Patients' and Researchers' Perspectives on the Impact of Patient Engagement in Rehabilitation Research

Conchita Edwin Saldanha

School of Physical and Occupational Therapy

McGill University, Montréal

Initial submission: August 2022

Final Submission: December 2022

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master of Rehabilitation Science

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Abstract

Background: The growing research on the effectiveness of rehabilitation interventions has sparked an interest in Knowledge Translation (KT), a call for including various stakeholders in research, and greater use of participatory approaches. This growth in research has led to an increase in Patient Engagement (PE) in health research and a focus on assessing its impact on various outcomes. Given that impact is likely highly context-dependent and that it may vary based on the stakeholders involved, the nature of the research, and the intended aim of engaging patients, there is a need to better understand what impact of PE means for both patients and researchers.

Objectives: The global aim of this research was to explore how patients and researchers define and evaluate the impact of PE in rehabilitation research and what challenges and opportunities they encounter during the evaluation of impact.

Methods: The study used a qualitative interpretive description methodology. Using purposive sampling, patients and researchers in the field of rehabilitation research were recruited to participate in a semi-structured interview. Thematic analysis was conducted based on Braun and Clarke's, six-phase process.

Results: A total of ten patient partners and nine researchers participated in the study. Two patient partners had been involved in research for 1-5 years, two for 6-10 years, and six for more than 10 years. Three researchers had worked with patient partners from 1-5 years, three from 6-10 years, and three for over 10 years.

The data from the interviews were organized into four themes that were common to both groups: 1) tapestry of perspectives and terminologies regarding impact: focuses on the variability in the terminologies used to define patient, PE, and impact of PE in research; 2) evolution of PE as a result of engagement: describes how PE has evolved over the last two

decades and resulted in researchers becoming less apprehensive about collaborating with patient partners; 3) multi-level nature of impact and its evaluation: Data on impact of PE were organized based on three dimensions: 1) the patient dimension: assessed by capturing the benefits and challenges faced by patients throughout the engagement process; 2) the research dimension: reflected in Altmetric scores, reach of an article, improvement in recruitment and retention rates; and 3) the practice dimension: determined by whether the engagement influenced the implementation of an intervention, thereby positively impacting the health and social outcomes of the patient; and 4) PE practices influencing evaluation of impact, which highlights the opportunities and challenges regarding impact evaluation.

Conclusion*:* Assessing the impact of patient engagement in research is key for advancing patient-oriented research. It is important for researchers to recognize the metrics that matter to patients and how they define engagement success. Training opportunities at the university level are needed to better prepare researchers to more meaningfully engage patients in research. This study identifies potential categories of impact and promising avenues for its evaluation. This knowledge contributes to the future development of robust measures of impact of patient engagement.

Résumé

***Mise en contexte*:** La recherche croissante sur l'efficacité des interventions de réadaptation a suscité un intérêt pour l'application des connaissances, un appel à inclure diverses parties prenantes dans la recherche et une plus grande utilisation des approches participatives. Cette croissance de la recherche a entraîné une augmentation de l'engagement des patients dans la recherche sur la santé et une attention particulière à l'évaluation de son impact sur divers résultats. Étant donné que l'impact est probablement très dépendant du contexte et qu'il peut varier en fonction des parties prenantes impliquées, de la nature de la recherche et de l'objectif visé par l'engagement des patients, il est nécessaire de mieux comprendre ce que signifie l'impact pour les patients et les chercheurs.

Objectifs: L'objectif global de cette recherche était d'explorer comment les patients et les chercheurs définissent et évaluent l'impact de l'engagement dans la recherche en réadaptation et quels sont les défis et les opportunités qu'ils rencontrent pendant l'évaluation de l'impact.

Méthodes: L'étude a utilisé une méthodologie de description qualitative interprétative. En utilisant un échantillonnage intentionnel, des patients et des chercheurs dans le domaine de la recherche en réadaptation ont été recrutés pour participer à un entretien semi-structuré. Une analyse thématique a été menée sur la base du processus en six phases de Braun et Clarke.

Résultats: Au total, dix patients partenaires et neuf chercheurs ont participé à l'étude. Deux patients partenaires étaient impliqués dans la recherche depuis 1-5 ans, deux depuis 6-10 ans, et six depuis plus de 10 ans. Trois chercheurs avaient travaillé avec des patients partenaires pendant 1 à 5 ans, trois pendant 6 à 10 ans, et trois pendant plus de 10 ans.

Les données des entretiens ont été organisées en quatre thèmes communs aux deux groupes : 1) tapisserie de perspectives et de terminologies concernant l'impact: met l'accent sur la variabilité des terminologies utilisées pour définir le patient, participation des patients, et l'impact de l'engagement des patients dans la recherche; 2) évolution de la participation du patient à la suite de l'engagement: décrit comment participation des patients a évolué au cours des deux dernières décennies et a permis aux chercheurs de moins appréhender la collaboration avec des patients partenaires; 3) la nature multi-niveaux de l'impact et de son évaluation. Les données sur l'impact de l'engagement des patients ont été organisées selon trois dimensions : 1) la dimension du patient : évaluée en capturant les avantages et les défis rencontrés par les patients tout au long du processus d'engagement; 2) la dimension de la recherche : reflétée dans les scores Altmetric, la portée d'un article, l'amélioration des taux de recrutement et de rétention; et 3) la dimension de la pratique : déterminée par le fait que l'engagement a influencé la mise en œuvre d'une intervention, ayant ainsi un impact positif sur les résultats sanitaires et sociaux du patient; et 4) les pratiques de participation des patients influençant l'évaluation de l'impact, ce qui met en évidence les opportunités et les défis de l'évaluation d'impact.

Conclusion: L'évaluation de l'impact de l'engagement du patient dans la recherche est essentielle pour faire progresser la recherche axée sur le patient. Il est important que les chercheurs reconnaissent les paramètres qui comptent pour les patients et la façon dont ils définissent le succès de l'engagement. Des possibilités de formation au niveau universitaire

sont nécessaires pour mieux préparer les chercheurs à associer les patients à la recherche de manière plus significative. Cette étude identifie des catégories potentielles d'impact et des pistes prometteuses pour son évaluation. Ces connaissances contribuent au développement futur de mesures robustes de l'impact de l'engagement des patients.

Acknowledgements

I would like to express immense gratitude to all those who have been a part of my graduate school journey in the last two years. Despite all the hardships that came along due to the pandemic, I had the opportunity to learn and grow not just on a professional level but personally as well.

I would like to thank my amazing supervisor, Dr. Aliki Thomas, for giving me this learning opportunity, trusting me with this project, being patient throughout my journey and above all, for being so empathetic towards all her students. Thank you for fueling my passion towards this topic and for your excellent mentorship.

I would also like to thank my committee members, Dr. Tania Janaudis-Ferreira and Dr. André Bussières for their constant feedback and encouragement throughout my thesis.

I have been very fortunate to have had the opportunity to work alongside my lab mates in the Knowledge Exchange and Education in the Health Professions (K.E.E.P) lab. I would like to thank them all for their constant support and feedback throughout my research project. A special thank you to my lab mate Dr. Catherine Giroux, a post-doctoral fellow in our lab for her patience and guidance throughout my data analysis. I appreciate and would also like to thank my classmates for being there through the difficult remote learning times and for creating a safe and healthy learning environment.

I would like to thank the School of Physical and Occupational Therapy for extending their help through emails, scholarships, and other learning opportunities.

A humble thank you to my alma mater, Ramaiah Medical College (RMC) for helping me become the clinician I am today and introducing me to the world of research. I am also grateful to RMC for introducing me to the two most important people in my life, my best friend Ridhi Verma, who has believed in me and motivated me to pursue this graduate

degree and my partner, Imraan Khan, for making me believe that everything is possible if you work hard for it.

I would like to thank the host family I live with, for accepting me in their humble abode and keeping me company during quarantine times. I would also like to thank all my friends, from Montreal and from India for regularly checking up on me and being therapeutic listeners.

Last but not the least, I would like to thank my parents, my grandparents, my brother and my extended family who have always supported me through difficult times and have always provided me with the push that I needed to complete all the tasks I have undertaken with great finesse.

Contribution of Authors

The research team contributing to this study brought important expertise in several domains. My primary supervisor, Dr. Aliki Thomas is an occupational therapist with a PhD in educational psychology and postdoctoral training in knowledge translation. Her area of research expertise includes using Integrated Knowledge Translation (IKT) approaches to study the uptake of Evidence Based Practice (EBP's). My committee members are Dr. André Bussières (AB) and Dr. Tania Janaudis-Ferreira (TF). Dr. Bussières is a chiropractor with a PhD in population health and has expertise in KT and in the development and implementation of practical guidelines. Dr. Janaudis-Ferreira is a physiotherapist and has an expertise in PE in rehabilitation, specifically, patients with chronic lung disease and transplant patients. The 2nd reviewer, Dr. Catherine Giroux is an educator by profession. She is a trained researcher with a background in Patient Engagement in Health Professions Education (HPE) with no clinical expertise. At the time of my master's work, she was completing a postdoctoral fellowship in the K.E.E.P lab.

I completed all the phases of this study with the support of the research team. Dr. Thomas was closely involved with all the phases of the study, through scheduled meetings and constant communication via email. She provided oversight and written feedback on the study protocol, ethics application, interview guides, data analysis, results, and discussion of this thesis.

Dr. Tania Janaudis- Ferreira and Dr. André Bussières provided written and verbal feedback on the protocol and a completed version of my thesis.

Dr. Simon Decary assisted me in the early stages of this study and provided feedback during the conceptualization of this study.

Dr. Catherine Giroux assisted me in analyzing the data for this study as a second reviewer.

My K.E.E.P lab colleagues provided feedback on my protocol presentation and written feedback on my interview guide.

I wrote this thesis in its entirety. Dr. Thomas provided me with extensive written feedback on the contents of each chapter as they were written and via regular meetings as needed. Dr. Thomas reviewed the final version of my thesis prior to submission.

List of Abbreviations

PE: Patient Engagement

POR: Patient-Oriented Research

PP: Patient Partners

KT: Knowledge Translation

IKT: Integrated Knowledge Translation

CIHR: Canadian Institutes of Health Research

SPOR: Strategy for Patient-Oriented Research

NIHR: National Institute for Health and Care Research

PCORI: Patient-Centered Outcomes Research Institute

EBP: Evidence-Based Practice

PPEET: Public and Patient Engagement Evaluation Tool

PEIRS: Patient Engagement in Research Scale

CBPR: Community Based Participatory Research

CAHS: Canadian Academy of Health-Sciences

Chapter 1: Introduction

This chapter presents an introduction to this thesis and is organized into five sections: (1) personal trajectory, (2) terminologies, (3) study rationale, (4) study objective, and (5) thesis organization.

1.1 Personal Trajectory

I am a female Physiotherapist with 2 years of clinical experience in neurological rehabilitation. My internship and clinical work experiences have brought me to pursue this research inquiry during my master's degree. During my bachelor's degree I was taught the basics of research but did not learn about knowledge translation. Later during my internship, we were expected to practice, based on treatment algorithms and evidence-based guidelines. During my journey as a clinical physiotherapist, I realized how important it was to adhere to evidence-based practice and to recognize the value of experiential knowledge as each patient is unique and responds differently to treatment. I encountered challenges when trying to apply evidence-based practice. For example, time was a major barrier. Working in a government or private setting does not permit you to give adequate treatment time to the patient because of the workload. But as a responsible clinician, I always asked my patients what they expected from their therapy and what their end goal was. By doing so, I realized that my patients felt heard and motivated to come for therapy, and in the end, most responded well to treatment. Ever since, I have come to appreciate the need to consider experiential knowledge in practice. Keeping in mind that the goal is to address the needs of the patients I worked with, there is no better way than to incorporate their lived experiences in therapy.

My experience working with patients has helped me reflect and realize that just

like there are barriers to addressing the needs of the patients in treatment, researchers also face certain barriers when including patients in research. The Patient Engagement (PE) mandate of funding agencies like the Canadian Institutes of Health Research (CIHR) can inadvertently contribute to tokenism. Therefore, I believe that the way to establish meaningful engagement in practice and limit tokenism is by demonstrating and conceptualizing the impact that engaging patients has on researchers and patients, on the research process, and on the practice outcomes of research. These reflections will serve as foundational, experiential knowledge for my study. However, since I (CS) will be conducting the interviews myself, I will remain careful to not impose my preconceptions on how I conduct and analyze my data and to adopt an inductive approach to data analysis. I did not establish or have any contact with my participants prior to the commencement of the study. I introduced myself to the participants during the day of the interview and provided them with my background and the details of the study and the consent form.

1.2 Terminologies

As it will become clearer throughout this thesis, several terms in the field of patient engagement are used interchangeably, and/or lack a clear definition, both of which may challenge the reader in situating the author's body of work in the larger field of study. It is for this reason that I begin with providing the definitions which I have drawn from to support my work. Specifically, I will define patient engagement, patient-oriented research, participatory research, and integrated knowledge translation.

Given that the focus of my thesis is on the impact of patient engagement, I then provide a more detailed description of the term impact, differentiate it from outcome, and offer supporting literature to justify my decision.

In this thesis, '*Patient Engagement' (PE)* is defined as, "When patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge." This definition is in accordance with the definitions on the CIHR Strategy for Patient-Oriented Research (Strategy for Patient-Oriented Research, 2019).

'Patient-Oriented Research' (POR) is referred to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices (Strategy for Patient-Oriented Research, 2019).

'Participatory research' is an umbrella term for a school of approaches that share a core philosophy of inclusivity, and that recognize the value of engaging those who are the intended beneficiaries, users, and stakeholders of the research, in the research process, rather than including them only as subjects of the research. Among the approaches included within this category are community-based participatory research, participatory rural appraisal, empowerment evaluation, participatory action research, community partnered participatory research, cooperative inquiry, dialectical inquiry, appreciative inquiry, decolonizing methodologies, participatory or democratic evaluation, social reconnaissance, emancipatory research, and forms of action research embracing a participatory philosophy (Cargo & Mercer, 2008).

'Integrated Knowledge Translation' (IKT) is defined as a form of KT where researchers and knowledge users (e.g. policymakers, clinicians) work together to determine research questions, decide on methodology, collect data, develop tools, interpret findings, and disseminate research results. This approach is intended to produce research findings that are more likely to be relevant to, and used by, the end

users (Canadian Institutes of Health Research, 2022).

The term *'patient'* is used as an overarching term, referring to an individual with lived experience of a particular health condition or a health service issue (Strategy for Patient-Oriented Research, 2019). The term *'Patient Partner'* (PP) is defined as patient, patient advocate, patient representative and/or carer who contributes to any level of patient engagement activities; this can also be substituted for other terms such as patient contributor (Karazivan et al., 2015).

The term '*Participant*' or '*Research Participant*", which is different from patient partner, is defined as a person who participates in human subject research, and may also be called a subject, study participant or volunteer of an experiment or trial (Vat et al., 2020).

'Researcher' is defined as someone who 1) has an academic or research appointment and is autonomous regarding their research activities; and 2) carries out research activities. Researcher experience is often measured by years of experience: Early career- within 5 years of the date of their first independent research appointment; Mid-career- individual at the time of application who has assumed his/her independent research position 5-15 years ago: and Senior researcher- individual at the time of application assumed his/her independent research position over 15 years ago. (Canadian Institutes of Health Research, 2022).

The term *'Rehabilitation Research'* encompasses a broad range of disciplines and methodologies covering the full spectrum of basic to applied science (Ommaya et al., 2013). Important themes for rehabilitation research include prevention, improvement, restoration, and replacement of underdeveloped or deteriorating function (Ommaya et al., 2013).

The term *'Impact'* can be defined as, "an effect on, change or benefit to the

economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia." (Research Excellence Framework., 2014). *Impact* can be defined as what is changed because of the engagement and how big that change is (Dillon et al.,2017). Therefore, *Impact* is the broader effect of outcomes, both positive and negative, of patient engagement. *Impact* may be direct or indirect, intended or unintended. For example, this may include study quality benefits such as improved recruitment and retention of study participants (Vat et al., 2020).

The term '*outcomes'* can be defined as decisions made, and things produced, as a direct result of patient engagement practices. One example is changes made in the design of a clinical trial resulting in a more relevant and appropriate research protocol. *Outcomes* may lead to impact on research and development (Vat et al., 2020). As such, though impact and outcome may be viewed as synonyms, they are distinct phenomena differentiated on the basis of temporality, that is, based on a phenomenon taking place over a certain period of time. Outcomes refer to the more **immediate** effects of engagement, for example, change in the research design and process (protocol, methods and methodology). Outcomes can also refer to personal benefits for patients, such as feeling valued or heard, and benefits for researchers, such as feelings of satisfaction for collaborating with patients. On the other hand, **intermediate or longer term effects** of engagement may be about improved retention and recruitment, improved quality of life, improved treatment interventions, change in policies, change in engagement practices, change in attitudes and behaviours of researchers, improved training or job opportunities for patient partners, and improved relationships due to long term partnerships. These longer-term effects would therefore be considered as *impact*.

1.3 Study Rationale

With the emerging interest in PE, there has been an emphasis on developing an

evidence base for engaging patients in research, and a focus on demonstrating its impact. The debate around the impact of PE focuses mainly on the lack of empirical data given that the existing evidence is considered weak and anecdotal. As such, there is a need to develop a robust evidence base for the evaluation of impact (Staley & Barron, 2019).

Impact is highly context-dependent (Staley & Barron, 2019). One of the most important contextual factors that influences outcomes of engagement is the researchers themselves; in particular, the skills, knowledge, values, and assumptions they bring with them to the PE experience (Staley & Barron, 2019). The different ways in which impact can be understood, and the lack of conceptual clarity regarding what impact is in the existing literature make it somewhat difficult to predict the impact for any given project. Given the complex nature of patient engagement, and in order to design optimal evaluation strategies that adequately capture this construct (impact), there is a need to understand the perspectives of the patient partners and researchers. In particular, we need to better describe and understand the context in which patient engagement takes place and the mechanism by which it occurs in a meaningful manner (Staley & Barron, 2019).

Evidence on the impact of PE can help various stakeholders (i.e., patients, researchers, clinicians, policy makers) decide on the methods that may be used to 1) maximally engage patients, that is, 'who' should be engaged; 2) 'when' should the engagement occur; and 3) 'how much' is needed for engagement to be considered meaningful (Dillon et al., 2017). Therefore, to advance our knowledge on PE and its impact, we must better understand what impact of PE means from the perspectives of patient partners and researchers and to identify and understand the evaluation strategies they adopt to address impact.

1.4 Study Objective

The objective of this study was to explore the perspectives of patients and researchers on the impact of PE in rehabilitation research.

The research questions guiding this study were:

1) What does impact of PE in rehabilitation research mean to patients and researchers?
2) How are patients and researchers evaluating the impact of PE in rehabilitation research?
3) What are the challenges and opportunities encountered in the evaluation of impact from the perspectives of patients and researchers?

1.5 Thesis Organization

This thesis is organized into five chapters subsequent to the present one: (2) Background and Literature Review; (3) Methodology and Methods; (4) Results; (5) Discussion and (6) Conclusion. These are followed by References and Appendices containing supporting documents referred to within Chapter 3.

Chapter 2: Background and Literature Review

This chapter presents an overview of the relevant literature followed by the relevance and expected contributions of this study. It is organized into (1) PE: terms and definitions, (2) history of PE, (3) impact of PE, (4) PE in rehabilitation research, (5) impact of PE in rehabilitation research, (6) study relevance, and (7) expected contributions.

2.1. PE: Terms and Definitions

As the cornerstone of healthcare research, PE involves partnering researchers with patients and their caregivers to facilitate healthcare and health services research (Bird et al., 2020; Rolfe et al., 2018). The Canadian Institutes of Health Research Strategy for Patient Oriented Research (SPOR) defines PE as, "When patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge" (Strategy for Patient-Oriented Research, 2019). Although patient engagement and patient-oriented research are both approaches that focus on patient-identified priorities, they do differ, in that the latter may or may not involve patients throughout the research process.

