the project's research priorities					
O5.4 Choosing the research questions					
O5.5 Development of study design and methods					
O5.6 Choosing study outcomes					
O5.7 Development of research ethics documents (e.g., consent forms)					
O5.8 Participant recruitment					
O5.9 Data collection					
O5.10 Data analysis and interpretation					
O5.11 Dissemination (i.e., sharing) of research findings to non-academic audiences (e.g., public presentation, summary of findings)					
O5.12 Dissemination (i.e., sharing) of research findings to academic audiences (e.g., peer-reviewed journal publication(s))					
O5.13 Sustainability of interventions					

5.14 The following questions ask about the perceived effects of the research partnerships. Not every question may be applicable to you. Please answer the questions as best you can.

In your opinion, to what extent does/ did the research partnership influence the following:

	No influence	A little influence	Moderate influence	Significant influence	Unsure
5.15 Health system policy changes					
5.16 Sustainability of partnerships					

5.17 Knowledge user empowerment					
5.18 Shared power relations, i.e., equity in decision making related to research and knowledge sharing					
5.19 Cultural revitalization, i.e., regaining cultural identity, languages or reviving traditions and customs					
5.20 Knowledge users' knowledge about the research process					
5.21 Knowledge users' research skills					
5.22 Researchers capacity for partnered research					
5.23 Reduction of health disparities					
5.24 Production of useful research findings for the knowledge users involved in the partnership					
5.25 Evidence-informed clinical decision making in healthcare by knowledge users					
5.26 Other, please specify:					

5.27 Is there anything else you would like to tell us about your views on the effects of partnered rehabilitation research? (Paragraph) \_\_\_\_\_

## Section 6: Respondent Characteristics

This section asks about you as an individual.

6.1 What is your profession?

- a. Nurse
- b. Occupational Therapist

- c. Orthotist
- d. Prosthetist
- e. Physician
- f. Physiotherapist/ Physical therapist
- g. Rehabilitation counsellor
- h. Social worker
- i. Speech Language Pathologist
- j. Other, please specify: \_\_\_\_\_

6.2 What country do you live in? \_\_\_\_\_

6.3 Please indicate the population group you identify with: **Check one.**

- a. White (only)
- b. South Asian (only)
- c. Chinese (only)
- d. Black (only)
- e. Filipino (only)
- f. Latin American (only)
- g. Arab (only)
- h. Southeast Asian (only)
- i. West Asian (only)
- j. Korean (only)
- k. Japanese (only)
- l. Visible minority
- m. White and South Asian
- n. White and Chinese
- o. White and Black
- p. White and Latin American
- q. White and Arab
- r. White and Southeast Asian
- s. White and Korean
- t. White and Japanese
- u. White and multiple visible minorities
- v. Multiple visible minorities
- w. Aboriginal/ Indigenous Peoples
- x. Prefer to self identify: \_\_\_\_\_
- y. Prefer not to answer

6.3 Please indicate the gender you identify with: **Check one.**

*Gender refers to the socially constructed roles, relationships, behaviours, relative power, and other traits that societies ascribe to women and men.*

- a. Agender: a person who does not relate to any gender identity, who does not experience gender or who places themselves beyond the gender spectrum.

- b. **Bigender/ multigender:** a person who identifies as having two genders. Multigender refers to a person who identifies as having more than one gender.
- c. **Gender fluid:** a person whose gender identity or expression changes or shifts along the gender spectrum.
- d. **Genderqueer:** a person who challenges social norms regarding gender with their identity, their gender expression, and their sexual practices.
- e. **Man**
- f. **Nonbinary:** a person whose gender identity does not align with a binary understanding of gender such as man or woman.
- g. **Transgender:** a person whose gender identity does not correspond with the sex they were assigned at birth.
- h. **Two-spirit:** used by some North American Indigenous people to indicate a person who embodies both female and male spirits or whose gender identity, sexual orientation or spiritual identity is not limited by the male/female dichotomy.
- i. **Woman**
- j. **Prefer to self identify:** \_\_\_\_\_
- k. **Prefer not to answer**

## Appendix 3: Survey disclosure form

### University of Manitoba, Bannatyne Campus Research Ethics Board

#### E-Survey consent disclosure

##### Partnered Rehabilitation Research E-Survey

Thank you for accessing the Partnered Rehabilitation Research e-survey. This study is a part of a research program undertaken by Brenda Tittlemier, PhD candidate, at the University of Manitoba. Brenda is advised by Dr. Kathryn M. Sibley, Associate Professor at the University of Manitoba.

#### Definitions

**Partnered rehabilitation research** is a collaboration between researchers and knowledge users during the rehabilitation research process. Knowledge users are people who can use the knowledge generated through research. Partnered research is also referred to using terms such as integrated knowledge translation, participatory action research, community-based participatory research.

**Rehabilitation** consists of interventions for people with health conditions. It aims to enhance function, optimize quality of life, independence, ability to adapt to changing circumstances, social integration, and minimize disability.

**Research** involves investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory.

#### Aims of the survey

Our survey is being conducted to **examine if and how partnered rehabilitation research is evaluated**. As well, our survey aims to **identify and describe the perceived effects of partnered rehabilitation research**. We know that partnered rehabilitation research occurs, but we are less clear if and how it is evaluated. There is also little information about the effects of partnered rehabilitation research. We expect the survey findings to increase our understanding of the evaluation and effects of partnered rehabilitation research. This information could be used to make decisions about how engaging in partnered rehabilitation research could be easier. The findings may also offer insights on how to promote the growth of partnered rehabilitation research.

Your participation will involve answering a series of questions about partnered rehabilitation research. Participation in this survey is **completely voluntary**. We **are not** collecting any identifiable, personal characteristics as part of the survey. There will be no way to identify participants from their responses. You do not have to answer questions if you don't want to. **All**

**responses will be kept confidential** by using secure, password protected methods to transfer and store the information. The findings will **only** be used for research purposes. Information from this study may be published and/or shared publicly, but only in summary form.

### **Eligibility**

You are eligible for our survey if you can read, write, and understand English; and have been involved in partnered rehabilitation research as either a researcher or knowledge user.

A **researcher** is an individual who carries out thoughtful inquiry or examination of a topic. This includes investigation or experimentation aimed at discovering and interpreting facts, revising theory, or practically applying the new theory. A researcher can be, but does not necessarily need to be, affiliated with an academic institution. As well, the researcher may be a graduate student, i.e., Masters or PhD.

