

CONCEPTUALIZATIONS OF IMPACT IN PATIENT PARTNERSHIP

EXPLORING CONCEPTUALIZATIONS OF IMPACT FROM THE PERSPECTIVES  
OF PATIENT PARTNERS WORKING WITH CANADIAN HEALTH SYSTEM  
ORGANIZATIONS: A QUALITATIVE STUDY

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## **Lay Abstract**

Patient partnership involves patients, family members, and caregivers working with healthcare organizations or research teams to improve health systems and services using their patient perspective and lived experience. A patient partner is an individual who works collaboratively with a health system organization for a length of time. Understanding how patient partners describe the impact of their involvement is important to ensure goals of this collaboration are achieved. In this study, we interviewed 35 patient partners from across Canada to learn how they describe impact, what kinds of changes they wish to see, and what helps them to achieve impact. We found that participants described both observed and perceived changes in their work. They also shared impacts they hope to achieve in the future and changes they expected following their involvement. These insights can help health system organizations enhance their partnership relationships and maximize achieved impact.

## **Abstract**

**Introduction:** As the patient partner role, described as the longitudinal and bi-directional involvement of patients, becomes increasingly integrated into health system organizations, it is imperative to understand the impacts of this engagement. The objective of this study is to explore how patient partners conceptualize and aspire to achieve impact through their partnership work, as well as to identify factors that may help to facilitate these impacts.

**Methods:** Guided by Interpretive Description methodology, we conducted 35 semi-structured interviews with patient partners working with health system organizations across Canada. Eligible participants self-identified as a patient, family member, or caregiver with over two years of experience as a patient partner. Participants were recruited through a previous survey, newsletter advertisements, and the research team's network. Data collection and analysis occurred concurrently in an iterative process and involved staged coding as well as the development of a thematic template consisting of themes and sub-themes related to conceptualizations of impact, aspirations of impact, and factors that facilitate impact.

**Results:** Participants described the impacts of their involvement in three main ways; observable versus perceived impacts, aspirational versus expected impacts, and factors that help to facilitate impact. Observable impacts involved extrinsic concrete changes, while perceived impacts involved a sense of intrinsic validation. Aspirational impacts encompassed changes participants hoped to see, and expected impacts were changes participants anticipated to occur. Lastly, participants highlighted multiple organizational supports that they perceived helped to facilitate impact.

**Conclusion:** Patient partners conceptualized their impact in various ways and commonly discussed observable and perceived impacts in relation to their work within their organization, and broader system change as an aspirational impact. Understanding how patient partners describe and aspire to impact can help organizations optimize impactful partnership work. Future research should explore how organizational staff conceptualize impact to compare these perspectives with those of patient partners.

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## List of Abbreviations

CPPS	Canadian Patient Partner Study
PPI	Patient and Public Involvement
PPEET	Public and Patient Engagement Evaluation Tool
ID	Interpretive Description
HiREB	Hamilton Integrated Research Ethics Board
JA	Julia Abelson
MV	Meredith Vanstone
CI	Caitlyn Ivany
LT	Laura Tripp
RD	Roma Dhamanaskar

## **Declaration of Academic Achievement**

The larger Canadian Patient Partner Study (CPPS) was funded by the Canadian Institutes of Health Research and conceptualized by Dr. Julia Abelson and Dr. Meredith Vanstone along with other co-applicants of the CPPS team. This thesis study was designed in collaboration by Caitlyn Ivany, Dr. Julia Abelson, and Dr. Meredith Vanstone. It was operationalized by Caitlyn Ivany, with interviewing assistance from Julia Rodgers, under the guidance of both Dr. Julia Abelson and Dr. Meredith Vanstone with input and assistance from other CPPS team members throughout. Caitlyn Ivany conducted the data analysis for this study with regular input from the CPPS team. This thesis manuscript was written by Caitlyn Ivany with revision by Dr. Julia Abelson, Dr. Meredith Vanstone, and Dr. Sheila Sprague.

## 1.0 Introduction

Patient partnership has become a prevalent practice and refers to the collaborative involvement of patients, family members, and caregivers in various aspects of health research and healthcare systems. (1) Over the past couple of decades, emphasis has been placed on the importance of users of health services to contribute to service improvement, patient-centered practices, and research priority setting, with the recognition that the lived experience provides a necessary perspective to incorporate when evaluating and enhancing aspects of our health system. (2) Health system organizations often strive to incorporate patient engagement as one of their goals, with increasing efforts being aimed at embedding patient partners at all levels of the health system such as the clinical, organizational, research, service improvement, and policy levels. (1–3) In Canada specifically, patient partnership has become a formalized initiative across health research and health systems and various frameworks have been developed to guide and support these activities. (4–6)

Understanding the impacts patient partnership and engagement can have on health research and the health system is valuable to establish and implement effective engagement strategies. (7) Patient partners often come into their roles seeking meaningful engagement and partnership that results in making a difference or an impact. However, there has been a lack of understanding and consensus surrounding the impact of patient and public involvement on health research and health systems as well as a lack of detailed discussion of factors that influence this potential impact. (8) This study aims to address this existing gap by exploring how patient partners describe and perceive forms of impact they have achieved and experienced in their work as well as impacts they aspire to achieve. Acknowledging different forms of impact from the patient partner perspective will deepen our understanding of the multifaceted nature of impact in

patient partnership. This study will also provide valuable insights to inform future development of strategies that aim to enhance and maximize the impact of patient partnership work. The following sections will cover a literature review on patient partnership in health systems, current approaches to conceptualizing and measuring impact, and enablers and barriers to patient partnership. This review will be followed by a section that outlines the current study's objectives.

## **2.0 Literature Review**

### ***2.1 Patient Partnership in Health Systems Organizations***

Patient partnership continues to be a growing movement and has become a common goal of healthcare systems as part of their efforts to move towards more patient-centered practices. (1,2) In 2011, the Canadian Institutes of Health Research (CIHR) introduced their Strategy for Patient-Oriented Research (SPOR) with the aim of improving health outcomes and patient experiences through integration of patient-relevant evidence into both the health system and clinical practice. (4) The launch of this strategy represented a significant institutional commitment to patient engagement and patient partnership in health research and health systems and was internationally aligned with similar investments in the UK and the US. (7,9)

The term 'patient-centeredness' has traditionally focused on the patient having more say in their care and individual patient-provider relationships. (10) However, this concept has evolved to incorporate and acknowledge the value of patients in other realms of health system activity such as patient safety and quality improvement, health system planning, design and decision-making, and policy and governance. (10–12) In addition to tangible outputs, engagement has also been associated with various benefits and intangible outcomes. Descriptions of these intangible benefits often tend to focus on benefits felt by the individual working with the

organization. Engaged patients have reported feeling more empowered, having increased self-esteem and confidence, as well as improved self-efficacy as a result of their partnership work. (2,13) An ethnographic study conducted by Armstrong and colleagues concluded that patients made distinctive contributions either as a ‘technology of persuasion’, in which the patient voice helped to persuade clinicians to address and improve current problems, or as ‘knowledge brokers’, in which patient partners helped to build connections between patients and healthcare professionals. (13) Subsequent literature demonstrated that shared decision-making had a positive impact on research partnerships and outcomes. (6)

With the growing incorporation of patient partnership and current evidence of the value of engagement, it is imperative to explore the different types of impacts that are achievable within a partnership collaboration including consideration of personal impacts, tangible and intangible outcomes, aspirations of making an impact, and factors that facilitate achieving impact. Understanding these elements can help patient partners and organizations collectively strive for maximal benefit from engagement.

## ***2.2 Current Approaches to Conceptualizing and Measuring Impacts***

Literature demonstrates that there are varying interpretations of impact and outcomes that resemble impact. Often the term ‘impact’ refers to and encompasses changes seen within an organization as a result of engagement. (14) In their systematic review of the impacts of patient and public involvement (PPI) on the UK National Health Service (NHS), Mockford and colleagues concluded that a key gap in the involvement evidence base is the lack of measurement tools and reporting of impacts resulting from involvement. (14) The authors found that the impacts of PPI on the NHS could be categorized as service planning and development,

informational development and dissemination, and changing attitudes of service users. (14)

However, the authors noted that with involvement being multifaceted, defining what constitutes ‘impact’ is complex and dependent on many factors such as context, policies, resources, and the culture of the organization. (14) Other researchers have echoed these findings and noted that impact can also be further understood and conceptualized by exploring context, engagement mechanisms, and types of outcomes. (15)

A recent systematic review examined UK-based literature that evaluated the process and outcomes of public involvement. (16) In this study which examined public involvement in health and social care research, the researchers’ findings indicated that one of the major components to ensure meaningful involvement from the perspectives of public partners was seeing and contributing to change. (16) This review also conceptualized impact in relation to various domains such as impacts on individuals and discrete outputs. (16) Impacts for partners involved impacts that were solely reflected in personal growth such as increased self-confidence and skill development. (16) Discrete outputs demonstrated the development of tangible products such as educational tools or training for researchers surrounding public involvement. (16) This review contributed to the existing literature by providing insights into the phenomenon of personal impacts as well as more tangible impacts.

Abelson and colleagues created the *Engage with Impact Toolkit* with the goal of developing an impact measurement framework and evaluation toolkit that organizations could use to assess the impact of their engagement activities. (17) The development of this tool reflects the shifting priorities from improving the quality of engagement to assessing the outcomes and impacts of engagement. (17) As part of the toolkit development process, a modified concept mapping methodology was used to conceptualize impacts that engagement can have at the levels

of people, programs, organizations, and health systems. (17) Results of the concept mapping process were reviewed and synthesized by a working group of patient partners, engagement specialists, researchers, and government personnel which led to the identification of eight domains of impact: knowledge and skills; confidence and trust; equity and inclusivity; priorities and decisions; effectiveness and efficiency; patient-centeredness; culture change; and patient outcomes and experience. (17) The development of this toolkit demonstrates how members working closely with patient partnership initiatives view impact.

Building on these current conceptualizations of impact, it is important to consider how impact is being measured in practice. Within patient partnership and engagement literature, there have been limited efforts to evaluate the impacts of involvement. (6,8) Commonly reported quantitative measures that aimed to evaluate impact included measuring recruitment rates, and surveying patient satisfaction. (8,18) However, these quantitative measures failed to consider contextual factors that may influence impact. (8)

Several systematic reviews have explored engagement evaluation methods used in health research settings. These reviews discussed the focus of evaluation tools as well as the kinds of impacts that were addressed. Mrklas and colleagues found that overall, tools for assessing health research partnership mainly focused on outcomes, followed by the process of partnership, and less frequently incorporated the measurement of impact. (19) Boivin and colleagues conducted a systematic review in both health research and health system settings. (20) These researchers found that tools that aimed to evaluate engagement outcomes commonly focused on perceived and self-reported impacts and a lower percentage of tools evaluated observed impacts. (20) Similarly, Bird and colleagues found that impacts of partnership in research mainly reflected impacts in terms of personal experience for the patient partner. (21) This involved discussion of

acquiring skills and knowledge, building a network of peers, advocating for change, and gaining confidence in themselves as patient partners. (21)

Other systematic reviews have explored applicable approaches for evaluating the impacts of partnership specifically in health system settings. Dukhanin and colleagues conducted a systematic review of publications that referenced evaluation tools for engagement in healthcare organization settings. (22) These researchers evaluated 44 different outcome metrics and posited that outcome evaluation tools could be grouped into three domains; internal, external, and aggregate outcomes. (22) Within these domains, impact and influence were measured on various levels including impact on engagement participants, services offered by the organization, and on the organization itself, as well as influence on the broader public and population health. (22) The review concluded that there were nearly double the amount of tools to measure success of engagement processes in comparison to outcome evaluation tools. (22) Additionally, the researchers noted that many outcome evaluation tools relied on measuring perceived benefits of engagement for the patient partner or the organization and argued that there should be more of a focus on documented changes as evidence of impact. (22) Dukhanin and colleagues also addressed a prominent limitation in the lack of universal terminology for engagement partners as well as consensus surrounding the aims of engagement with healthcare organizations. (22) This lack of universal terminology could have hindered their literature search and potentially resulted in missing relevant literature on engagement evaluation. These limitations of the absence of universal terminology and aims of engagement in different settings has been reflected in other literature as well, with emphasis placed on the need for differentiation between varying forms of partnership as this can also assist with further development of research that adequately addresses the types of impacts patient partners have in their roles. (19,23)

An evaluation tool identified in Dukhanin and colleagues' systematic review was the Public and Patient Engagement Evaluation Tool (PPEET) by Abelson and colleagues. (24) The PPEET has provided a generic evaluation tool that can be used by an array of health system organizations to evaluate their public and patient engagement efforts. (24) Although primarily used for assessing procedural elements of engagement, the PPEET also touches on the impacts of engagement. This tool was structured around four principles of engagement; integrity of design and process, influence and impact, participatory culture, and collaboration and common purpose. (24) The tool consists of three different questionnaires to assess the core principles from various perspectives including those participating in, planning and executing, and providing leadership for engagement initiatives. (24) As an example of the PPEET in practice, the tool was used as a preliminary step before utilizing the Engage with Impact toolkit to evaluate the impacts of engagement on the Chronic Pain Network. (7)

Overall, although there is a growing emphasis in the literature on engagement evaluation approaches in both health research and health system settings, there is a lack of consensus amongst these tools pertaining to conceptualizations of impact. Additional research addressing impacts of patient partnership at the health system organization level would therefore be beneficial to further enhance engagement evaluation efforts overall. It is imperative to explore and consider different kinds of impact, including forms of perceived and observable impacts, to enhance our understanding of the value of patient partnership and to further inform approaches to achieve impact.

