Recognizing patient partner contributions to health research

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ABSTRACT

Patient engagement in research has many benefits including the alignment of research aims, projects, and outcomes with those of the ultimate end-user. As a result, patient engagement is becoming increasingly established in many areas of health research. Missing from this growing body of evidence are details about how patient partners (i.e., individuals with lived experience of a health condition including informal caregivers, family and friends) are compensated for their contributions as well as existing barriers or challenges to compensation. The overall aim of my thesis is to synthesize and assess the current landscape of patient partner compensation. First, I conducted a systematic review that identified a cohort of published patient engagement research and assessed the prevalence of reporting compensation and identified current compensation practices. Second, we surveyed researchers identified by the systematic review and their affiliated institutions to understand researcher attitudes towards compensation and any experienced barriers and challenges to offering financial compensation to patient partners. Third, we conducted a scoping review to synthesize available guidance and policy documents that inform patient partner compensation. Broadly, these projects found that: 1) reporting of patient partner financial compensation is modest and non-financial methods of compensation (e.g., co-authorship) are reported more often, 2) researchers are generally positive about their abilities and intend to offer financial compensation to patient partners, however institutional barriers including lack of policy or support persist, and 3) the majority of identified guidance recommend offering financial compensation to patient partners and discuss benefits of such practices including fostering a sense of equality between researchers and patient partners. Findings from this thesis may influence research practices by informing stakeholders of the benefits of offering financial compensation to patient partners and guiding the development of compensation strategies. Lastly, findings may inform implementation strategies at the institutional and funder level, including adoption of guidance and procedure, to better support researchers in navigating compensation.

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CHAPTER 1: Introduction

1.1 PATIENT ENGAGEMENT IN RESEARCH

Engaging individuals with lived experience in research that is relevant to their health and well-being is increasingly recognized as important to improve research quality. This may also ensure research results or products are meaningful to the ultimate end-user. The term *patient engagement in research* is used to describe "meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation".(1) Here, patients are commonly referred to as *patient partners* and become members of research teams or collaborate in the research process. The term *patient* is inclusive of individuals with lived experience of a health condition including informal caregivers, family and friends that are engaged in research.(2) This differs from the more traditional role of being a participant in research studies as the research is designed, conducted, and reported 'with' patients not 'on', 'about' or 'for' them.(3) While terminology in this space is variable, we will use the terms *patient engagement in research* and *patient partner* for the purposes of this thesis.

Patient engagement in research can occur across all aspects of the research enterprise and to different degrees. At the project level, patient partners can be involved in developing study design, statistical planning, interpretation of results and dissemination.(4) Additionally, patient partners can hold positions on committees to oversee research conduct or inform future research initiatives by identifying research priorities, defining and prioritizing research outcomes that are most important to patients (e.g., James Lind Alliance Priority Setting Partnerships).(5)(6) To date, several frameworks have been developed to guide researchers, institutions and patient partners through navigating the stages and levels of patient engagement in research. Indeed, Greenhalgh and colleagues identified 65 frameworks to support patient engagement in research.(7) Institutions, including the National Institutes of Health and Care Research (NIHR)(3) and the International Association of Public Participation (IAP2)(8), have defined different levels of engagement (i.e., Inform, Consult, Involve, Collaborate and Empower) based on the impact that patient partners have on research decision-making.

There are two common arguments in support of patient engagement in research. First, researchers have an ethical imperative to include patient partners in developing and conducting research.(9) By including the patient perspective, research is inclusive of those who are most impacted by the work and outputs may be more accepted by the end-user.(10) As a result of patient engagement

in research, there is an enhanced sense of researcher accountability and transparency, which ultimately builds trust between the public and research.(9)(11) Second, patient engagement has been observed to enhance research through improved quality, greater relevance of research projects and more effective dissemination of study findings.(5,12) This is because patient partners represent the ultimate end user of the research findings, thus having their perspectives in shaping and delivering research enhances applicability. As a result, patient engagement in research is gaining considerable traction in biomedical research, from preclinical laboratory research to clinical trials and knowledge translation.(13–16)