For SPOR, the term 'patient' is used as an overarching term, referring to an individual with lived experience of a particular health condition or a health service issue (Strategy for Patient-Oriented Research, 2019). In some areas of healthcare, where individuals may be uncomfortable being labelled as 'patients', other terms such as clients, consumer- survivors, people with lived experience are used (Gallivan et al., 2012). Each term has its unique connotations, strengths, and limitations and ought not to be used interchangeably.

The language used to define PE differs globally. In Canada, the SPOR initiative uses the terms PE and Patient Oriented Research, whereas in the United Kingdom, the term

Patient and Public Involvement (PPI) is used, denoting the active involvement of the public in research (Hayes et al., 2012; Strategy for Patient-Oriented Research, 2019).

Although PE shares some features with other participatory approaches in research such as integrated knowledge translation, patient-centered research, participatory action research and community based participatory research (Mallidou et al., 2018), in my thesis I will use the term 'Patient Engagement' to refer to the active engagement of patients throughout the research cycle as defined by the Strategy for Patient-Oriented Research, 2019. I will use the term 'patient-partner' (Sunderji et al.,2019) to refer to those with lived experience of illness or disability who engage in rehabilitation research. The term 'patient engagement' is central in the SPOR initiative in Canada and aligns with the rationale and aims of my research (Strategy for Patient-Oriented Research, 2019).

2.2. History of Patient Engagement

The concept of PE in research emerged over the last two decades, in large part due to a need to actively engage patients throughout the research cycle to address patient-identified priorities leading to relevant research outcomes (Manafo et al., 2018). With recent advances in technology and the increased access to information, patients are becoming more knowledgeable about their health conditions and healthcare options; this has resulted in a paradigm shift from a traditional and paternalistic approach in healthcare to a more patient centered approach (Manafo et al., 2018).

The concept of PE originated from the disabled people's movement in 1962 (Beresford, 2005). In the UK, a group of individuals with lived experiences of disability, invited academic researchers to conduct independent research in the institutions they were living in. The aim for these individuals was that research findings will give their views added credibility and expose the discrimination that they were subjected to due to their disability.

It was believed that this process would enhance the credibility to the research. Though the researchers accepted the proposal, they argued that the psychological distress experienced by patients with disabilities was due to the disability, rather than a result of disabling social arrangements and institutionalization. Patients felt betrayed by this response stating that their wish for autonomy was being overlooked. Though the researchers claimed that they had attempted to conduct neutral, balanced, and scientific research (Miller & Gwynne, 1972), Paul Hunt, a leader of the disabled people's movement identified several biases in the study and critiqued it for its failure to ground disability in a more individualistic perspective. This experience triggered an exploration of a different and more patient-centered approach to research (Beresford, 2005).

Since the disabled people's movement in 1962, PE in research has progressed due to arguments underpinning four main perspectives, namely, *consequential, epistemological, moral, and political value systems* (Aubin et al., 2019). Studies that aim to build on these four perspectives, needs, and priorities of patients are firmly grounded in the social imperative of engaging those who are most affected by health care research in the research process (Aubin et al., 2019). These arguments are well reflected in the popular slogan used by advocates of patient involvement, "nothing about us, without us" (NIHR, 2006).

The *consequentialist argument* postulates that PE in healthcare research improves the quality, credibility, and relevance of the research (Entwistle et al., 1998). Authors such as Boote (2010), Entwistle (1998), and Oliver (1996) documented how patients can positively contribute to research by being part of every step of the research process, from suggesting relevant research questions and outcomes, to assisting in participant recruitment and data collection, interpretation, helping with dissemination, and ensuring that the consent forms are user friendly (Boote et al., 2010). It appears that the fundamental

premise of this argument is that engaging patients in research will assist the processes of disseminating and translating the research findings so that the research generated is more relevant and applicable to the target group specifically, and the general population more broadly. For example, engaging patients in research can help limit the use of scientific jargon and make the results more accessible and understandable to the public.

The epistemological argument makes claims about the value and importance of experiential knowledge and the different ways of knowing (Entwistle et al., 1998). Epistemology is a branch of philosophy dealing with the study of knowledge; theory of knowledge, asking questions such as, "what is knowledge?", "what do people know?". Epistemology focuses on the knowledge that can be considered legitimate, in this context patient experiences, and what knowledge patients can convey to others through the lens of a person with disability. In the context of PE, the epistemological argument challenges the positivist paradigm (Crotty, 1998), with its claims of one absolute and objective truth, and it differentiates user involvement from the traditional approaches where patients' role is largely one of research participant. According to Beresford (2005), "the shorter the distance between direct experience and interpretation, the less distorted, inaccurate and damaging resulting knowledge can be" (p.5). Therefore, stakeholders other than patients who undertake research and interpret the patient's knowledge and experiences should try to get 'as close' to the raw data as possible. Stakeholders with experience of health problems can help improve the quality of research by providing insights that can enhance the development, conduct, interpretation, and use of research (O'Donnell & Entwistle, 2004).

The *moral argument* emphasizes the importance of empowering disadvantaged and vulnerable groups through transparency and accountability from researchers (Harrison & Palmer, 2015). Engaging patients in research minimizes the risk of objectification,

encourages diversity and preserves the respect for the right of citizenship. For example, In the UK, the patients are contributors to publicly funded research as they pay taxes and are part-owners of the NHS. It is therefore their moral and ethical right to engage in research.

Finally, the *political argument* contends that PE introduces democratic ideals, so that the knowledge generated through research serves the interest of the public and the funding is spent responsibly. This is intended to lead to the democratization of science and the research process (Entwistle et al., 1998). The political argument has spurred the rise of PE in research through funding opportunities. Funding bodies require that research teams make explicit how and why patients will be involved in in the preparation of funding applications and in the research process should the study be funded (Canadian Institutes of Health Research, n.d.; Harrison & Palmer, 2015).

2.3. Impact of PE

The empirical literature on the benefits of engaging patients and caregivers in research is limited. In a qualitative study conducted by Hoven et al. (2018), patient partners identified benefits of engaging in research both at the personal and professional level. The study conducted semi-structured telephonic interviews with eleven patient research partners and six researchers to gain insights on their motivation for and their experiences of the long-term collaboration. For instance, the patient partners reported that collaborating with researchers and other patient partners was therapeutic, in that it helped them adjust to the group and to the rehabilitation process. Engagement was a source of continued motivation as patients could voice their opinions and experiences. At a professional level, engaging in research increased the relevance of the research; it was better tailored to target population's needs and included insights and perspectives outside the world of research and academia (Hovén et al., 2018). Systematic reviews by Brett et al. (2010) and

Crocker et al. (2018) investigating the impact of patient and public involvement (PPI) on rates of enrolment and retention in clinical trials, found that PE in research has a positive impact on participant recruitment and retention rates. Out of the 26 studies included in the review by Crocker et al. (2018), data from 19 trials could be pooled in a meta-analysis to evaluate the impact of PPI on 'enrolment' and from 5 trials for 'retention'. PPI interventions modestly but significantly increased the odds of participant enrolment. The exploratory subgroup analysis suggested that engaging with people with lived experiences of the condition under study is significantly associated with improved enrolment rates. Whereas, due to a paucity of eligible studies, finding for retention rates were inconclusive (Crocker et al., 2018). Another review by Esmail et al. (2015) evaluated the hypothesized impacts of engagement using qualitative methods, relying on retrospective accounts and self-reports of engagement experiences through focus groups, individual interviews, informal observations, and surveys with open-ended questions. The authors found that PE accelerates the translation and uptake of research findings, particularly when patients are engaged in the research process early (Esmail et al.,2015). Overall, it seems that engaging patients in research improves the quality of research, sometimes via the patient's knowledge and experience, thereby generating evidence that is more relevant to the needs of the patients and the various stakeholders (Esmail et al., 2015).

The literature also highlights some of the potential negative effects of engagement. As described by Barber et al. (2012), Brett et al. (2014) and Russell et al. (2020), patients engaging in research early during the course of their illness or care process may experience emotional distress while sharing their experiences or listening to others'. Additionally, patients can experience frustration due to a) lack of opportunities to influence the direction of the research; b) overwork and fatigue; c) lack of time; d) financial burden because of working as volunteers e) lack of role clarity; f) tokenistic involvement; g) burden of responsibility; and

h) feelings of being unheard or not taken seriously, i) perceived insensivity of health professionals and researchers, j) increased use of jargon, k) frustrations with rigid views of experts and other assumptions, and l) low self-esteem. According to Russell et al., (2020) one of the reasons for this lack of recognition of the negative aspects could be that PE has been formalised into institutional structures and research practices, which makes it difficult to critique, even though there is much to be learned from both the positive and negative experiences of PE (Russell et al., 2020).

Most recently a review by Aubin et al. (2019), found a lack of robust evidence on the impact of PE in research, and suggested two possible explanations for this finding: 1) inconsistency in the terminology used to refer to PE in research along with no established indexing terms in bibliographic databases; and 2) challenges in measuring the impact of PE in research. The authors suggested that these challenges stem from the absence of rigorous frameworks that may be used to develop measures of impact, a lack of a valid and reliable instruments to measure change, and no known direct causal link between PE in research and health policy/services or health outcomes (Aubin et al., 2019).

2.4. PE in Rehabilitation Research

The growth in research on the effectiveness of rehabilitation interventions has sparked an interest in knowledge translation (KT) (Bussières et al., 2016; Menon et al., 2009; Montpetit-Tourangeau et al., 2020; Moore et al., 2017; Zidarov et al., 2013). KT is a process used to support the uptake of research findings in practice (Straus et al.,2009). It is proposed that one of the reasons for the research to practice gap is unsuccessful dissemination of research findings to the target audience (Rogers, 2003). However, there has been increasing recognition that new knowledge will not necessarily make its way to the intended audience without active dissemination and implementation efforts. Those studying

evidence use at the management and policy levels have described the two very different cultures of research and decision making and proposed strategies that can bridge this cultural chasm (e.g., by employing a knowledge broker) (Lomas, 2007).

In the last decade, researchers have focused on the importance of the interaction between the researchers and knowledge users in optimizing the uptake of research arguing that the source of the research to practice gap is knowledge production (Bowen & Graham, 2013). That is, research findings often remain 'unused' because researchers fail to adequately address the problems that concern patients, clinicians, and various decision-makers (Van De Ven & Johnson, 2006). Indeed, limited involvement of end users (i.e., those most likely to benefit for the results of the research) in research is one of the main reasons for the underutilization of research evidence into clinical practice (Haines, 1998; Sackett et al., 1997).

Developments in the field of KT incorporate a call for including various stakeholder groups (e.g., patients, families, managers, policy makers) in research and a more widespread use of participatory approaches. The shift towards more patient-centered approaches to healthcare has sparked interest in PE in health research and its impact on various outcomes. It is hypothesized that collaborating with multiple stakeholders and integrating diverse perspectives will strengthen the research by acknowledging the needs of the patient partners, having targeted research questions, and enhancing the applicability of the final product (Bowen & Graham, 2013; Camden et al., 2015).

In rehabilitation, several authors (Camden et al., 2015; Menon et al., 2009; Morris et al., 2011) have also called for greater involvement of stakeholders in the research process for several reasons. First, stakeholder involvement facilitates participant recruitment as the study questions and knowledge that will be generated from the research will address patients' needs. For example, a randomized controlled trial evaluating the effectiveness of

osteopathy for children with cerebral palsy included queries from families, in consultation with families and osteopaths. The recruitment target was exceeded and was attributed to the importance of the topic for patients and their families and, their involvement the trial procedures (Wyatt et al., 2011). Second, stakeholder engagement helps in setting the research agenda and prioritizing topics that are highly relevant to patients (Morris et al., 2011). This, in turn, will facilitate communication of research findings to the patient and a greater understanding of the results. A scoping review by Camden et al. (2015) on strategies used in partnerships and evaluation of impact found that engaging patients in research can lead to generation of knowledge that is more relevant to the needs of the patient and facilitate the knowledge dissemination process. Third, stakeholder engagement is mandatory in certain funding calls from funding agencies, as researchers are held accountable for the use of public funds which should result in actionable knowledge (Camden et al., 2015; Entwistle et al., 1998). This growing literature and call from funding agencies suggest that patient engagement in rehabilitation research has the potential to greatly benefit patients, their caregivers, the public, and the researchers. By valuing the contribution of patients, the quality of rehabilitation research can be significantly enhanced, ensuring that the research conducted is relevant, feasible and easily transferrable (Harrison & Brooks, 2015).

2.5 Impact of PE in Rehabilitation Research

Despite the growing interest in PE in research, few studies have attempted to demonstrate or measure its impact on the stakeholders involved, the research outcomes, and the practice outcomes. There is heterogeneity in terms of different definitions of impact (Harris et al., 2018). In Canada, the Canadian Academy of Health-Sciences Panel on Return of Investment in Health Research (CAHS) describes impact using a logic model and includes proximal outputs and outcomes of advancing knowledge (for e.g., traditional academic outputs such as number of publications) (CAHS, 2009). The Research Excellence Framework. (2014), UK, defined impact as, "an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia."

Impact can be defined as what is changed as a result of the engagement and how big that change is (Dillon et al., 2017). Impact relates to the research (e.g., research instruments, outcome measures, data collection, design and delivery, time, and cost),the people involved (e.g., members of the public involved in research, academic researchers, and funders) or the power imbalances between the researchers and the participants; the latter being scarcely captured as agreed upon by Dillon et al. (2017) and Russell et al. (2020).

Impact is a broader effect of PE outcomes and could be both positive and negative (Vat et al., 2020). Patient Engagement has been formalized into institutional structures and research practices; some have argued, however, that researchers have over reported on the positive impacts of PE in research and under reported on what might be construed as negative impacts (Denegri et al., 2015; Russell et al., 2020; Staniszewska et al., 2011). Nonetheless, conflicting interests due to lack of clarity of individual roles, overworking, lack of time, and financial burden have been identified as some of the negative benefits of impact (Russell et al., 2020).

Further, there has been increasing attention to the challenges associated with the

evaluation of the impact of PE in research. This literature appears to converge on 4 possible reasons, namely, 1) Variability in the terms used to refer to PE; 2) Paucity of measures of impact; 3) Existence of several PE frameworks, though not representative of patient input; and 4) Concerns regarding tokenistic engagement.

Variability in the terms used to define PE: Aubin et al. (2019) discussed the inconsistency in the terms used to refer to PE. These include patient-oriented research, user engagement, consumer engagement, patient and public involvement, service user engagement. Also, the bibliographic databases lack established indexing terms thereby limiting the potential for standardized reporting (Aubin et al., 2019).

Paucity of measures of impact: Studies on stakeholder engagement do not address evaluation strategies, which are essential to inform and support engagement activities (Esmail et al., 2015). The majority of existing measures evaluate the context and processes of PE and the perceived self-reported impacts. The Guidance for Reporting Involvement of Patients and Public tool (GRIPP2) (Staniszewska et al., 2017) or the Patient Engagement in Research (PEIR) Framework (Hamilton et al., 2018) identify what is important to report in PE in research, but there are few valid and reliable measures that are based on observable impacts and can capture evidence-based outcomes of impact (Aubin et al., 2019).

The Patient Engagement in Research Scale (PEIRS) was one of the first scales designed to assess the patients' perceptions of being meaningfully engaged as patient research partners in health research (Hamilton et al., 2018). The PEIRS is a validated self-report questionnaire that is derived from PE in Research (PEIR) framework (Hamilton et al., 2018). The PEIR scale consists of seven subscales that aligns with the eight organizing themes on the PEIR framework (Appendix 1, page 85). Each item, rated on a 5-point Likert scale from 0-4, from 0 being strongly agree to 4 being strongly disagree, requires the respondent to reflect upon their experiences as a research partner projects, they have been

involved in (Hamilton et al., 2018).

In Camden et al.'s (2015) scoping review the authors of the included studies that attempted to evaluate the impact of PE did not use standardized measures. Due to the heterogeneity of the literature on PE in rehabilitation research, most studies in the review reported difficulty in finding evidence in the field due to the variety of search terms. To advance the practice and study of PE in research, the authors suggested making explicit what elements or aspects of PE are being used and how, with definitions when possible. It would be optimal to involve representatives from other stakeholder groups to have a broader perspective on the subject (Camden et al., 2015).

Existence of several PE frameworks, though not representative of patient input: A recent systematic review summarized 65 frameworks developed to assess the nature and extent of public involvement in research (Greenhalgh et al., 2019) produced a new taxonomy and resources which can assist researchers in classifying future studies involving patient partnership. The frameworks were grouped into five main categories: power focused, priority setting, study focused, report focused and partnership focused frameworks. The findings suggest that a single framework will not be useful to cover all the aspects, strengths, and limitations compared to a range of resources that can be adapted for the same. Few studies included in the review were in middle and low-income countries, which do not have a strong culture of PE in research. Moreover, frameworks that make assumptions of such a culture have limited success (Greenhalgh et al., 2019).

Concerns regarding tokenistic engagement: A systematic review by Majid (2020), highlighted challenges such as tokenism which represents a power differential in favor of healthcare professionals; tokenism can limit the scope in the role and function of patients and lead to little or no meaningful change in the research (Majid, 2020). Including the patient's perspectives can bring about a change from a tokenistic to a meaningful

engagement approach (Hamilton et al., 2018).

Owing to pressures related to funding calls, researchers can inflate the Impact of PE, a phenomenon referred to as impact sensationalism which is another challenge to impact assessment (Russell et al., 2020). Lack of skill and training, obtaining funding in the initial stages of research, financial and logistical barriers, linguistic variations, and use of jargon are some other challenges associated with assessment of impact cited in the literature (Aubin et al., 2019; Thompson, 2009).

Based on this literature, it appears that there are several challenges that make the evaluation of impact difficult (Russell et al., 2020). Impact is highly context-dependent (Staley & Barron, 2019). One of the most important contextual factors that influences outcomes of engagement is the researchers themselves; in particular, the skills, knowledge, values and assumptions they bring with them to the PE experience (Staley & Barron, 2019). The subjective nature of impact makes it somewhat unpredictable for any given project. Given the complex nature of engagement, in order to build on evaluation strategies, we need to precisely define the form it takes, mainly the context and the mechanism (Staley & Barron, 2019). The debate around the impact of PE focuses mainly on the lack of empirical data. The existing evidence is considered weak and anecdotal. There is thus a need to develop robust evidence base for the same (Staley & Barron, 2019).

2.6. Relevance of this Study

The findings from Esmail et al. (2015) suggest that engaging patients in research may improve the quality of research, sometimes via the patient's knowledge and experience, thereby generating evidence that is more relevant to the needs of the patients (Esmail et al., 2015).

Rigorous evidence on the impact of PE can help various stakeholders to explore the

best methods for engagement, that is, 'who' should be engaged, 'when' should the engagement occur and 'how much' is needed for engagement to be considered meaningful (Dillon et al., 2017). Identifying and understanding the best methods for PE may accelerate the uptake and implementation of knowledge to optimize patient care (Camden et al., 2015). Therefore, it is essential to better understand impact from the perspectives of patient partners and researchers to gain clarity on what PE means to each group and to explore the various evaluation strategies adopted by the rehabilitation stakeholders to address impact. Evidence gained through empirical methods, such as surveys, focus groups and interviews, will shed light on the impact of engagement, if it is worth doing, and to identify if, when, where, and how engagement brings benefits.