### ***2.3 Enablers and Barriers to Patient Partnership***

In a broad sense, there are many enablers that support successful patient partnership, and many barriers that hinder this process. The literature often discusses these factors in relation to both successful engagement and making an impact. However, it is important to note that these do not always go hand in hand. For example, there may be adequate support to foster a successful partnership but that does not necessarily mean an impact was made. As previously mentioned, often there is a lack of clear articulation of the impacts of involvement. This highlights the importance of understanding how patient partners conceptualize impact and what facilitates or hinders this.

Various frameworks have outlined levels of engagement and factors that influence this engagement. For example, Carman and colleagues posited that engagement is a continuum. At the lower end of the continuum, patients have limited power over decisions and actions while at the higher end of the continuum, patients have more shared power and collaboration with organizations. (5) Components that can influence engagement at all levels of the continuum encompass individual, organizational and societal factors. (5) Individual factors of the patient include their motivation, ability to engage, and experiences with the health system. (5) Organizational factors include culture surrounding patient engagement, government involvement, policies and practices, and organizational leadership. (5) Lastly, societal factors include social norms, national and local policies, and the influence these have on patients' perception of their ability to contribute. (5)

Additionally, a study conducted by Evans and colleagues tracked public involvement in eight different research projects and identified that several contextual and organizational factors

supported effective and successful partnership including adequate leadership, feedback given to patient partners, allocating engagement staff, and adequate resources. (15) Similarly, subsequent research added that adequate planning, communication of engagement plans across the organization, training, and mentorship further supported patient partnership. (9,10,12) The link between these reported factors for successful engagement and achieving impact is unclear, further prompting for exploration of this relationship.

Barriers to patient partnership include the burdensome time demands of being a patient partner, tokenism felt in some organizations, lack of support for engagement practices, lack of resources, poor communication practices, and power imbalances. (2,10) Many factors also negatively affect the willingness of patients to engage such as potential discrimination, inequality, patients beliefs about their role, negative experiences with the health system, etc. (6,9) Exploring how these barriers relate to or influence a patient partner's conceptualization of impact or ability to achieve impact in collaboration with the organization can help the advancement towards more effective partnership practices capable of enacting impact.

Overall, it is important to explore and gain a better understanding of how these various enablers and barriers to patient partnership subsequently influence conceptualizations of impact, as well as change, or lack of change, that is enacted in health system organizations.

#### ***2.4 Significance of the Proposed Study***

As identified in the literature, there is a current lack of qualitative data from the perspective of patient partners that examines how patient partners in Canada conceptualize impact. An exploration of how patient partners describe impacts, rather than discussion or evaluation of only impacts that have been achieved, is needed to further advance efforts towards

achieving and assessing varying forms of impact based on both patient partner and organizational goals. The Canadian Patient Partner study (CPPS) provided a unique opportunity to address this gap. This qualitative study will explore conceptualizations of impact and aspirational impacts through the analysis and interpretation of interview discussions with patient partners. These findings will build upon the current literature surrounding impact evaluation approaches which have commonly highlighted perceived impacts. We aim to broaden this focus and add to the current literature by addressing all forms of impacts described by the participants in our study, including both observable and perceived impacts. Utilizing patient partner perceptions to address various kinds of impact will allow for the exploration of nuanced experiences consisting of both objective and subjective forms of impact that may be context specific. This study will contribute valuable information and help to create a more comprehensive conceptualization of impact from the patient partner perspective. The broader aim of this study is to optimize future patient partnership efforts in health system organizations.

### **3.0 Objectives**

The purpose of this analysis is to explore how patient partners conceptualize and aspire to make an impact in their roles. We aim to explore impact comprehensively by incorporating both how patient partners describe types of impact as well as impacts that have been achieved in their work. This analysis will provide valuable and meaningful information for those working in the Canadian patient partnership landscape surrounding the conceptualizations of impact, further prompting organizations implementing partnership to utilize this information to maximize impactful partnership work.

The objective of this research is to understand how patient partners conceptualize and aspire to achieve impact through their partnership work. This will be answered by pursuing the following research questions:

- How do patient partners describe the impacts they have experienced through their own work and the impacts they aspire to?
- Which organizational factors do they think may facilitate these impacts?

These objectives will be explored by analyzing patient partner interview data from the Canadian Patient Partner Study (CPPS). The methodological details will be discussed in the next chapter.

## **4.0 Methods**

### ***4.1 Setting***

The CPPS consists of multiple studies that aim to gain an understanding of the roles and experiences of patient partners working with Canadian healthcare organizations. (1) The study phases consist of a systematic search and synthesis of the patient partnership literature, a survey of patient partners across Canada, and interviews with both patient partners and organizational staff who participate in or support patient partnership activities across a wide range of health system organizations. The CPPS study is presently in the third and final phase and this current study will utilize qualitative interview data with patient partners to explore how these individuals conceptualize impact.

This current study specifically focuses on patient partners' experiences of and conceptualizations of impact within their patient partnership work conducted in Canada. This study was led by the CPPS team located at McMaster University which includes methodologists and highly experienced researchers in the patient engagement and partnership landscapes. Collaborators include researchers, patient partners, and health system decision-makers located across Canada.

### ***4.2 Study Design***

This qualitative study used Interpretive Description (ID) methodology. Data collection consisted of one-on-one interviews conducted via Zoom with patient partners who have experience working with Canadian health systems organizations. The use of Interpretive Description allowed us to engage in a meaningful exploration of conceptualizations of impact without being tightly bound to rigid methodological frameworks. In alignment with analysis

approaches utilized in Interpretive Description, data collection and analysis occurred simultaneously and involve a staged coding process.

### ***4.3 Methodology***

Interpretive Description as described by Sally Thorne is a pragmatic, inductive analytic approach that aims to understand clinical or applied phenomena and generate findings with meaningful implications to that discipline. (25) This methodology, which originated in nursing research and has been used in many applied health disciplines, draws from other traditional qualitative methodologies while focusing on interpreting meaning and finding significance within the data. (25) This approach recognizes the presence of multiple and shared realities as well as the influence of context on human experience. (26) The use of Interpretive Description methodology allowed us to analyze interview data in a manner that assisted in interpreting meaning attributed to impact.

### ***4.4 Philosophical Stance and Theoretical Lens***

Interpretive Description philosophically aligns with constructivist and naturalistic origins, while reflecting the movement away from strictly following traditional qualitative methodological approaches. (26,27) This framework of ID acknowledges that realities are socially and experientially created, and research on these subjective experiences requires a degree of interpretation on the researcher's part. (27) The epistemological standpoint of Interpretive Description is informed by aspects of naturalistic inquiry outlined by Lincoln and Guba. (25) Some of these aspects of Interpretive Description include the conduct of studies in as naturalistic a context as possible, attending to the value of subjective knowledge and experience, the acknowledgement of influence of socially constructed elements on human experience, the

concept of multiple simultaneous realities, and the influence of the researcher as the inquirer in the interpretation of research findings. (25) Additionally, constructivist and interpretivist lenses share many commonalities, and can help to form the framework and scaffolding of ID studies due to their common goals of understanding lived experience. (28) Interpretive Description aligns with a constructivist perspective where emphasis is placed on how knowledge is socially constructed, highlighting the notion that participants' understandings of their realities are influenced by their social and cultural context. (28) Interpretive Description can also align with an interpretivist approach where focus is placed on interpreting and understanding human experiences through participant narrations. (28) Using these research paradigms, this study explored the ways in which patient partners interpret and attribute meaning to the concept of impact in relation to their partnership work.

Symbolic interactionism is an important interpretivist approach to note in this study as we seek to understand and interpret meanings attributed to impact. Symbolic interactionism holds roots in pragmatism, emphasizing process and change and the idea that reality is subject to multiple interpretations. (28) Although symbolic interactionism is commonly associated with grounded theory work, this theoretical lens can be applied alongside other qualitative methodologies to help unravel intricacies of socially constructed meanings of a phenomenon and to uncover the subjective experience of participants. (29) Interpretive Description and symbolic interactionism share roots in pragmatism and focus on contextualized action, as well as the principle that human experience can only be understood through inductive inquiry. (30) Adopting this lens for this study will allow for the recognition that the concept of impact can be constructed by individual's interpretations of the patient partnership landscape that they work in.

Using the perspective of symbolic interactionism will help to recognize that social interactions are dynamic and open-ended which can influence how individuals attribute meaning to impact.

#### ***4.5 Sampling and Recruitment***

Patient partner interviewees were purposively sampled from those who completed the initial CPPS survey in the Fall of 2020, and those who responded to newsletters advertisements regarding participation in an interview. Information for this current interview phase of the CPPS study was also distributed to the team's contacts working within patient partnership to request for the circulation of our study information to patient partners in their organizations.

In this study, the term 'patient partner' refers to people (patients, clients, family members, and caregivers) drawing on their past or current lived experiences with the health system who have longitudinal, bidirectional involvement with health organizations for the purposes of system improvement. (1,23) Patient partners were eligible to participate if they self-identified as a patient, family member, or caregiver who has >2 years of experience partnering with a health system organization in Canada, were able to communicate in English or French, were over 16 years of age, were able to provide either written or oral consent, and lived in Canada. Eligible participants were emailed an invitation to participate in the interview phase of the CPPS. If the participant wished to participate in an interview, they were sent a RedCap link with a unique code to review and complete an online informed consent form and provide their interview availability.

Purposive sampling for maximum variation is widely used in qualitative research to identify and recruit participants who are experienced in the phenomenon of study. (25) This sampling technique was used and followed seven criteria to ensure maximum variation of

participation; i) length of tenure in advisor roles, ii) range and multiplicity of roles, iii) organization type and level, iv) socio-demographic characteristics, v) type of lived experience catalyzing involvement, vi) identify as a patient or family caregiver, and vii) geographical representation. After they had been selected, participants were then emailed to schedule an interview. We also used purposive sampling for theoretical aims following the first few interviews to attempt to recruit individuals with experience that would help to expand upon concepts in the data. Additionally, we aimed to diversify our sample by inviting participants with unique demographic profiles such as younger individuals, patient partners with less experience, and partners who had not previously completed the CPPS survey.

#### ***4.6 Sample Size and Data Saturation***

As noted by Sally Thorne, there is no firm rule for what is considered to be an adequate sample size for an Interpretive Description study, and rather that a sample size is dependent on the researcher being able to generate a claim on the necessary number of participants needed for study results to be valuable. (25) Thorne posits that the idea and use of data saturation to determine sample size implies that an experience has been heard frequently enough that it can be anticipated and no further exploration is needed, however this is not the case in many applied disciplines as each participant's experiences are subjective and socially as well as contextually constructed with endless possibilities for new insight. (25) Thorne instead encourages researchers to demonstrate credibility, outline their logic for data sufficiency from the research question to the study conclusions, and add meaningful information to the study discipline. (31)

For this study, Malterud's concept of information power is used to operationalize decisions about data sufficiency, with an emphasis placed on working towards gaining a deeper

understanding of the various conceptualizations of impact from the perspectives of patient partners. (32) The concept of information power posits that the more relevant information and data a study sample provides, the smaller this sample needs to be for a study to achieve sufficient information power. (32) Malterud's information power is suitable for Interpretive Description as it is a pragmatic model for assessing sample size and recognizes the variability in the subjective experiences of participants. (32) This model is made up of five components that are used to estimate a necessary sample size in qualitative interview studies; aim, specificity, theory, dialogue, and analysis. (32) The aim of this study is broad due to the goal of understanding conceptualizations of impact. The study sample specificity is sparse as the study eligibility criteria is quite broad. This study does not use any explicit theory as guidance, but rather uses conceptual ideas from the literature about impacts in patient partnership to further explore interpretations of study findings. The interviews have strong dialogue, however this is ultimately dependent on each participant as well as potentially rapport built during each session between the interviewer and participant. Lastly, analysis will involve comparing and contrasting conceptualizations of impact within each transcript, indicating the need for a larger sample size. With consideration of these elements that influence information power, a sample size of 25-30 should provide a diverse range of perspectives to help describe and understand conceptualizations of impact in patient partnership.