In order to further support the integration of patient engagement in research, funding agencies, including Canadian Institutes of Health Research (CIHR) and National Institutes of Health and Care Research (NIHR), have put forward funding calls specifically to support patient engagement in research.(2,17) In Canada, researchers are further supported by 11 provincially and territorially located Strategies for Patient-Oriented Research (SPOR) Support Units, which facilitate and promote patient engagement in research across Canada. Indeed, SPOR adheres to four key principles to guide patient engagement in research: Inclusiveness, Support, Mutual Respect and Co-build.(1) Support, in particular, implies creating a team environment that is welcoming of individual perspectives and honest interactions between team members.(1) This can be achieved by allowing patient partner flexibility and offering financial compensation for engagement. Indeed, one major challenge to patient engagement in research is to create an environment where all team members are comfortable and respectful in their roles to allow for meaningful patient engagement in research.(18) The term *meaningful engagement* has been coined to represent engagement that is not tokenistic or insincere.(18) A key aspect of meaningful patient engagement in research is the recognition of patient partner contributions as this supports how patient partners are valued and acknowledged, thus avoiding tokenism.(18)

1.2 PATIENT PARTNER COMPENSATION

While offering support to patient partners is a guiding principle of patient engagement in research, there is little available evidence of how compensation has been operationalized. Compensation is defined as the act of awarding something to someone in exchange for a service.(19) Methods of compensation can be non-financial (e.g., co-authorship, token of appreciation) or financial (e.g., honoraria, salary)(Box 1).(19) Excluded from this is reimbursement of out-of-pocket expenses from engagement that are necessary to enable an individual to be engaged in research as a patient partner (e.g., travel, accommodations, parking). Patient partners should not pay out-of-pocket to be engaged in research. Indeed, there has been much debate regarding the appropriate ways in which patient partner

contributions can and should be acknowledged, including the need for financial compensation or offering something of monetary value in exchange for patient engagement in research.(20–22) For my thesis, the primary focus is on financial compensation but details of other forms of compensation will be acknowledged wherever possible. I decided to focus on financial compensation because it has been proposed as a method to improve diversity in research by facilitating patient engagement in research with patient partners from different socioeconomic backgrounds.(20) However, financial compensation methods are not well understood. For the purposes of this thesis, I have also focused on patient engagement in academic healthcare research. Although patient engagement occurs in many other settings (e.g., industry), we are most interested in understanding the role played by researchers and research institutions in patient partner compensation.

Box 1. Definitions of methods to compensate patient partners (19,23,24)

TERM	DEFINITION
NON-FINANCIAL COMPENSATION	Offering gifts, tokens of appreciation or services in exchange for patient engagement in research. Examples of this are: co-authorship on manuscripts or research material, facilitating patient partner attendance at a conference, education, or gifts (e.g., flowers, care package).
FINANCIAL COMPENSATION	Financial compensation extends beyond patient partner reimbursement for out-of-pocket expenses and includes offering something of monetary value in exchange for their engagement in research. Examples of this are: honoraria, cash, or salary (formal payroll). Gifts or gift cards (for grocery stores, restaurants, retail stores, pre-paid credit cards etc.) are considered financial compensation when the value is informed by a formal conversion (i.e., 2 hours of work at $25 per hour = $50 gift or gift card value or using fair market value) or patient partners decide that they want to receive payment in the form of gifts or gift cards.