2.7. Expected Contribution

PE in Rehabilitation research is an emerging area of study. Findings from this project are expected to contribute new knowledge about how researchers and their patient partners conceptualize and evaluate the impact of PE in rehabilitation research. Evidence on the conceptualization and evaluation of impact could lead to the exploration of best practice methods to engage and sustain PE in research. Exploring the challenges encountered by the researchers and their patient partners while evaluating impact can help identify the potential solutions and could maybe lead to the development of a valid measure in the future. Exploring the opportunities encountered by the researchers and their patient partners could also help in the mitigation of tokenistic practices and impact sensationalism and could lead to more effective and meaningful PE practices with the aim of producing actionable knowledge. Identifying and understanding the best methods for PE may accelerate the uptake and implementation of knowledge that could be used to bridge the knowledge to practice gap, thereby having a positive influence on the research and care

for patients.

Chapter 3: Methodology and Methods

This chapter consists of the methodology and methods of this study, in the following sections: (1) study design, (2) participants and recruitment, (3) data collection and study instrument, (4) data analysis, (5) ethical considerations, and (6) strategies for rigor/ trustworthiness.

The COnsolidated Criteria for REporting Qualitative Research (COREQ) (Tong et al., 2007) checklist was used to guide the reporting of the method and results section (Appendix 2, page 86).

3.1 Study Design

I used interpretive description, a methodology that is used to generate knowledge that is relevant for the clinical context of the applied health disciplines (Thorne et al., 2004). As an inductive methodological approach, ID aims to create ways of understanding clinical phenomena that yields implications for practice (Thorne et al., 2004). Interpretive description is aligned with a naturalistic approach to inquiry, and it recognizes that human experience is socially constructed and influenced by the context where the experience takes place. Therefore, it is used to examine a phenomenon by identifying patterns in human experiences while also acknowledging the fact that there will be individual differences (Thorne et al., 2004).

3.2 Participants and Recruitment

The participants were adult patient partners and researchers who have engaged (or are engaging) in rehabilitation research.

Eligibility criteria for patient partners

The eligibility criteria for patient partners were 1) having been engaged in rehabilitation research for a minimum of two years; 2) able to speak either English or

French; and 3) having no speech, language, and/or cognitive difficulties.

Patients who were not involved in research as partners, whose primary role was that of a research participant only, and who were under the age of 18 years and/or had cognitive impairment were excluded from the study

Eligibility criteria for researchers

The eligibility criteria for researchers were 1) having a minimum of two years of experience in the field of PE in rehabilitation research and in any area of rehabilitation research (i.e., stroke, Traumatic Brain Injury, Musculoskeletal) and 2) able to speak either English or French.

Researchers who did not collaborate with patient partners but had involved patients as research participants only were excluded from the study.

Sample size

According to Lincoln and Guba (1985), sample size determination can be guided by the criterion of informational redundancy, that is, sampling can be terminated when no new information is obtained by sampling more units (Lincoln & Guba, 1985). Nevertheless, sampling in qualitative research has a primary emphasis on obtaining a comprehensive understanding by continuing to sample until no new substantial information is acquired (Huberman & Miles, 1994). The concept of information power, which was introduced by Malterud et al. (2015), in qualitative research, suggests that the more information power the sample provides, the smaller the sample size needs to be and vice versa (Malterud et al., 2015). Recommendations for qualitative studies require a minimal sample size of at least 12 participants to achieve thematic sufficiency (Braun & Clarke, 2013), although the sample size justification cannot be based just on this reasoning. In this study, we aimed to recruit 20 participants (10 in each group), based on recommendations made in studies that have employed ID methodology (Thorne et al., 2004).

Sampling strategies

Participants were recruited using purposive sampling to solicit the views of a diverse set of participants. This sampling strategy is employed to provide richly textured information to the phenomenon under investigation (Vasileiou et al., 2018). This involves selection of individuals or a group of individuals that are knowledgeable or experienced with the phenomenon of interest. Purposive sampling was followed by snowball sampling to recruit additional patient partners (Chaim, 2008).

Recruitment

Recruitment announcements were disseminated via the co-author's networks and the McGill School of Physical and Occupational therapy (SPOT), Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), and SPOR websites (https://cihr-irsc.gc.ca/e/51036.html). The centers and organizations include over 30 researchers in SPOT (https://www.mcgill.ca/spot/research), 95 researchers in CRIR (https://crir.ca/en/about/about-crir/) working across the broad spectrum of rehabilitation research.

Once eligible researchers and patient partners were identified, an invitation was sent via email asking for their interest in participating in the study. A follow up email was sent two weeks later. Once they had agreed to participate, a consent form was sent, and a date and time for the interview was scheduled. The interviews were conducted on Zoom with ten patient partners and nine researchers. There were no drop-outs.

3.3 Data collection and Study Instrument

In-depth interviews

The interviews were conducted by CS (who at the time of the study was a 2nd year master's student at the School of Physical and Occupational Therapy (SPOT) at McGill University) on ZOOM, at a time that was convenient for participants. Each interview lasted between 60-90

minutes and was audio and video-recorded with consent. All interviews were conducted in English as all participants were comfortable with this language. Field notes were written immediately after the interview to capture participants' insights that could be useful while developing the preliminary codebook. Interviews were recorded and transcribed verbatim. The interviewer had no prior relationship with the participants.

I developed an interview guide based on a review of the literature on PE and meetings with the team members (Appendix 3, page 88). I consulted the PEIR framework as a reference only while developing the interview guide for patient partners but did not strictly adhere to it (Hamilton et al., 2018). The interviewer introduced herself prior to the commencement of the interview. She provided the participants with her professional background, explained the purpose of the study and presented the consent form. The interview proceeded only once the participant consented to the process.

During the interviews, the interviewer began with questions regarding the participants' experience of working with each other (i.e., patient with researcher and vice versa) and their understanding of PE. For example, the following two questions were asked (Appendix 3, page 88) to both groups of participants: 'Describe your experience of working with a patient partner or describe your experience of being a patient partner'; 'what according to you is patient engagement and is it similar to or different from other terminologies or concepts used in the literature.' These questions were asked to ease the participants into the topic of interest (i.e., PE) and gauge their understanding of PE, so that the interviewer could then delve deeper into the topic of impact. The interview guide consisted of open-ended questions such as "what does impact mean for you? How do you know when the research has made an impact?" Probing questions were used to further explore an aspect of a participant's experience. No repeat interviews were conducted. Once the interview guide was drafted, the interviewer sought feedback on its content from my

Knowledge Exchange and Education in the Health Professions (K.E.E.P) lab peers and committee members. Based on their feedback, the guide was revised, and pilot tested on one researcher and one patient partner who were not involved in the study.

3.4 Data Analysis:

The first author (CS), along with a postdoctoral fellow at the K.E.E.P lab (CG), conducted a thematic analysis of the interview data based on Braun and Clarke's, six-phase process (Braun & Clarke, 2019). Thematic analysis included both inductive and deductive approaches. In ID, the process of data analysis cannot be purely inductive (Thorne et al.,2004). Keeping in mind the constructs of the PEIR framework allowed the first author to see the potential alignment between the constructs and the findings from the interview. The constructs were also used to help the team identify codes that best represented the data. At the same time, Thorne does caution about moving beyond the original theoretical framework, in order to bring new conceptual insights to a phenomenon; in this study, it would ensure that interpretations were not limited by the conceptual boundaries of the PEIR framework (Thorne et al., 2004). Trustworthiness was safeguarded through a process of iterative coding, peer review, and creation of data summaries (Braun & Clarke, 2019). Thematic analysis consisted of the following 6 phases (Braun & Clarke, 2019) :

Phase 1: Data familiarization and writing familiarization notes.

This first phase requires the researcher to get immersed in the data through repeated and active reading of the transcripts. The first author (CS) listened to the recorded interviews and read the transcriptions. By doing so, she could obtain a sense of the range of participants' accounts.

Phase 2: Systematic Data coding.

CS re-read the transcripts and began to identify points of commonality. In collaboration with a senior researcher (AT), and a post-doctoral fellow (CG) with expertise in qualitative

analysis, CS created a preliminary codebook which underwent constant revision throughout the process of coding. The initial codebook was applied to all the transcripts, and a second round of coding was conducted manually. CS and CG reviewed initial responses from each transcript, reviewed six transcripts independently and then compared the findings to maximize trustworthiness (3 from each group). CS coded the remaining transcripts independently.

Phase 3: Generating initial themes from coded and collated data.

This step involves collating related coded data excerpts into potential themes. After the preliminary codes were created, CS and CG independently started looking for patterns and themes in the codes. Codes with similar patterns were organized into subthemes.

Phase 4: Developing and reviewing themes.

This step involves verifying if the themes work in relation to the coded excerpts and the entire data set. CS and CG discussed the sub-themes and grouped them into preliminary themes. The preliminary themes were then discussed with AT, CS's supervisory committee and the K.E.E.P lab members (M.Sc. and PhD students) for feedback. Following these extensive consultations and discussions, CS and CG discussed and agreed upon six themes, which were originally reflecting the interview data on PE and its impact.

Phase 5: Refining, defining, and naming themes.

The six themes underwent constant revision based on feedback from the supervisory committee and the K.E.E.P lab members. Some themes were renamed after discussion and feedback. Clear definitions and names for each theme, and its underlying subthemes were generated.

Phase 6: Writing the report- Final analysis and write-up of the report.

Through discussions with AT, CS produced a final report of the themes, subthemes and corresponding quotes. Keeping in mind the constructs from the PEIRS framework allowed

the team to explore the potential alignments with the findings from the interviews. The results from the preliminary analyses were sent to respective participants to ensure it adequately captured what they had shared during the interviews.

3.5 Ethical Considerations

This study received ethics approval on December 21, 2021, from the Institutional Review Board (IRB) of McGill University's faculty of Medicine, Review Number A12-B98-21B/ (21-12-028). Informed consent was obtained prior to conducting the interviews and the participants were reminded of the possibility to withdraw from the study at any time. The participant names and files have been strictly kept confidential throughout the course of the study and for publication and conferences purposes. Only I, along with my supervisory committee, have access to these files.

3.6 Strategies for Ensuring Rigor/ Trustworthiness

I have worked closely with my supervisory committee to ensure the trustworthiness of the findings. I have had regular debriefing meetings with my supervisor, committee, and lab mates for the development of my interview guides and codebook and for reviewing transcripts during the coding process. A summary of the analyzed transcripts was reviewed a second time by the respective participants as member checks (Guba, 1981). Prior to completing the analysis, I circulated a summary of the results to my supervisory committee and lab mates for feedback. Regular consultation with my supervisor has helped me to ensure that my methods are congruent with the methodology used.

Chapter 4: Results

In this chapter, I present the (1) demographic details of the participants, along with (2) the four themes that were common to both patient and researcher groups. In this section I report the data on impact only and not on PE.

Theme 1 and 2 represent the understanding of patients and researchers with regard to the impact of engagement in rehabilitation research which addresses the first research question.

Theme 1: *Tapestry of perspectives and terminologies* regarding impact reflects how patients and researchers in rehabilitation research define and understand the impact of PE.

Theme 2: *Evolution of PE as a result of engagement* identifies the impact of PE that has occurred as a result of engagement over the last two decades.

Theme 3: *Multi level nature of impact* and its evaluation addresses the second research question and highlights how patients and researchers categorize impact and the promising avenues for impact evaluation.

Theme 4: *PE practices influencing impact evaluation* represent the challenges and opportunities in the evaluation of impact, which answers the third research question.

The results from all interviews suggest considerable overlap between PE in rehabilitation research and those within other fields of research.

4.1 Demographic Information

Ten patient partners and nine researchers participated in the study. There were no drop-outs. Of the ten patient partners, seven were women and three were men. Two patient partners held PhDs, two had completed a university level degree, and six had completed college (CEGEP). Two patients had experience collaborating with researchers from one to five years, two from six to ten years and six for over ten years. Six patient partners had a diagnosis of arthritis, two had sustained an amputation, one was a kidney transplant recipient, and one had congenital cerebral palsy.

Among the nine researchers, six were women and three were men. Seven researchers had completed post-doctoral studies, one had completed a PhD and one had completed master's level of education. Three researchers had worked with patient partners from one to five years, three from six to ten years and three who had worked with patient partners for over ten years. Three researchers also had lived experience of a health condition/disability (i.e., pediatric asthma, congenital blindness, rheumatoid arthritis).

4.2 Themes

Theme 1: Tapestry of perspectives and terminologies regarding impact: This theme highlights the wide array of terms used to refer to patients, PE, and impact of PE in research. This theme addresses the first research question, as to how patients and researchers perceive the impact of engagement in research. Participants noted that these variations render the operationalization of PE challenging. This in turn makes it difficult to determine the impact of any given project. This theme included one subtheme: 1.1) diversity of terminologies to represent impact of PE.

1.1 Diversity of terminologies to represent impact of PE: This subtheme reflects on how participants view impact and use synonyms to express their understanding of impact. When participants were asked to define the term impact in their own words, terms such as "change", "benefits", "outcomes", "relevance", and "difference" came up several times. They indicated that impact of PE could be of varying magnitude, whether small or big, and could be on the research process, on the participants themselves, and in the long term, on the treatment interventions or health policies that could have an influence on improving the patients' quality of life. According to P1*, "I think impact can be as small as the wording on a consent form, or It could be huge things like a total change in the way the research question is asked, or an intervention is delivered. But it doesn't matter if it's small, or if it's*

really substantial, I think there can be impacts throughout the research process, and on the research itself and the results will have an impact on the community."

Researchers identified the impact of PE mainly on the research process and outcomes, "*there are a couple of categories of impact, one of them being like the impact on research quality. So, things like, how well does the project align with the patient family, the quality of the methods used, the quality of the data collected. I think there's impact on like research success.*" Whereas patients' identified impact as a change in the way engagement affects practice, treatment interventions, outcome measures, raises awareness amongst researchers and in the end on the members of the public and the community. "*I hope that at its best the impact of patient engagement is ultimately to inform best practices patient care because ideally, research findings are going to be integrated back into care in an iterative constant improvement type of way. But as a minimum standard I hope patient engagement begins to do is to at least help, policymakers', clinicians', researchers to think about patient benefit, maybe in a way that they hadn't done."* Some participants also identified impact to not be an immediate effect of engagement. For example, according to P2, *"The ultimate impact of patient engagement is patient benefit. For example, while using an outcome measure for hand assessment, looking for a tool that the patient can actually use. If it does not serve the best interest of the patient, it's kind of a waste of funding. The endpoint should be benefiting the community, the patient, even though it might take a long time to get there. It might not be immediate, but eventually it will benefit the public."*

The variability across the definitions of impact could be a result of the diversity of the terminologies that are used to represent patient engagement. For example, patients are sometimes referred to as volunteers, a term that many partners do not agree with as it takes away from the true essence of PE and does not reflect their lived experience as

expertise. For example, as one participant indicated, "*not everyone can be patient partners, and it drives me crazy when people say I'm just a volunteer. But we're not volunteers, we're making an impact in changing our healthcare system, and you're an equal partner there, and they can't do this work without us and if you don't feel that way then you're in the wrong business, as I would say it takes away the value from the rest of us, especially when they're willing to do it for free. Then there's inequities across."*

Researchers have their own preferences regarding how to refer to patients. Some researchers in the field of rehabilitation prefer using terms such as "people with lived experiences" instead of patients. According to R1, *"I will first drop the word patient because I don't think that's really the perfect term for engaging people with lived experience. It's a very medical term and as a rehabilitation researcher, I'm not interested in that model."*

Similarly, some terms were used interchangeably to refer to PE such as patient-oriented research, community-oriented research, consumer led research. P2 defined PE as, *"A patient partner being fully integrated into the research team and participating on their own. They should be able to contribute their experiential knowledge and their ideas, regardless of whether or not they're at a scientific level. Their insights and experiences as a patient are just as valuable."* Another patient explained, "*I think it's really all the same and demands the same core principles*, *otherwise it's not really meaningful, and nobody wants to be a token."* Terms such as "equity", "relationship building", "reciprocity", "fit and co-development", and "co-creating" came up several times when the researchers tried to define PE. According to R2, *"I think the hallmark of patient engagement is really the equity piece of it, like making sure that a patient partner is an equal member of the research team. Recognizing them as experts, because of their lived experience and what they've been through, not because they have X literacy level, or because they have worked*

as X profession. But because they have gone through this experience that is relevant to inform the project, I think it's very important."

Theme 2: Evolution of PE as a result of engagement: This theme captured the progress and growth of PE over the last two decades: specifically, there was an emphasis on awareness of the different roles patients can take, and how these have led to an increased collaboration between patients and researchers. This theme addresses the first research question on how patients and researchers understand the term "impact" and highlights how impact is a long-term effect of engagement that could take years of consistent collaboration and longitudinal follow ups for changes to take place. These changes have been a result of increasingly engaging patients in research over the last two decades. Patient partners have worked hard to bring about these changes. Some of the long-term changes which result from engagement were found to be on a personal level; patients expressed that over the years, researchers have started to value their perspectives. This is reflected in a change in researchers' attitudes and beliefs about engaging patients in research, "*In the beginning they were kind of very weary of us, or of me, thinking she's just a patient, she doesn't know anything. Now it comes to the point where they're looking for people like me, and telling a lot of the different groups, that they have to have a patient associated with them in order to get funding.* They reported less use of jargon due to patient feedback. They added that researchers are trying to use lay terms to make patients feel included and making research findings more accessible to patient partners, "*Now the results are more accessible, and I think as a patient when I first started even the language was different. Now it seems like they really dumb it down and make it more readable."*

Researchers have recognized the value of patients' lived experiences and are making active efforts to engage patients throughout the research cycle. This has bought up the topic of compensation which is a result of long-term engagement of patients in research. According to

P3, *"some researchers are not quite sure how to engage with patient partners. They're a little afraid of it. They sometimes make assumptions about how you might be able to contribute. And then the thing that I've seen change and I think I've played partly a role in that is the concept of compensation or payment for the patient partners on the team. That's something that I've really tried to champion over the years. But back when I started*, *I would never get payment, so I would take time off work to be involved."*

Researchers have become more aware of the benefits of PE and the collaborations have increased over the last two decades. R2 explained, *"I had learned a difficult lesson during my post-doctoral research where I developed an online peer support program for caregivers of people who are on a ventilator in the community and I did it the wrong way. I created this intervention, tried to launch it, and ultimately, I don't think it was very successful in large part, because I didn't at the outset have good input from the family caregivers that it was meant to serve as well as the patients that they were caring for, and so I didn't have good uptake and enrollment was difficult."*

Some researchers are relatively new to this approach, whereas others have patients writing grant proposals on their own. "*I'm at the level where patient partners now write part of the grants. They write actual sentences in the grants, not only commenting. And I've gone a step even further now, which is they are co-authors of the publication of the project."* This could be a step to moving from collaboration to a more user led (e.g., INVOLVE, UK) approach. Patients suggested that some organizations are engaging patients in a very meaningful manner, whereas some still follow tokenistic approaches. Even though these changes are not an immediate effect of engagement and are evolving over time, it is not impossible if meaningful PE practices are followed.

Theme 3: Multi-level nature of impact and its evaluation: This theme alluded to the

different levels of impact and the variability of existing evaluation tools used to assess impact. This theme addresses the second research question on how patients and researchers are evaluating the impact of PE in rehabilitation research. Participants identified potential impacts of PE and suggested promising avenues for evaluating at least the tangible impacts. This theme included two subthemes: 3.1) categories of impact, and 3.2) promising avenues for evaluating impact.