A **knowledge user** is any person who can use the knowledge resulting from research to make informed decisions. May include (but is not limited to): people with lived experience of a health condition (e.g., patients or family members of patients), health professionals and health system decision and policy makers.

### **Survey details**

We are using Survey Monkey to do our survey. Survey Monkey is a secure platform. It encrypts data during and after the survey is completed, (i.e., in transit and at rest). **We will ensure anonymity** by excluding all respondent information from the results, i.e., names, e-mail addresses, IP addresses, custom variables. Survey responses will be retained in cloud storage in the Canadian Data Centre. Once the survey closes, the responses will be exported and stored using secure measures. Survey responses will be deleted from Survey Monkey once the responses are securely stored. The privacy policy for Survey Monkey can be found at <https://www.surveymonkey.com/mp/legal/privacy-policy/>. Data will be retained securely for seven years at the University of Manitoba.

The survey will be open for six weeks. The survey takes most people approximately 15 minutes to complete. If you agree to complete the survey, Survey Monkey will automatically save your progress. This means you can close the survey and return to finish it later. You can return to your place in the survey by clicking on the link in the email that was sent to you. We will ensure Survey Monkey is disabled from tracking IP addresses.

The **risks of participating are low**. There are no direct benefits to you for participating. Findings from this survey may enhance our understanding of partnered rehabilitation research practices. We expect this information could encourage the use of partnered rehabilitation research. Ultimately, partnered rehabilitation research may improve individual health outcomes. As well, it could improve how healthcare systems function. There are **no costs** to you to participate in this study.

At the end of the survey, you will also have the option to participate in future studies, i.e., focus group or interviews about partnered rehabilitation research. If you are interested in participating, you will be asked to provide your name and contact information in a separate link at the end of the survey. Again, this information cannot be linked to your survey responses.

This study has been approved by the University of Manitoba Health Research Ethics Board (Ethics number: HS25974 (H2023:132)). They can be reached at [bannatynereb@umanitoba.ca](mailto:bannatynereb@umanitoba.ca) or 204 789-3255.

The completion of this study requires your free and informed consent. Submitting the survey implies your willingness to participate, and your free and informed consent. As well, submitting the survey implies that you understand the above conditions regarding participation in the study.

If you would like a summary report (PDF) of the study findings, or have any questions, please contact Brenda Tittlemier.

1. Do you consent to participate in this survey?

- a. Yes → skip logic to 2.1
- b. No → skip logic to the end of the survey message

## Appendix 4: Interview consent form

### **RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM (Interview)**

**Study title:** Exploring the effects of partnered rehabilitation research: A qualitative study of the experiences of researchers and knowledge users

**Principal Investigator:**

Brenda Tittlemier, PhD Candidate, MSc, BMR (PT), University of Manitoba, 753 McDermot Avenue, 3rd Floor Chown Building, Winnipeg, MB, R3E 0T6

**Co-Investigators:**

Kathryn Sibley, Associate Professor, Department of Community Health Sciences, University of Manitoba

Juliette Cooper, Professor Emeritus, College of Rehabilitation Sciences University of Manitoba

Roberta L. Woodgate, Distinguished Professor, College of Nursing, University of Manitoba

Linda Li, Professor, Department of Physical Therapy, University of British Columbia

You are being asked to participate in an interview for a research study about partnered rehabilitation research. Take your time to review this consent form. Discuss any questions you may have with the study staff, your friends, or family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

**Objectives of the study**

This study is being conducted to understand the evaluation and effects of partnered rehabilitation research. Partnered rehabilitation research occurs when researchers and knowledge users (e.g., clinicians, decision makers, policy makers, etc.) work together to conduct rehabilitation research.

**Participants selection**

You are being asked to participate in this study because as a researcher or knowledge user who has been involved in partnered rehabilitation research, your experiences can deepen our understanding about whether partnered rehabilitation research is being evaluated, how, and what the effects of the partnership are. Approximately sixteen individuals, eight researchers and eight knowledge users, will be asked to participate in this study.

### **Study procedures**

You will be asked to fill out a brief participant demographic questionnaire. The principal investigator will conduct an individual interview using MS Teams with you. The interview could last up to 60 minutes. During the interview, you will be asked questions relating to your experience with partnered rehabilitation research. These questions will help us to better understand the evaluation and effects of these partnerships.

The interviews will be video recorded. The sessions will be transcribed by MS teams. The principal investigator will review the transcribed interview to ensure there is no loss of confidentiality and confirm the accuracy of the information you provided. You will also have a chance to review the transcript if you would like.

### **Confidentiality and data security**

Information obtained from participants will be kept strictly confidential. All study data will be stored electronically on the University of Manitoba server on a password-protected account. The video recording will be transcribed and both the video and transcribed data stored securely on the server.

Interviewees will be identified by a unique study ID and date during analysis, and in reporting will be completely anonymized. A study personnel log will be used to document who has access to original data. All study data, including the recordings and transcripts, will be kept for a maximum of five years. Study data will be destroyed as per the University of Manitoba's IST data destruction guidelines. Results of the study will be published in open-access, peer-reviewed journals. You have the option to receive a summary of the study findings.

Despite our best efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurances purposes only.

### **Risks and Discomforts**

There are no known risks to participating in this study. The study is an opportunity for you to discuss your experiences of and perspectives on engaging in partnered rehabilitation research. You may describe a negative experience, and this can be upsetting for some people. You do not have to answer any questions that make you feel uncomfortable or that you find upsetting.

### **Benefits**

There may or may not be a direct benefit to participants of this study. We hope the information learned from this study will benefit those involved in partnered rehabilitation research to better conduct their research.

**Costs**

There is no cost to you to participate in this study.

**Payment for participation**

You will be provided with a \$25 gift card (online) after completion of the interview as a token of appreciation for their time and contributions to the study.

**Permission to Quote:**

We may wish to quote your words directly to highlight a specific point in reports and publications related to this study. However, you will not be directly identified as the speaker of those quotes.

Please place an “X” beside either Yes or No regarding the following statement:

Researchers may publish documents that contain quotations by me under the following conditions:		
Yes:	No:	I agree to be quoted directly if my name is not published (I remain anonymous).

**Voluntary Participation/ Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate, or you may withdraw from the study at any time. You will not be affected in any way if you decline participation or withdraw from the study. If you withdraw from the study, your video recording and transcribed interview will be deleted from where they are stored (if already not done).