Arguments have been made both for and against compensation of patient partners. Without financial compensation, patient partners are considered volunteers - defined as individuals who donate their time and energy to benefit others without motivation of financial gain.(25) Generally, volunteerism benefits society and can be personally rewarding. For example, most health charity work is volunteer based and highly impactful.(26–28) As volunteers, patient partners may feel as though they can express

their opinions freely without the pressures of receiving payment. This sense of comfort may encourage honesty and sustained patient engagement in research. However, voluntary patient engagement in research may lead researchers to believe that it is unnecessary to compensate patient partners simply because they are providing patient partners with a unique opportunity.(29) There are arguments against volunteerism and in support of financially compensating patient partners for their contributions; one of which being that financial discrepancies between team members may perpetuate power imbalances.(20) When patient partners are the only unpaid members of the research team it implies that in order for the patient voice to be heard a patient partner must have the means to allocate unpaid time and energy to research.(20) Some argue that paying patient partners for their involvement in research is essential to promote inclusivity and to dissolve barriers to meaningful patient engagement in research.(18,20) Additionally, compensation can encourage participation by reflecting the type of commitment that is expected from patient partners.(12)(20)

Similar to the arguments in support of patient engagement in research, there are principle based arguments for and against patient partner compensation, as well as practical consideration.(18–20,30) First, it can be challenging to assign a monetary value to a unique skill set and lived experience in a respectful manner.(31) Often patient partners are compensated below their current wage, thus there remains a volunteerism aspect. Additionally, when engaging with unique populations, it is important to consider cultural significance of payment. For example, when offering financial compensation to Indigenous patient partners it is crucial to present payment as a token of appreciation rather than in exchange for Indigenous knowledge.(24) Second, there are incongruences between when compensation requires consideration (i.e., budgeting at the funding application stage), acquisition of funding to financially support patient engagement in research, and initiation of patient engagement. If patient partner compensation is not organized before research funding is secured, it can be difficult to incorporate in a project budget.(19,31) This may be particularly challenging for researchers who are interested in engaging patients but have no prior experience. Finally, it is important to consider the financial implications of remuneration. For example, compensation may be considered taxable income and can then interfere with disability payments or income tax rates.(23,24)

Despite barriers to compensation, patient partner recognition, including financial compensation, contributes to each of the four guiding principles of patient engagement according to CIHR (i.e., Inclusiveness, Support, Mutual Respect, Co-Build).(1) Hence, organizations that value and support patient engagement in research also understand the importance of valuing patient partner contributions and the impacts that compensation can have on engagement. To support the need for compensation,

including financial, several national organizations have developed publicly available policies to provide researchers with the guidance necessary to appropriately compensate patient partners for their contributions to research.(19,24,32,33)

1.3 KEY EVIDENCE GAPS IN FINANCIAL COMPENSATION OF PATIENT PARTNERS

While there are arguments suggesting that patient partner financial compensation is beneficial, three key evidence gaps persist.

First, there has yet to be an assessment of the current reporting of patient partner financial compensation or understanding of the current recognition practices being used by researchers. We must improve our understanding of reporting patient partner recognition to assess whether the key principles and standards for patient engagement in research are being met by researchers. It is unclear if researchers are transparent in reporting their recognition strategies, which is necessary to allow for comparisons to be drawn across different recognition methods.

Second, it is unclear what barriers or challenges are experienced by researchers and institutions when offering financial compensation to patient partners as well as researcher attitudes around patient partner financial compensation. Evidently, researchers and institutions play major roles in financial compensation of patient partners. Thus, to further support researchers and institutions in offering compensation, we need to understand the challenges of financial compensation.

Third, while we know of guidance developed by several national organizations to facilitate patient partner financial compensation, a synthesis of these policies is required. More specifically, it is unclear how existing documents are similar and where they may differ. It is important that researchers are informed and enabled with guidance necessary to navigate patient partner compensation. Developing a comprehensive overview of available guidance may help researchers decide which guidance documents they should use to develop their compensation strategy and may help organizational leaders refine their own procedures based on findings.

1.4 PERSONAL EXPERIENCE WITH PATIENT ENGAGEMENT IN RESEARCH

My first experience with patient engagement in research was when I had the opportunity to work on a project supported by the Ontario SPOR SUPPORT Unit (OSSU). Over six months, I worked with four patient partners with lived experience of blood cancer to co-develop documents and services to support trial participants of an early-phase clinical trial assessing the efficacy of a novel immunotherapy (CLIC-01 trial).(34) Not only were we successful in co-creating tangible research products that would help support

cancer patients, but I was personally impacted by this project. In fact, these experiences inspired me to pursue graduate school so that I could become an expert in patient engagement in research and continue to advocate for the involvement of patients in developing and conducting health research.