3.1 Categories of Impact: This sub-theme captures the different ways in which patients and researchers viewed the potential impacts of PE, the importance of identifying the metrics that matter to each group and keeping a record of how PE was conducted. Researchers' and patients' categorized impact as short, intermediate and long-term at a personal and professional level. Short term impact was described as changes in the research process, such as changes in the research protocol for funding applications, research question, methods, analysis or results. "*The short-term impact would be like changing the study design or translating that in some way*, *like a patient, friendly form, a decision aid, or something like that."* On the intermediate level and long-term level, in rehabilitation research, engagement may: improve retention and recruitment rates of participants, lead to change in treatment interventions by promoting the uptake of research findings in practice or changes in engagement practices as well as in in policies, attitudes and behaviors of researchers; improve training or job opportunities for patient partners; improve quality of life and health and social outcomes of patients, and improve relationships between patients and researchers due to long-term partnerships. *"Change in the way a treatment intervention is delivered maybe is more of a medium or long-term goal, right? It becomes difficult to measure these things. But I hope with the next generation of people it's interesting to see some of those impacts and enable some of*

those conversations to happen, and that reflection at the end of the day to realize that using some of these tools is not going to reduce your role. The personal benefits for example included, engaging in research improves motivation for patient partners and they feel heard, for researchers, engaging with patients makes them feel good and look good even though both patients and researchers said that there are no direct immediate impacts of engaging in research. Professionally, engaging with patients is considered the right thing to do and could improve career or teaching opportunities for researchers and patients. R3 elaborated, *"We don't have very good metrics yet, for the impact of patient engagement. I think there are a couple of categories of impact, one of them being like the impact on research quality. So, things like, how well does the project, methods and quality of the data align with the patient's needs? I think there's impact on like research success. And this could include things like, do projects that engage patients get funded more often? Are there more publications and presentations? How many of those presentations were undertaken by the patient partner? And then there's impact on the patient partners themselves. And I think this is a key one. Like this is the metric that we should be prioritizing. What does it mean to patients to be involved? What have they gained from the process? The benefits, the challenges, their experiences, and the areas for improvement. And then, finally, I think for projects that have the goal of impacting practice. Ultimately, we need to think about how patient engagement impacts practice? Did it make the implementation of an intervention more successful? Was there greater uptake of that intervention? Did the intervention more positively impact the health and social outcomes for patients? Or if the study was meant to improve a certain type of practice, did that practice change lead to better care, quality, or better patient experiences."* Rehabilitation is composed of a series of complex interventions that can change depending on the stage of a disease or disability and that aims to improve

patients' QOL, health and social outcomes. It is vital that rehabilitation research mirrors this complexity. To achieve these important outcomes and optimize the uptake of research findings, patients should be considered as partners in the research process. Indeed, improving QOL, health and social outcomes of the patient, improving the uptake and implementation of research findings, change in practice interventions, considering patients as partners and providing them with job opportunities were named as some of the long-term impacts of engagement by the participants in this study.

3.2 Promising avenues for evaluating impact: This subtheme captures current practices related to evaluating impact with some future directions. Although there is no uniform measure used across different research teams, researchers have stated using tools such as the PPEET, PEIRS and the Community-Based Participatory Research (CBPR) toolkit for impact evaluation. One researcher stated, *"If we want to go quantitative for a moment, an easy way of doing this is by identifying studies in the same domain that have used patient engagement approach versus studies that have not and to simply compare their impact statistics. You could also evaluate the properties of the journals that actually have published these things and see if studies that include client representation actually get published in better or worse journals. So that would be an interesting way of just looking at the academic side of it. Now, if you want to go a proxy pathway, the obvious target would be the clinicians and the rehabilitation professionals. So, the proxy pathway, how would you measure this at the level of the individual person with the impairment. This is likely where qualitative work is going to be. The richest to actually see whether this is working from the perspective of the person living with them. What you could also do is you could do the reverse and see whether you can measure if it is working or not."*
Although researchers are using some of the tools mentioned above, in rehabilitation

research and according to our findings, longitudinal follow-ups are essential to demonstrate the impact of engagement. A number of existing tools only focus on the immediate impact of engagement on research processes and research outcomes and as such, do not consider the intermediate and long-term impacts pf engagement. Further, QOL, health and social outcomes of patients, job opportunities, change in clinical practice, uptake and implementation of research findings, change in policies, improved relationships and trust should likely be considered in future evaluation tools. *So, I think that the ideal way of assessing the success of this has to be longitudinal. There's no way around it. It would need to be at the level of the person at the level of the clinician, and then we could see where the policy has changed as well as the result of this."*

A patient partner suggested that *"I think you must have a balance between scales and qualitative data. I think the qualitative can give you some really rich stories. And give you, particular instances where impact was observed, or suggestions for improvement or recommendations. To measure it quantitatively, you're going to be looking for publications or presentations of any sort or collaborating with patient partners at team meetings. These are concrete things. But I think it's still going to be hard quantitatively to find out their actual engagement."* Researchers also expressed, *"I think frameworks are a good starting point for standardization and generalizability. We must be careful about not following frameworks so rigidly for the sake of following it and forgetting that patient engagement should inherently be a responsive, adaptable process that's tailored to patients. They're engaging in a particular study and I think it's great to have a framework that provides some direction, but I think it can be detrimental to get so hung up on a framework that it takes away from the spirit of patient engagement."*

Theme 4: PE practices influencing the evaluation of impact: This theme addresses the third

research question, that is, what are the challenges and opportunities encountered by patients and researchers during the evaluation of impact. It highlights the challenges and opportunities regarding impact evaluation and includes the following subthemes 4.1) culture of the academy; 4.2) importance of longitudinal follow ups; 4.3) difficulty in the operationalization of impact; 4.4) having the right resources and support; and 4.5) limiting tokenism.

4.1. Culture of the academy: This subtheme captured the culture of the academic environment and how it may not be conducive to meaningful PE. Patient partners reported that the academic culture with its focus on performance and productivity is not conducive to the nurturing of meaningful partnerships with patients as this takes time and effort (that is often not rewarded in formal promotions and tenure reviews). A participant expressed her concerns regarding the funding timelines by saying, "*The challenge for researchers is that they have to respond to a call for funding, and if that call for funding isn't in alignment with their research, they're not going to be competitive enough for that grant so identifying research priorities in advance and using those to guide it is almost like a ready toolkit, should a call come up. Once the grant call goes up, the window of time is very short before the PI goes in and creates the team respectfully bringing patient partners. Then it's months before the team hears whether they can move to full submission or not. Is that truly good patient engagement, or is it better to wait until that funding is guaranteed and move forward?*"

Patient partners also expressed concerns regarding safe working environments and patient privacy and confidentiality as illustrated by this quote: "*I was unhappy about that in this recent application that we just did. Everybody's an academic except the patients, right? So, everybody has their university address and their university phone number*

shielded. Whereas it's my personal phone number and my personal address on this research application, and I'm not that thrilled that I don't have the same protection."

Another patient partner said, "*I wonder sometimes if the whole structure of the academic world is just not set up for a real partnership. There's like certain metrics for promotion and we need to sort of gain that stability. And in some ways I feel bad for researchers, maybe it's my HR hat I can't take it off, but it strikes me that it's not the most conducive working conditions to get the best out of people, because I think if you're going to engage any knowledge user, including patients it's about building relationships over the long term and I just don't know if the academic world is really set up for that in any form."*

The academic environment manifests its culture through its performance expectations of researchers. Researchers are used to being team leaders, which can make it difficult for some to collaborate with patient partners. This could also be due to lack of standardized training in PE. One researcher reported: *"Researchers are well intended as are our clinicians and patients, but when they live in separate worlds, it's very challenging to ensure that what is relevant to one world is equally relevant in another, unless those people are all at the table. The struggle is that attention between standardization and individualization, just like in the same in receiving medical care. You want to know there's some standard for that particular disease, but you also want to have it individualized to the patients. The same is true for patient engagement in research. There needs to be some standards and some processes, and some supports in place."*

One of the highlighted gaps within the academic culture is the apparent scarcity of research material on engagement practices and impact of engagement in rehabilitation research. A potential cause put forth by a participant, *" researchers should make a note of the entire process of engagement and use it as a reference for future research. They should also publish all the research that is done with patient partners. This can help avoid*

repetition and prevent wasting of funds." Expanding the existing knowledge base can help judicious allocation of future funds and avoid repetition of research.

4.2. Importance of longitudinal follow ups: This subtheme highlights how it is difficult to demonstrate impact if there are no longitudinal follow ups. Some participants noted that longitudinal follow ups provide a stronger basis for demonstrating the impact of PE. For example, one researcher said, *"We need people to engage in it. This is longitudinal, it's going to be tricky to find people that will stick with you for long enough to actually do this. I think one of the opportunities might be that this will change how we justify grant applications, because longitudinal data gives you a stronger basis to stand on."* One of the participants said that it is difficult to evaluate PE practices, let alone the impact of such practices*. "But we can't even evaluate how to engage patients, let alone the impacts. Like the tangible impacts on you know, policies or clinical practice or like, that's where the impact is, that's where the people are, you know, actually doing this work at the end of the day."* Keeping these considerations in mind as operationalizing, defining impact, and identifying potential impacts could be the first steps towards meaningful PE.

4.3. Difficulty in the operationalization of impact: This subtheme referred to the main challenge of developing a measure of impact because of the lack of conceptual and operational clarity. Participants described how the impact of PE is unique to each individual and varies across different stakeholders involved in the project. This was exemplified in the following quote, *"But when it gets down to things like the impact on the patient partner themselves, so much of that is subjective, like what one patient partner benefits or gains from the involvement in project X will likely be quite different from what another patient partner gets from project Y. It also probably depends on like the nature of the project, or how they were engaged. And so, I think that there's so much*

that makes it challenging to say like we can compare these impacts across studies."

4.4. Having the right resources and supports: This subtheme highlights the importance of resources and supports that could enhance patient participation in research, and suggestions for transitioning from tokenistic to meaningful PE practices. This subtheme highlights the following resources and supports that could be offered to PP: compensation and, modes of communication and networking. *Compensation* was brought up by patients more so than by researchers. Even when not compensated for their time, they would appreciate a minimum level of support in the form of a lunch or paid parking so that they may feel included in the team. For example, supports can be offered in various ways as expressed by P4: "*It involves just supporting people in terms of training, although I think, number one priority is to help them get up to speed with what's going on. And maybe just having a mentor attached to them so they can help explain. And you know maybe that is letting them sit in on a meeting sometime or whatever it is."* Another patient partner said that *"But there's also support in other ways in you know paying for somebody's parking, paying their subway fair to get to the meeting, giving them like doing like a zoom 101, because it's their first time on a zoom call, and they have no clue what they're doing."*

Some researchers recognize the importance of compensating patients for their valuable skillset as expressed by R4, *"If patient partners are not compensated for their work, then we're still creating that power imbalance. Making them feel like their time is not worth it. No, their time is worth it. And we need these people that are experts in patient partnerships. We need to compensate everybody according to their needs. If someone wants to be paid and wants to be compensated with like parking and nothing else, it's really their choice, and they want to volunteer, they can do that, and if someone doesn't*

want to be on the paper, you can't force them to be on the paper as an author. But you should give all these options."

Patient partners also spoke about the different *modes of Communication and Networking* and highlighted the importance of constant communication and feedback between patient partners and researchers in the pursuit of authentic PE. As patient partners, they expect to be informed at every step of the research process and would like to receive feedback on their work. *"As patient partners, we don't seem to get evaluated. I've been part of the research group now for 7 or 8 years, never has anyone evaluated my work. I'm assuming I am doing good because I'm involved in a lot of things. But they never came back and said, this is what you do, this is what could be improved, and I don't know why they're not doing that. Even in this report I did for health Canada and for anything about patient engagement, it's important to give feedback. We don't have problems giving feedback to the researchers like you can do that."* Patient partners often do not hear about the study findings, and as a result, they feel lost in the process. This was exemplified by this patient quote: "*If you're on a research team and you're not included in the emailed chains and team meetings and if you're not provided with the results, if you don't know what's going on with the project, it's really hard to engage. I want a team, and I'm actually begging them to tell me what's going on. Have we developed the measures, or have we recruited anybody and if you're so in the dark that you don't know anything, it's really hard to feel supported at all? So, it's really important that communication involves the patient like an equal on the team."*

Patient and researcher qualities are also essential for meaningful PE. As one patient partner said: *"I don't have the knowledge that the research team would have so they're accepting of that, and they help me grow as well and that they're willing to invest that time in me as a patient partner. So, I really look for a team that's welcoming*, *inclusive,*

and that's willing to listen to my comments and ideas without judgement. So that I can contribute fully to the team."

R5 expressed, *"For my co-authors, I write them emails personally. Same thing with patients, I talk with them once, every week or two depending on the phase of the project. You use the same active communication, and you build the relationship."* Patients' and researchers' listed characteristics that are essential to fostering meaningful PE, such as, being open minded, being willing to listen, trust, respect, reciprocity, and humility, that could lead to successful long-term relationships. This was exemplified in this quote by R6. *"Humility is the most important thing. You need a team that's flexible, organized or trained. It's the culture of the team. It is difficult to do patient engagement when all your personal interests or the team interests is only problem producing publication."*

4.5. Limiting Tokenism: This subtheme describes the best ways to engage patients to minimize tokenism. Most of the patient partners expressed that, ideally, they should be involved in the research project from the beginning; however, they are, for the most part, only engaged after the formulation of the research question and not during the conceptualization of project. This leads to unmet needs as their priorities are not being addressed. P5 expressed, *"I think that the researcher was much better than some at considering the priorities that matter most to patients and is completely open to being alerted to things that she might have missed in the methods, or that sort of thing. She's very humble that way and is completely committed to a process of constant improvement in her own professional life."*

Chapter 5: Discussion

The purpose of this study was to explore how patients and researchers define and evaluate the impact of PE in rehabilitation research. The data from the interviews were organized into four themes that were common to both groups– with some of the embedded subthemes reflecting the unique perspective of one group only: 1) tapestry of perspectives and terminologies regarding impact, 2) evolution of PE as a result of engagement, 3) multi-level nature of impact and its evaluation, and 4) PE practices influencing impact evaluation. These themes evoke key concepts and values on PE that have been discussed in the literature to varying degrees.

Based on the study findings, the discussion will highlight 1) the different approaches and beliefs that are similar to PE; 2) influence of authentic PE on the impact of engagement 3)how PE has evolved over the last two decades: the long term changes that have taken place as a result of engagement; and 4) impact and the different categories of impact along with promising avenues for its evaluation.

PE practices in rehabilitation that were gleaned from this study and the suggestions for impact evaluation are similar to the practices in other disciplines (Barello et al., 2012). For example, according to Aubin et al. (2019) engaging patients in research helps researchers identify patient priorities (Aubin et al., 2019). Their unique lived experiences highlight how one size does not fit all; for example, patients with the same health condition can experience different symptoms at different intensities (for e.g., in rheumatoid arthritis, one patient could complain of fatigue, whereas another could complain more of pain). The majority of the patients in this study were living with chronic arthritic pain. Their motivation for collaborating with researchers relied on their desire to help other patients in the long term.

1) <u>Different approaches and beliefs similar to PE</u>

Based on the results, PE appears to share some features with various other participatory approaches such as Integrated Knowledge Translation (IKT), Patient-Centered Research, Participatory Action Research, Community Based Participatory Research (Nguyen et al., 2020). However, our participants have a different understanding of the concept of PE which they attribute to the culture of the academy, the organization where they received their training, or the area of practice within rehabilitation more broadly. This mirrors recent conversations in the literature about what differentiates patients from researchers (including culture) and how the differences are reflected in the terms that are being used (Harrington et al., 2020).

In rehabilitation, terms are used interchangeably based on the different contextual factors influencing practice. For example, according to the participants in this study, the term 'patient' is a medical term and is inappropriate for describing individuals with lived experience. Given the biopsychosocial nature and values of rehabilitation professions such as OT and PT (Curtis, 1998), it may not be surprising that the term patient does not resonate with the rehabilitation professionals in this study. However, there is one major common assumption that underlies both integrated knowledge translation (Graham & Tetroe, 2007) and participatory action research (Freire, 1978): engagement of patients throughout the research process for maximal benefit to the patient and the community. Researchers in this study were not overly worried about the semantics; rather, they seemed concerned more with the operationalization of PE in practice. Whilst clarity in terminology may be part of the academic culture, it seems less important for patient partners involved in research (Aubin et al., 2019). What seems clear from our data is that for authentic PE to occur, different stakeholders on both sides need to discuss and agree on terminologies.

2) Influence of authentic PE on the impact of engagement

The results suggest that one condition for authentic PE is to have patients involved

from the onset of the research and throughout the research process. This early involvement has the potential to increase the rigor and credibility of the research and influence the outcome, including the likelihood of a positive impact. This finding is consistent with the literature on the core tenets of PE (Strategy for Patient-Oriented Research, 2019), which advocates for continuous engagement.

The views on the timing and level of engagement were not unanimous among participants, mostly due to various barriers to meaningful engagement. Researchers reported the influence of funding on research timelines as one of the barriers to early engagement. Patients agreed with the researchers and questioned the possibility of ever having a meaningful relationship given the culture of the academy. Similarly, difficulty in longitudinal follow-up is another barrier to engagement; indeed, the feasibility of incorporating patients in all stages of research in a single study has been questioned (Harrington et al., 2020).

Despite what is being advocated in the literature on the timing and level of engagement, studies to date have found that patients are rarely involved in decisions about the research question, the data analysis, and the dissemination and implementation of the research findings (Aubin et al., 2019; Hoddinott et al., 2018; Skovlund et al., 2020). For example, in our study, participants indicated that even though they were engaged early in the research process, it was most often after the formulation of the research question. In their view, this occurred because researchers are used to leading teams and have yet to relinquish professional control. Our findings suggest that for more meaningful PE to occur, the research question should address the priorities of the patients or at the very least, be formulated only once different patient groups have been consulted. This could also help nurture the relationships between patients and researchers that could lead to more meaningful PE (Bird et al., 2020).

Another key feature of PE in rehabilitation research is when patients or researchers play dual roles, leading to some confusion amongst the team members. For example, researchers who live with chronic diseases and share their experiences in a research setting are usually critiqued for doing so as it brings about their potential 'dual role' (Richards et al., 2022). An example of this commitment to role clarity was the development of "terms of reference" which was created to ensure role clarity and to help patients collaborate in the phases of research that they are most comfortable with. Having an organized way to clarify roles prior to engagement (Muller et al., 2019) may help mitigate the risk of role confusion.

3) Evolution of PE over the last two decades

According to the patient partners, researchers have become more aware of the benefits of PE and are engaging patient partners more in their research. This has resulted in less jargon during interactions and deliberate efforts at making the findings more understandable to the patient population. This appears to be a winning condition for the creation of a positive relationship between patients and researchers (Manafo et al., 2018).

To that effect, there has been a shift from patients being considered as 'passive recipients' *of research* to active participants in the process. Indeed, the growing literature on PE (10-fold- increase over the last decade) and mandates from funding bodies that applicants demonstrate inclusion of patients in their research (Islam & Small, 2020) suggest that there is a mounting interest in the role that patients play in research. A qualitative study by Vroonland et al. (2019), compared the analysis of grant proposals before and after receiving feedback from a patient organization. The analysis showed that researchers were open to feedback in most of the sections of the study (e.g., eligibility criteria, communication with and safety of the research participants, clarity of the proposal). However, they considered the methods and analysis of results sections to be in their wheelhouse and were less open to suggestions that questioned the relevance of the study

after the grant proposal was approved. The flexibility and willingness to consider feedback on the methods section of grant proposals differed across researchers (Vroonland et al., 2019).

The results of this study also indicate that compensation for patient partners is key for rewarding and recognizing their time and lived experience. Expecting volunteerism from patient partners heightens the power imbalances and does not create optimal working conditions for engagement (Richards et al., 2022). A commentary identifying potential barriers and solutions to patient partner compensation in research defines compensation as payment, salary, wages, honorarium, or resources to build capacity/skill with respect to engagement; it can be used interchangeably with payment. According to Richards et al. (2022), compensation or payment of patient partners is not the same as the process of reimbursing their expenses to be a part of the research team (e.g., paying for parking, offering them lunch) For some patient partners, compensation might not be monetary; rather, it may be helping them to build their own capacity for engagement (Richards et al., 2022). For example, in the UK, honorary contracts offer a way for patient partners to have access to an institutional email address, library, short courses, and other resources that might otherwise not be possible (Richards et al., 2022).