**Questions**

If you have any questions or concerns related to this study, please contact the principal investigator (B. Tittlemier).

This study has been approved by the University of Manitoba, Health Research Ethics Board (ethics#). For questions about your rights as a research participant, you may contact the University of Manitoba, Health Research Ethics Board at [bannreb@umanitoba.ca](mailto:bannreb@umanitoba.ca) or (204) 789-3389. Please do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all your questions.

**Statement of consent:**

I have read all four pages of the consent form. I have had a chance to ask questions about this study. I received satisfactory answers to all my questions in a language I understand.

The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor, or family member) I may have with the study team has not affected my decision to participate.

I understand I will be given a copy of this consent form after signing it. I understand that my participation is voluntary, and I may withdraw from the study at any time. I understand my data may be withdrawn prior to publication if I do withdraw. I freely agree to participate in this study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Health Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of my legal rights as a participant in this study.

I consent to the recording of my interview. Please indicate with an "X". Yes: \_\_\_\_\_ No: \_\_\_\_\_

**Participant printed name:** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Signature** \_\_\_\_\_

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

**Printed name:** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Signature:** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

## Appendix 5: Semi-structured interview guide

Zoom/ MS teams' settings checklist: (as able)

Make sure participant is using a nickname

Encourage a private location for the meeting

Lock the meeting

Remind participant (s) they can keep camera off

Participant (s) muted until start

Turn off: automatic Recording, IP Address Access Control, hosts can give participants the permission to record locally, privacy chat feature, and screen sharing

Turn on: recording disclaimer, ask participants for consent when a recording starts, ask host to confirm before starting a recording, and live closed captioning

5 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

Hello, thank you for taking the time to meet with me today. Before we start, this interview is being recorded to make sure I capture all the information. Please let me know if you have any concerns.

I have received your signed consent form. However, I would like to confirm you consent to participate in this interview.

[If no concerns], we will start the recording now. [start the recording using 'Record to the Cloud' option].

Thank you once again for making yourself available for interview. My name is Brenda Tittlemier. I am a PhD candidate at the University of Manitoba. I am also trained as a physiotherapist. I currently work in a physiotherapy department in a hospital setting increasing the uptake of physiotherapy evidence to inform clinical practice, decision-making, and physiotherapy delivery in the hospital. My PhD studies are focused on the area of partnered rehabilitation research, which is researchers and knowledge users collaborating, partnering, or working together during research.

I am conducting these interviews because I am interested in learning more about rehabilitation research projects that are conducted in partnership between researchers and knowledge users. Knowledge users are the intended users of research and may include (but are not limited to) clinicians, patients, caregivers, policy makers, or decision-makers. Much of rehabilitation research is conducted by researchers affiliated with academic university settings. However, there is growing interest in rehabilitation research that is conducted by rehabilitation researchers and knowledge users who work together (collaborate or partner) on research. I am

interested in the positive or negative effects, i.e., consequences, of these partnerships (individuals working together) on the research process or research outcomes, and how the partnerships are evaluated. I may sometimes refer to these partnerships between rehabilitation research and knowledge users as ‘partnered rehabilitation research’, ‘rehabilitation research partnerships’, or ‘rehabilitation research teams.’

This interview will involve open-ended questions. You do not have to answer any questions you do not want to. I have some questions and topics planned that I’d like to discuss with you, but I’ve also left some time to discuss any other thoughts or reflections you have about partnered rehabilitation research at the end.

For all questions, please feel free to draw on your experiences from partnered rehabilitation research that you have been part of.

Do you have any questions before we begin?

5 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

### Section 1: Introduction

I am going to start by asking you questions about yourself.

Can you tell me a bit about yourself? For instance, what do you do?

Can you tell me a bit about your experience working in collaboration with [insert researcher or knowledge user, depending on interviewee] on rehabilitation research projects?

How did you become involved in partnerships?

How many partnerships have you been involved in?

Could you tell me more about those partnerships?

10 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

### Section 2: Effects of partnered rehabilitation research on the research process

I am now going to ask your perceptions or thoughts about the effects, i.e., consequences, of partnered rehabilitation research on the research process.

As a reminder, please think about the rehabilitation research partnerships you have been involved in, when answering the questions.

Research objective	Research question (s)
Explore the effects of partnered research on the research process.	How do you think researchers and knowledge users working together affected the research process? These can be positive or negative effects. Take your time and provide as much detail as you would like.

	<p><i>Probe:</i> When I say ‘research process’ I am referring to setting the project’s priorities, choosing research questions, development of the study design and methods, choosing study outcomes, developing ethics documents, recruiting participants, collecting, and analyzing data, and interpreting and sharing results with academic and non-academic populations, and sustainability of interventions. What is your experience like as a [researcher or knowledge user] collaborating with [researcher or knowledge user] on any of these aspects of the research process and what were the effects?</p> <p><i>Probe:</i> To clarify, I am not asking about the effects of the research project itself. For example, I am not asking about whether the research project improved patient related outcomes. Rather, I am specifically asking about the collaboration between the researchers and knowledge users and whether it affected the research process. For example, what effect (or consequence) was there by involving the knowledge users in decision making related to the research process?</p> <p><i>1a:</i> In your view, what were some of the good and/or bad things that happened when <b>you</b> partnered with [researchers or knowledge users] in the research process? Do you think anything about the research process would have been different if knowledge users were not on the research team?</p> <p>I noticed you didn’t say [insert research process not mentioned]. Did you consider involving knowledge users [or being involved] in this part of the research?</p> <p>3a. Do you think it would have made a difference if knowledge users were involved in this phase of the research process?</p> <p>3b. How so?</p>
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10 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

Section 3: Effects of partnered rehabilitation research on research outcomes

Now I am going to ask your perceptions or thoughts about the effects, i.e., consequences, of partnered rehabilitation research on research outcomes.

Again, please think about the rehabilitation research partnerships you have been involved in, when answering the questions.