From working with patient partners, I learned how to communicate complicated scientific concepts in accessible ways, navigate discussing personal or sensitive topics, work in a multi-disciplinary group setting, and fine-tune my interpersonal skills. Unfortunately, I have yet to see these skills taught in traditional research environments. Additionally, before I started working with patient partners, I often lost sight of the real-life impacts of my research. Working alongside patients has helped me become a more well-rounded trainee and allowed me to see the real-life implications of my research. Throughout my thesis, I have been fortunate to be guided by a multi-disciplinary group of thesis advisory committee members including a patient partner; a novel position. While I learned a lot from conducting my thesis projects, hearing firsthand experiences from Maureen Smith had an immeasurable impact on the advice that I will take forward in my new role supporting researchers in conducting patient engagement research.

I have had my own experiences with providing patient partner recognition, including financial compensation. For example, I personally struggled with inputting patient partner co-author affiliations in journal submission systems. As well, I dealt with removing clauses from financial compensation contracts that were insulting to patient partners. I have seen first-hand how financial compensation can be beneficial and the barriers to appropriately recognizing patient partners for their hard work. I am grateful to have had the opportunity to conduct this research and answer some of my own questions around patient partner recognition.

1.5 THESIS OBJECTIVES

The overall objective of this thesis is to enhance our understanding and knowledge of current practices for compensating patient partners, with a focus on financial compensation, and identify available guidance that is used to inform these decisions. This thesis will address knowledge gaps in this area by focusing on the following objectives:

1. Assess the prevalence of reporting patient partner financial compensation
2. Identify current patient partner compensation practices (financial and non-financial)
3. Determine researcher and institutional leader attitudes and beliefs around financially compensating patient partners

4. Identify perceived barriers to patient partner financial compensation from the perspective of researchers and institutional leaders
5. Identify and summarize policies and guidance documents that address compensation of patient partners

1.6 THESIS ORGANIZATION

- My thesis is manuscript-based. After providing this background and rationale for the thesis (Chapter 1), I present a series of three papers (Chapters 2 to 4), a reflection piece (Chapter 5) and an integrated discussion (Chapter 6). Papers presented in Chapters 2, 3, and 4 are pending submission, however each protocol is published as a larger research program.(35)

- **Chapter 2** is a systematic review aiming to assess the prevalence of reporting patient partner recognition and identify current recognition strategies among a cohort of patient engagement research.

- **Chapter 3** is a cross-sectional survey aiming to gain an understanding of researcher beliefs about their compensation efforts and identify challenges and barriers experienced by both researchers and institutional leaders when offering financial compensation to patient partners.

- **Chapter 4** is a scoping review aiming to provide a comprehensive overview of available guidance and policy documents detailing recommendations for patient partner compensation.

- **Chapter 5** discusses patient engagement in research embedded within the development and conduct of this thesis.

- **Chapter 6 p**rovides a summary of key findings from Chapters 2, 3, and 4, and provides an integrated discussion of the implications of findings.

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CHAPTER 2: Systematic review

Recognizing patient partner contributions to health research: a systematic review

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Preface to Chapter 2

This chapter presents the results of a systematic review designed to assess the prevalence of reporting patient partner compensation and identify current compensation strategies among a cohort of published patient engagement in research. The results improve our understanding of the current landscape of patient partner compensation. Corresponding authors of included studies and their institutions form the sampling frame for the cross-sectional survey described in Chapter 3.

ABSTRACT

Introduction: Patient engagement in research refers to collaboration between researchers and patients (i.e., individuals with lived experience including informal caregivers) in developing or conducting research. While patient engagement is becoming increasingly common, little is known about how patient partners are recognized for their role. To address this, we conducted a systematic review to assess the prevalence of reporting patient partner compensation and identify current compensation practices (non-financial and financial) among a cohort of studies that reported patient engagement in research.