#### ***4.7 Consent***

When participants were notified of the interview phase of the CPPS, either via email following completion of the CPPS survey or through advertisements, they were given in-depth information on the CPPS so that they were able to make an informed decision whether to participate in an interview. If participants wished to participate, they were sent a RedCap form to

collect informed consent, and demographic and contact information. All consent and information forms were approved by the Hamilton Integrated Research Ethics Board (HiREB). A member of the research team then emailed participants to set up a virtual interview time over Zoom.

Following completion of the interview, participants were offered an honorarium in the form of a gift card to thank them for their time.

#### ***4.8 Data Collection***

The semi-structured patient partner interview guide was developed following the previous phases of the CPPS consisting of a literature review and quantitative survey. Areas of theoretical interest identified in the literature review were considered in the development of interview guides. The CPPS research team and the two patient partners on the project utilized the survey data to design an interview guide that explored intriguing concepts related to the patient partner experience and any outlier survey results. The developed guide was reviewed and revised by all members of the research team before being piloted with three interviewees to assess if the questions were easy to understand and elicited robust responses. The guide was then further edited and continued to evolve with emerging theoretical insights throughout the interview phase of the CPPS.

The interview guide [Appendix 1] consists of open-ended questions including, but not limited to, outlining the kinds of patient partner work they have participated in, why they chose to be a patient partner and their motivations to continue in their role, how their role is shaped and if there are any policies that help to outline their role, harms or barriers they have encountered, whether they have quit or considered quitting any of their roles, and how their partnership work has changed over time. Specifically related to impact, patient partners were asked the following questions:

- Have you seen the work you and your colleagues do have impact? How is it visible?
- When we think about things organizations have done to support you in making meaningful contributions and building your capacity to provide value or make an impact, what are some of those things?

These two questions directly prompted discussion of different kinds of impact and provided rich data for this study. Conceptualizations and discussions of impact also arose in participants' responses to other interview questions. Participants are informed at the beginning of the interview that the aim of the session is to discuss their experience working with health system organizations, rather than their experiences with research.

Interviews began in November 2022 and finished in September 2024. Interviews were audio- and video-recorded. Interview transcripts were then sent to a transcription company to be transcribed verbatim. A member of the research team then de-identified these transcripts prior to beginning analysis.

#### ***4.9 Data Analysis***

Interpretive Description utilizes an inductive analytic approach, in which data collection and analysis occur concurrently, to seek understanding of the phenomena being studied. (26) It is important to note that ID does not rigidly prescribe a step-by-step process with which to conduct a study, but rather encourages a range of analytic strategies to best suit the present study. (25) In alignment with the inductive nature of Interpretive Description, for this study all patient partner interview transcripts were reviewed periodically by a member of the research team to ensure relevant data is being captured to address our research objectives. NVivo software was used for review of transcripts and qualitative coding.

This study used template analysis which is an approach that involves developing a coding template that is applied to subsequent transcripts throughout the analysis. (33) Template analysis allows researchers to develop more extensive themes while keeping a record of analytical decisions to outline how various interpretations during analysis lead to certain conclusions. (33) Analytic memos were documented as needed to engage with the data and begin to make sense of and attribute meaning to participants' experiences. This qualitative analysis explored responses that demonstrate how participants conceptualize and interpret impact both in interview questions that explicitly discuss impact as well as other areas involving discussions of impact.

Analysis began with a member of the research team immersing themselves in the data to grasp a good understanding of the data while also allowing for new insights and themes to arise. (33) Codes and themes relevant to the conceptualization of impact were highlighted. Then, an initial thematic template was created that includes relevant codes and themes to the study purpose. (33) This template was applied to organize, analyze, and code the data followed by condensing and reflecting on created codes. (33) Data was compared and contrasted across transcripts throughout the analysis process. (33)

To demonstrate rigour, an audit trail was developed throughout the analysis. An audit trail provides detailed information on how various data interpretations and decisions were made in order to explicitly outline the analytic process. (25) The development of an audit trail also involves remaining conscious of any biases and assumptions made by the researcher that may influence interpretations of the data and consequently the study's outcomes. (25) Use of an audit trail helps to enhance the credibility and transparency of a study's findings and further demonstrates rigour and trustworthiness of the results. (25)

#### **4.10 Rigour**

Throughout this study, Lincoln and Guba's criteria for achieving trustworthiness (credibility, transferability, dependability, and confirmability) were used to establish rigour. (34) These criteria and associated strategies to achieve trustworthiness are well suited for Interpretive Description studies as they help to demonstrate the credibility of a researcher's interpretations to help enhance transparency and the overall quality of the study. (34) Credibility parallels with internal validity used in quantitative studies and refers to whether the researcher provides evidence to support that the results accurately reflect the study's subject, ensuring that readers can trust the findings. (35) Peer review or debriefing, a strategy outlined by Guba and Lincoln, was used in this study to achieve credibility. (34) This involved discussion of the data with the larger research team throughout data analysis to assist with interpreting themes in the data and to address any potential biases that influenced interpretations of the data. Additionally, to further establish credibility, throughout data analysis researcher reflexivity was emphasized through the development of a reflexive journal to address any biases and provide the thought process behind interpretations. (36) Transferability, which parallels with external validity, requires that the researcher provides detailed contextual information to allow readers to assess whether the study results apply to varying contexts or situations. (35) To address transferability, a large number of interviews were conducted following maximum variation sampling and the semi-structured interview guide aimed to collect thick, descriptive data to allow for the discovery of prevalent patterns and themes in various contexts. (34,36) Dependability and confirmability parallel reliability and objectivity respectively. (34) Dependability refers to whether the researcher provides enough detail about the study process to allow for the study to be replicated. (35) Confirmability involves the researcher demonstrating that the study results are grounded in the

data and reflect the participants' experiences. (35) A strategy to address these two criteria that was used in this study was the development of an audit trail which was comprised of detailed documentation of how specific points of data lead to certain decisions, reflections, and interpretations as well as how the researcher's own biases may have influenced the resulting interpretation. (34)

#### ***4.11 Reflexivity***

I am a Masters student in Health Research Methodology at McMaster University with an undergraduate degree in the Life Sciences therefore my perspectives are informed by extensive exploration of research methodology and health care topics. I have participated in research within the patient engagement landscape for the duration of my Masters degree. My positionality includes identifying as a female and as a white-presenting individual, though my ethnicity encompasses both white and Southeast Asian. This position may skew views and perspectives towards understanding partnership and the Canadian healthcare system as being predominantly shaped by Western healthcare practices and cultural norms, as well as from the viewpoint of a white individual experiencing the healthcare system. This may potentially lead to overlooking diverse participant experiences, however with this awareness of my positionality I commit to aiming to overcome this by recognizing the diverse array of potential experiences and perspectives, as well as factors that impact these experiences.

Potential biases include my academic focus on patient engagement within a predominantly Western context, which may lead me to favor interpretations aligned with these experiences. I am an individual who has not needed extensive health care treatment or services for certain conditions and who has had mainly positive experiences with the healthcare system. I

also have no experience working as a patient partner. These factors may bias my perspectives in the direction of positive views of health services. My identification as a woman and my ethnic background may influence my interactions with participants which can potentially affect the rapport that is built throughout interviews as well as participants' openness during data collection.

To mitigate potential biases and their influence on this research, I commit to continuously reflecting upon my assumptions and biases and how they are affecting study interpretations. I aim to utilize the diverse perspectives and experiences of our research team to ensure data is critically examined from other viewpoints. The research team also aims for a diverse participant pool to capture a wide range of experiences and views on patient partnership.

#### ***4.12 Role and Team Composition***

The CPPS research team consists of eleven members, two of which are patient partners from the Patient Advisors Network. JA and MV are the co-leads of the study. Three team members work at McMaster University, and the remaining researchers are from the University Health Network, the University of Calgary, and the Nova Scotia health authority.

For this specific study, the members of the team from McMaster University (CI, JA, MV, LT, and RD) assisted with the development of the research questions and study design, as well as provided input on the analysis and interpretation of the results. CI and RD conducted participant interviews. CI took the lead on coding and analyzing the patient partner interview transcripts, while the larger McMaster team provided guidance, support, and feedback throughout the analysis.

#### ***4.13 Ethics***

Ethics approval for the larger CPPS was obtained from the Hamilton Integrated Research Ethics Board (HiREB). All data collection and management strategies were adherent to the Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans. Participants were informed of the study aims both in the informed consent on RedCap prior to the interview and at the start of the interview session. Informed consent information was provided in plain language and participants had the opportunity to clarify any questions they had. Participants were reminded that they have the right not to participate and withdraw at any point, as well as the right to skip any interview questions they do not want to answer. Interview data was anonymized following transcription. All study files are stored in password-protected folders on MacDrive and only the study team has access to these files.

Although ethical challenges were unlikely to be a major concern in this study, it is important to acknowledge the potential challenges or adverse situations that may arise. The context of some of this study's interview questions may cause negative or harmful personal experiences to surface, which can result in adverse feelings or emotions for the participant when discussing such personal stories. Participants are reminded at the start of their interview session that they can refrain from answering any question they feel uncomfortable with.

## 5.0 Results

### 5.1 Participant Characteristics

Thirty-five patient partners participated in a semi-structured interview. Most participants were over the age of 50, female, white, from Ontario, and attended university. Participants had a range of experience including years as a patient partner and the number of organizations they had partnered with. Table 1 describes participant demographics.

*Table 1. Participant Characteristics*

Characteristic		n (%)
Age (years)	20-29	1 (2.9)
	30-39	4 (11.4)
	40-49	5 (14.3)
	50-59	13 (37.1)
	60-69	8 (22.9)
	70-79	4 (11.4)
Gender	Man	7 (20)
	Woman	26 (74.3)
	Transgender	1 (2.9)
	Non-binary	1 (2.9)
Race	White	27 (77.1)
	South Asian	4 (11.4)
	Black	2 (5.7)
	Latino	1 (2.9)
	Indigenous	1 (2.9)
Province of residence	Ontario	15 (42.9)
	Nova Scotia	4 (11.4)
	British Columbia	4 (11.4)

	Alberta	4 (11.4)
	Quebec	2 (5.7)
	Manitoba	2 (5.7)
	Newfoundland and Labrador	1 (2.9)
	Saskatchewan	1 (2.9)
	New Brunswick	1 (2.9)
	Prince Edward Island	1 (2.9)
Highest level of education	High school	4 (11.4)
	Apprenticeship	1 (2.9)
	College	5 (14.3)
	University	25 (71.4)
Number of years of patient partner experience	0-2	1 (2.9)
	3-5	9 (25.7)
	6-10	12 (34.3)
	11-20	12 (34.3)
	21-30	0 (0)
	>30	1 (2.9)
Number of organizations participant has worked with	1-3	19 (54.3)
	4-6	6 (17.1)
	7-9	2 (5.7)
	10-12	4 (11.4)
	Unsure	4 (11.4)

## 5.2 Overview of Findings

Participants discussed and conceptualized impact in three main ways; observable versus perceived impacts, aspirational versus expected impacts, and factors that help to facilitate impact. A thematic template was developed and served as a guide throughout data analysis [Appendix 2].

Participants described two distinct types of impact: observable and perceived. Observable impacts involve concrete changes that can be seen even by those not directly involved. In contrast, perceived impacts refer to experiences in which participants feel their contributions have made a difference, even if the changes are not immediately noticeable. Perceived impacts often manifest as a sense of internal validation and empowerment in their role as a patient partner. The distinction between these two forms of impact underscores the juxtaposition between extrinsic, outward-facing changes that are visibly evident resulting from a patient partners' work, and intrinsic, personal feelings of impact experienced by patient partners. This finding highlights the multifaceted nature of impact in patient partnership, involving the interaction of both objective evidence of change and subjective experiences of contribution.

Participants also discussed aspirational impacts, which encompassed impacts that patient partners hope to see, as well as expected impacts, which referred to what patient partners anticipate is most likely to occur with the recognition that broader change takes time. These conceptualizations of impact demonstrated the contrast between personal goals of achieving impact as a patient partner and the potential gradual nature of impact within partnership.

Lastly, participants highlighted components that they recognized as facilitators of impact. There was notable overlap between these facilitators of impact in the form of different organizational supports, and various forms of observable and perceived impacts. This overlap and relationship between types and facilitators of impact further highlights the nature of extrinsic and intrinsic forms of impact and how these can be recognized in various organizational supports.