Research objective	Research question (s)
Explore the effects of partnered research on research outcomes.	<p>In your view (or experience), how did researchers and knowledge users working together affect the results or research outcomes? These can be positive or negative effects. Take your time and provide as much detail as you would like.</p> <p><i>Probe:</i> When I say ‘research outcomes’ I am referring to health system policy changes, sustainability of partnerships, knowledge user empowerment, shared power relations, cultural revitalization, knowledge users’ knowledge about the research process, knowledge users’ research skills, researchers’ capacity for partnered research, reduction of health disparities, production of useful research findings for knowledge users, and evidence-informed clinical decision making by knowledge users.</p> <p><i>Probe:</i> To clarify, I am not asking about the effects of the research project itself. Rather, I am specifically asking about the collaboration, partnering, and working together between the researchers and knowledge users and whether it affected research outcomes. A research outcome may be research or knowledge user capacity for partnered research.</p> <p><i>4a:</i> What were some of the good and/or bad things that were the result of the partnership on the results or research outcomes?</p> <p>Were there any other effects on the results or research outcomes that we have not discussed in the previous question that you experienced?</p>

10 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

#### Section 4: Evaluation of partnered rehabilitation research

I’m going to move on to a different topic now. I would like to know more about how the effects of the partnership were evaluated or measured. In this case, please think about the effects that you mentioned in the previous questions. I can remind you what those were if you need. Please let me know.

Research objective	Interview question (s)
Explore how effects of the partnership were evaluated.	<p>Can you tell me if the effects of the partnership you mentioned in the previous questions were formally evaluated or measured?</p> <p><i>Probe:</i> When I say “formally” evaluated or measured, I am referring to using specific methods, like a survey, interview, or focus group, to measure the effects.</p>

	<p>[If answer “yes” to question 6] Can you tell me how the partnership was evaluated or measured?</p> <p><i>Probe:</i> For instance, did you have to fill out a questionnaire or survey? Did you talk about them in an interview or focus group?</p> <p>7a. I noticed you said, ‘questionnaire or survey’. Do you remember if you developed those together, as a research team. Or did you use a questionnaire or survey that was already developed?</p> <p>7b. So, you developed the questionnaires and surveys as a team. How did this happen? For instance, did you have meetings to talk about what should go into the questionnaire or survey? How did you decide what went into the questionnaire or survey?</p> <p>[If answer “yes” to question 6] Can you explain, or do you recall why the approaches you mentioned were used to evaluate the partnership? It is okay if you are unsure or do not know.</p> <p><i>Probe:</i> For instance, did you decide on those approaches as a group. Or did someone tell you that was how they would be evaluated.</p> <p><i>Probe:</i> Were the approaches chosen because of the research groups’ familiarity with them? Or for convenience?</p> <p>[If answer “yes” to question 6] Do you think there is value in evaluating the partnership? Why or why not?</p> <p>[If answer “no” to question 6] To clarify, the partnership (s) that you were involved in was not formally evaluated. Why do you think that was?</p> <p>10a. Do you think there is any value in evaluating the partnership? Why or why not?</p>
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10 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

Section 5: How partnered rehabilitation research contributes to effects

Thank you again for all your insights so far. We are nearly done. Now I’m going to ask your perceptions on how partnered rehabilitation research may influence the effects on the research process or outcomes. Please feel free to be as detailed as you would like.

Research objective	Interview question (s)
Explore how partnered rehabilitation research affects the research process and outcomes.	<p>How do you think the collaboration between researchers and knowledge users led to effects on the research process?  <i>Probe:</i> For instance, you mentioned the partnership resulted in [interviewer insert answers from question 1]. In what ways did the researchers and knowledge users collaboration contribute to these effects on the research process?</p> <p>11a: What is it about [answer from question 11] that contributed to effects of the partnership?</p> <p>How do you think the collaboration between researchers and knowledge users during rehabilitation research led to effects on the research outcomes?  <i>Probe:</i> For instance, you mentioned the partnership resulted in [interviewer insert answers from question 4]. In what ways did the researchers and knowledge users collaboration contribute to these effects on the research process?</p> <p>12a: What is it about [answer from question 12] that contributed to effects of the partnership?</p>

10 minutes (start time: \_\_\_\_\_ end time: \_\_\_\_\_)

We are approaching the end of our time and questions. Is there anything else that you would like to share about your experiences in partnered rehabilitation research?

Finally, as part of the study we aim to present participants with a summary of their responses to ensure their accuracy and to provide participants with an opportunity to add/modify their information as needed. Would you like to be contacted about this?

With this we have come to the end of the interview. Thank you for your time and information. Your participation is greatly appreciated.

## Appendix 6: Reflexive thematic analysis

As per Braun and Clarke<sup>114,118</sup>

Stage of thematic analysis	Description	Practical application of stage of analysis
Transcription	Recorded interviews transcribed verbatim.	Interviews transcribed via MS teams or zoom. I will review transcripts to ensure participants cannot be identified.
Reading and familiarization	Immersing self in the dataset by reading, & re-reading data, i.e., transcribed interviews, to become very familiar with them; A casual process but reading should still be active, analytical, and critical; Gaining loose impressions or concepts/ ideas of the data.	I will ensure accuracy of the transcripts by watching or listening to interviews and comparing them to transcribed interviews. I may also need to “clean up” the transcripts, i.e., ensure they are in a format that can be easily read. I will re-read each transcript several times to become familiar with the data in them. This will be a reflective and analytical process, but I am not coding yet.
Coding	Identifying aspects of data that relate to research questions; Coding can be complete i.e., identify and analyze everything of interest or relevant; or selective, i.e., specific instances/ phenomena to code; Codes are a word or phrase that capture the essence of a bit of data that may be useful; Codes are the building blocks of analysis; Data can be coded in multiple ways; Codes can be data derived, i.e., reflect semantic content, or researcher derived, i.e., invoke researcher conceptual and theoretical framework to identify meaning in the data; Coding can be completed many ways, i.e., pen and paper, coding program.	I may use pen and paper to complete the coding process. I will aim to perform complete coding, that is analyzing everything of interest. I will read a sentence and highlight or underline words or phrases that I feel are useful. I will code one interview at a time, until all interviews are completed. During the coding process, I will meet with members of the PhD committee or entire committee. I may code the entire interview or code parts of the interview at a time, before meeting with the committee. We will discuss how coding is going, or the preliminary codes I am establishing. I will identify interesting or useful quotes from the