Methods: Web of Science and Scopus were used to conduct a forward citation search of the Guidance for Reporting the Involvement of Patients and the Public (GRIPP I and II) reporting checklists. Studies that engaged patients as research partners or described patient engagement in research were eligible. Two independent reviewers screened full texts and extracted data from included studies. Data pertaining to compensation methods (financial and non-financial) and reported barriers to financially compensating patient partners were extracted. Quantitative data were presented descriptively, and qualitative data were thematically analysed.

Results: The search identified 843 studies and 316 studies were included. The most common reported method of non-financial compensation was informal acknowledgement on research outputs (65%, n=206) and co-authorship (49%, n=156). Seventy-nine studies (25%) reported offering financial compensation (i.e., honoraria, salary) to all or some patient partners, and 205 (65%) studies did not report on financial compensation. Fourteen studies reported barriers to offering financial compensation and two key barriers include lack of funding to support compensation and absence of institutional policy or guidance.

Discussion: In a cohort of studies reporting patient engagement in research, most offered non-financial methods of compensation to patient partners. Researchers may need support and encouragement from institutions and funding agencies to navigate patient partner financial compensation.

INTRODUCTION

Patient engagement in research is the inclusion of patients, defined as individuals with lived experience of a health issue and informal caregivers including family and friends(1), in the research process.(2) It is research carried out 'with' patients and not 'on', 'about' or 'for' them.(3) Patient engagement has many benefits including improved study quality, better clinical trial recruitment, and aligning research priorities with those of the ultimate end user.(4) As a result, patient engagement is being increasingly adopted in areas across health research.(4–6)

Despite the growing popularity of patient engagement in research, little evidence is available on how patient partners are recognized for their contributions to research. Recognizing patient partner contributions, by offering non-financial or financial compensation, has been proposed as a strategy to encourage continued patient engagement and demonstrate their efforts are valued.(7) Feeling valued is an essential component of creating an inviting team atmosphere, which plays a pivotal role in supporting sustained and active patient engagement in research.(8) Smith and colleagues have argued that, in order to avoid insincere patient engagement, patient partners must be appropriately recognized and compensated for their contributions.(9) Patient partner recognition methods can be non-financial (e.g., co-authorship) or financial (e.g., honoraria). Specifically, financial compensation can be seen as a subset of broader patient partner compensation for engagement in research; but may also serve as a facilitator by addressing important barriers to engagement.(10) Without financial compensation, only patient partners with time and resources will be eligible to be patient partners, creating barriers for individuals of different socioeconomic statuses to being engaged.

Several patient oriented organizations have developed guidance documents to support researchers in developing compensation strategies (both non-financial and financial methods), and funding agencies have guidelines in place to help applicants budget for engagement.(11–16) For example, the Department of Defense in the United States, which is one of the top international funding agencies, developed a unique policy to guide compensation of veterans for their involvement in research.(17) Additionally, groups of individuals with patient partner experience are spearheading the conversation about compensation. Richards and colleagues have published a how-to guide for researchers and a commentary about barriers to financial compensation from the patient partner perspective.(10,18) Despite the existence of guidance and policies, it remains unclear the extent to which researchers are recognizing patient partners financially for their contributions, how patient partners are compensated, and researcher perceived barriers to offering financial compensation.

It is important that we further our understanding of the current landscape of reporting patient partner compensation first; to ensure that recognition of patient partners is being reported on. This promotes transparency thus allowing stakeholders to compare varying recognition strategies. Second, it is crucial that key principles and expectations of patient engagement in research developed by organizations such as health research funders, including appropriate recognition, are being met.(1) The aims of our systematic review were to answer the following research questions: *What is the prevalence of reporting patient partner financial compensation and how are researchers recognizing patient partners for their contributions to research?* To address these research questions, we assessed the prevalence of reporting patient partner recognition among published research that engaged patients, identified non-financial and financial methods of recognition, the monetary values of financial compensation, and any guidance documents used. Review findings will provide a contemporary overview of compensation reporting, recognition strategies, and help inform implementation strategies for the research community to support patient partner compensation.