### ***5.3 Describing Impact***

Participants described impact as instances where they could directly observe things that had changed (observable impacts) or outcomes they believed had happened as a result of their patient partner activities (perceived impacts). Patient partners describe both distinct phenomena as impact even though the former can be noticeable to others while the latter relies on the patient partner's perceptions and may not be observed or experienced by any other individual. These contrasting depictions of impact highlight the extrinsic versus intrinsic nature of impacts, where the observable impacts are demonstrated through external visible change and perceived impacts derive from internal thoughts and feelings. Observable impacts were discussed more often than perceived impacts, and almost all participants who felt perceived impacts also addressed observed impacts. The overlap of both forms of impact discussed in one interview emphasizes that the concept of impact is fluid and shaped by the topic or experience being discussed.

Participants also described impact in relation to its absence in situations where they felt their efforts had not made a difference or nothing observable resulted from their efforts. These experiences provide nuance to conceptualizations of impact, highlighting instances in which participants shared frustrations with the lack of change despite their efforts. These less fruitful experiences can also help to stimulate ideas surrounding areas of improvement in patient partnership.

#### *Observable Impact*

Observable impact encompassed discussions of impact that were readily identifiable, concrete, visible or measurable products resulting from their patient partner work. Additionally, observable impact encompasses instances where patient partners recognize the influence of their

involvement, and can trace actions or decisions back to activities or projects they were involved in. These observable impacts were external and extrinsic in nature and took on various forms including increased patient partner involvement within the organization, developed products, identifiable changes, and policy changes.

Many participants discussed a shift in magnitude towards increased involvement of patient partners. This encompassed both a growth in the number of patient partners working with an organization and an expansion of their roles and involvement. Participants highlighted the development of organizational structures that facilitated increased patient partner inclusion across various teams and projects, as well as the creation of new roles to ensure patient partner contribution. One participant connected this concept of increased inclusion of patient partners to the organization valuing the contributions of patient partners when asked how they think organizations can demonstrate the impact patient partners have.

“The size. Like if all of a sudden they only have three patient partners, and now they have 23, that's going to show that they had some impact. When they're being appointed now to the governor's committee, and they're actually going to meetings. That's an impact.” –

P94

Additionally, participants attributed impact to instances in which they saw patient partners being involved in more executive and senior level groups within the organization. Increased involvement of patient partners at higher organizational levels demonstrated strengthened support for engagement and provided further opportunities for the incorporation of the patient partner perspective.

“...and now the executive committee has invited, they want someone from our committee to actually sit on the executive meetings. And vice versa, they're going to have someone sit on ours. Which is a huge thought change because before it would just be like they'll send you minutes or whatever, they'll send you the highlights. But now they're actually going to have, let us have a voice on their committee and back. So I think it's just as we evolve and as they see what we do and there's just more and more, it's just expanding in ways like that. You know, wanting us to participate, asking us for advice, asking us to do the prep work on something.” – P171

Overall, the increased participation and integration of patient partners were recognized as positive, observable impacts that strengthened partnership efforts.

Participants frequently discussed the development of tangible products as “direct” observable impacts of their patient partner activities. As described by one participant:

“I'm on a committee called the Patient Education Committee where we have, we review all the educational materials through the [disease specific centre], to make sure that they're easy to understand. So we've had direct impact on everything that is being told to a patient as well as given to a patient, that they can understand it.” – P49

The creation of a digital tool kit developed in collaboration with organizational partners was used by another participant as a way to portray tangible changes arising from the contributions of patient partners:

“But I think the tangible change that I'm seeing is we're building the toolkit, which is something I'm a part of. The digital subcommittee, we can see the ways that they're

really trying to integrate better strategies to now digitise the whole healthcare system, and we're seeing the ways that they are listening to us.” – P189

These developed products were widely recognized as extrinsic impacts, as they led to tangible and observable changes. Other tangible products that participants identified included engagement guides, published documents and literature, patient and family surveys, research grants, organizational guidelines, and digital products such as an app to assist patients with their appointments.

Other impacts were discussed as identifiable changes, rather than tangible and concrete outputs. This form of observable impact included instances where participants recognized that their input had been implemented and had led to visible changes. For an impact to be considered identifiable, participants often emphasized the importance of receiving external feedback or follow-up from the organization, confirming that their contributions had influenced change.

“So it was very cool to actually not only give my opinion but they really focused on the feedback loop. So the next meeting, if those changes were implemented, or they began to change and update things, there was always a return of, “Hey guys. So we heard back from so-and-so and they told us...” This is a photo. This is what happened with this.” –

P102

This external feedback to confirm impact highlights the extrinsic nature of some identifiable changes. These identifiable changes varied in scope and included impacts made at various levels. For example, identifiable change was discussed at the individual patient care level. One participant noted seeing a direct difference in patient care resulting from their input. “And my input directly made a difference in the patient care. Directly made a difference in the training,

because some of the things I said on a committee got implemented, that wouldn't have been said, had I not been there” (P24). This also illustrates that externally identifiable changes, even if not in the form of tangible products, contribute to a patient partner’s conceptualization of impact. Participants also highlighted other identifiable changes that signified impact at a more project-specific level or within broader organizational processes. These impacts were acknowledged when patient partners saw their feedback implemented by the organization.

“Just the fact that we've been able to make a difference. I've seen the organization implement things that we've suggested. They take action on our advice. We're not, the patient partners are just not people there as, “Okay, I'll listen to you because I have to tick a box,” but they actually implement off of what the patient partners are saying.” – P49

Lastly, some participants discussed policy or procedural changes within the organization or larger governance bodies resulting from their patient partner work. These changes were observable, but not necessarily always tangible or in the form of a product. One participant discussed their involvement in a focus group that they perceived resulted in a change made by their provincial government regarding implementation of a waiting list to receive a family physician.

“And so for at least the focus group, that was chaotic, they sent out their kind of like two or three page like this is what the focus group said and these are the feedback. And stuff and the [Provincial] government did implement a waiting list for GPs and so this last week someone I'm working with at the hospital is like – I got a GP finally, they're taking all my things.” – P130

Another participant shared how their involvement in a partnership group contributed to a change in the screening age for colon and rectal cancer. “I think just the satisfaction that we’re doing something. I know the one with colon/rectal cancer, I was on a group that helped. I don’t know how much I put into it, but we lowered the age for a screening” (P72).

Overall, these diverse experiences of observing impact – whether through the increased involvement of patient partners, the development of tangible products, recognizing various identifiable changes, or the implementation of their feedback – offer valuable insight into how patient partners conceptualize impact based on extrinsic factors and discernible changes.

### *Perceived Impact*

Participants also shared feelings about ways they were making a difference or an impact that was not necessarily observable. For example, participants discussed perceiving they made an impact when they received feedback from organizational staff that their contributions and role as a patient partner are valuable to the organization. Perceived impacts included positive feelings when sharing personal experiences, receiving external validation, internal recognition, and positive shifts in organizational partners’ perspectives surrounding patient partnership. Some of these perceived impacts are solely internal and intrinsic feelings, while others resulted from external attitude shifts or expressions of value. It is important to note that these attitude changes or shifts in perspective were forms of perceived rather than observable impacts because there was no change that could be seen but rather the patient partner perceived that shifting attitudes served as an impact. Perceived impacts were therefore exemplified when participants did not provide concrete examples of visible changes. This demonstrates the varied experiences that can be conceptualized as sources of achieved impact from the patient partner perspective.

Sharing personal experiences and providing perspectives as a patient or a caregiver provided participants with strong perceptions of impact. The feeling of impact evoked by sharing personal stories was described by one participant in the following way: “The good thing is when you tell your personal story it has a very profound impact. It's very real. It's not conceptual. You can really feel it” (P168). Participants attributed impact to providing their unique voice, recognizing that there is inherent value and a resulting feeling of personal empowerment from sharing their story in addition to the potential use of their experiences to help influence observable change. This connection is demonstrated by the following participant quote surrounding the value of providing the patient perspective.

“Personally, I gain a lot by having the opportunity to be a voice, to be a part of it, to know that I can influence change and that I can bring up things that perhaps the committee hasn't considered, because I have a different viewpoint, because I'm not in the medical field. So, I really value that.” – P80

This participant quote also demonstrates the direct tie that can sometimes be present between personal empowerment from sharing experiences, which is a form of perceived impact, and the potential to influence change in the form of observable impact. This connection is not always the case, as a disconnect between perceptions of impact and observed changes often occurs in which the participant may personally feel they have made an impact but there is a lack of observable changes to reflect that impact.

Similarly, participants attributed perceived impact to internal feelings of value resulting from scenarios in which the participant felt welcomed by an organization, felt like they belonged, or felt that their thoughts were valuable and useful without any influence of external recognition.

These experiences didn't always result in distinct impacts, however participants perceived impact relating to feeling valued as a patient partner. For example, one participant discussed being involved in an accreditation process and noted the importance of feeling valued in that process.

“Being part of an accreditation where it's fully being thrown in to the accreditation and being interviewed by accreditation surveyors, how is the patient family caregiver in your [provincial health team], and being able to share that, and then seeing and feeling valued as a continue part of that process, I think that's really important.” – P185

Another participant highlighted feeling like their work is helping to improve outcomes at the patient level after participating in a research poster session. Although there was no direct output from this session, the participant internally felt their work was making a difference down the line.

“And we did a poster session in there. And I came away with that I guess enthusiastic, that I was contributing to something greater than just work in [Eastern province] and greater than just contributing to research. It was actually working its way down to improving the outcomes for patients.” – P119

In contrast to more intrinsic feelings of perceived impact, many participants also attributed feelings of impact to extrinsic recognition and expressions of value by the organization they were working with. This included being verbally recognized or valued by organizational staff members or witnessing staff discussing the value of their involvement:

“I think the main thing is that I was invited to join. That I was approached and told that my experience would be really valuable and that they wanted to hear from me. So I guess that’s the biggest thing, because I was like, “Why would I, why do you want to hear from me, I’m just whatever.” I’m not, I don’t have any experience, I was thinking, for a health team. But then so many people would say, “Gee, you know so much about homelessness,’ or whatever. And it’s just personal experience.” – P171

This perceived impact relies heavily on an organizational staff’s input as it stems directly from interactions with and verbal praise from organizational staff. This is in sharp contrast to feeling impact as a result of sharing personal experiences which was mainly an internal feeling for the patient partner regardless of organizational staff’s actions. Similarly, participants described how their perceptions of impact resulted from being included and invited to collaborate. Another participant noted that they can recognize the difference they make as a patient partner because they feel heard and are continually asked to participate.

“In terms of how has my impact been seen, I think definitely at the [council 1], if people get an opportunity to be heard at that council, is phenomenal. So we continually see that we are making a difference because we are asked to do repetitive, so people come back to us to say, that was great, can we do this again around this issue? So that repetitive seeking advisory and seeking feedback. So I think that’s really key.” – P185

A final form of perceived impact involved positively shifting organizational partners’ perspectives and attitudes towards patient partnership. Participants often noted that because of their involvement, they perceived a lasting impact had been made on organizational staff members towards further acceptance of patient partnership. For example, one participant stated,

“I think I have made some impact, I've been told, for some people who had to leave, because they moved to a different job or whatever that what I shared, helped change, shift their perspectives for the better” (P183). Another participant noted the longitudinal impact of patient partner involvement and the psychological effect this may have in the future of healthcare.

“So it's communication with the individual that – ensuring that – you know, they're not getting paid, they're giving their time freely, and a good patient partner's always contributing something in some way, shape or form. It doesn't always bubble up to the top, but what it does is it permeates the group that they're with, and it has a psychological effect. This is something that, in my opinion, healthcare undervalues.” – P65

Overall, experiences of perceived impact – such as sharing personal experiences, receiving expressions of value and internal feelings of value, as well as sensing a shift in attitudes toward patient involvement – provide important insight into how patient partners describe impacts that may not always be visible. These intrinsic feelings of impact or feelings of value resulting from extrinsic recognition highlight the less tangible yet equally meaningful ways in which patient partners conceptualize impact.

### *Lack of Impact*

Although there was plenty of discussion involving different types of impact patient partners have been able to contribute to and achieve in their work, a few participants also described partnering experiences in which they felt like their work was not having any sort of impact and there was no resulting change or action because of their efforts. In the below quote, a participant describes their experience with two projects, one with a provincial health authority and one with a provincial health organization. The first project they discuss aimed to improve

trans and gender diverse patient inclusion, while the second project involved reviewing physician training documents. With both these projects, there was an overall lack of implementation or action on the organization's part, leaving the patient partner perceiving no impact, despite the work they completed in these projects.