		interviews during this process. I may read the interviews a few times, as I complete the coding process.
Generating themes	Deeper analysis to identify patterns in the codes; Looking for ideas that recur across the dataset; Patterns to capture the different elements that are most meaningful to answer the research question; A theme is broader than a code, contains many facets, and is the central organizing concept; A theme contains lots of different ideas related to centralizing concept; Codes combine to form themes; Review codes and collated data looking for similarity; A theme can be distinct but still fit together with other themes; May have overarching themes and/or sub-themes; Themes are provisional at this point	After all the interviews are coded, I will re-read all the interviews and begin identifying the codes that share similarities. At this stage, I may develop an excel spreadsheet or word document that groups the codes together. I feel this may help me to generate preliminary themes. Throughout this stage I will continue to meet with my committee to discuss the preliminary themes.
Reviewing themes	Process to ensure that the themes fit well with the coded data and the research question; Involves re-reading codes, collated data, and the whole data set; Aim to ensure the themes capture the meaning of the data in relation to the research question	I will review my research questions and objectives. As I re-read the interviews, I will think about the codes and preliminary themes to ensure they align with my research questions and objectives. Discussion about codes and themes will continue with my PhD committee.
Defining and naming themes	Process of defining the focus, scope, purpose, and/ or boundaries of the themes; typically, a few short sentences; Be creative (!)	In collaboration with my PhD committee, we will finalize the themes and sub-themes.
Writing and finalizing analysis	Process of writing; Analysis develops; Narrative that is written which tells the story of the theme about the content and meaning of the data; Select vivid and compelling extracts from the breadth of data to illustrate facets of the theme; Can use an illustrative approach for a thick and rich description of the data; Present themes logically; Situate final analysis in current literature	Using a narrative approach, I will pragmatically describe the themes and sub-themes I generated. I will aim to stay close to the data as I do this. I will discuss the meaning of the themes and sub-themes and how they relate to outcomes and evaluation of research partnerships in rehabilitation. I may develop a

		table to summarize the themes or sub themes. I will include quotes that capture the themes or sub themes. I will compare the results with existing literature.
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## References

1. World Health Organization. *Rehabilitation in Health Systems*. Geneva, 2017.
2. Wade DT. What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clin Rehabil*. 2020;34(5):571–583.
3. Arienti C, Patrini M, Pollock A, Lazzarini SG, Oral A, Negrini S. A comparison and synthesis of rehabilitation definitions used by consumers (Google), major Stakeholders (survey) and researchers (Cochrane Systematic Reviews): a terminological analysis. *Eur J Phys Rehabil Med*. 2020;56(5):682–689.
4. Meyer T, Kiekens C, Selb M, Posthumus E, Negrini S. Toward a new definition of rehabilitation for research purposes: a comparative analysis of current definitions. *Eur J Phys Rehabil Med*. 2020;56(5):672–681.
5. Menon A, Korner-Bitensky N, Kastner M, McKibbin KA, Straus S. Strategies for rehabilitation professionals to move evidence-based knowledge into practice: a systematic review. *J Rehabil Med*. 2009;41(13):1024–1032.
6. Jones C, Roop S, Pohar S, Albrecht L, Scott SD. Translating knowledge in rehabilitation: Systematic review. *Phys Ther*. 2015;95:663–677.
7. Prakash V, Hariohm K, Balaganapathy M. Barriers in implementing evidence-informed health decisions in rural rehabilitation settings: A mixed methods pilot study. *Journal of Evidence-Based Medicine*. 2014;7(3):178–184.
8. Anaby D, Korner-Bitensky N, Steven E, et al. Current rehabilitation practices for children with cerebral palsy: Focus and gaps. *Phys Occup Ther Pediatr*. 2017;37(1):1–15.
9. Moore JL, Friis S, Graham ID, Gundersen ET, Nordvik JE. Reported use of evidence in clinical practice: A survey of rehabilitation practices in Norway. *BMC Health Serv Res*. 2018;18(1):379.
10. Lamontagne ME, Gargaro J, Marier-Deschenes P, et al. A survey of perceived implementation gaps for a clinical practice guideline for the rehabilitation of adults With moderate to severe traumatic brain injury. *J Head Trauma Rehabil*. 2018;33(5):306–316.
11. Bowen S, Graham I. Integrated Knowledge Translation. In: Straus SE TJ, Graham ID, ed. *Knowledge Translation in Healthcare*. 2nd ed. UK: John Wiley & Sons; 2013:14–23.
12. Gagliardi AR, Berta W, Kothari A, Boyko J, Urquhart R. Integrated knowledge translation (IKT) in health care: a scoping review. *Implement Sci*. 2016;11:38.
13. Merriam-Webster Dictionary. Research. Merriam-Webster.com Dictionary. <https://www.merriam-webster.com/dictionary/research>. Published 2022. Accessed October 7, 2022.
14. Graham ID, Kothari A, McCutcheon C, Integrated Knowledge Translation Research Network Project (Leads). Moving knowledge into action for more effective practice, programmes and policy: protocol for a research programme on integrated knowledge translation. *Implement Sci*. 2018;13(1):22.
15. Jull JE, Davidson L, Dungan R, Nguyen T, Woodward KP, Graham ID. A review and synthesis of frameworks for engagement in health research to identify concepts of knowledge user engagement. *BMC Med Res Methodol*. 2019;19(1):211.