METHODS

Given our focus to descriptively summarize the patterns of reporting recognition practices, we opted to conduct a systematic review of studies reporting patient engagement in research to examine the reporting practices regarding recognition of patient partners for their engagement role. To achieve this we identified studies that cited Guidance for Reporting the Involvement of Patients and the Public (GRIPP2)(19) checklist to report engagement activities and outcomes. We chose studies that reference GRIPP as it was an efficient, specific, and targeted search strategy to identify a cohort of published patient engagement in research. This decision was also due to feasibility given the rapid emergence and abundance of published patient engagement in research.(20) Previous studies have demonstrated a very low rate of reporting patient engagement in research(21), thus the specificity of a broad literature search would be exceedingly low rendering the review infeasible. Using this forward citation search, we were more likely to capture a cohort of patient engagement in research that report recognition strategies. Our systematic review was conducted in accordance with methodology detailed in the Cochrane Handbook for Systematic Reviews of Interventions (22) and is prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) reporting guidelines (Appendix 1).(23) The protocol was published as part of a larger research program (24) and can be found on the International Prospective Register of Systematic Reviews (PROSPERO ID: CRD42022303226). A patient partner (MS) was engaged in this study; we completed a Guidance for Reporting the

Involvement of Patients and the Public (GRIPP2)(19) checklist to summarize engagement activities and outcomes (Appendix 2).

Eligibility criteria

In accordance with systematic review methodology, it is recommended to structure eligibility criteria as Population, Intervention, Comparator, and Outcome (PICO). However, for the purposes of this review, there were no restrictions on the PICO criteria of included studies. We included studies that are written in English, reference the GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklists (I or II)(19,25) and engaged or described engaging patients in health research, in which members of the public or patients (i.e., an individual with lived experience of a health condition as well as informal caregivers, including family, friends, or members of patient organizations) are engaged as partners (provided input, guidance, consultation on at least one element of the research process).(2)

Studies that engaged patients as partners as well as participants (i.e., subjects of research) were included in the review, while studies that only engaged patients as research participants were excluded. Examples of research engagement include priority-setting, governance, developing the research question, identifying study outcomes, selecting study design, informing statistical analysis, interpreting study findings and disseminating results.(26) We included all study designs (e.g., qualitative, quantitative, knowledge synthesis, mixed-methods research etc.). Studies that described the patient engagement in research component as part of a larger research project were included. Studies that interviewed patients about their experiences as patient partners were excluded as patients were the subjects of research.(27) Conference abstracts and commentaries were also excluded. A full list of inclusion and exclusion criteria can be found in Appendix 3.

Search Strategy and Information Sources

We conducted a forward citation search of the GRIPP checklists (I and II)(19,25) in Scopus and Web of Science on October 14, 2021. An information specialist (Lindsey Sikora, Health Sciences Research Librarian, University of Ottawa) was consulted when developing the forward citation search strategies. While there were no date restrictions, all included studies were published after the GRIPP I publication date (2011).

Selection process

All records identified by the literature search were uploaded to DistillerSR (a cloud-based software program that facilitates systematic reviews) (Evidence Partners Incorporated, Ottawa, Canada).(28)

After duplicate removal, reviewers (GF, TS, FA) screened records in duplicate by full-text according to prespecified eligibility criteria. The screening process was piloted for the first 20 articles to ensure reliability between reviewers. Eligibility criteria were refined to improve clarity if reviewers were inconsistent in screening. A third reviewer (DAF or MML) was consulted if reviewers could not reach consensus. Reasons for exclusion were recorded.