Training on PE was an important finding in this research. SPOR Canada provides certain guidelines and resources on how to engage patients in research (Strategy for Patient-Oriented Research, 2019). Different patient groups have different levels of engagement. For example, The Patient Oriented Research Curriculum in Child-Health (PORCCH) (Macarthur et al., 2021) is a series of interactive online modules that was developed collaboratively with stakeholders across Canada to help understand the benefits of PE in research. Similarly, there are available modules on some of the patient organization groups, but there is no standardized training available at the university level. The qualitative

study by Vroonland et al. (2019), suggests that researchers had multiple contradictory views on the training and supports provided to patient experts. Some researchers are interested in patients lived experience (as expertise), whereas others expect patients to have some basic training in research. Patients on the other hand, felt that training was an essential component for both themselves as patient partners as well as for researchers. Researchers in our study reported that the patients' lived experience serves as the expertise that is needed during the research process. This suggestion aligns with the epistemological arguments supporting PE (Entwistle et al., 1998), which stress on how patients' lived experience and expertise are legitimate sources of knowledge (Entwistle et al.,1998). Training patient partners in research can lead to a phenomenon called 'proto professionalization' of patients (Vroonland et al., 2019); 'proto professionalization' reflects an alignment between the patients' and the researchers' thinking such that the 'pure' patient experience gets lost. The risk with proto professionalization is that it could lead to tokenism and lack of patient partner diversity, as some marginalized populations could have language barriers that would preclude them for example, from reading grant proposals in English or French (Vroonland et al., 2019).

Importantly, our data showed that patients are seldom aware of the researchers' true motivations; that is, whether researchers are engaging them because of a genuine interest in seeking their input, or because of the expectations from several funding agencies that that they do so. Patients suggested that the organizations and funding bodies should better assess true meaningful engagement. Providing a justification to funding agencies on the criteria for acceptance of feedback along with demonstrating the level of engagement of the patient partner in research could be a good way to identify if engagement is tokenistic or meaningful (Vroonland et al., 2019).

4) Impact and the different categories along with promising avenues for its evaluation

Participants in this study used words such as change, relevance, benefits, outcomes, and difference to define impact. These words were not used as synonyms for impact; rather, they reflected participants' understanding of impact in lay terms. These terms appear to suggest that impact can be defined as change in the way the research is conducted as a result of engagement, whether big (i.e., change in the research process or outcomes), or small (i.e., changes to the consent form) (Dillon et al., 2017). According to the literature, impact is a broader effect of outcomes and could be both positive or negative, direct or indirect, and intended or unintended (Vat et al., 2020). One suggestion was that team leaders, whether researchers or patients, should keep documenting everything that they do to keep track of areas in need of improvement. Similarly, all results should be published, whether statistically significant or not, as publication of negative findings could reduce research waste and optimize the use of scarce funds (Russell et al., 2020).

Given the complex nature of impact, participants suggested that measures of impact should comprise both qualitative and quantitative items to capture lived experience as well as more discrete dimensions. For example, patient satisfaction and the benefits or challenges that the patients have encountered throughout the research process. It may indeed be worthwhile to develop measures that include both types of items. Considering the current limitations in the quantitative impact assessment tools for PE, qualitative assessments guided by robust conceptual models may be valuable tools for identifying and understanding impact of PE (Luger et al., 2020).

A few suggestions put forth to circumvent this limitation were anticipating outcomes prior to engagement to assist the demonstration of impact. Similarly, there is some literature that suggests that creating logic models (by highlighting short-term outcomes to achieve long-term impact) can help program evaluators to focus on specific objectives and

identify appropriate metrics to measure PE (Merker et al., 2022). Our participants' understanding of impact suggests that there is still a need to operationalize the term in order to be able to assess it.

Our data suggests that there are several advantages to demonstrating impact. Demonstrating impact could: 1) lead to increased awareness of the benefits of PE (consequentialist argument), 2) help researchers understand the value of the patients lived experience as expertise (epistemological argument) , 3) help in the transition from tokenistic to meaningful PE (moral argument), and 4) ensure the funding is used judiciously (political argument). These benefits align with the four arguments that form the basis of PE in research, i.e., consequentialist, epistemological, moral and political (Entwistle et al., 1998).

Our results suggest that variability lies not only in how PE is defined; it lies in how it is understood, named, and in the way researchers and their patient partners evaluate impact. For example, participants identified potential categories of impact and suggested promising avenues for the assessment of impact. Our data suggests that measurement could be based on a balance between qualitative and quantitative measures guided by the research question. Similarly, our participants identified the different aspects that impact can be observed on 1) impact on the patients themselves, 2) impact on the research and, 3) impact on practice. These results mirror what has been published in the literature. For example, a qualitative study by Merker et al. (2022), highlighted that adding patients to the research team would have an impact at multiple levels: 1) impact on participants (patients and researchers): personal and job satisfaction, awareness and appreciation of research and better communication; 2) impact on quality and relevance of research: improvements in grant submissions, research studies and study instruments; and ultimately 3) impact on practice: improvement in interventions (Merker et al., 2022). A mixed methods approach could be used to further substantiate the claims.

According to Richards et al. (2022), metrics such as altmetric scores, number of publications, conference presentations, and amount of grant funding required are part of the academic reward system. Even though there have been calls to consider aspects of research quality, including PE (Richards et al., 2022), the reality is that these quality measures are not yet norms in assessment of research. In this context, a partnership with patients might even negatively impact researchers as the metrics they are typically evaluated on do not acknowledge the value and expertise of patients and the time requirements to conduct meaningful research with patient partners (Richards et al., 2022). Participants listed evaluation tools that could be used to assess impact such as the Public and Patient Engagement Evaluation tool (PPEET) (Abelson et al., 2016) and the Patient Engagement In Research Scale (PEIRS) (Hamilton et al., 2018). These evaluation tools have been cited in literature as tools available to track researchers' assessment of the context, process, or outcomes of PE, but many are not based on a conceptual framework and/or lack psychometric validation (Boivin et al., 2018). Additionally, conceptual models defining impacts of PE often ignore personal benefits for patients and the researchers they work with (Dillon et al., 2017). The PPEET was developed as a result of collaboration between researchers and the patients and public. It consists of three questionnaires to evaluate public and patient engagement: participant, project, and organization questionnaires. The PPEET provides flexibility for additional questions that add to the unique features of the respective organizations (Abelson et al., 2016).

The PEIRS is a validated self-report questionnaire derived from the PE in Research (PEIR) framework (Hamilton et al., 2018) and is used to evaluate meaningful PE. It was one of the first scales designed to assess the patients' perceptions of being meaningfully engaged as patient research partners in health research (Hamilton et al., 2018). Some of the participants in this study suggest that it could be used as a scale to measure the impact of

patient engagement even though this scale was designed to evaluate meaningful PE. Therefore, to gain more clarity on the topic of impact, there is a need for training or discussions among various stakeholders on the various existing measures and their uses.

Some researchers mentioned tools that are more flexible and could be used in any context, while others felt that we should not strictly adhere to a tool to evaluate PE and its impact, as it takes away from the true essence of PE. Researchers in this study highlighted that when implementing PE practices in research, the challenge lies in standardizing practices for every individual. Every individual and organization is unique and will have its own way of engaging patients in research. This could be another reason for the variability of perspectives amongst stakeholders, as one size does not fit all.

Based on our results and on the literature, we still lack the diversity of patients (marginalized population, based on education, socio economic status, patients in the acute phase, naïve patient partners) (Cope et al. 2022; Reynolds et al. 2021; Richards et al. 2022). We postulate that there are possible reasons for the lack of diversity in the patient partners 1) not feeling heard and involved optimally in some research teams; 2) being approached for the grant proposal phase without a clear idea of the whole project, 3) not being involved in regular communications with the researchers or not receiving follow up emails on the results of the study; 4) not having access to free articles; 5) not being compensated for their time; 6) not being involved throughout the entire research process; and 7) having insufficient motivation to participate it the project. These issues should be explored further in subsequent studies.

Patient diversity in research is essential for rich and diversified feedback. Some researchers are unsure of patients' education level and think that someone with a low socio-economic status might not be able to engage optimally. Diversity will need to be part of the development of new measures such that new instruments can capture the

perspectives of different patients.

Researchers also state that longitudinal follow ups are essential if we want to evaluate the impact of patient engagement but that becomes difficult as sometimes the patient partners engaged on a particular research team do not stay for a long period. Based on our findings, if we can mitigate this barrier, the data provided by longitudinal follow ups will give provide a stronger basis for subsequent work.

Implications and future directions

To summarize, patients and researchers identified potential categories of impact of PE in rehabilitation research, along with promising avenues for the evaluation of impact. Participants also provided suggestions for improving PE practices that could result in more meaningful and authentic PE. Considering the scarcity of research in PE in the field of rehabilitation, this study highlighted the different ways patients and researchers understand impact of PE in rehabilitation research along with the barriers and facilitators to impact assessment. The results also highlight the current practices of engagement and the diverse ways in which impact has been evaluated based on participants' understanding. In the future, it may be worthwhile to develop measures that comprise both qualitative and quantitative items to capture lived experience as well as more discrete dimensions. Future studies should also consider some of the longer-term impact constructs such as improved QOL, health and social outcomes of patients, improved job opportunities for patient partners, change in practice and treatment interventions, improved uptake and implementation of research findings, change in policies, improved relationships, and trust while developing impact evaluation measures. This should be done by involving different stakeholder groups and identifying the metrics that matter the most to patient partners.

Chapter 6: Conclusion

In this chapter I present a, (1) conclusion for this study along with (2) the strengths and limitations of this study.

6.1 Conclusion

Assessing the impact of patient engagement in research is key for advancing patient-oriented research. This study identified potential categories of impact and promising avenues for its evaluation which might contribute to the future development of robust measures of impact of patient engagement in rehabilitation research. Short term impact appears to refer to the more immediate outcomes of a study, which may be easier to measure; intermediate and long term impact on the other hand, such as quality of life, health and social outcomes of the patient, increased job opportunities for patient partners, change in practice and treatment interventions, improved uptake and implementation of research findings, change in policies, improved relationships, and trust as a result of engagement, requires longitudinal follow ups and are more difficult to capture. Determining the anticipated short-term outcomes prior to engagement can help to better identify the longer-term impact. These long-term impact constructs are vital when trying to develop a robust measure to evaluate impact of engagement.

The main aim of rehabilitation is to improve the quality of life of patients through the implementation of evidence based and patient-centered interventions (Aadal et al., 2022), both of which can fall under the broader category of long-term impacts of engagement. Engaging patients in rehabilitation research may therefore help generate results which may have a more meaningful impact on patients and their families though the development of robust outcome measures and treatment interventions.

The rehabilitation process requires an iterative approach that considers the patients' needs and goals, ultimately to optimize function and quality of life. Rehabilitation research

is no different. An evolving and tailored approach can positively modify both patient centric and research outcomes, thereby influencing impact (Aadal et al., 2022). The inherent expansive and complex nature of rehabilitation research warrants an individualized approach. To address this complexity, the rehabilitation research must mirror the rehabilitation process (Aadal et al., 2022). Longitudinal follow-ups can be beneficial in rehabilitation research to demonstrate the impact of engagement. It is important for researchers to understand the metrics deemed valuable by patients their perception of successful engagement within the process. Training opportunities at the university level for researchers can help prepare them for more meaningful engagement of patients within research.

6.2 Strengths and Limitations

Finding an equal number of patient participants and researchers in rehabilitation research was challenging. I used snowball sampling, and this resulted in nine participants. I expected language to be another potential barrier as both French and English language speakers were included in this study however, all participants preferred to be interviewed in English. The response rate for the interview invitations was a concern at the outset. When researchers and patients did not respond to the invitation within 2 weeks, a follow up email was sent.

One of the strengths of the study was that I interviewed two stakeholder groups, that is, patients and researchers across Canada. Though these stakeholder perspectives added value to my study in understanding the complex nature of impact of PE, one of the limitations of this study was the lack of diversity of my participants. I had almost six patient partners who were involved in research for over six years. Therefore, I could not capture the perspectives of many novice patient partners. I also had a majority of patient partners who had arthritis. It would be good to have a perspective of patient partners from groups other

than those from the arthritis community.

References

Aadal, L., Nielsen, T. L., Jensen, A. B., Bjerrum, M., Nielsen, C. V., & Angel, S. (2022). What Does It Take for Research to Be Rehabilitation Research? *Frontiers in Rehabilitation Sciences, 3*, 1-6. doi:https://doi.org/10.3389/fresc.2022.823159

Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2016). Supporting quality public and patient engagement in health systems organization: Development and Usability testing of the PPEET. *Health Expectations, 19*(4), 817-827. Doi:https://doi.org/10.1111/hex.12378

Aubin, D., Hebert, M., & Eurich, D. (2019). Importance of measuring the impact of patient-oriented research. *Canadian Medical Association Journal, 191*(31), E 860-64. Doi: https://doi.org/10.1503/cmaj

Baker, S. E., Edwards, R., & Doidge, M. (2012). How many qualitative interviews is enough?: expert voices and early career reflections on sampling and cases in qualitative research. *National Centre for research methods review paper*.

Barello, S., Graffigna, G., & Vegni, E. (2012). Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. *Nursing Research and Practice*, 1-7. doi:10.1155/2012/905934

Beresford, P. (2005). Developing the theoretical basis for service user/ survivor-lead research and equal involvement in research. *Epidemiologia e Psichiatria Sociale, 14*(1), 4-9. Doi :https ://doi.org/10.1017/S1121189X0000186X

Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M. H., . . . Carroll, S. L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. *Health Expectations, 23*(3), 523-539. Doi:https://doi.org/10.1111%2Fhex.13040

Boivin, A., L'Espérance , A., Gauvin, F.-P., Dumez, V., Macauley, A. C., Lehoux, P., & Abelson, J. (2018). Patient and Public Engagement in research and health system decision making: A systematic review of evaluation tools. *Health Expectations, 21*(6), 1075-1084. Doi:https://doi.org/10.1111/hex.12804

Boote , J., Baird, W., & Beecroft, C. (2010). Public involvement at the design stage of primary health research: A narrative review of 74and examples. *Health policy, 95*(1), 10-23. Doi:https://doi.org/10.1016/j.healthpol.2009.11.007

Bowen, S. J., & Graham, I. D. (2013). From Knowledge translation to engaged scholarship: promoting research relevance and utilization. *Archives of Physical Medicine and Rehabilitation, 94*(1), 3- 8. Doi:https://doi.org/10.1016/j.apmr.2012.04.037

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. Doi:https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners.* London: SAGE Publications.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597. doi:https://doi.org/10.1080/2159676X.2019.1628806

Brett, J., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S., & Bayliss, H. (2010). The PIRICOM study: a systematic review of the randomization, measurement, impact and outcomes of patient and public involvement in health and social care research. 1-292.

Brett, J., Staniszweska, S., Mackford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities. *The Patient Centered Outcomes Research, 7*, 387-395. Doi: 10.1007/s40271-014-0065-0

Bussières , A. E., Zoubi, F. A., Stuber, K., French, S. D., Boruff, J., Corrigan, J., & Thomas, A. (2016). Evidence-based practice, research utilization, and knowledge translation in chiropractic: a scoping review. *BMC Complementary and Alternative Medicine, 16*(216), 1-15. Doi:https://doi.org/10.1186%2Fs12906-016-1175-0

CAHS), Canadian Academy of Health Sciences-Panel of Return of Investment in Health Research. (2009). *Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investments in Health Research.* Ottawa, ON: Canadian Academy of Health Sciences. doi:http://www.cahs-acss.ca/wp-content/uploads/2011/09/ROI_FullReport.pdf

Camden, C., Shikako-Thomas, K., Nguyen, T., Graham, E., Thomas, A., Sprung, J., . . . Russell, D. J. (2015). Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disability and Rehabilitation, 37*(15), 1-11. Doi:http://dx.doi.org/10.3109/09638288.2014.963705

Canadian Institutes of Health Research. (n.d.). Retrieved from https://cihr-irsc.gc.ca/e/51036.html

Canadian Institutes of Health Research. (2022, 09 07). Retrieved from CIHR: https://cihr-irsc.gc.ca/e/34190.html

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annual review of public health, 29*, 325-50. doi:https://doi.org/10.1146/annurev.publhealth.29.091307.083824

Chaim, N. (2008). Sampling Knowledge: The Hermenutics of Snowball Sampling in Qualitative Research. *International Journal of Social Research Methodology, 11*(4), 327-344. Doi:https://doi.org/10.1080/13645570701401305

Cope, E. L., McTigue, K. M., Forrest, C. B., Carton, T. W., Fair, A. M., Goytia, C., . . . Angove, R. S. (2022). Stakeholder engagement infrastructure to support multicenter research networks: Advances from the clinical research networks participating in PCORnet. *Learning Health*

Systems, 1-11. Doi:https://doi.org/10.1002/lrh2.10313

Crocker, J., Hughes-Morley, A., Petit-Zeman, S., & Rees, S. (2018). Assessing the impact of patient and public involvement on recruitment and retention in clinical trials: a systematic review. *Trials, 16*(91). Doi:https://doi.org/10.1186/1745-6215-16-S2-O91

Crotty, M. (1998). *The Foundations of Social Research: Meaning and perspective in the research process.* London: SAGE Publications. Doi:https://doi.org/10.4324/9781003115700

Curtis, R. S. (1998). Value and Valuing in Rehabilitation. *JOURNAL OF REHABILITATION, 64*, 42-47.

Denegri, S., Coldham, T., Eglin, S., Frost, R., Kerridge, L., & & Matthews, R. (2015). Going the extra mile: improving the nation's health and wellbeing through public involvement in research.

Dillon, E. C., Tuzzio, L., Madrid, S., Olden, H., & Greenlee, R. T. (2017). Measuring the Impact of Patient Engaged Research: How a methods workshop identified critical outcomes of Research Engagement. *Journal of Patient Centred Research and Reviews, 4*(4), 237-46. Doi:http://dx.doi.org/10.17294/2330-0698.1458

Entwistle, V. A., Renfrew, M. J., Yearley, S., Forester, J., & Lamont, T. (1998). Lay perspectives: advantages for health research. *Education and Debate, 316*(7129), 463-466. Doi:10.1136/bmj.316.7129.463

Esmail, L., Moore, E., & Rein, A. (2015). Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *Journal of Comparative Effectiveness Research, 4*(2), 133-45. Doi:https://doi.org/10.2217/cer.14.79

Freire, P. (1978). Pedagogy of the oppressed. In J. Beck, *Toward A Sociology Of Education* (pp. 374-386). New York: Routledge.

Gallivan, J., Burns, K. K., Bellows, M., & Eigenseher, C. (2012). The many faces of Patient Engagement. *Society for participatory medicine, 4*(32).

Graham, I. D., & Tetroe, J. (2007). CIHR Research: How to translate health research knowledge into

effective healthcare action. *Healthcare Quarterly, 10*(3), 20-22.

Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., & Chant, A. (2019). Frameworks for supporting patient and public involvement in research: Systematic Review and co- design pilot. *Health Expectations, 22*(4), 785-801. Doi:https://doi.org/10.1111/hex.12888

Guba, E. G. (1981). Criteria For Assessing The Trustworthiness Of Naturalistic Inquiries. *ECTJ, 29*, 75- 91. Doi:https://doi.org/10.1007/BF02766777

Haines, A. (1998). Making better use of research findings. *BMJ, 317*(7150), 72-75. Doi:https://doi.org/10.1136/bmj.317.7150.72

Hamilton, C. B., Hoens, A. M., Backman, C. L., McKinnon, A. M., McQuitty, S., English, K., & Li, L. C. (2018). An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expectations, 21*(1), 396-406. Doi:https://doi.org/10.1111/hex.12635

Hamilton, C. B., Hoens, A. M., McQuitty, S., McKinnon, A. M., English, K., Backman, C. L., . . . Li, L. C. (2018). Development and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assesss the quality of engagement from the patient perspective. *PLOS one, 13*(11), 1-18. Doi:https://doi.org/10.1371/journal.pone.0206588

Harrington, R. L., Hanna, M. L., Oehrlein, E. M., Camp, R., Wheeler, R., Cooblall, C., . . . Perfetto, E. M. (2020). Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group. *Value in Health, 23*(6), 677-688. Doi:https://doi.org/10.1016/j.jval.2020.01.019

Harris, J., Cook, T., Gibbs, L., Oetzel, J., Salsberg, J., Shinn, C., . . . Wright, M. (2018). Searching for the Impact of Participation in Health and Health Research: Challenges and Methods. *BioMed Research International*, 1-11. doi:https://doi.org/10.1155/2018/9427452

Harrison, M., & Palmer, R. (2015). Exploring patient and public involvement in stroke research: a

qualitative study. *Disability and Rehabilitation, 37*(23), 2174-83. Doi:https://doi.org/10.3109/09638288.2014.1001525

Harrison, S. L., & Brooks, D. (2015). Active Patient Engagement: Long Overdue in Rehabilitation Research. *Physiotherapy Canada, 67*(4), 305-307. Doi:https://doi.org/10.3138%2Fptc.67.4.GEE

Hayes , H., Buckland , S., & Tarpey, M. (2012). Briefing notes for researchers: public involvement in NHS, public health and social care research. *Public Health and Social Care Research*.

Hoddinott, P., Pollock, A., O'Cathain, A., Boyer, I., Taylor, J., MacDonald, C., . . . Donovan, J. L. (2018). How to incorporate patient and public perspectives into the design and conduct of research. *F1000 Research, 7*(752), 1-33. Doi:https://doi.org/10.12688/f1000research.15162.1

Hovén, E., Eriksson, L., D'souza, Å. M., Sörensen, J., Hill, D., Viklund, C., . . . Lampic, C. (2018). What makes it work? Exploring experiences of patient research partners and researchers involved in a long term co-creative research collaboration. *Research involvement and engagement, 6*(33), 1-12. Doi:https://doi.org/10.1186/s40900-020-00207-4

Huberman, M. A., & Miles, B. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook.* Thousand Oaks: Sage Publications.

Islam, S., & Small, N. (2020). An annotated and critical glossary of the terminology of inclusion in healthcare and health research. *Research Involvement and Engagement, 6*(14), 1-9. Doi:https://doi.org/10.1186/s40900-020-00186-6

Kaisler and Missbach, R. (2020). Co-creating a Patient and Public Involvement and Engagement 'how to' guide for researchers. *Research Involvement and Engagement*.

Karazivan, P., Dumez, V., Flora, L., Pomey, M.-P., Grande, C. D., Ghadiri, D. P., . . . Lebel, P. (2015). The patient as partner approach in health care: a conceptual framework for a necessary transition. *Acad Med, 90*(4), 437-41. Doi:https://doi.org/10.1097/acm.0000000000000603

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Newbury Park: SAGE publications.

Lomas, J. (2007). The in between world of knowledge brokering. *BMJ, 334*(7585), 129-132.

Luger, T. M., Hamilton, A. B., & True, G. (2020). Measuring Community-Engaged Research Contexts, Processes, and Outcomes. *THE MILBANK QUARTERLY, 98*(2), 493-553. Doi: https://doi.org/10.1111/1468-0009.12458

Macarthur, C., Walsh, C. M., Buchanan, F., Karoly, A., Pires, L., McCreath, G., & Jones, N. L. (2021). Development of the Patient-Oriented Research Curriculum in Child Health. *Research Involvement and Engagement, 7*(27), 1-5. Doi:https://doi.org/10.1186/s40900-021-00276-z

Majid, U. (2020). The Dimensions of Tokenism in Patient and Family Engagement: A Concept Analysis of the Literature. *Journal of Patient Experience, 7*(6), 1610-1620. Doi:https://doi.org/10.1177%2F2374373520925268

Mallidou, A. A., Frisch, N., Doyle-Waters, M. M., Macleod, M. L., Ward, J., & Atherton, P. (2018). Patient-oriented research competencies in health (PORCH) for patients, healthcare providers, decision-makers and researchers: protocol of a scoping review. *BMC, 7*(101), 1-10. Doi :https ://doi.org/10.1186/s13643-018-0762-1

Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research, 1*(13), 1-8. Doi:http://dx.doi.org/10.1177/1049732315617444

Manafo, E., Petermann, L., Ping, M.-L., & Vandall-Walker, V. (2018). Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Research Policy and Systems, 16*(5), 1-11. Doi:https://doi.org/10.1186/s12961-018-0282-4

Menon, A., Korner-Bitensky, N., Kastner, M., McKibbon, A. K., & Straus, S. (2009). Strategies for rehabilitation professionals to move evidence-based knowledge into practice: A systematic review. *Rehab medicine, 41*(13), 1024-32. Doi:https://doi.org/10.2340/16501977-0451

Merker, V. L., Hyde, J. K., Herbst, A., Solch, A. K., Mohr, D. C., Gaj, L., . . . Dryden, E. M. (2022). Evaluating the impacts of patient engagement on health service research teams: lessons from the veterans consulting network. *J GEN INTERN MED , 37*, 33-41. Doi:https://doi.org/10.1007/s11606-021-06987-z

Miller, E. J., & Gwynne, G. V. (1972). *A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and the Young Chronic Sick.* London: Tavistock Publications.

Montpetit-Tourangeau, K., Kairi, D., Ahmed, S., Anaby, D., Bussieres, A., Lamontagne, M.-È., . . . Thomas, A. (2020). A strategic initiative to facilitate knowledge translation research in rehabilitation. *BMC Health Services Research, 20*(1), 973. Doi:https://doi.org/10.1186/s12913-020-05772-8

Moore et al., J. (2017). *Knowledge Translation in rehabilitation: a shared vision.* Paediatric physical therapy: American physical therapy association.

Morris, C., Shilling, V., McHugh, C., & Wyatt, K. (2011). Why is it crucial to involve families in all stages of childhood disability research. *Developmental medicine and child neurology, 53*(8), 769-71. Doi:https://doi.org/10.1111/j.1469-8749.2011.03984.x

Muller, I., Santer, M., Morrison, L., Morton, K., Roberts, A., Rice, C., . . . Yardley, L. (2019). Combining qualitative research with PPI: reflections for using the person-based approach for developing behavioural interventions. *Research Involvement and Engagement, 5*(34), 1-8. Doi:https://doi.org/10.1186/s40900-019-0169-8

Nguyen, T., Graham, I. D., Mrklas, K. J., Bowen, S., Cargo, M., Estabrooks, C. A., . . . Wallerstein, N. (2020). How does Integrated Knowledge Translation (IKT) compare to other collaborative research approaches to generating and translating knowledge? Learning from experts in the field. *Health research policy and systems, 18*(35), 1-20. Doi:https://doi.org/10.1186/s12961- 020-0539-6

NIHR. (2006). Retrieved from http://www.invo.org.uk/about-involve/

O'Donnell, M., & Entwistle, V. (2004). Consumer involvement in research projects: the activities of research funders. *Health Policy, 69*(2), 229-238. Doi:https://doi.org/10.1016/j.healthpol.2003.12.011

Oliver, S. (1996). The progress of lay involvement in the NHS Research and Development programme. *Journal of Evaluation in Clinical Practice, 2*(4), 273-280. Doi:https://philpapers.org/go.pl?id=OLITPO7&proxyId=&u=https%3A%2F%2Fdx.doi.org%2F10.1111%2Fj.1365-2753.1996.tb00057.x

Ommaya, A. K., Adams, K. M., & Wittenburg, G. F. (2013). Opportunities in Rehabilitation Research. *Journal of rehabilitation research and development, 50*(6). doi:10.1682/JRRD.2012.09.0167

PCORI. (2019, December 2). *Patient-Centered Outcomes Research Institute. Engagement rubric for applicants*.

Price, P. C., Jhangiani, R. S., Chiang, I.-C. A., Leighton, D. C., & Cuttler, C. (2017). *Psychological measurement.* Pressbooks.

Research Excellence Framework. (2014). *UK Research and Innovation*. Retrieved from Decisions on assessing research impact. https://www.ukri.org/about-us/research-england/research-excellence/ref-impact/

Reynolds, J., Ogden, M., & Beresford, R. (2021). Conceptualising and constructing 'diversity' through experiences of public and patient involvement in health research. *7*(53), 1-11. Doi:https://doi.org/10.1186/s40900-021-00296-9

Richards, D., Cobey, K. D., Proulx, L., Dawson, S., Wit, M. D., & Toupin-April, K. (2022). Identifying potential barriers and solutions to patient partner compensation (payment) in research. *Research Involvement and Engagement, 8*(7), 1-11. Doi:https://doi.org/10.1186/s40900-022- 00341-1

Rogers, E. M. (2003). *Diffusion of Innovations.* New York: Free Press.

Rolfe, D. E., Ramsden, V. R., Banner, D., & Graham, I. D. (2018). Using qualitative Health Research methods to improve patient and public involvement and engagement in research. *Research Involvement and Engagement, 4*(49), 1-8. Doi:https://doi.org/10.1186/s40900-018-0129-8

Russell, J., Fudge, N., & Greenhalgh, T. (2020). The impact of public involvement in health research: What are we measuring? Why are we measuring? Should we stop measuring it? *Research Involvement and Engagement, 6*(63), 1-8. Doi:https://doi.org/10.1186/s40900-020-00239-w

Sackett, D., Rosenburg, W., & Richardson, W. (1997). *Evidence based medicine. How to practice and teach EBM.* New York: Churchill Livingstone.

Skovlund, P. C., Nielsen, B. K., Thaysen, H. V., Schmidt, H., Finset, A., Hansen, K. A., & Lomborg, K. (2020). The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, control trial. *Research Involvement and Engagement, 6*(43), 1-16. Doi:https://doi.org/10.1186/s40900-020-00214-5

Staley, K., & Barron, D. (2019). Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation? *Research Involvement and Engagement, 5*(14). Doi:https://doi.org/10.1186/s40900-019-0147-1

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., . . . Morris, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ, 358*(3453). Doi:https://doi.org/10.1136/bmj.j3453

Staniszewska, S., Mockford, C., Gibson, A., Herron-Marx, S., & Putz, R. (2011). *Moving forward: Understanding the negative experiences and impacts of patient and public involvement in health service planning, development and evaluation.* Bristol: Policy Press. Doi:http://www.policypress.co.uk/display.asp?K=9781847427502&

Strategy for Patient-Oriented Research. (2019). *Strategy for Patient-Oriented Research – Patient Engagement Framework*. Retrieved from Canadian Institutes of Health Research: http://www.cihr-irsc.gc.ca/e/48413.html.

Straus, S. E., Tetroe, J. M., & Graham, I. D. (2009). Defining knowledge translation. *Journal of Clinical Epidemiology, 64*(1), 6-10. Doi:https://doi.org/10.1016/j.jclinepi.2009.08.016

Sunderji, N., Angl, E. N., Polaha, J., & Gao, C. (2019). Why and how to use patient-oriented research to promote translational research. *Families, Systems, & Health, 37*(1), 1-9. Doi:https://doi.org/10.1037/fsh0000405

Thompson, J. (2009). Health researchers attitudes towards public involvement in health research. *Health Expectations*.

Thorne, S. (2016). *Interpretive Description.* Taylor & Francis.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. *Sage journals, 3*(1), 1-11. Doi :https ://doi.org/10.1177%2F160940690400300101

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. doi:https://doi.org/10.1093/intqhc/mzm042

Tourangeau et al., K. (2020). *A strategic initiative to facilitate knowledge translation research in rehabilitation.* BMC health services research.

Van De Ven, A. H., & Johnson, P. E. (2006). Knowledge for theory and practice. *Academy of management review, 31*(4), 802-821.

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size strategies in interview-based studies: a systematic review. *BMC Medical Research Methodology, 18*(148), 1-18. Doi:https://doi.org/10.1186/s12874-018-0594-7

Vat, L. E., Finlay, T., Schuitmaker-Warnaar, T. J., Dphil, N. F., Robinson, P., Boudes, M., & Diaz, A. (2020). Evaluating the "return on patient engagement initiatives" in medicines research and development: a literature review. *Health Expectations, 23*, 5-18.

Doi:https://doi.org/10.1111/hex.12951

Vroonland, E., Schalkers, I., Bloemkolk, D., & Dedding, C. (2019). Patient Involvement in cardiovascular Research: A qualitative impact evaluation. *Research Involvement and Engagement, 5*(29). Doi:https://doi.org/10.1186/s40900-019-0165-z

Wyatt, K., Edwards, V., Franck, L., Britten, N., Creanor, S., Maddick, A., & Logan, S. (2011). Cranial osteopathy for children with cerebral palsy: a 84andomized control trial. *Archives dis child, 96*(6), 505-12. Doi:https://doi.org/10.1136/adc.2010.199877

Zidarov, D., Poissant, L., & Thomas, A. (2013). Knowledge translation in physical therapy: From theory to practice. *Disability and Rehabilitation*, 1-7. Doi:http://dx.doi.org/10.3109/09638288.2012.748841

Appendix

1. Patient Engagement in Research Scale

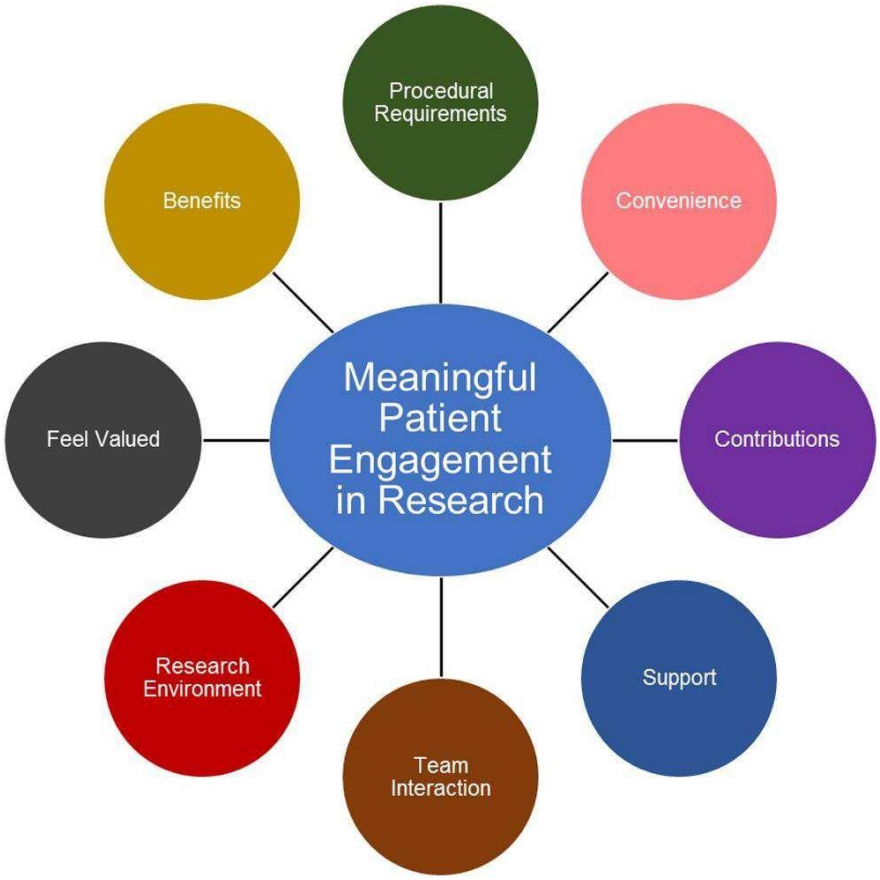

Fig 1: Development and Pre-testing of the PEIRS. Adapted from Hamilton, et al., 2018.

2. COREQ Guidelines

Topic	tem No.	Guide Questions/Description	eported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	15/39
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	14/39
Occupation	3	What was their occupation at the time of the study?	14/39
Gender	4	Was the researcher male or female?	14
Experience and training	5	What experience or training did the researcher have?	14/39
Relationship with Participants			
Relationship established	6	Was a relationship established prior to study commencement?	15/40
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	15/40
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? . Bias, assumptions, reasons and interests in the research topic	15
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	36
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, secutive, snowball	38
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, Email	38
Sample size	12	How many participants were in the study?	38
Non-participation	13	How many people refused to participate or dropped out? Reasons?	38
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	38
Presence of non-Participants	15	Was anyone else present besides the participants and researchers?	not sure
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	43-44
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	39
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	39
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	39
Field notes	20	Were field notes made during and/or after the inter-view or focus group?	39
Duration	21	What was the duration of the inter views or focus group?	38
Data saturation	22	Was data saturation discussed?	37
Transcripts returned	23	Were transcripts returned to participants for comment and/or	42

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and Findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	40-41
Description of the coding Tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	40
Software	27	What software, if applicable, was used to manage the data?	NA
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	44-58
Data and findings consistent	30	Was there consistency between the data presented and the findings?	44-58
Clarity of major themes	31	Were major themes clearly presented in the findings?	44-58
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	44-58

3. Interview Guide (English)

Patients' and researchers' perspective on the impact of patient engagement in rehabilitation research.

Total participant time: 60-90 minutes

Interview briefing: The objective of this interview is to explore your perspective on the impact of patient engagement in rehabilitation research along with the challenges and opportunities that you encounter while working with patients and researchers.

Impact can be defined as what is changed as a result of the engagement and how big that change is. Impacts can be classified as relating to the research (e.g., research instruments, outcome measures, data collection, design and delivery, time, and cost) or to the people involved (e.g., members of the public involved in research, academic researchers, and funders).

All the information you provide will be kept strictly confidential. Your participation is voluntary. Please take the time you need to review the consent form. You can withdraw your participation at any given point during the study. Please do not hesitate to reach out to me if you have any questions

(The interview questions will be refined based on feedback, pilot testing and as the study progresses)

INTERVIEW

Consent form process

Introduction:

- I will introduce myself to the participant
- The purpose of the study will be explained to the participant.
- The participant will be made aware, and consent will be taken for the audio and video recording.
- I will inform the participants that I will be taking notes as they speak.
- Will once again remind the participants about the confidentiality and withdrawal from the study.
- Demographic data will be collected from the participants:
- For researchers
    1. Profession
    2. Gender
    3. Years of experience doing research
    4. Education
- For patient partners
    1. Profession
    2. Gender

3. Years of experience as a patient partner
4. Education

- A brief overview regarding the interview will be provided and the participants will be given the option of not answering a particular question if it makes them uncomfortable.
- Participants will be given a chance to ask any question or clarify their doubts before the interview begins.

The questions will be focused on the following areas:

Where the researcher started: Their original plans, values, assumptions
What recommendations were made by the patients and why?
What changes were made in response? What recommendations did the researchers take on board and why?
What outcomes were observed?
What outcomes were observed by the researchers and their patient partners?

INTERVIEW QUESTIONS

[*Give a brief description at the end of each section to make sure I have understood what the participants are saying and to give them the opportunity to modify or rephrase their comments*.]

For patient partners:

Questions	Probes
1) Tell me about your experience of being involved as a patient partner	• For how many years have you been involved as a patient partner • What was your role as a PP • What made you interested in working as a patient partner? • What made you interested in working with a particular research team? • How did you become a part of this research team? • Who prioritises the research topic? • What recommendations have you made to the research team? • What recommendations did the researchers take on board • Why do you think they picked those recommendations? • What outcomes were observed? • Do you feel a sense of belonging in the team?