16. Bowen S, Botting I, Graham ID, et al. Experience of health leadership in partnering with university-based researchers in Canada - A call to "re-imagine" research. *Int J Health Policy Manag.* 2019;8(12):684–699.
17. Al Zoubi FM, Menon A, Mayo NE, Bussieres AE. The effectiveness of interventions designed to increase the uptake of clinical practice guidelines and best practices among musculoskeletal professionals: a systematic review. *BMC Health Serv Res.* 2018;18(1):435.
18. De Gruyter E, Ford G, Stavreski B. Economic and social impact of increasing uptake of cardiac rehabilitation services--A cost benefit analysis. *Heart Lung Circ.* 2016;25(2):175–183.
19. Linkewich E, Avery L, Rios J, McEwen SE. Minimal clinically important differences in functional independence after a knowledge translation intervention in stroke rehabilitation. *Arch Phys Med Rehabil.* 2020;101(4):587–591.
20. Grimshaw J, Eccles M, Lavis J, Hill S, Squires J. Knowledge translation of research findings. *Implement Sci.* 2012;7:1–17.
21. Camden C, Shikako-Thomas K, Nguyen T, et al. Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disabil Rehabil.* 2015;37(15):1390–1400.
22. Straus S, Tetroe J, Graham I. Introduction. In: *Knowledge Translation in Healthcare.* UK: John Wiley & Sons; 2013:3–14.
23. Zych MM, Berta WB, Gagliardi AR. Conceptualising the initiation of researcher and research user partnerships: a meta-narrative review. *Health Res Policy Syst.* 2020;18(1):24.
24. CIHR. Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. In. Ottawa: Canadian Institutes of Health Research; 2015:1–30.
25. Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expect.* 2014;17(5):637–650.
26. Brush BL, Mentz G, Jensen M, et al. Success in long-standing Community-Based Participatory Research (CBPR) Partnerships: A scoping literature review. *Health Educ Behav.* 2020;47(4):556–568.
27. Hoekstra F, Mrklas KJ, Khan M, et al. A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: A first step in synthesising the research partnership literature. *Health Research Policy and Systems.* 2020;18(1).
28. Roberge-Dao J, Yardley B, Menon A, et al. A mixed-methods approach to understanding partnership experiences and outcomes of projects from an integrated knowledge translation funding model in rehabilitation. *BMC Health Serv Res.* 2019;19(1):230.
29. Cox R, Kendall M, Molineux M, Miller E, Tanner B. Consumer engagement in occupational therapy health-related research: A scoping review of the Australian Occupational Therapy Journal and a call to action. *Aust Occup Ther J.* 2021;68(2):180–192.
30. Merriam-Webster Dictionary. Evaluation. Merriam-Webster Dictionary. <https://www.merriam-webster.com/dictionary/evaluation> Published 2023. Accessed April 21, 2023.

31. King G, Servais M, Kertoy M, et al. A measure of community members' perceptions of the impacts of research partnerships in health and social services. *Eval Program Plann.* 2009;32(3):289–299.
32. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Front Public Health.* 2018;6:149.
33. Boivin A, L'Esperance A, Gauvin FP, et al. Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. *Health Expect.* 2018;21(6):1075–1084.
34. Hoekstra F, Mrklas KJ, Sibley KM, et al. A review protocol on research partnerships: a Coordinated Multicenter Team approach. *Syst Rev.* 2018;7(1):217.
35. Belcher B, Palenberg M. Outcomes and impacts of development interventions. *American Journal of Evaluation.* 2018;39(4):478–495.
36. Creswell J. *Research Design.* Fourth ed. Thousand Oaks, California: Sage Publications; 2014.
37. Sibley KM, Roche PL, Bell CP, Temple B, Wittmeier KDM. A descriptive qualitative examination of knowledge translation practice among health researchers in Manitoba, Canada. *BMC Health Serv Res.* 2017;17(1):627.
38. Graham ID, Tetroe J. Some theoretical underpinnings of knowledge translation. *Acad Emerg Med.* 2007;14(11):936–941.
39. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: Time for a map? *J Contin Educ Health Prof.* 2006;26(1):13–24.
40. Greenhalgh T, Wieringa S. Is it time to drop the 'knowledge translation' metaphor? A critical literature review. *J R Soc Med.* 2011;104(12):501–509.
41. McKibbin K, Lokker C, Wilczynski N, et al. A cross-sectional study of the number and frequency of terms used to refer to knowledge translation in a body of health literature in 2006: a Tower of Babel? *Implement Sci.* 2010;5(16):1–11.
42. Ospina M, Taenzer P, Rashed S, et al. A systematic review of the effectiveness of knowledge translation interventions for chronic noncancer pain management. *Pain Res Manag.* 2013;18(6):e129–e141.
43. Yost J, Ganann R, Thompson D, et al. The effectiveness of knowledge translation interventions for promoting evidence-informed decision-making among nurses in tertiary care: a systematic review and meta-analysis. *Implement Sci.* 2015;10:98.
44. Cahill LS, Carey LM, Lannin NA, et al. Implementation interventions to promote the uptake of evidence-based practices in stroke rehabilitation. *Cochrane Database Syst Rev.* 2020;10(10):CD012575.
45. Flynn R, Cassidy C, Dobson L, et al. Knowledge translation strategies to support the sustainability of evidence-based interventions in healthcare: a scoping review. *Implement Sci.* 2023;18(1):69.
46. Drahota A, Meza R, Brikho B, et al. Community-academic partnerships: A systematic review of the state of the literature and recommendations for future research. *The Milbank Quarterly.* 2016;94(1):163–214.

47. Jull J, Giles A, Graham ID. Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implement Sci.* 2017;12(1):150.
48. Nguyen T, Graham ID, Mrklas KJ, et al. How does integrated knowledge translation (IKT) compare to other collaborative research approaches to generating and translating knowledge? Learning from experts in the field. *Health Res Policy Syst.* 2020;18(1):35.
49. Hoekstra F, Mrklas KJ, Khan M, et al. A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature. *Health Res Policy Syst.* 2020;18(1):51.
50. Harrison M, Graham I. *Knowledge Translation in Nursing and Healthcare: A Roadmap to Evidence-informed Practice.* John Wiley & Sons, Inc.; 2021.
51. Sibbald S, Tetroe J, Graham I. Research funder required research partnerships: a qualitative inquiry. *Implement Sci.* 2014;9.
52. Tittlemier B, Cooper J, Steliga D, Woodgate R, KM. S. A scoping review to identify and describe the characteristics of theories, models, and frameworks of health research partnerships. In: University of Manitoba; 2021.
53. Sutton A, Clowes M, Preston L, Booth A. Meeting the review family: exploring review types and associated information retrieval requirements. *Health Info Libr J.* 2019;36(3):202–222.
54. Boland L, Kothari A, McCutcheon C, Graham ID, Integrated Knowledge Translation Research Network. Building an integrated knowledge translation (IKT) evidence base: colloquium proceedings and research direction. *Health Res Policy Syst.* 2020;18(1):8.
55. Belone L, Lucero JE, Duran B, et al. Community-based participatory research conceptual model: Community partner consultation and face validity. *Qual Health Res.* 2016;26(1):117–135.
56. Zych MM, Berta WB, Gagliardi AR. Initiation is recognized as a fundamental early phase of integrated knowledge translation (IKT): qualitative interviews with researchers and research users in IKT partnerships. *BMC Health Serv Res.* 2019;19(1):772.
57. Walker L, Avant K. *Strategies for Theory Construction in Nursing.* Sixth ed: Pearson Education; 2019.
58. Kerlinger F. *Foundations of Behavioral Research.* Third ed. USA: Holt, Rinehart & Winston; 1986.
59. Wallerstein N, Oetzel J, Duran B, Tafoya G, Belone L, Rae R. What Predicts Outcomes in CBPR? In: Minkler M, Wallerstein N, eds. *Community-based participatory research for health: From Process to outcomes.* John Wiley & Sons; 2008.
60. Oetzel JG, Wallerstein N, Duran B, et al. Impact of participatory health research: A test of the community-based participatory research conceptual model. *Biomed Res Int.* 2018;2018:7281405.
61. Banner D, Bains M, Carroll S, et al. Patient and public engagement in integrated knowledge translation research: Are we there yet? *Res Involv Engagem.* 2019;5:8.
62. Gagliardi AR, Kothari A, Graham ID. Research agenda for integrated knowledge translation (IKT) in healthcare: What we know and do not yet know. *J Epidemiol Community Health.* 2017;71(2):105–106.