Data collection process

Two reviewers (GF, TS) independently extracted data from studies included in the systematic review using a data extraction form in DistillerSR. Data extraction was piloted for the first five studies to ensure extraction was consistent. After one piloting exercise, the reviewers extracted data from sets of 20 studies and resolved conflicts between each set. A third reviewer (DAF or MML) was consulted if reviewers could not reach consensus.

Data items

Extracted items included study characteristics (e.g., author information, source of funding etc.), patient engagement characteristics (e.g., level of engagement, type of stakeholder engaged etc.), details of patient partner compensation (financial and non-financial practices), stated reasons for or against offering financial compensation to patient partners, and any reported benefits, challenges, barriers and enablers to financial compensation. Patient engagement activities were categorized as *Consult*, *Collaborate*, and *Empower* levels of engagement in accordance with definitions developed by the National Institute for Health and Care Research (NIHR).(29) It is important to note that studies could achieve more than one level of engagement. Engagement activities were categorized as occurring at different stages of the research process (e.g., study design, data collection, data analysis etc.), governance (i.e., member of a committee overseeing the research project), general priority setting (i.e., identifying research priorities to inform future research) or general outcome derivation (i.e., identifying outcomes to be captured in future studies). A full list of data extraction items can be found in Appendix 4.

Study risk of bias assessment

No formal quality assessment was conducted for included studies since the aim of the review is to describe the scope of patient partner compensation.

Synthesis methods

Patient engagement and compensation details (stakeholders engaged, length of engagement, type of financial compensation offered etc.) were extracted and presented descriptively using tables. Prevalence of reporting patient partner financial compensation was calculated. Qualitative data (justification for or against financial compensation, reported benefits, challenges, barriers and enablers to patient partner compensation) were analyzed descriptively in accordance with the 6-step approach developed by Braun and Clark (2006).(30) Verbatim statements were extracted by two independent reviewers (GF, TS) and stored in a locked excel file. Statements were organized in rows. Two independent reviewers (GF, SN) read through extracted verbatim statements and generated initial codes within each of the five domains (benefits, challenges, barriers, enablers, justification). Reviewers met regularly to resolve discrepancies between initial codes. Initial codes were collated into overarching themes and reoccurring themes were combined. The frequency of reported themes was recorded. Finally, themes were named based on the overall message of the included codes.

Subgroup analysis

Prespecified subgroup analyses of reporting patient partner financial compensation were performed according to funding (funded vs. non-funded) and level of engagement (consult, collaborate, empower).(31) Given that levels of engagement are ordered based on the level of impact that patient partners have on decision making, we compared studies that achieved consult, collaborate, or empower as the highest levels of engagement. A post hoc subgroup analysis by country (comparing studies conducted in the United States, Canada and the United Kingdom with the remaining studies) was conducted following consultation with a group of patient partners. Subgroup proportions were compared using Chi-square tests.

Patient engagement in this research study

One patient partner (MS) informed project development (e.g. review proposals and protocols, identifying sources, research question generation) and provided feedback on project conduct (data extraction, interpretation). Monthly meetings occurred with the patient partner to discuss research findings as the systematic review progressed. We co-developed a terms of reference document a priori to document details of engagement (i.e., expectations, project goals etc.). Our patient engagement in research plan was informed by INVOLVE's seven Core Principles of Engagement (32) and the CIHR SPOR Patient Engagement framework.(1) Co-authorship and financial compensation were agreed upon with the patient partner and offered as a method of acknowledgement according to the SPOR Evidence

Alliance Patient Partner Appreciation Policy (33). The aim of collaboration was to ensure that the patient perspective was considered throughout the project. Further details of patient engagement in this project can be found in Chapter 5.

RESULTS

Search results

Our search retrieved 843 studies. After removing duplicates, 518 studies were screened and assessed for eligibility and a total of 316 studies were included in the systematic review. Screening results are presented using a PRISMA flow diagram (Figure 1). A full list of included studies can be found in Appendix 5.