2) How would you define patient engagement in research?	• How according to you is patient engagement similar to or different from IKT, POR, COPR
3) How would you define impact in the context of patient engagement	• How do you think engaging patients in research have an impact and on what aspects? Do you think engaging patients in research can impact people, professionals, organisations? Please explain • On what aspects did you observe the impact of patient engagement? -personal, professional, organisational etc. • What according to you are there short, intermediate, and long-term impacts of patient engagement in research? • According to you is it possible to assess impact? • Have you tried evaluating the impact of PE in research? If yes, what methods have you employed for the same? • What were the end results?
4) What challenges and/ or opportunities did you come across while assessing the impact?	• What did you do to mitigate those barriers? • What was the result of that?
5) In case of conflicting interests, how would you resolve them?	• Whose opinion is usually taken into consideration while resolving a conflict? (Patient-partner or researcher)
6) How do you ensure that the research carried out is not tokenistic or done under organizational pressure? /How do you ensure that the research you conduct with PPs is meaningful to you?	• Can you describe instances where you were unable to contribute in a way that kept research meaningful to you? • Can you describe times when your contribution felt tokenistic? • Cn you describe situations when the research was driven by certain pressures and had little meaning to you?
7) According to you, is there anything else that can or needs to be done to improve the patient partner-researcher relationship?	• What team characteristics can foster optimal patient engagement?
Is there anything else that you wish to add?	

For researchers

Questions	Probes
1. Tell me your experience of working with a patient partner	• For how many years have you worked with patient partners? • What phases of the research cycle have patient partners been involved in? • How did you start? Your original values, assumptions, priorities. • What made you interested in working with a patient partner? • Who prioritizes the research topic? • What recommendations have the patient partners made to the research team? • What recommendations do you usually take on board and why? • What outcomes were observed?
2. How would you define patient engagement?	• How according to you is patient engagement similar to or different from other approaches that involve patients?
3. How would you define impact in the context of patient engagement?	• How do you think engaging patients in research has an impact? • On what aspects did you observe the impact of patient engagement? -personal, professional, organizational etc. • What according to you are the short, intermediate, and long-term impacts of patient engagement in research? • What according to you is the best way to assess impact? • Could you share your experiences where you have tried evaluating/ assessing impact? (What methods have you employed) • What were the end results/ outcomes?
4. What challenges and/ or opportunities did you come across while assessing the impact?	• What did you do to mitigate those barriers? • What was the result of that?

5. In case of conflicting interests, how would you resolve them?	• Whose opinion is usually taken into consideration while resolving a conflict? (Patient-partner or researcher)
6. How do you ensure that the research carried out is not tokenistic? /How do you ensure that the research you conduct with PPs is meaningful to you?	• How do you identify your PPs and make sure your approach isn't tokenistic? • Can you describe instances where you were unable to contribute in a way that kept research meaningful to you? • Can you describe times when your contribution felt tokenistic? • Can you describe situations when the research was driven by certain pressures and had little meaning to you?
7. According to you, is there anything else that can or needs to be done to improve the patient partner-researcher relationship?	• What team characteristics can foster optimal patient engagement?
Is there anything else that you wish to add?	

Debriefing and closing:

Do you have any questions regarding what we discussed today?

Thank you very much for taking the time to share your perspectives on the impact of patient engagement in research. If you have any further questions, please do not hesitate to contact us.

4 Guide D'entrevue

Titre du projet de recherche l'opinion or les perspectives des patients et des chercheurs sur l'impact de l'engagement des patients dans la recherche en réadaptation.

Durée totale de l'entretien : 60-90 minutes

Résumé de l'entretien : L'objectif de cet entretien est d'explorer votre point de vue de l'impact de l'implication des patients dans la recherche en réadaptation, ainsi que des défis et des opportunités rencontrés dans le partenariat ou la collaboration avec les patients et les chercheurs.

L'impact peut être défini comme ce qui a changé à la suite de l'engagement et l'ampleur de ce changement. Les impacts peuvent découler de la participation à la recherche (par exemple, les instruments de recherche, les mesures des résultats, la collecte de données, la conception et la réalisation, le temps et le coût) ou de l'implication des personnes or parties prenantes (Par exemple, les membres du public impliqués dans la recherche, les chercheurs universitaires et les bailleurs de fonds).

Veuillez noter que toutes les informations partagées dans le cadre de cette entrevue seront strictement confidentielles. Votre participation est volontaire.

Veuillez prendre le temps nécessaire pour lire le formulaire de consentement. N'hésitez pas à me contacter si vous avez des questions. Vous pouvez retirer votre participation à tout moment de l'étude.

(Les questions de l'entretien seront affinées en fonction des réactions, des tests pilotes et au fur et à mesure de l'avancement de l'étude).

L'entretien

Processus du formulaire de consentement

Introduction :

Avant de début la collecte de données, j'aimerai partager avec vous ceci :

- Présentation au participant
- L'objectif de l'étude sera expliqué au participant.
- Le participant sera mis au courant, et son consentement sera pris pour l'enregistrement audio.
- J'informe les participants que je vais prendre des notes pendant qu'ils parlent.
- Je rappellerai encore une fois aux participants la confidentialité des informations recueillies durant l'entrevue et le retrait de l'étude à n'importe quel moment.
Vous avez le droit de ne pas répondre à certaines questions si elles vous mettent mal à l'aise. Veuillez simplement me l'indiquer.
- Vous pouvez poser des questions ou demander des clarifications à tout moment durant la collecte de données.

- Des données démographiques seront recueillies auprès des participants :
- Pour les chercheurs, les données sociodémographiques colligées incluent :

1. Profession
2. Sexe
3. Nombre d'années d'expérience dans la recherche
4. Éducation

- Pour les patients partenaires

1. Profession
2. Sexe
3. Nombre d'années d'expérience en tant que patient partenaire
4. Éducation

Les questions porteront sur les domaines suivants :

Où le chercheur a commencé : Ses plans initiaux, ses valeurs, ses hypothèses
Quelles recommandations ont été faites par les patients et pourquoi ?
Quels changements ont été apportés en réponse ? Quelles recommandations les chercheurs ont-ils prises en compte et pourquoi ?
Quels résultats ont été observés ?
Quels résultats ont été observés par les chercheurs et leurs partenaires patients ? (Staley., 2015)

QUESTIONS D'ENTRETIEN

Pour les patients partenaires:

Questions	Sondes
1) Parlez-moi de votre expérience d'implication en tant que patient partenaire.	• Depuis combien d'années êtes-vous impliqués dans la recherche en tant que patient partenaire ? • À quelles phases de la recherche avez-vous participé ? • Qu'est-ce qui vous a incité à travailler comme patient partenaire ? • Qu'est-ce qui vous a incité à collaborer ? avec une équipe de recherche particulière ? • Comment êtes-vous devenu membre de cette équipe de recherche ? • Qui donne la priorité au sujet de la recherche ? • Quelles recommandations avez-vous faites à l'équipe de recherche ?

	• Quelles recommandations les chercheurs ont-ils prises en compte? Pourquoi pensez-vous qu'ils ont choisi ces recommandations ? • Quels résultats ont été observés ? • Ressentez-vous un sentiment d'appartenance à l'équipe ?
2) Comment définiriez-vous l'engagement des patients dans la recherche ?	• Selon vous, l'engagement du patient est-il similaire ou différent de la recherche orientée vers le patient ? Veuillez expliquer
3) Comment définiriez-vous l'impact dans le contexte de l'engagement des patients ?	• Pensez-vous que la participation des patients à la recherche a un impact ? Si oui, veuillez expliquer comment ? • Pensez-vous que la participation des patients à la recherche peut avoir un impact sur les personnes, les professionnels et les organisations ? Veuillez expliquer • Sur quels aspects avez-vous observé l'impact de l'implication des patients ? -personnel, professionnel, organisationnel, etc. • Selon vous, quels sont les impacts à court, moyen et long terme de l'implication des patients dans la recherche ? • Selon vous, est-il possible d'évaluer l'impact ? • Avez-vous essayé d'évaluer l'impact de l'EP dans la recherche ? Si oui, quelles méthodes avez-vous employées pour ce faire ? • Quels ont été les résultats finaux ?
4) Quels défis et/ou opportunités avez-vous rencontrés lors de l'évaluation de l'impact ?	• Qu'avez-vous fait pour atténuer ces obstacles ? • Quel en a été le résultat ?
5) En cas de conflits d'intérêts, comment les résolvez-vous ?	• Quelle opinion est généralement prise en considération lors de la résolution d'un conflit ? (Patient-partenaire ou chercheur)
6) Comment vous assurez-vous que les recherches menées ne sont pas	

symboliques ou effectuées sous la pression de l'organisation ?	
7) Selon vous, y a-t-il autre chose qui peut ou doit être fait pour améliorer la relation patient-partenaire-chercheur ?	• Quelles caractéristiques de l'équipe peuvent favoriser un engagement optimal du patient ?
Souhaitez-vous ajouter quelque chose ? Ou y-t-il quelque chose d'important que nous n'avions pas évoqué et que vous aimeriez aborder?	

Pour les chercheurs

Questions	Sondes
1)Racontez-moi votre expérience de travail avec un patient partenaire.	• Depuis combien d'années travaillez-vous avec des patients partenaires ? • À quelles phases du cycle de recherche avez-vous participé ? • Comment avez-vous commencé ? Vos valeurs, hypothèses et priorités initiales. • Qu'est-ce qui vous a incité à travailler avec un patient partenaire ? • Comment identifiez-vous vos patients partenaires et vous assurez-vous que l'approche n'est pas symbolique ? • Qui donne la priorité au sujet de recherche ? • Quelles recommandations les patients partenaires ont-ils faites à l'équipe de recherche ? • Quelles recommandations prenez-vous généralement en compte et pourquoi ? • Quels résultats ont été observés ?
2) Comment définiriez-vous l'engagement des patients ?	• Selon vous, l'engagement du patient est-il similaire ou différent de la recherche orientée vers le patient ? Veuillez expliquer
3) Comment définiriez-vous l'impact dans le contexte de l'engagement du patient ?	• Pensez-vous que la participation des patients à la recherche a un impact ? Si oui, veuillez expliquer comment ? Pensez-vous que la participation des patients à la recherche peut avoir un impact sur les personnes,

	les professionnels et les organisations ? Veuillez expliquer • Sur quels aspects avez-vous observé l'impact de l'implication des patients ? -Personnels, professionnels, organisationnels, etc. • Selon vous, quels sont les impacts à court, moyen et long terme de l'implication des patients dans la recherche ? • Selon vous, est-il possible d'évaluer l'impact ? • Avez-vous essayé d'évaluer l'impact de l'EP dans la recherche ? Si oui, quelles méthodes avez-vous employées pour ce faire ? • - Quels ont été les résultats finaux ?
4) Quels sont les défis et/ou les opportunités que vous avez rencontrés lors de l'évaluation de l'impact ?	• Qu'avez-vous fait pour atténuer ces obstacles ? • Quel en a été le résultat ?
5) En cas de conflits d'intérêts, comment les résoudriez-vous ?	• Quelle opinion est généralement prise en considération lors de la résolution d'un conflit ? (Patient-partenaire ou chercheur)
6) Comment vous assurez-vous que les recherches effectuées ne sont pas symboliques ?	
7) Selon vous, y a-t-il autre chose qui peut ou doit être faite pour améliorer la relation patient-partenaire et chercheur ?	• Quelles caractéristiques de l'équipe peuvent favoriser un engagement optimal du patient ?
Souhaitez-vous ajouter quelque chose ? or y-t-il quelque chose d'important que nous n'avions pas évoqué et que vous aimeriez aborder?	

Débriefing et clôture :

Avez-vous des questions concernant ce dont nous avons discuté aujourd'hui ?

Merci beaucoup d'avoir pris le temps de partager vos perspectives sur l'impact de l'engagement des patients dans la recherche. Si vous avez d'autres questions, n'hésitez pas à nous contacter.

5. Consent Form (Patients)

Principal Investigator
Dr. Aliki Thomas
School of Physical and Occupational Therapy
Faculty of Medicine and Health Sciences, McGill University
3654 Promenade Sir-William-Osler
Montreal, Quebec H3G 1Y5
Tel (514) 398-4496
Email: aliki.thomas@mcgill.ca

Research Team
Dr. Tania Janaudis-Ferreira, McGill University
Dr. André Bussières, McGill University
Conchita Saldanha, MSc Student, McGill University
Tel: (438) 226-8503
Email: conchita.saldanha@mail.mcgill.ca

Project Title: ***"Patients' and Researchers' perspective on the impact of patient engagement in rehabilitation research"***

Objective of the study

The objective of this study is to understand how patient partners and researchers *define* and *evaluate* the impact of Patient Engagement (PE) in rehabilitation research, and to explore the challenges and opportunities encountered by patient partners and researchers during the evaluation of impact of PE.

Nature of your participation

You are being asked to participate in a qualitative study by:
Taking part in a 60 to 90-minute semi-structured individual interview which will be conducted on an online platform, (such as zoom, teams, skype), at a time of your convenience. We would like to hear about your perspectives on 1) the impact that patient engagement has on rehabilitation research, 2) how you evaluate this impact and 3) the challenges and opportunities that you have encountered during the evaluation of impact.

Personal benefits from participating in the research project

You will not personally benefit from the study. We anticipate that the information we obtain will help us better understand your perspectives on 1) the impact that patient engagement has in rehabilitation research, 2) how you evaluate impact and 3) the challenges and opportunities that you have encountered during the evaluation of impact.

Risks associated with participating in the study

This study poses minimal risks to the participants involved. You may experience some fatigue from participating in the study. If you do, kindly request a break from the interviewer.

Confidentiality

All personal information gathered about you during the study will be coded to ensure anonymity. The names will be removed and replaced by a unique study-specific ID number generated by the research team, thereby protecting your identity. This ID number and all the information linked to your number including personal contact information will be kept in a separate password protected computer file at all times and only the research team members will have access to it. The research data will be kept in a locked room, on a password protected computer for a period of seven years following the end of the study, after which it will be securely destroyed in line with the university policy and procedures. No confidential or identifying information will appear in any analysis or discussion of the results.

Voluntary participation and Withdrawal of the participation of the subject

Your participation in this research study is completely voluntary. You can, at any time, put an end to your participation in the study. You may decline to answer any question in the interview that you do not wish to answer, without negative consequences.

If you wish to withdraw from the research study you may contact the principal investigator Aliki Thomas, Ph.D., at (514) 398-5456 or via email at aliki.thomas@mcgill.ca OR you may contact Conchita Saldanha, MSc Rehabilitation Sciences student at (438) 226-8503 or via email at conchita.saldanha@mail.mcgill.ca at any time in the study.

Information we collect from you (including any personal information or responses) from the interview will be retained and included in the analysis, unless you inform the research group otherwise by the end of the study (i.e., May 2022). Information collected to this point will be destroyed if that is your decision. After May 2022, we cannot remove your data as it will have been de-identified, aggregated and analysed.

The results of the research study will be presented in summary form and may be published; identity, and/or any identifying information will not be revealed in any scientific reports or conferences. At the end of the study (i.e., Aug 2022), should you be interested in receiving a summary of the overall findings, you can contact Dr. Aliki or Conchita through the email address provided to you.

The ethics committee at McGill University may access and review the records containing your personal information in order to ensure its proper management. The research study you are participating in may be reviewed for quality assurance to make sure that the required laws and guidelines are followed.

Responsibility Clause

While agreeing to participate in this study, you do not give up any of your legal rights nor release to the researchers, partners, or institutions involved in your legal and professional obligations.

Compensatory Indemnity

Participants will not be receiving any compensation for their participation in the study.

Contact Information

If you have any questions regarding the study, you may contact the principal investigator Aliki Thomas, Ph.D., at (514) 398-5456 or via email at aliki.thomas@mcgill.ca or Conchita Saldanha, MSc Rehabilitation Sciences student at (438) 226-8503 or via email at conchita.saldanha@mail.mcgill.ca at any time during the study. This project has been approved by the McGill Institutional Review Board. If you have any questions about your rights as a project participant, or any questions about the research or any adverse event, you may contact Dr. Aliki Thomas or Conchita Saldanha at the contact information provided above. If you have any questions about your rights as a research participant, you may contact the Ethics Officer at the Faculty of Medicine and health Sciences at 514-398-8302 or ilde.lepore@mcgill.ca.

Consent

I acknowledge that I have read this information form. I understand this study, the nature, and extent of my participation, as well as the benefits, risks, and inconveniences to which I will be exposed as presented in this form. I have been given the opportunity to ask questions concerning any aspects of the study and have received answers to my satisfaction. I voluntarily agree to take part in this study and acknowledge that by reading this information form, and by completing the online survey I give consent to participate in this study. I am aware that I can withdraw from the study at any time without prejudice of any kind. I certify that I have had sufficient time to consider my decision to participate in this study. I acknowledge that by providing consent to take part in this study, I do not give up any of my legal rights.

Name of Participant (print) _____

Signature of Participant _____

Signed at _____, the _____, 20 _____.

Responsibility of the Principal Investigator or representative

I, the undersigned, _____, certify
(print)
(a) having explained to the research participant the terms of this form
(b) having answered all the questions, he/she has asked in this regard

(c) having clearly indicated that he/she remains free, at any time, to end his/her participation in the above-described research study
(d) that I will give him/her a signed and dated copy of this form.

_____

Signature of the Principal Investigator or representative

Signed at _____, the _____20 __."

6. Formulaire De Consentement (Les Patients)

Chercheur principal
Dre. Aliki Thomas
École de physiothérapie et d'ergothérapie
Faculté de médecine et des sciences de la santé, Université McGill
3654 Promenade Sir-William-Osler
Montréal (Québec) H3G 1Y5
Tél. (514) 398-4496
Courriel: aliki.thomas@mcgill.ca

Équipe de recherche
Dre. Tania Janaudis-Ferreira, Université McGill
Dr. André Bussières, Université McGill
Conchita Saldanha, Étudiante en maîtrise en sciences de la réadaptation, Université McGill
Tél. : (438) 226-8503
Courriel : conchita.saldanha@mail.mcgill.ca

Titre du projet : " La perspective des patients et des chercheurs sur l'impact de l'engagement des patients dans la recherche en réadaptation".

Objectif de l'étude

L'objectif de cette étude est de comprendre comment les partenaires patients et les chercheurs définissent et évaluent l'impact de l'engagement des patients dans la recherche en réadaptation, et à explorer les défis et les opportunités rencontrés par les partenaires patients et les chercheurs durant cette évaluation.

Nature de votre participation

Nous vous invitions à participer à un entretien individuel semi-structuré de 60 à 90 minutes. Cette entrevue serait réalisée par le biais d'une plateforme électronique en ligne, au moment qui vous convient. Les questions porteraient sur trois aspects : 1) l'impact de l'engagement des patients dans la recherche sur la réadaptation; 2) la façon dont vous évaluez cet impact; et 3) les défis et les opportunités que vous avez rencontrés lors de l'évaluation de l'impact.

Avantages personnels de la participation au projet de recherche

Vous ne tirerez aucun avantage personnel de la participation à cette étude. Cependant, votre contribution permettra d'obtenir des informations qui vont aider à l'avancement des connaissances sur l'engagement des patients- partenaires dans le domaine de la santé, et principalement en réadaptation.

Risques associés à la participation à l'étude

Cette étude présente des risques minimes pour les participants impliqués dans l'étude. Vous pouvez ressentir une certaine fatigue en participant à l'étude. Si tel est le cas, veuillez nous l'indiquer et nous allons prendre de moments de pause pour vous accommoder.

Confidentialité

Toutes les informations personnelles recueillies à votre sujet au cours de l'étude seront codées afin de garantir l'anonymat. Les noms seront supprimés et remplacés par un numéro d'identification unique propre à l'étude et généré par l'équipe de recherche, protégeant ainsi votre identité. Ce numéro d'identification et toutes les informations liées à votre numéro, y compris les coordonnées personnelles, seront conservés à tout moment dans un fichier informatique distinct auquel seuls les membres de l'équipe de recherche auront accès. Les données de recherche seront conservées dans une pièce fermée à clé, sur un ordinateur protégé par un mot de passe, pendant une période de sept ans après la fin de l'étude, après quoi elles seront détruites conformément à la politique et aux procédures de l'Université McGill. Aucune information confidentielle ou identifiante n'apparaîtra dans l'analyse ou la discussion des résultats.