“[Provincial health authority], I haven't heard anything about anything they did coming out of that. And yeah – and then [Provincial health organization #2], the big project with the documents, I personally don't think they've implemented it in that kind of document sense, I think they decided that it was a lot of reading and not very useful.” – P130

Consequently, participants often expressed frustration with this lack of impact after putting in effort to work with an organization. This highlights the role of the organization in achieving impact from the patient partner perspective. One participant emphasized their experience repeatedly sharing their patient journey with the team they worked with to improve and inform a research project. However, despite sharing their input based on personal experiences, the participant felt their involvement was tokenistic and did not result in any form of impact or positive change for the overall research project which continued to contain elements that may be harmful to patients.

“Awesome, I'll relive it all day long, if we're going to have some impact from it. But if I'm just reliving it, so that all of you can feel like you've engaged me, I'm good, send the gift card by mail. I don't need to be there for that. Let's just call it a day. So I think that there's been a lot of those conversations over the early years of the pandemic, we're now starting to see there is a bit of a shift. It's too slow. It's not impactful enough. And often, we're still being ignored, because that's the way research does it.” – P81

This quote contrasts the positive experiences discussed above in which participants felt a form of perceived impact after sharing their story. Feelings of perceived impact through sharing stories is largely dependent upon the patient partner and whether they feel a sense of impact by providing their perspective. It likely also depends on the reactions patient partners receive. Sharing personal stories elicits feelings of perceived impact when these stories are valued. As we see in the above quote, the participant felt ignored and that they were reliving their experiences by sharing their story leading to a sense of lack of impact.

The frequent occurrence of scenarios where participants felt their work lacked impact provides insight into where efforts to achieve some form of impact fell short from the patient partner perspective. These instances highlight areas where participants believed they could have made a difference, but external factors or organizational constraints ultimately hindered their impact. Overall, descriptions of a lack of impact were often rooted in external factors such as the absence of some form of external change, rather than from internal feelings or perceptions.

#### ***5.4 Aspiring to Impact – Aspirations versus Expectations***

Aside from achieved impacts, participants frequently discussed impacts they aspire to and those they expect to occur. Aspirational impacts refer to changes a patient partner hopes but doesn't necessarily expect to see occur. These could be impacts they set out to achieve when they first became a patient partner, impacts they hope to make in their current role, or aspirations for patient partnership as a field. Expectations of impact refers to what patient partners anticipate is most likely to happen and involves the recognition that impact and change can take time. Many participants recognized that immediate results from their efforts are unlikely and sometimes making an impact is a gradual process.

Participant descriptions of aspirational impacts captured their visions of what they strive to achieve through their partnership work, or how they see partnership in the future. One participant, as demonstrated in the quote below, spoke passionately about the desire to be welcomed and heard, wanting to have a seat at the table as a patient partner, and trying to make a difference for this to happen.

“I would be part of the decision making body of [Provincial health authority]. I would be at the table, and I would be welcome. I would be able to speak and not be judged and not be ostracised for it, and not be excluded. [...] And when I speak, what I say will have the same value, same weight as everybody else at the table and not being ignored or pressed or belittled or made fun of, or anything like that and be demonised and be devalued. It would be just to, like a valued community member taken at their word, and be empowered like everybody else at the table. And be able to co-design and shift the language, shift the outcome, to improve my community's health, and ask me for feedback, at every level of the decision making process at the co-creating of whatever it is we're creating. And it's not there, that's not there, but that's what I wish for.” – P51

Participants similarly discussed their own personal goals as a patient partner, how they would like to make an impact, or their motivations behind the impacts they would like to make as a patient partner. A common personal goal related to making an impact surrounded providing an outside voice and perspective. One participant stated, “You go in, you make the impact that you think you could, you get your voice out there and then for your own sanity and mental health you pull back.” (P18). In a similar stance, another participant emphasized wanting to see the impacts of their work and the differences they helped with.

“You want to feel that you can look at something and see that it's different because you were a part of it; that in some way having you there in the room had an impact on a decision that was made to make things easier, better for people who are using the system now.” – P168

Some personal goals demonstrated a desire for making a lasting impact towards systemic change, as one participant highlighted, “So I love the advocacy. I love creating system change. And I love being part of something bigger. So for me, it’s knowing that I’m creating a system.” (P185). In alignment with this goal, another participant emphasized wanting to enact change that results in a ripple effect rather than change the system.

“And the need to do something, the outcome of something. Maybe not necessarily seeing the outcome but how I describe my work is planting a seed. So I plant the seed and then I sit back and watch to see where that seed goes and how it grows. That's how I see what I do. I'm not there to change the system, I'm there to plant a seed of improvement or a different thought [...] So that's where I feel my role is, is that I'm a person at the table, I'm equal, and I want to share what I've been through to help change things. But it's not the change, right? Like I don't need to see the change to feel fulfilled, I just need to see a seed planted...” – P96

In terms of expectations of impacts participants anticipate occurring, participants frequently described experiences in which their work has not yet led to change or impact but is expected to do so in the future. This acknowledgement reflects an acceptance that system and organizational changes, especially large-scale changes, often take time and although an impact may not be observable right away, a positive impact may be made in the future. Many

participants commented that it is not realistic to expect an immediate change resulting from their efforts. This notion is emphasized in the following quote.

“Some people are automatic system thinkers. And I think as a [profession 1] I’m just a system thinker. But sometimes it’s tricky. So I would say that’s one thing patient partners need to be aware of is, what is system change? And even though we give our voices and share lots of things, it doesn’t always happen overnight because system change does not happen overnight. So understanding that we still have to be really patient. We can share lots and give our feedback, but everything takes time.” – P185

One participant discussed their experience with and influence on health policy and highlighted that their work on a national strategy and federal policy may not have an impact until the future.

“...so taking the work that I had done at [children's hospital], as part of the autism family advisory group, I kind of finally felt like I was having some influence on policy by going to work at the – not work, but you know what I mean, volunteer with the [national health organization] on the issue of a national autism strategy. Because I felt like, OK, this is actually going to inform the policymakers, when they make decisions around federal public policy. And so I knew that that was going to be a long haul as well, from a federal policy perspective, because we all know that federal policy takes time.” – P144

Lastly, one participant discussed a potential ripple effect in which a patient partner’s efforts may not be accepted and enact change in the moment but could shift attitudes and result in impact for future projects.

“I often explain it through that lens, it's a numbers game. So you're going to put as much good as you can in and you're going to get stuck in as many places and do as much work as you can. The reality is some of it's going to take and some of it will not be received.

Either the people around the table can't receive it, you're ahead of your time.

Congratulations for being brilliant, but they're not in a place to receive what you've just given them. That doesn't mean that the impact, it won't happen down the road, though. As a community builder, as a community developer, we often talk about ripples. So you're throwing a rock in today, and having no idea where it's going to ripple off to. You may feel, walking away from a project, you didn't have impact. But you don't know what you left planted in those brains that might percolate for the next project or the project after that.” – P81

Overall, the distinction between aspirations and expectations in terms of making an impact highlights another way in which patient partners conceptualize impact. For some patient partners, they aim to ‘plant a seed’ or create ‘ripples’ in the sense that they acknowledge the time it takes for change to occur and are not fixated on seeing immediate impacts of their work as long as they are able to see potential positive impacts occurring in the future. Other patient partners aim to see a visible result or outcome following their involvement and the notion that change takes time may be a source of frustration. Understanding these conceptualizations of impact can help both patient partners and organizational staff with setting goals of partnership and recognizing what kinds of impacts both parties are aiming for.

### ***5.5 Factors Facilitating Impact***

Participants frequently highlighted various key factors that facilitated their ability to achieve impact. These factors encompassed various forms of organizational support that enabled patient partners to feel their contributions were meaningful and influential. Conversations surrounding facilitating factors mostly occurred in response to an interview question inquiring what organizations have done to support the patient partner in making meaningful contributions and building their capacity to make an impact.

Participants reflected on their relationships and communication with organizational staff, emphasizing the pivotal role of leadership in shaping patient partnership. Many highlighted how the attitudes and actions of organizational leaders influenced the effectiveness of engagement efforts, the organization's commitment to including patient partners, and whether organizational staff see the value of patient partners. As illustrated in the following quote, the organizational leaders responsible for engagement and patient partnership activities heavily influences the scope of the patient partner role and subsequent impact.

“It’s a very committed group of individuals that really want to see change in their community for the better and are willing to roll up their sleeves to get there. And they really have a passion for bringing in more and more people to help do that. And so that’s always great, too, that you can show up and know that this group is actually making tangible changes. It’s not just a group you can talk and talk and talk and nothing, you know, and at the end of the year you go, “Well, it’s a nice thing to do but nothing’s happened.” And this leader, yes, she’s a personal friend, but she gets stuff done. [...] Things get knocked off the list. And so that’s also a good feeling, that you can see that

there's a difference being made and that there's an awareness happening and there's lots of Town Halls happening, and from that you see that there's some positive things resulting from. So you know that the hard work is making a difference in your system.” –

P171

Another participant, when asked what organizations have done to support them in making an impact, described the importance of having knowledgeable organizational staff and an engagement lead in place. Other participants shared similar notions and emphasized the value of providing patient partners with a point of contact in the organization to direct their questions and comments.

“You have to have the right staff in place. Everyone should have an engagement lead if they know that they themselves cannot do this work, or they don't think they'd be able to focus as much attention on this. They should have an engagement lead that's reaching out to those folks to have that. But then the engagement lead needs to have that knowledge about what is patient partnership. What does that look like? It's not just saying, here, just read this and then give me a yes or no, is that okay. It is actually that codesign. So an understanding of hearts, latter for sure, understanding the importance of that, obviously lots of understanding of EDI and the implications of collecting data and the impact that has on lots of different folks in our communities. It's important to ensure that they have an understanding of assessment and evaluation of engagement to be able to ensure that we're doing it properly and we're moving ahead.” – P185

Several participants also mentioned that being provided with onboarding and training opportunities from the organization was a facilitator of impact. Adequate onboarding processes

and training activities were noted as contributors to patient partners feeling like they understand their role and can make an impact in their work. One participant noted the positive impact of sufficient onboarding when first joining an organization. This participant also highlighted the importance of recognition from the organizational staff that their involvement was valued, which relates back to a previously discussed form of perceived impact resulting from expressed value and recognition.

“I guess in onboarding me, they gave me a good outline of what the position was, what to expect from it. And then in my first meeting the head of the group and the chief anesthesiologist of [Western province] says, this is an important thing. We at this table, your voice is as important as mine. We're not – we don't – and so basically just saying directly to me, you're valued here. This is a relatively new position to have patient advocates on this, as opposed to just on a project. We're overseeing the project, overseeing physician training and quality improvement. It's a new thing for us. But your voice is important here. And actually directly, clearly stating to me, not only in their terms of reference or any of it, but actually directly saying that to me in the meeting. So that was a big – made a big difference.” – P24

In this participant's experience, this recognition from organizational staff occurred in the presence of other group members which can help to set the tone for future engagement with that patient partner. Additionally, one participant mentioned “I think some are providing onboarding training now which was a positive thing towards letting people understand their value.” (P187), which highlights the relationship between knowing your role as outlined by the organization and knowing your value as a patient partner.

Lastly, active inclusion of patient partners was noted as an organizational support that facilitates impact. Actively including patient partners refers to the intentional and meaningful integration of patients in various areas within the organization while ensuring their perspectives are valued and contribute to change, rather than their involvement being tokenistic, therefore facilitating patient partners' capacity to make an impact. This factor is closely related to the previously discussed observable impact of increased patient partner involvement. Both concepts involve a description of the increased efforts put towards involving patient partners in various areas of organizational work, while also ensuring this involvement is purposeful. In these instances, this inclusion was interpreted to assist in facilitating the capacity of a patient partner to make an impact. For example, one participant discussed the active involvement of patient partners in many different groups in the hospital they work with, as well as the involvement of patient partners in strategic planning.

“And so again, they really value the feedback of the patient partner because they're including us structurally in how they staff and in their program design. So that I would say that [children's hospital] takes it seriously for sure. That's including by the way actually in their strategic plan they've incorporated a number of patient partners from different groups in their strategic planning, because I'm involved in that as well.” – P144

Another participant discussed similar notions regarding the positive influence of actively including patient partners in various committees to ensure the patient voice is represented.

“There's been a number of projects and not only me but other patient partners and parent partners have been involved in. And the [children's hospital] for sure truly values that voice and patient partners are included on any type of redesign or quality committees.