63. Hamzeh J, Pluye P, Bush PL, Ruchon C, Vedel I, Hudon C. Towards an assessment for organizational participatory research health partnerships: A systematic mixed studies review with framework synthesis. *Eval Program Plann.* 2019;73:116–128.
64. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. *Health Res Policy Syst.* 2020;18(1):17.
65. Manafo E, Petermann L, Mason-Lai P, Vandall-Walker V. Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Res Policy Syst.* 2018;16(1):5.
66. Braveman P, Arkin E, Orleans T, Proctor D, Acker J, Plough A. What is health equity? *Behavioral Science & Policy.* 2018;4(1):1–14.
67. Ma JK, Ramachandran S, Sandhu A, et al. Tailored interventions for supporting physical activity participation in people with arthritis and related conditions: A Systematic Review. *Current Treatment Options in Rheumatology.* 2022;8(4):117–142.
68. Engle G. The need for a new medical model: A challenge for biomedicine. *Science.* 1977;196:129–136.
69. Engle G. The clinical application of the biopsychosocial model. *J Med Philos.* 1981;6(2):101–123.
70. Wade D. Describing rehabilitation interventions. *Clinical Rehabilitation.* 2005;19:811–819.
71. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ.* 2008;337:a1655.
72. Ntusi NAB. Health and rehabilitation sciences in a clinical context. *SAMJ.* 2019;109(3):139–141.
73. Jesus TS, Landry MD, Dussault G, Fronteira I. Human resources for health (and rehabilitation): Six Rehab-Workforce Challenges for the century. *Hum Resour Health.* 2017;15(1):8.
74. Wade D. Rehabilitation - a new approach. Part four: A new paradigm, and its implications. *Clin Rehabil.* 2016;30(2):109–118.
75. Stucki G. International Classification of Functioning, Disability, and Health (ICF): A promising framework and classification for rehabilitation medicine. *Am J Phys Med Rehabil.* 2005;84(10):733–740.
76. Wade D. Rehabilitation - a new approach. Part two: the underlying theories. *Clin Rehabil.* 2015;29(12):1145–1154.
77. Wade DT, Smeets RJ, Verbunt JA. Research in rehabilitation medicine: methodological challenges. *J Clin Epidemiol.* 2010;63(7):699–704.
78. Sibley KM, Hoekstra F, Kothari A, Mrklas K. Effects, facilitators, and barriers of research coproduction reported in peer-reviewed literature. In: Graham ID, Rycroft-Malone J, Kothari A, McCutcheon C, eds. *Research Co-Production in Healthcare.* John Wiley & Sons Ltd; 2022:54–73.
79. McLean R, Graham ID, Carden F. Evaluating research coproduction. In: Graham ID, Rycroft-Malone J, Kothari A, McCutcheon C, eds. *Research Co-Production in Healthcare.* John Wiley & Sons Ltd; 2022.
80. Boivin A, Richards T, Forsythe L, et al. Evaluating patient and public involvement in research. *BMJ.* 2018;363:k5147.

81. Smith H, Budworth L, Grindey C, et al. Co-production practice and future research priorities in United Kingdom-funded applied health research: A scoping review. *Health Res Policy Syst.* 2022;20(1):36.
82. Hoffmann C, Stoykova BA, Nixon J, Glanville JM, Misso K, Drummond MF. Do health-care decision makers find economic evaluations useful? The findings of focus group research in UK health authorities. *Value Health.* 2002;5(2):71–78.
83. Maxwell J. Conceptual framework: What do you think is going on. In: *Qualitative research design: An interactive approach* 2005: 33–63.
84. Ravitch S, Mittenfelner Carl N. *Qualitative Research: Bridging the Conceptual, Theoretical, and Methodological.* Thousand Oaks, California: SAGE Publications Ltd.; 2016.
85. Kivunja C, Kuyini AB. Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education.* 2017;6(5).
86. Johnson RB, Onwuegbuzie AJ. Mixed methods research: A research paradigm whose time has come. *Educational Researcher.* 2004;33(7):14–26.
87. Nowell L. Pragmatism and integrated knowledge translation: exploring the compatibilities and tensions. *Nurs Open.* 2015;2(3):141–148.
88. Crotty M. *The Foundations of Social Research.* London, England: SAGE Publications Inc.; 1998.
89. Barth CA. Meeting the needs of people with physical disabilities in crisis settings. *Bull World Health Organ.* 2019;97(12):790–790A.
90. Padenhauer LM, Gerhardus A, Mozygemba K, et al. Making sense of complexity in context and implementation: the Context and Implementation of Complex Interventions (CICI) framework. *Implement Sci.* 2017;12(1):21.
91. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *Journal of Mixed Methods Research.* 2007;1(2):112–133.
92. Teddlie C, Tashakkori A. Common “Core” characteristics of mixed methods research: A review of critical issues and call for greater convergence. *American Behavioral Scientist.* 2012;56(6):774–788.
93. Palinkas LA, Aarons GA, Horwitz S, Chamberlain P, Hurlburt M, Landsverk J. Mixed method designs in implementation research. *Adm Policy Ment Health.* 2011;38(1):44–53.
94. Creswell J, Plano Clark V. Core Mixed Methods Design. In: Creswell J, Plano Clark V, eds. *Designing and Conducting Mixed Methods Research.* Third ed. Los Angeles: Sage Publications; 2018.
95. Feters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs- principles and practices. *Health Serv Res.* 2013;48(6 Pt 2):2134–2156.
96. Lewis KB, Graham ID, Boland L, Stacey D. Writing a compelling integrated discussion: A guide for integrated discussions in article-based theses and dissertations. *Int J Nurs Educ Scholarsh.* 2021;18(1).
97. Prince M, J D-M. Cross-sectional surveys. In: Das-Munshi J, Ford T, Hotopf M, Prince M, R. S, eds. *Practical Psychiatric Epidemiology.* Second ed.: Oxford Academic; 2020.