Participation volontaire et retrait de la participation du sujet

Votre participation à cette étude de recherche est entièrement volontaire. Vous pouvez, à tout moment, mettre un terme à votre participation à l'étude. Vous pouvez refuser de répondre à toute question à laquelle vous ne souhaitez pas répondre, sans préjudices quelconques, durant l'entrevue.

Si vous souhaitez vous retirer de l'étude, vous pouvez contacter le chercheur principal Aliki Thomas, PhD., au (514) 398-5456 ou par courriel à aliki.thomas@mcgill.ca OU vous pouvez contacter Conchita Saldanha, étudiante en sciences de la réadaptation au (438) 226-8503 ou par courriel à conchita.saldanha@mail.mcgill.ca à tout moment de l'étude.

Toutes les informations colligées à votre sujet durant l'entrevue (y compris les informations personnelles ou les réponses) seront conservées et incluses dans l'analyse, sauf si vous informez l'équipe de recherche du contraire avant la fin de l'étude (c'est-à-dire en mai 2022). Dans ce cas, celles-ci seront détruites. Après mai 2022, nous ne pourrons pas supprimer vos données car elles auront été dépersonnalisées, agrégées et analysées.

Les résultats de l'étude de recherche, qui seront présentés sous forme de résumé, pourront être publiés, mais l'identité et/ou toute information d'identification ne seront pas révélées dans les rapports découlant de ce projet, ni dans les matériels de communication préparées pour conférences scientifiques. À la fin de l'étude (c'est-à-dire en août 2022), si vous souhaitez recevoir un résumé des conclusions générales, vous pouvez contacter la Dre. Aliki ou Conchita à l'adresse électronique qui vous a été fournie.

Le comité d'éthique de l'Université McGill peut accéder aux dossiers contenant vos renseignements personnels et les examiner afin d'en assurer la bonne gestion. L'étude de recherche à laquelle vous participez peut faire l'objet d'un examen d'assurance de la qualité afin de s'assurer que les lois et les directives requises sont respectées.

Clause de responsabilité

En acceptant de participer à cette étude, vous ne renoncez à aucun de vos droits légaux et ne déchargez pas les chercheurs, partenaires ou institutions impliqués de leurs obligations légales et professionnelles.

Indemnité compensatoire

Les participants ne recevront aucune compensation pour leur participation à l'étude.

Coordonnées des personnes-ressources

Si vous avez des questions concernant l'étude, vous pouvez contacter le chercheure principale Aliki Thomas, Ph.D., au (514) 398-5456 ou par courriel à aliki.thomas@mcgill.ca ou Conchita Saldanha, étudiante à la maîtrise en sciences de la réadaptation au (438) 226-8503 ou par courriel à conchita.saldanha@mail.mcgill.ca à tout moment de l'étude. Ce projet a été approuvé par le Conseil de révision institutionnel de McGill. Si vous avez des questions sur vos droits en tant que participant au projet, ou sur la recherche ou tout événement indésirable, vous pouvez contacter la Dr Aliki Thomas ou Conchita Saldanha aux coordonnées indiquées ci-dessus.

Si vous avez des questions concernant vos droits en tant que participant, vous pouvez contacter l'Agente d'éthique de la Faculté de Médecine et des Sciences de la santé au 514-398-8302 ou ilde.lepore@mcgill.ca

Consentement

Je reconnais avoir lu ce formulaire d'information. Je comprends les objectifs de cette étude, la nature et l'étendue de ma participation, ainsi que les avantages, les risques et les inconvénients auxquels je serai exposé(e), tels que présentés dans ce formulaire. J'ai eu la possibilité de poser des questions sur tous les aspects de l'étude et j'ai reçu des réponses satisfaisantes. J'accepte volontairement de prendre part à cette étude et je reconnais qu'en lisant ce formulaire d'information et en remplissant l'enquête en ligne, je donne mon consentement à participer à cette étude. Je suis conscient(e) que je peux me retirer de l'étude à tout moment sans préjudice d'aucune sorte. Je certifie que j'ai eu suffisamment de temps pour réfléchir à ma décision de participer à cette étude. Je reconnais qu'en donnant mon consentement à participer à cette étude, je ne renonce à aucun de mes droits légaux.

Nom du participant.e. (en caractères d'imprimerie) _____

Signature du participant.e. _____

Signé à _____, le _____, 20 _____.

Responsabilité de la chercheuse principale ou de sa représentante

Je, soussigné(e), _____, certifie

(Imprimer)

(a) avoir expliqué au participant à la recherche les termes de ce formulaire
(b) avoir répondu à toutes les questions qu'il/elle a posées à ce sujet
(c) avoir clairement indiqué qu'il/elle reste libre, à tout moment, de mettre fin à sa participation à l'étude de recherche décrite ci-dessus
(d) que je lui remettrai une copie signée et datée de ce formulaire.

_____

Signature de la chercheuse principale ou de sa représentante

Signé à _____, le _____20 __."

7. Consent Form (Researchers)

Patients' and researchers' perspective on the impact of patient engagement in rehabilitation research

Principal Investigator
Dr. Aliki Thomas
School of Physical and Occupational Therapy
Faculty of Medicine and Health Sciences, McGill University
3654 Promenade Sir-William-Osler
Montreal, Quebec H3G 1Y5
Tel (514) 398-4496
aliki.thomas@mcgill.ca

Research Team
Dr. André Bussières
McGill University
andre.bussieres@mcgill.ca

Dr. Tania Janaudis-Ferreira
McGill University
tania.janaudis-ferreira@mcgill.ca

Conchita Saldanha
MSc Rehabilitation Sciences student,
McGill University
Tel (438) 226-8503
conchita.saldanha@mail.mcgill.ca

Introduction

We are inviting you to participate in a research project involving healthcare professionals and their respective patient partners from rehabilitation sciences in Canada. We are seeking to understand your perspectives on the impact of patient engagement in rehabilitation research.

Before agreeing to participate in this study, please take the time to read and carefully consider the following information. This consent forms explains the aim of the study, the procedures, the advantages, risks, inconvenience as well as the persons to contact, if necessary. Please do not hesitate to contact the research team if you have any questions or concerns regarding the research project.

Purpose of the study

A shift from paternalistic to more patient-centered healthcare approaches had led to an increased interest in Patient Engagement (PE) in research. There are limited studies that measure the impact of PE on stakeholders and/or on the research outcomes.

Therefore, this study aims to understand how patient partners and researchers *think about* and *evaluate* the impact of PE in rehabilitation research, and to explore the challenges and opportunities encountered by patient partners and researchers during its evaluation.

Nature of your participation

You are being asked to participate in a qualitative study by:
Taking part in a 60 to 90-minute semi-structured individual interview which will be conducted on online platforms, at a time of your convenience. We would like to hear about your perspectives on 1) the impact that patient engagement has in rehab research, 2) how you evaluate impact and 3) the challenges and opportunities that you have encountered during the evaluation of impact.

Personal benefits from participating in the research project

You will not personally benefit from the study. We anticipate that the information we obtain will help us better understand your perspectives on 1) the impact that patient engagement has in rehab research, 2) how you evaluate impact and 3) the challenges and opportunities that you have encountered during the evaluation of impact.

Risks associated with participating in the study

This study poses minimal risks to the participants involved. You may experience some fatigue from participating in the study. If you do, kindly request a break from the interviewer.

Confidentiality

All personal information gathered about you during the study will be coded to ensure anonymity. The names will be removed and replaced by a unique study-specific ID number generated by the research team, thereby protecting your identity. This ID number and all the information linked to your number including personal contact information will be kept in a separate password protected computer file at all times and only the research team members will have access to it. The research data will be kept in a locked room, on a password protected computer for a period of seven years following the end of the study, after which it will be securely destroyed in line with the university policy and procedures. No confidential or identifying information will appear in any analysis or discussion of the results.

Voluntary participation and Withdrawal of the participation of the subject

Your participation in this research study is completely voluntary. You can, at any time, put an end to your participation in the study. You may decline to answer any question in the interview that you do not wish to answer, without negative consequences.

If you wish to withdraw from the research study you may contact the principal investigator Aliki Thomas, Ph.D., at (514) 398-5456 or via email at aliki.thomas@mcgill.ca OR you may contact Conchita Saldanha, MSc Rehabilitation Sciences student at (438) 226-8503 or via email at conchita.saldanha@mail.mcgill.ca at any time in the study.

Information we collect from you (including any personal information or responses) from the interview will be retained and included in the analysis, unless you inform the research group otherwise by the end of the study (i.e., May 2022). Information collected to this point will be destroyed if that is your decision. After May 2022, we cannot remove your data as it will have been de-identified, aggregated and analysed.

The results of the research study will be presented in summary form and may be published; identity, and/or any identifying information will not be revealed in any scientific reports or conferences. At the end of the study (i.e., Aug 2022), should you be interested in receiving a summary of the overall findings, you can contact Dr. Aliki or Conchita through the email address provided to you.

The ethics committee at McGill University may access and review the records containing your personal information in order to ensure its proper management. The research study you are participating in may be reviewed for quality assurance to make sure that the required laws and guidelines are followed.

Responsibility Clause

While agreeing to participate in this study, you do not give up any of your legal rights nor release to the researchers, partners, or institutions involved in your legal and professional obligations.

Compensatory Indemnity

Participants will not be receiving any compensation for their participation in the study.

Contact Information

If you have any questions regarding the study, you may contact the principal investigator Aliki Thomas, Ph.D., at (514) 398-5456 or via email at aliki.thomas@mcgill.ca or Conchita Saldanha, MSc Rehabilitation Sciences student at (438) 226-8503 or via email at conchita.saldanha@mail.mcgill.ca at any time in the study. This project has been approved by the McGill Institutional Review Board. If you have any questions about your rights as a project participant, or any questions about the research or any adverse event, you may contact Dr. Aliki Thomas or Conchita Saldanha at the contact information provided above.

If you have any questions about your rights as a research participant, you may contact the Ethics Officer at the Faculty of Medicine and health Sciences at 514-398-8302 or ilde.lepore@mcgill.ca.

Consent

I acknowledge that I have read this information form. I understand this study, the nature, and extent of my participation, as well as the benefits, risks, and inconveniences to which I will be exposed as presented in this form. I have been given the opportunity to ask questions concerning any aspects of the study and have received answers to my satisfaction. I voluntarily agree to take part in this study and acknowledge that by reading this information form, and by completing the online survey I give consent to participate in this study. I am

aware that I can withdraw from the study at any time without prejudice of any kind. I certify that I have had sufficient time to consider my decision to participate in this study. I acknowledge that by providing consent to take part in this study, I do not give up any of my legal rights.

Name of Participant (print) _____

Signature of Participant _____

Signed at _____, the _____, 20 _____.

Responsibility of the Principal Investigator or representative

I, the undersigned, _____, certify

(print)

(a) having explained to the research participant the terms of this form

(b) having answered all the questions, he/she has asked in this regard

(c) having clearly indicated that he/she remains free, at any time, to end his/her participation in the above-described research study

(d) that I will give him/her a signed and dated copy of this form.

_____

Signature of the Principal Investigator or representative

Signed at _____, the _____20 __."

8. Formulaire De Consentement (Les Chercheurs)

Point de vue des patients et des chercheurs sur l'impact de l'engagement des patients dans la recherche en réadaptation

Chercheure principale
Dre. Aliki Thomas
École de physiothérapie et d'ergothérapie
Faculté de médecine et des sciences de la santé, Université McGill
3654, promenade Sir-William-Osler
Montréal (Québec) H3G 1Y5
Tél. (514) 398-4496
aliki.thomas@mcgill.ca

Équipe de recherche

Dr. André Bussières
Université McGill
andre.bussieres@mcgill.ca

Dre. Tania Janaudis-Ferreira
Université McGill
tania.janaudis-ferreira@mcgill.ca

Conchita Saldanha
Étudiante en maîtrise en sciences de la réadaptation,
Université McGill
Tél (438) 226-8503
conchita.saldanha@mail.mcgill.ca

Introduction

Nous vous invitons à participer à un projet de recherche impliquant les professionnels de la santé en réadaptation et les et ls partenaires patients respectifs dans le domaine des sciences de la réadaptation au Canada. Nous cherchons à comprendre votre point de vue sur l'impact de l'engagement des patients dans la recherche en réadaptation.

Avant d'accepter de participer à cette étude, veuillez prendre le temps de lire attentivement les informations suivantes or ci-dessous. Ce formulaire de consentement explique le but de l'étude, les procédures, les avantages, les risques, les inconvénients ainsi que les personnes à contacter, si nécessaire. N'hésitez pas à contacter l'équipe de recherche si vous avez des questions ou des inquiétudes concernant le projet de recherche.

Objectif de l'étude

Le passage d'une approche paternaliste des soins de santé à une approche plus centrée sur le patient a suscité un intérêt accru pour l'engagement des patients dans la recherche. Il

existe peu d'études qui mesurent l'impact de l'engagement des patients sur les parties prenantes et/ou sur les résultats de la recherche.

Par conséquent, cette étude vise à mieux comprendre comment les partenaires patients et les chercheurs perçoivent et évaluent l'impact de l'engagement des patients dans la recherche en réadaptation, et à explorer les défis et les opportunités rencontrés par les partenaires patients et les chercheurs durant cette évaluation.

Nature de votre participation

Nous vous invitions à participer à un entretien individuel semi-structuré de 60 à 90 minutes. Cette entrevue serait réalisée par le biais d'une plateforme électronique en ligne, au moment qui vous convient. Les questions porteraient sur trois aspects : 1) l'impact de l'engagement des patients dans la recherche sur la réadaptation; 2) la façon dont vous évaluez cet impact; et 3) les défis et les opportunités que vous avez rencontrés lors de l'évaluation de l'impact.

Avantages personnels de la participation au projet de recherche

Vous ne tirerez aucun avantage personnel de la participation à cette étude. Cependant, votre contribution permettra d'obtenir des informations qui vont aider à l'avancement des connaissances sur l'engagement des patients- partenaires dans le domaine de la santé, et principalement en réadaptation.

Risques associés à la participation à l'étude

Cette étude présente des risques minimes pour les participants impliqués dans l'étude. Vous pouvez ressentir une certaine fatigue en participant à l'étude. Si tel est le cas, veuillez nous l'indiquer et nous allons prendre de moments de pause pour vous accommoder.

Confidentialité

Toutes les informations personnelles recueillies à votre sujet au cours de l'étude seront codées afin de garantir l'anonymat. Les noms seront supprimés et remplacés par un numéro d'identification unique propre à l'étude et généré par l'équipe de recherche, protégeant ainsi votre identité. Ce numéro d'identification et toutes les informations liées à votre numéro, y compris les coordonnées personnelles, seront conservés à tout moment dans un fichier informatique distinct auquel seuls les membres de l'équipe de recherche auront accès. Les données de recherche seront conservées dans une pièce fermée à clé, sur un ordinateur protégé par un mot de passe, pendant une période de sept ans après la fin de l'étude, après quoi elles seront détruites conformément à la politique et aux procédures de l'Université McGill. Aucune information confidentielle ou identifiante n'apparaîtra dans l'analyse ou la discussion des résultats.

Participation volontaire et retrait de la participation du sujet

Votre participation à cette étude de recherche est entièrement volontaire. Vous pouvez, à tout moment, mettre un terme à votre participation à l'étude. Vous pouvez refuser de

répondre à toute question à laquelle vous ne souhaitez pas répondre, sans préjudices quelconques, durant l'entrevue.

Si vous souhaitez vous retirer de l'étude, vous pouvez contacter le chercheur principal Aliki Thomas, PhD., au (514) 398-5456 ou par courriel à aliki.thomas@mcgill.ca OU vous pouvez contacter Conchita Saldanha, étudiante en sciences de la réadaptation au (438) 226-8503 ou par courriel à conchita.saldanha@mail.mcgill.ca à tout moment de l'étude.

Toutes les informations colligées à votre sujet durant l'entrevue (y compris les informations personnelles ou les réponses) seront conservées et incluses dans l'analyse, sauf si vous informez l'équipe de recherche du contraire avant la fin de l'étude (c'est-à-dire en mai 2022). Dans ce cas, celles-ci seront détruites. Après mai 2022, nous ne pourrons pas supprimer vos données car elles auront été dépersonnalisées, agrégées et analysées.

Les résultats de l'étude de recherche, qui seront présentés sous forme de résumé, pourront être publiés, mais l'identité et/ou toute information d'identification ne seront pas révélées dans les rapports découlant de ce projet, ni dans les matériels de communication préparées pour conférences scientifiques. À la fin de l'étude (c'est-à-dire en août 2022), si vous souhaitez recevoir un résumé des conclusions générales, vous pouvez contacter la Dre. Aliki ou Conchita à l'adresse électronique qui vous a été fournie.

Le comité d'éthique de l'Université McGill peut accéder aux dossiers contenant vos renseignements personnels et les examiner afin d'en assurer la bonne gestion. L'étude de recherche à laquelle vous participez peut faire l'objet d'un examen d'assurance de la qualité afin de s'assurer que les lois et les directives requises sont respectées.

Clause de responsabilité

En acceptant de participer à cette étude, vous ne renoncez à aucun de vos droits légaux et ne déchargez pas les chercheurs, partenaires ou institutions impliqués de leurs obligations légales et professionnelles.

Indemnité compensatoire

Les participants ne recevront aucune compensation pour leur participation à l'étude.

Informations de contact

Si vous avez des questions concernant l'étude, vous pouvez contacter le chercheure principale Aliki Thomas, Ph.D., au (514) 398-5456 ou par courriel à aliki.thomas@mcgill.ca ou Conchita Saldanha, étudiante en sciences de la réadaptation au (438) 226-8503 ou par courriel à conchita.saldanha@mail.mcgill.ca à tout moment de l'étude. Ce projet a été approuvé par le Conseil de révision institutionnel de McGill. Si vous avez des questions sur vos droits en tant que participant au projet, ou sur la recherche ou tout événement indésirable, vous pouvez contacter la Dr Aliki Thomas ou Conchita Saldanha aux coordonnées indiquées ci-dessus.

Si vous avez des questions concernant vos droits en tant que participant, vous pouvez contacter l'Agente d'éthique de la Faculté de Médecine et des Sciences de la santé au 514-398-8302 ou ilde.lepore@mcgill.ca

Consentement

Je reconnais avoir lu ce formulaire d'information. Je comprends les objectifs de cette étude, la nature et l'étendue de ma participation, ainsi que les avantages, les risques et les inconvénients auxquels je serai exposé(e), tels que présentés dans ce formulaire. J'ai eu la possibilité de poser des questions sur tous les aspects de l'étude et j'ai reçu des réponses satisfaisantes. J'accepte volontairement de prendre part à cette étude et je reconnais qu'en lisant ce formulaire d'information et en remplissant l'enquête en ligne, je donne mon consentement à participer à cette étude. Je suis conscient(e) que je peux me retirer de l'étude à tout moment sans préjudice d'aucune sorte. Je certifie que j'ai eu suffisamment de temps pour réfléchir à ma décision de participer à cette étude. Je reconnais qu'en donnant mon consentement à participer à cette étude, je ne renonce à aucun de mes droits légaux.

Nom du participant.e. (en caractères d'imprimerie) _____

Signature du participant.e. _____

Signé à _____, le _____, 20 _____.

Responsabilité de la chercheuse principale ou de sa représentante

Je, soussigné(e), _____, certifie

(Imprimer)

(a) avoir expliqué au participant à la recherche les termes de ce formulaire
(b) avoir répondu à toutes les questions qu'il/elle a posées à ce sujet
(c) avoir clairement indiqué qu'il/elle reste libre, à tout moment, de mettre fin à sa participation à l'étude de recherche décrite ci-dessus
(d) que je lui remettrai une copie signée et datée de ce formulaire.

_____

Signature de la chercheuse principale ou de sa représentante

Signé à _____, le _____20 __."