[...] I've seen definite patients and families that have an interest in a certain area are often paired up with a committee from the beginning and they are representative of patient voice. And I do find that it is done in a way that it's done early and the consultation is meaningful." – P100

It is important to note that patient partners often emphasized that they appreciated expressions of value from organizational staff. These experiences of recognition were sometimes discussed as a facilitator of impact, however these scenarios usually did not lead or could not be directly tied to an impact being made. This appreciation provided by organizational staff potentially elicits feelings of value for the patient partner and may help to motivate them to continue to engage in their role with the hopes of one day achieving some form of impact. This relationship between expressions of value received from the organization and whether external impacts occur is an interesting area for further research.

Overall, interviewees identified several external factors that facilitated their impact as patient partners. Exploring these facilitating factors helps to enhance our understanding of the organizational elements needed to support patient partners in making a difference in their roles.

### ***5.6 Summary of Findings***

In conclusion, participants described impact in numerous ways, referencing both observable and perceived impacts and their extrinsic or intrinsic nature. Discussions of impact also demonstrated differences between aspirational and expected impacts, highlighting that although these concepts are related, aspiring to impact and expecting impact are distinct conceptualizations. Lastly, recognizing the organizational supports that facilitate impact is essential as their effective implementation can empower patient partners to make meaningful contributions.

## 6.0 Discussion

In this study, we aimed to understand how patient partners working with Canadian health system organizations conceptualize and aspire to achieve impact in their partnership work. Following interviews with 35 patient partners, we outlined various ways in which participants describe impact. Participants understood impact to be both externally observable and internally perceived. Observable impacts included various forms of developed products, policy changes, increased involvement of patient partners, and other identifiable changes. Perceived impacts consisted of internal feelings of value, receiving value from organizational staff, positive feelings from sharing personal stories, and shifting attitudes of organizational staff. Observable impacts were discussed more frequently overall than perceivable impacts. We also identified differences in how participants discussed their aspirations, or hopes, for impact versus their anticipated or likely expectations of impact. Aspirational impacts were broader hopes of change whereas expected impacts were typically smaller, with many participants acknowledging that large-scale change takes time. Lastly, we identified organizational supports participants discussed as facilitators of impact such as effective organizational leaders, onboarding and training opportunities, and active inclusion of patient partners in organizational activities.

Our analysis identified multiple ways in which patient partners described their impact. These descriptions of impact were conceptually similar but often differed from the terminology used in previous literature. What we categorized as observed and perceived impacts resembled what other authors have described as external and internal impacts. For example, a systematic review by Wearn and colleagues demonstrated organizational impacts from research including changes to the organization's services, increased patient representation within the organization, and a culture shift in which organizational staff began to recognize the benefits and importance

of patient involvement. (16) Wearn et al. also noted impacts to the engaged partner which included enhancing their self-confidence and skill set. (16) Similarly, other research by Bombard and colleagues in the area of engagement to improve patient care classified outcomes as either products of engaging patients or impacts of engagement on patients. (2) These were subsequently termed ‘quality care outcomes’ and ‘patient experience outcomes’ respectively. (2) In the case of both Wearn et al.’s and Bombard et al.’s reviews, organizational impacts were observed through both tangible outputs and demonstrated through a culture shift. (2,16) Additionally, Mockford and colleagues as well as Crawford et al. also identified changing attitudes of both service users and providers as prominent impacts resulting from patient and public involvement, along with service planning and informational development. (14,37) These past literature findings align with our participants’ views that increased involvement of patient partners can be understood as an observed impact. This similarity reinforces the idea that having more patient partners involved in organizational activities can be seen as a visible form of impact and reflects enhanced ongoing partner engagement. In contrast, our findings portrayed the shifting of organizational staff attitudes towards recognizing the value of partnership as a perceived impact. This contrast likely arises from the differing framing in these reviews as the researchers focused on specific impacts to organizations and patient partners separately. Our study took a more intuitive approach to discussions of impact, where patients partners described a shifting of organizational perspectives as perceived based on how this impact felt to them, rather than resulting from explicit acknowledgement or confirmation by the organization. Our study therefore builds upon insights in the current literature by providing a different way to look at and discuss shifts in organizational staff attitudes, further prompting discussions of whether these shifts constitute meaningful impact even in the absence of formal recognition or measurable outcomes.

These previous literature reviews have also touched upon discrete and tangible impacts resulting from engagement. Wearn et al.'s and Bombard et al.'s systematic reviews noted discrete outputs of involvement which included the development of products such as educational tools or training for researchers in collaboration with engaged partners. (2,16) In our study, although we used differing terminology, these kinds of developed products were discussed as observable impacts. Overall, the similarities between our study and past research demonstrates the potential inclination to understand sources of impact as either an internal or external source – what our study describes as perceived versus observable impacts. Although our descriptions of observable impacts align with previous research surrounding discrete impacts, as noted above some contrasts can be seen between existing literature and our study's descriptions of perceived impacts.

Other past literature has highlighted the differences between a patient partner's perception of their impact and an organizational staff or researcher's perspective of impacts the patient partner has achieved or influences they have had on the organization. In 2018, Greene et al. looked at the influence of patient partners on quality improvement efforts. (3) These researchers reported patient partners' reflections on the impacts of their involvement, including learning more about their health, building a community, and becoming an advocate for their health needs. (3) Quality improvement leaders perceived the impacts of patient partners as providing a patient perspective on new policies, improving organizational communication with patients, and improving patient education efforts. (3) This emphasis on personal growth for patient partners is further supported by results of a scoping review by Bird and colleagues. These researchers noted that the impact resulting from patient partnership in research mainly focused on personal experiences and gains, such as feeling empowered by providing the patient voice,

acquiring skills, and building a community. (21) In contrast, our findings show that participants mainly described perceived impacts as impacts they feel they have made within the organization that are not necessarily visible or tangible, rather than just solely impacts on themselves. Our participants also discussed positive personal impacts resulting from their work such as feeling internally valued in their role. These contrasts between our study and past literature may reflect the nature of data collection. Greene et al. conducted surveys to explore perceptions of the impacts of patient partner contributions, while Bird et al. synthesized findings from many studies that utilized different evaluation approaches and incorporated engagement at various levels. (3,21) These forms of data collection may have prompted participants to respond in a certain way, while our semi-structured interviews provided more open-ended discussion on impacts participants have seen in their work. Although we did not capture organizational staff's perception of the impact of patient partners in this study, the comparison of these two perspectives could provide interesting insight as to whether there are discrepancies pertaining to what is considered a perceived impact. Additionally, Anderson and colleagues published a study that captured both patient advisor's and organizational staff's perspectives. (38) Similar to our methodology, Anderson et al. conducted a qualitative interview study to examine the impacts of engagement in hospital planning and improvement. (38) However, their research specifically focused on hospitals with a high engagement capacity, and recruited engagement managers, clinicians, and patient and family advisors involved with these hospitals. (38) Other research has also noted factors that contribute to engagement capacity in similar hospital contexts, but researchers have noted that further assessment of engagement approaches and their impact on clinical outcomes is needed. (39) Anderson and colleagues were able to capture impacts related to engagement managers, clinicians, and patient advisors, however, in contrast with our study,

this study did not characterize these impacts based on whether they were perceived or observed in nature. Despite this and aligning with our findings of types of impacts, these researchers found that prominent impacts to patient and family advisors were feeling valued and heard, greater appreciation for patient engagement amongst staff, and increased capacity for incorporation of engagement in various hospital departments. (38) Our study builds upon the findings produced by Anderson et al. by presenting data that span various health system organizations and providing a different way to categorize and think about these impacts.

Participants in our study discussed observable impacts and outputs more frequently than they discussed perceived impacts. This contrasts with the emphasis in previous literature on the evaluation of outcomes of patient partnership and engagement which have demonstrated a focus on perceived impacts more than tangible outputs. A systematic review by Dukhanin and colleagues gathered information about evaluation tools for engagement in healthcare organizations. (22) These researchers evaluated 44 outcome metrics which they separated into domains of internal, external or aggregate outcomes. (22) In the case of this review, internal outcomes related to either outcomes on engagement participants or on the organization itself, while external outcomes involved influences on the broader public. (22) Dukhanin and colleagues found that many evaluation tools rely on measuring perceived benefits of engagement and they argued that tools should instead measure tangible outcomes. (22) Additionally, Boivin and colleagues found that the most common focus amongst tools aiming to evaluate engagement outcomes was perceived and self-reported impacts rather than observable impacts. (20) This previous focus on perceived impacts in evaluation tools provides an interesting point for consideration. Dukhanin et al. posited that the absence of tools evaluating tangible outcomes may be a result of information of tangible changes being readily available through other means,

such as documented changes in policies or processes, and therefore there is less of a need for an evaluation tool to explicitly address these impacts. (22) In our study, the more frequent discussion of observable impacts makes sense as these are likely the first kinds of impacts to come to mind when participants were asked what impacts they have *seen* in their work. Overall, given these differences of focus on either observed or perceived impacts, our study adds to the current findings by providing the patient perspective and emphasis on observable impacts.

Current evidence presents more literature that explores engagement in health research settings, rather than in health systems contexts. A systematic review by Vanstone and colleagues that aimed to describe how patient partners are engaged in health systems found a predominant number of eligible studies pertaining to patient partnership in health research contexts, and significantly fewer studies that looked at engagement in health planning and policy contexts. (23) With regard to impact evaluation, systematic reviews evaluating partnerships within health systems contexts included only a limited number of relevant studies, with many studies excluded for focusing primarily on engagement in health research settings. (22) A study conducted on engagement within the hospital context reiterated this notion and reported that a substantive amount of previous literature focuses on the role of engagement for prioritization of research questions or the design and conduct of research studies. (38) Literature has also discussed that approaches to engagement vary across different contexts and health fields. As emphasized by Carman and colleagues in their framework for patient engagement in health and health care, engagement can be described as a continuum that ranges from levels of direct care, organizational design and governance, and policy making, with each of these levels incorporating varying amounts of patient participation and collaboration depending on the goals of engagement. (5) Despite this knowledge, the similarities and differences between impacts of

engagement in research and with health systems has not been widely explored. The disparity in the amount of published literature on engagement between health research and health system contexts may reflect differing objectives of these two sectors. In academic and research settings, a common priority is to conduct and disseminate findings of research studies, which may explain the breadth of literature on engagement in these contexts. In contrast, health systems organizations may place less of a focus on publishing findings of or evaluating their engagement efforts, contributing to a lack of literature in this context in comparison to research settings. Additionally, researchers in health research contexts are likely more adept at applying different methodologies and conducting rigorous evaluations of their engagement, whereas health system organizations may not have staff with expertise in research-based evaluation efforts. Given these reasons, the smaller scope of relevant research pertaining to impacts of patient partnership specifically in health system contexts in comparison to health research settings is understandable. However, relating this disparity to practice, Accreditation Canada (AC) is an independent non-governmental organization that operates globally to enable health and social services organizations to meet national and global standards of excellence. (40) AC has focused on patient experience and engagement and launched a people-centred care program (PCC) in 2020 along with the development of a conceptual framework for understanding essential elements of PCC practice in organizational contexts. (40) AC standards also require patient engagement in governance, leadership, and service delivery. (41) AC releases an impact report every year to share ways the organization has contributed to changing the current health care quality landscape. Their most recent 2024 report did not present any information pertaining to the success or impacts of the PCC specifically, but the report briefly mentioned the strengthening of patient partnerships and emphasized that AC's standards set the bar for organizations to

demonstrate how to effectively engage partners in their work. (40) Programs provided by AC have been reported to positively influence the quality of services provided by a healthcare organization if coherence, organizational buy-in, and organizational action is established. (42) Given the emphasis AC places on engagement, further reporting of engagement amongst accredited organizations would be helpful to determine the impacts of engagement implementation in the context of health system organizations. Additionally, the lack of relevant literature pertaining to accreditation requirements of incorporating engagement and the outcomes following these enforced standards highlights a need for further research surrounding impacts of engagement in accredited organizations. Our study provides these accredited organizations with an exploration of conceptualizations of impact from the perspectives of patient partners engaged with health systems organizations. These results will be helpful to organizations looking to examine the impacts of their engagement efforts and can potentially help to bridge the gap between findings surrounding impacts of engagement in health research and health systems contexts.