98. Cohen SB. Survey Methods in Health Services Research. In: Levy A, Goring S, Gatsonis C, Sobolev B, van Ginneken E, Busse R, eds. *Health Services Evaluation*. New York, NY.: Springer; 2019:661–694.
99. Wang X, Cheng Z. Cross-sectional studies: Strengths, weaknesses, and recommendations. *Chest*. 2020;158(1S):S65–S71.
100. Ruel E. 100 Questions (and Answers) About Survey Research. In: Thousand Oaks, California 2019: <https://methods.sagepub.com/book/100-questions-and-answers-about-survey-research>. Accessed 2023/02/03.
101. Hulley SB, Cummings SR, Browner WS, Grady DG, Newman TB. Estimating Sample Size and Power: Applications and Examples. In: *Designing Clinical Research*. Third ed. Philadelphia: Wolters Kluwer; 2007:367.
102. Sibbald SL, Kang H, Graham ID. Collaborative health research partnerships: a survey of researcher and knowledge-user attitudes and perceptions. *Health Res Policy Syst*. 2019;17(1):92.
103. Mrklas KJ, Boyd JM, Shergill S, et al. Tools for assessing health research partnership outcomes and impacts: a systematic review. *Health Res Policy Syst*. 2023;21(1):3.
104. International Association of Public Participation. IAP2 Spectrum. [https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20\(1\).pdf](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf). Published 2021. Accessed July 20, 2021.
105. Scott K, Ummer O, LeFevre AE. The devil is in the detail: Reflections on the value and application of cognitive interviewing to strengthen quantitative surveys in global health. *Health Policy Plan*. 2021;36(6):982–995.
106. Willis G. Cognitive interviewing in survey design: State of the science and future directions. In: Vannette D, Krosnick J, eds. *The Palgrave Handbook of Survey Research*. 2018:103–107.
107. Conrad FG, Blair J. Sources of error in cognitive interviews. *Public Opinion Quarterly*. 2009;73(1):32–55.
108. Sibley KM, Khan M, Touchette AJ, et al. Characterizing Canadian funded partnered health research projects between 2011 and 2019: A retrospective analysis. *Health Research Policy and Systems*. 2023;21(1).
109. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res*. 2004;6(3):e34.
110. Eysenbach G. Correction: Improving the quality of web Surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *Journal of Medical Internet Research*. 2012;14(1).
111. Bradshaw C, Atkinson S, Doody O. Employing a qualitative description approach in health care research. *Glob Qual Nurs Res*. 2017;4:2333393617742282.
112. Kim H, Sefcik JS, Bradway C. Characteristics of qualitative descriptive studies: A systematic review. *Res Nurs Health*. 2017;40(1):23–42.
113. Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health*. 2000;23:334–340.
114. Braun V, Clarke V. *Successful Qualitative Research: A Practical Guide for Beginners*. Thousand Oaks, California: SAGE Publications Ltd.; 2013.

115. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med*. 2022;292:114523.
116. Hennink MM, Kaiser BN, Marconi VC. Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qual Health Res*. 2017;27(4):591–608.
117. Morse J. Determining sample size. *Qualitative Health Research*. 2000;10(1):3–5.
118. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*. 2021;13(2):201–216.
119. Petty NJ, Thomson OP, Stew G. Ready for a paradigm shift? Part 2: introducing qualitative research methodologies and methods. *Man Ther*. 2012;17(5):378–384.
120. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349–357.
121. Mrklas KJ, Merali S, Khan M, et al. How are health research partnerships assessed? A systematic review of outcomes, impacts, terminology and the use of theories, models and frameworks. *Health Res Policy Syst*. 2022;20(1):133.
122. Michie S, van Stralen M, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*. 2011;6(42):1–11.
123. Rycroft-Malone J, I DG, Kothari A, McCutcheon C. Research Coproduction: An Underused Pathway to Impact. *Int J Health Policy Manag*. 2024;13:8461.
124. Richards DP, Poirier S, Mohabir V, Proulx L, Robins S, Smith J. Reflections on patient engagement by patient partners: how it can go wrong. *Res Involv Engagem*. 2023;9(1):41.
125. Chudyk AM, Stoddard R, McCleary N, et al. Activities and impacts of patient engagement in CIHR SPOR funded research: A cross-sectional survey of academic researcher and patient partner experiences. *Res Involv Engagem*. 2022;8(1):44.
126. Omar S, Williams CC, Bugg LB, Colantonio A. "Somewhere along the line, your mask isn't going to be fitting right": Institutional racism in Black narratives of traumatic brain injury rehabilitation across the practice continuum. *BMC Health Serv Res*. 2024;24(1):834.
127. Kitching GT, Firestone M, Schei B, et al. Unmet health needs and discrimination by healthcare providers among an Indigenous population in Toronto, Canada. *Can J Public Health*. 2020;111(1):40–49.
128. Willmott TJ, Pang B, Rundle-Thiele S. Capability, opportunity, and motivation: an across contexts empirical examination of the COM-B model. *BMC Public Health*. 2021;21(1):1014.
129. Dyson J, Cowdell F. How is the Theoretical Domains Framework applied in designing interventions to support healthcare practitioner behaviour change? A systematic review. *Int J Qual Health Care*. 2021;33(3).
130. Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Health*. 2011;38(2):65–76.
131. MacKinnon DP, Fairchild AJ, Fritz MS. Mediation analysis. *Annu Rev Psychol*. 2007;58:593–614.

132. Wade DT. Defining rehabilitation: An exploration of why it is attempted, and why it will always fail. *Clin Rehabil.* 2021;35(12):1650–1656.
133. Negrini S, Selb M, Kiekens C, et al. Rehabilitation definition for research purposes. A global stakeholders' initiative by Cochrane Rehabilitation. *Eur J Phys Rehabil Med.* 2022;58(3):333–341.
134. Mielke J, Brunkert T, Zullig LL, et al. Relevant Journals for Identifying Implementation Science Articles: Results of an International Implementation Science Expert Survey. *Front Public Health.* 2021;9:639192.