Past literature has shown that patient partners have reported prioritizing engagement opportunities that will allow them to make an impact on the health system or in the organization they work with. (1) This desire to enact change is a form of aspirational impact and is commonly discussed in engagement literature. Many patient partners in our study discussed their personal goals for engaging as a partner, with most noting the aim to improve the health system or provided services using their experience and perspective as a patient. A study by Ocloo and Matthews on the progression of patient and public involvement in healthcare improvement noted that a major component needed for involvement is a clear purpose to outline a shared understanding of the goals of involvement and the opportunities for individuals to shape this

process. (6) Despite broad goals of enhancing meaningful engagement, there is a lack of research that investigates how patient partners distinguish between aspirational goals and expected outputs of partnership. Addressing this gap in the literature is critical to ensure alignment between patient partner expectations and organizational goals and timelines. When this alignment is not present, patient partners may experience negative emotions, such as discouragement or dissatisfaction, particularly if they don't feel like their efforts are leading to meaningful impact. Further supporting this point, Wearn and colleagues have previously identified frustration and disappointment as unintended consequences of engagement which commonly stemmed from misalignment of expectations between partners and researchers as well as frustration with project timelines. (16) As our study emphasizes, often impact within the health system takes time and although it can be expected in the future, patient partners may feel a lack of impact if they anticipated more timely or immediate change. Understanding and clarifying timelines of expected impacts as well as plans to address aspirational impacts from both the patient partner's and organization's perspectives can help to avoid adverse emotions and strengthen collaborative efforts to achieve impact.

When addressing facilitating factors, it is important to distinguish facilitators of effective partnership or engagement and facilitators of impact amongst partnership with health system organizations. There is an array of literature that touches on facilitating factors to ensure successful engagement and other literature evaluating outcomes of engagement, however, there is a lack of evidence that directly connects facilitating factors to an achieved impact or outcome. In previous literature related to patient partnership and engagement in research, Wearn and colleagues demonstrated that facilitators of meaningful public involvement included having adequate staff and amount of organizational support in place to effectively carry out

involvement. (16) Similarly, a 2014 study by Evans and colleagues tracked public involvement in eight different research projects and also found that leadership responsible for engagement was a key contextual factor potentially leading to impact, however, this impact and relationship to effective leadership was not formally assessed. (15) Our study adds to these findings by emphasizing that there are key qualities that assist organizational leaders in acting as facilitators of impact. For example, being proactive in their engagement efforts and recognizing the value of partnership were mentioned by patient partners as valuable qualities in organizational staff members. The recognition of and appreciation for patient partners was also noted in a scoping review by Bird and colleagues as a facilitator to an effective partnership. (21) This scoping review also found that other facilitators to effective partnership included ongoing training for patient partners and involving patient partners in core research decisions and meetings. (21) These findings are further evident in survey-based research. Results from the Canadian Patient Partner Study survey by Abelson and colleagues also reported that the most helpful supports provided by an organization were staff support, ongoing training, and developed relationships with other patient partners. (1) In alignment with these findings, our study demonstrated that patient partners discussed onboarding and training opportunities as well as the active inclusion of patient partners as facilitators of impact. It can be assumed and aspired to that these facilitators of successful engagement discussed in past literature help to facilitate impact, however this direct link cannot be established without further research.

### ***6.1 Significance of Findings***

This study has provided qualitative evidence surrounding various ways in which patient partners conceptualize impact. These findings can help to complement the current evidence base of evaluation approaches for engagement and partnership. Through the analysis and

interpretation of our in-depth qualitative data, we identified a distinction between perceived and intrinsic impacts and those that are observed and extrinsic impacts, adding a novel viewpoint of impact to the current literature. While observed and extrinsic impacts were discussed more frequently, the majority of participants who described these types of impacts also highlighted perceived impacts. In most cases, both types of impact were discussed in relation to past achievements. This emphasizes that both forms of impact are achievable within patient partnership work, however our findings do not clearly depict whether one form of impact is more valuable than the other. By acknowledging and shedding light on these different ways in which patient partners view impact, we gain a deeper understanding of the diverse perspectives amongst patient partners. This study can help to inform future partnership efforts in health system organizations and encourages conversations between patient partners and organizations surrounding what each party considers impact to increase the likelihood that these impacts are achieved.

## ***6.2 Implications for Patient Partnership in Health Systems Organizations***

The results of this study have important implications for the future of patient partnerships in health system organizations. Firstly, we have identified differences in how patient partners conceptualize and describe impact through discussion of both observed and perceived impacts. This highlights the need for impact and partnership goals to be clearly discussed and outlined between an organization and patient partners prior to initiation of the partnership. This study also emphasizes the need for ongoing communication and impact evaluation to ensure the patient partner's and organization's goals are met, considering the different conceptualizations of intrinsic and extrinsic impact. Identifying applicable evaluation approaches to assess the achievement of both observed and perceived impacts can also help organizations determine

whether the goals they set out to achieve in collaboration with their patient partners have been met from both the organization's and patient partner's perspectives.

Additionally, there were discrepancies amongst patient partners in terms of impacts they aspired to and impacts they expected to occur in the future based on previous partnership efforts or initiatives. Some patient partners were content with putting effort and time into initiatives where they knew they were unlikely to see change soon, whereas other patient partners were looking to make a more immediate impact. Recognizing and acknowledging the differences in patient partners' goals can help support more effective collaboration between organizations and patient partners to reach a consensus on expectations. As patient partnership is a collaboration, ideally the organization and patient partner need to align on their goals before working together.

Lastly, our findings highlighted key organizational supports that patient partners discussed as factors that helped to facilitate impact. These factors included onboarding and training opportunities, active inclusion of patient partners, and having the right leadership staff for engagement initiatives. Participant's interview data allowed us to explore potential links between these facilitators and impact based on patient partners' perspectives and experiences. In past research, as discussed above, this relationship may not be as clear as common focuses were facilitators of meaningful or effective engagement rather than specifically facilitators of impact. Our study findings highlight that organizations should consider and evaluate how various potential facilitating factors directly connect to impact, noting that implementing organizational support is imperative for successful and impactful partnerships with health system organizations.

### ***6.3 Methodological Considerations***

In reviewing the literature before conducting this study, it was evident that there was a lack of studies involving topics related to patient partnership with Canadian health system organizations that used Interpretive Description methodology. ID originated in nursing research and is commonly used in other applied health disciplines to understand clinical phenomena and determine implications for future practice. (26) The framework of ID acknowledges that every individual's reality is shaped by social context and experiences, therefore researching and deriving meaning from these subjective experiences requires interpretation by the researcher. (27) With this framework in mind, Interpretive Description is well suited for a study like this one which aims to elicit descriptions of participant experiences. Although this is not a clinical study, the use of ID in this context allowed us to analyze interview data in a manner that helped to assist in interpreting meaning attributed to impact. This study challenges and prompts the use of ID in other non-clinical settings such as studies in the field of patient partnership and engagement. Other applied disciplines have utilized ID, such as medical education research, as it is a flexible qualitative methodology that can address experiential questions, advance knowledge, and produce applicable outcomes. (33) Patient partnership research often has underlying goals of improving healthcare practices, services, or policies through the incorporation of the patient perspective. The goals of this area of research therefore align with the purposes of using ID, given that ID explores meaning and aims to generate practical and applied knowledge that is grounded in subjective experiences to further inform practice. (25,26) Although ID methodology has not been widely applied yet in patient partnership research, it shares key commonalities with studies that typically use ID as both types of studies address patient populations and the patient experience but in different settings. Additionally, ID acknowledges that a researcher's

interpretations are a product of their personal experiences and biases, and therefore encourages reflexivity. (25) This facet of ID is important when conducting research in patient partnership as we must remain thoughtfully aware of how our perspectives may influence how we make sense of data. It is impossible to eliminate all biases, making it imperative to engage in reflexive processes when interpreting data.

Additionally, we did not engage in member checking to validate data interpretations with participants. The practice of member checking aims to ensure credibility and rigor of the findings from a qualitative study and involves going back to participants and asking them to confirm the accuracy of the researcher's data interpretations. (25,34,43) This practice does not align with the goals of an Interpretive Description study where the researcher's role is to make sense of and generate insights from a range of subjective experiences rather than confirming individual experiences. (25) Sally Thorne posits that ID studies should aim to extend beyond what one participant may articulate to explore commonalities and uncover insights that we would not necessarily be able to address from only one participant's account of their experiences. (25,26) While member checking may not be considered an ideal practice for Interpretive Description methodology, researchers who support this approach may consider this lack of participant validation of data interpretations as a gap in ensuring rigor and trustworthiness of our study findings.

A final methodological decision to consider is the approach to data sufficiency. When using Interpretive Description methodology, Sally Thorne posited that sample size is dependent on the researcher being able to generate an idea for the number of participants needed for their study results to be valuable. (25) With this in mind, for this study, we chose Malterud's approach of information power to operationalize decisions about data sufficiency. Information power poses

that the more relevant data a sample provides, the smaller the sample needs to be to achieve sufficient information power. (32) This approach also recognizes the subjective variability in the experiences of patients, making it a suitable approach to data sufficiency in ID studies. (32) A different approach to data sufficiency commonly used in qualitative research is data or theoretical saturation in which a point is reached where the researcher is confident that no new variations on the theory would likely occur in new data. (25,31) We did not use the concept of saturation as Thorne has noted, there is never an endpoint for discovering new information and diversity in themes. (25,31) Additionally, the concept of data saturation in ID is not an intended result as the applied nature of the methodology values and recognizes the infinite number of variations in subjective experiences. (33) A final approach to data sufficiency that we deemed as inappropriate for this study is the Thoughtful Clinician test. This test requires that an individual with expert knowledge of the study phenomenon confirms that the interpretive data descriptions provide findings that resonate with and can be applicable to clinical practice as well as highlights new understandings of the phenomenon. (26) We did not choose to use the Thoughtful Clinician test as this research is not intended to produce clinically applicable findings but rather aims to explore the nuanced experiences of patient partners. Identifying a suitable ‘clinician’ or individual with expert knowledge in the field with the necessary experience to validate our findings would be challenging given the breadth of our data. Our data reflects a wide range of subjective experiences of patient partners across different health system organizations. An expert tasked to validate these findings may not recognize or be able to account for the influence of this contextual variability. Moreover, the lack of standardized practices in the field of patient partnership would complicate confirming findings from one expert’s perspective. For these reasons, we chose to stray away from relying on external expert validation to confirm data

sufficiency and instead focused on the diversity of participant experiences to guide our interpretations. Overall, after consideration of other approaches to data sufficiency in qualitative research, we decided for the purposes of our study, Malterud's approach of information power would be the most suitable.

#### ***6.4 Ethical Considerations***

We had no major concerns regarding ethical challenges in the conduct of this study. Participants provided informed consent after acknowledging the study aims and were further informed of our objectives at the start of their interview session. Appropriate measures were taken to keep any identifying information private to protect participants' identities. Additionally, participants were reminded during their interview that they had the right to skip questions or withdraw at any point. We do not anticipate that this study's research question or exploration of this topic poses any harm to participants.

However, some of the interview questions may have prompted the discussion of sensitive topics or experiences that may have elicited adverse feelings for the participant. Reflecting on difficult experiences could have triggered emotional distress or discomfort for the participant. To mitigate this, participants were reminded at the start of their interview that they could skip any questions they did not want to answer. Even with this reminder, there is still the risk of emotional upset for patient partners following the completion of an interview due to discussion of negative experiences. This potential emotional toll may negatively impact a patient partner's view of their partnership work as well as their motivation to continue.

### ***6.5 Strengths and Limitations***

This study has some strengths which contribute to the robustness of these findings. Our study captured the perspectives of patient partners with varying numbers of years of experience. Their involvement also spanned a diverse range of types of organizations including provincial and federal health organizations, international organizations, municipal councils, and hospital committees. This broad array of experiences allowed for rich discussions and offered valuable insight into the integration of patient partnership in different health system organizations as well as how impacts vary based on organization type. Additionally, to our knowledge, this research is among the first studies in the field of Canadian patient partnership to utilize Interpretive Description methodology. This study helps to provide insight into the usefulness of this methodology in exploring patient perspectives even in a non-clinical setting.

Many tools quantify and evaluate outcomes of patient partnership or engagement. (8,19,20) Mrklas and colleagues found that the most common tool types for measuring the outcomes of health research partnerships were surveys, questionnaires, and scales. (19) Additionally, only 4% of the tools they found measured impacts and 44% measured outcomes and impacts simultaneously. (19) Mrklas et al. noted that definitions for the terms ‘outcome’ and ‘impact’ were provided in less than half of the included studies and these terms were frequently used interchangeably. (19) Our study contributes to the field as although we did not specifically aim to examine the state of evaluation of patient partnership, our qualitative data emphasizes the significance of subjective experiences of impact that may not always be easily quantifiable. Our qualitative approach also allowed participants to elaborate on their experiences, providing the opportunity for a deeper exploration of the various ways patient partners conceptualize impact.

Acknowledging these various conceptualizations and experiences can help to advance the current understanding of partnership evaluation.

This study has some limitations that should be acknowledged when interpreting these findings. Firstly, there is a lack of demographic diversity in our study population. The majority of participants were over the age of 50, identified as female and white, from Ontario, and attended university. The perspectives of this demographic group may not be representative of all patient partners across Canada. However, similar demographic characteristics were represented in the broader Canadian Patient Partner Survey study, emphasizing the continued discussion surrounding the representativeness of patient partners. (1) These demographic findings prompt future research in this area to determine how well these demographic groups capture the experiences of health system users. (1) Lastly, the interpretations made in this study are influenced by and limited to the historical and geographical context in which this research was conducted and therefore these findings may not be transferable to all health system settings and time periods.

## ***6.6 Next Steps***

In this study, we have explored various ways in which patient partners describe and aspire to impact. The next steps following this study would be to explore whether there are differences in conceptualizations of impact based on the type of organization the patient partner works with. Future research would also benefit from increasing the demographic diversity of patient partners to establish if there are different conceptualizations of impact amongst different demographic groups. Additionally, examining how organizational staff conceptualize impact and comparing this to the perspective of patient partners could provide valuable insights into

potential discrepancies. Lastly, this research encourages organizations conducting patient partnership to establish what is considered impact in collaboration with their patient partners to ensure maximal benefits from engagement.

## **7.0 Conclusion**

In conclusion, patient partners discussed various conceptualizations of impact, impacts they aspire to achieve, and organizational factors that help to facilitate impact. Participants discussed both observable and perceived impacts in relation to their work and often noted broader system change as a form of impact they aspired to or expected to occur. Overall, this study provides a novel look into a patient partner's perspective of impact. By recognizing the ways patient partners perceive and strive for impact, organizations can optimize impactful partnership work. Future research would benefit from the exploration of evaluation tools that can be used or developed to address these different kinds of impact as well as the determination of how organizational staff members conceptualize impact related to patient partnership.

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## APPENDIX 1 – Canadian Patient Partner Interview Study – Interview Guide

*Thank you for agreeing to join me for this interview. Today we will be talking about your experiences, perspectives and motivations as a patient partner involved in patient engagement within Canadian health systems. The purpose of this study is to describe the patient partnership landscape in Canada from the perspective of both patient partners and organizational leaders and practitioners. We are more interested in talking about patient partnership in health system organizations, rather than research. We understand you might have experience in both, and that your understanding of patient partnership might be informed by your experiences in research. That's ok, but where it is possible to talk about your work with health systems organizations, please focus on that. Do you have any questions before we begin? [Answer any questions] Okay, we'll start now.*

**Questions in grey are to be skipped, only return if there is time.**

### Informed Consent Script:

Affirm that they provided consent via RedCap. Do you have any questions about the information you consented to on that survey?

I'll remind you that you have the right not to participate, the right to skip any questions you don't want to answer, and the right to withdraw at any time.

Are you ready to begin?

### Review of Demographic info

You provided us with some information about your experience as a patient partner on the previous survey. I pulled up that information before our interview today to give myself some context for our conversation.

I see you've worked as a patient partner for X years, at X organizations, and that you typically spend XX hours a month on patient partner activities.

### Initial Questions:

1. Could you give me a brief summary of the kind of patient partner work you have done? For example, what kinds of organizations have you worked with? In what jurisdictions?
2. If you met someone at a dinner party and were going to explain what a patient partner was, how would you explain this role?
  - a. Sometimes it's easier to explain things in reverse. What is a patient partner NOT? I'll give you an example: a patient partner is not someone who fills out a survey on how the clinic could be improved and never interacts with that organization again.
3. Did you have a vision for what you wanted to do as a patient partner?
  - a. Do you see patient partnership as an advocacy role?
4. Why did you choose to be a patient partner?

- a. What experience do you draw from in this role? Probe: experience with healthcare system, professional or educational experience?
- b. Did you have a vision for what you wanted to do as a patient partner?
  - i. Have your experiences matched this vision? (What’s different; what’s the same?)

### Structural

1. When you think about your roles as a patient partner, would you say that role is mostly shaped by you, mostly shaped by the organization or somewhere in between?
  - a. By “mostly shaped by you”, I mean by your interests, experiences and abilities. By “mostly shaped by the organization”, I mean by their needs, staff, and resources.
  - b. What aspects of your experience or priorities have shaped this role?
  - c. What aspects of the organization’s priorities have shaped this role?
2. Can you think of any policies or guidance that has shaped your patient partner role? These could be policies or rules relevant to the organization or outside of it.
  - a. Probe: organizational, financial/income/tax, regulatory?
  - b. Do you think these policies help promote fair engagement or ethical engagement? If so, how? Can you give me an example?
3. What organizational staff do you interact with in your role as a patient partner?
  - a. How have these interactions shaped your role if at all?
  - b. What traits or skills do you think organizational staff need to work with patient partners?
4. When we think about things the organizations have done to support you in making meaningful contributions and building your capacity to provide value or make an impact, what are some of those things?
  - a. Staff roles?
  - b. Resources?
  - c. Training?
  - d. Connection to others (PPs, clinicians, policy-makers, patients)
  - e. Anything that you haven’t experienced but that you wish the organizations would do to support your contributions?
  - f. Overall, have you felt well supported in this role by the organization?
5. When you think back to all the organizations you have partnered with, are there certain types of roles or things different organizations did that really supported your contribution?
  - a. If you could design your own PP work to be most meaningful and impactful, what instructions would you give to the organization? What resources would you need?
  - b. I’ll now ask this question in the reverse- what aspects of the organization have impeded your ability to contribute meaningfully?

### Experiential

1. Earlier I asked what your motivations to start being a patient partner were. Now, after all the time you have spent doing this work, what are your motivations to continue?
2. What benefits do you view as most important? For example, what keeps people in the role?
  - a. Benefits to you, benefits to other groups (what groups, what benefits)?
3. Have you experienced harms doing this work? What were they?
4. Have you seen the work that you and your colleagues do have impact? How is it visible?
  - a. To whom? What kind of impact?
  - b. Levels: people (selves, partners in this work), organization, system
5. What are the most significant barriers you have faced in your role as a patient partner?
  - a. Why are these the most significant?
6. Have any of your patient partner roles ended?
  - a. How did they end?
  - b. Did you decide to leave?
  - c. Was the end point known at the beginning?
  - d. Can you envision an end point to ongoing work? What is it?
7. Have you ever considered quitting any of your patient partner roles?
  - a. Why or why not?
  - b. What changes do you think need to be made to prevent others from quitting?
8. How do you learn to fit in with an organization in your patient partner role?
  - a. How do you learn to be productive when working with that organization?
  - b. How do you learn what to do to have impact?
  - c. Do you think you are seen as having credible knowledge by the organization?
    - i. Is there anything you do to be seen as more credible or knowledgeable?
9. When thinking about what people want patient partnership to look like, we often hear about meaningful engagement/partnership. Often this is framed by patient partners as engagement where they feel heard, valued, and like they are able to make a difference and is often contrasted to tokenistic engagement. Another way to frame this idea of meaningful engagement is through “justice” (i.e., promoting engagement that is fair).
  - a. What would fair or just engagement look like to you?
    - i. What do you see as your role is making this happen? What do you see as the organization’s role?
  - b. What barriers do you think there are to promoting fair engagement?
    - i. What resources are needed?

### Change over time

1. What aspects of your patient partner work have changed over time?
  - a. What aspects seem to stay the same?
  - b. Are these things you are glad to see remain stable, or would you like them to change?

- c. [for those that should change] why do you think they haven't changed?
2. How do your experiences and contributions change as you have been in this role for a long time?
  - a. What is the role of organizational relationships in this change?
  - b. What is the role of individual growth and capacity building?
3. How do you see partnership work in 3-5 years? What about asking them what they think should change and why?
  - a. What will be the same? What will be different?
  - b. Recently we have seen a movement towards greater concern for equity, diversity, and inclusion in patient partnership. How do you think this has changed or will change the patient engagement landscape?
4. That is the end of my questions. Is there anything else that you'd like to share with me that we didn't talk about?

## APPENDIX 2 – Thematic Template

Category	Code	Description	Sub-Code	Description
Describing Impact	Observable Impact	Patient partners discussing impact when it is readily identifiable, discernable, concrete, or in the form of measurable products of patient partner work. These outcomes can be observed structurally within the organization demonstrated as increased patient partner involvement, in the form of a product, identifiable changes that are not in the form of a product, or a change in a policy or process resulting from the influence of patient partner involvement. Observable impacts also encompass patient partners seeing the influence of their involvement in some form and tracing actions or decisions back to activities or projects they were involved in.	Increased Patient Partner Involvement	Discussion of more patient partners being onboarded, increased organizational structures for inclusion of patient partners, providing roles for partners, etc. Developments that are relevant to patient partnership and help to enhance partnership efforts.
			Developed Products	Discussion surrounding tangible products that were developed as a result of engagement efforts or patient partnership work (ex. pamphlets, training material, resources, KT products, etc.).
			Identifiable Changes	Discussion of patient partners noting their input has been implemented and that they have seen changes made by the organization because of their involvement or feedback. This includes changes to patient care, implementation of patient partner feedback on a certain project or process, the organization reporting back to partners regarding changes that have been implemented, etc. This also encompasses instances in which participants mentioned seeing a change/impact or seeing a difference because of patient partner involvement without going into specifics of what that change/impact was.
			Policy Change	Discussion surrounding any change to policies, procedures, processes or governance within the organization resulting from work patient partners were involved in.
	Perceived Impact	Patient partners discussing impacts that are not necessarily visible, but rather instances in which the patient partner perceives their contributions have influenced an impact or a change. These instances of perceived impact can involve	Sharing Experience	Discussions where participants noted and emphasized that their act of sharing their personal experiences had an impact or contributed to making an impact. This code does not apply when a participant discusses sharing their experience without the connection to a perceived sense of impact.
			Expressions of Value	Discussion of instances in which being recognized as valued by the organization and providing value to the organization resulted in

		experiences where a patient partner attributes impact to feeling valued or receiving expressions of value, positive feelings attributed to a perceived impact of sharing their personal experiences, and a perceived shifting of attitudes amongst organizational staff.		perceived impact. This includes being verbally recognized and valued by organizational members, hearing staff discuss the value of patient partner involvement, participant’s suggestions being valued and considered, being continually asked to be involved, etc.
			Internal Feelings of Value	Discussion surrounding experiences in which the participant has felt internal feelings of value in their work because of scenarios in which the participant felt welcomed by an organization, felt like they belonged, or felt that they’re thoughts have been valuable and useful to the organization.
			Shifting Perspectives	Discussions in which participants have noted and attributed perceived impact to organizational staff’s or other individual’s perspectives or attitudes shifting in a positive direction regarding patient partnership. This can include instances in which the participant has engaged with organizational staff and left a lasting impact on how the staff see patient partnership, initiating a shift towards wanting to incorporate patient partnership more within the organization, etc.
	Lack of Impact	Discussion surrounding the patient partner feeling like their work did not have any sort of impact and there was no resulting change or action as a result of their efforts.		
<b>Factors Facilitating Impact</b>	Organizational Supports	Discussion surrounding various organizational supports or factors that facilitated the patient partner perceiving that they could make/have an impact or supports that helped to achieve impact. This category of themes required an explicit link between the facilitating factor and the potential for impact or link to an achieved impact.	Leadership Staff Qualities	Discussion surrounding the influence of the organizational staff leaders on the impact made by patient partners. This can include instances in which the participant notes how effectively an organizational staff leader facilitated engagement activities or relationships, how proactive the staff member is regarding inclusion of engaged partners, whether there is an engagement lead and point of contact for patient partners, whether staff responsible for engagement see the value of the roles of patient partners, etc.
			Onboarding and Training Opportunities	Discussion of how the presence of onboarding sessions and training opportunities have contributed to patient partners being able to understand their role and make an impact or contribute to change.

			Appreciation, Recognition, and Expressed Value	Discussion of participants noting situations in which an organizational staff member has verbally recognized and appreciated the value of patient partners, including instances in which a participant discusses their input and feedback was heard and noted as valuable to the organization. Note: these scenarios of appreciation and recognition differ from the above code of “Expressions of Value” as this code encompasses instances in which a participant was supported by staff to make an impact in their work and this was shown through verbal recognition of the value of the patient partner voice, rather than the above perceived impact sub-code that involves scenarios in which a perceived impact was made and shown through the expressions of value from others.
			Active Inclusion of Patient Partners	Discussion of the active involvement and inclusion of patient partners in various areas of organizational work, therefore facilitating the capacity of a patient partner to make an impact. This also includes discussion of timing of onboarding patient partners.
Aspiring to Impact	Aspirational Impacts	Discussion surrounding impacts that patient partners aspire to or aim to achieve in their partnership work.	Personal Goals	Discussion surrounding the participant’s personal goals, motivations, or agenda in relation to making an impact or working in patient partnership.
	Potential Future Impact	Discussion surrounding experiences in which change or impact has yet to occur but is anticipated for the future, including the recognition of the length of time it may take for an impact to be seen.		