Study characteristics

Most studies originated in the United Kingdom (60%, n=190) followed by Canada (16%, n=51) and Denmark (5%, n=15) (Appendix 6). The earliest study was published in 2011 and the largest proportion of studies was published in 2020 (27%, n=84), followed by 2021 (24%, n=77) (Appendix 7). The search was conducted in 2021. Most studies (84%, n=265) were funded (Appendix 8A) and 33 (12%) funded studies reported receipt of funding specifically to support patient engagement (Appendix 8A). Most funded studies received funding from government agencies (75%, n=200) (Appendix 8B).

Patient engagement in research characteristics

Studies reported engaging a variety of stakeholders including patients (78%, n=246), caregivers (35%, n=111), and members of patient organizations (16%, n=50) (Appendix 9). A median of five patient partners were reported for each study with a range of 1-705 patient partners. The study reporting 705 patient partners details three engagement efforts, including a conference event attended by patient partners.(34)

Studies described engagement activities as occurring at various stages across the research process including governance (24%, n=76), funding acquisition (17%, n=54), priority setting (17%, n=52), study design (79%, n=250), data collection (14%, n=45), data analysis (43%, n=137), dissemination of results (50%, n=157), developing patient engagement plan (8%, n=24), and ethics application development (0.3%, n=1) (Appendix 10).We identified studies that engaged patient partners in general priority setting exercises (13%, n=42) and general outcome derivation (5%, n=16). Level of engagement in research were *Consult* (35%, n=111), Collaborate (23%, n=73), and Empower (6%, n=19) (Appendix 10). We identified six studies (2%) that engaged patient partners at all three levels.

Prevalence of reporting financial compensation and current practices

Of the 316 studies, 62 (19%) reported offering financial compensation to all patient partners, 17 (5%) studies reported offering financial compensation to some patient partners, 32 (10%) explicitly reported that patient partners were not offered any form of financial compensation, and 205 studies (65%) did not report on financial compensation (Table 1).

Of the 79 (25%) studies that reported offering financial compensation to some or all patient partners, 43 studies (54%) provided details of compensation in the methods section (Appendix 11). The most common reported method of financial compensation was honoraria (58%, n=46). Sixteen (20%) studies reported offering financial compensation based on task completion (e.g., attended meeting, document review etc.), while other studies used units of time (e.g., half-day meeting, per hour) to inform the monetary value of financial compensation (14%, n=11). One study that offered patient partners a salary reported compensating patient partners at "0.1 full-time equivalent" for the duration of the study. The majority of studies did not report the monetary value of financial compensation (72%, n=57). In terms of payment frequency, thirteen (16%) studies reported providing financial compensation as a one-time payment, four (5%) studies paid patient partners immediately after completion of a task, and one (1%) study provided patient partners with an annual payment. Most studies (77%, n=61) did not report on payment frequency.

The most referenced documents used to inform the development of a financial compensation strategy are different variations of guidance developed by the National Institute for Health Research (NIHR) and INVOLVE (n=22) including *Payment and Recognition for Public Involvement (14), Policy on payment of fees and expenses for members of the public actively involved with INVOLVE (35),* and *Recognition payments for public contributors (36)* (Appendix 12). Five studies used local minimum wage rates or national costs of living to inform the monetary value of financial compensation offered to patient partners.

Non-financial compensation practices

The most common reported method of non-financial compensation was informal acknowledgement on research outputs (e.g., acknowledgement section in publications, dissemination documents, presentations) (65%, n=206) and co-authorship (49%, n=156) (Table 2). Additional methods of non-financial compensation include facilitating patient partner attendance at conferences (7%, n=2) and offering training opportunities (12%, n=4). Fifty-two studies reported offering co-authorship and financial compensation to patient partners. Two studies listed a patient partner as the first author of the

manuscript. Twenty-eight (9%) studies reported not offering any form of non-financial compensation to patient partners.

Subgroup analysis

Studies that reported receipt of funding were significantly more likely to report financial compensation of patient partners when compared to studies that did not receive funding or did not report funding (χ^2=6.614, p<0.01). Similarly, there is a significant difference of reporting patient partner financial compensation between studies that engage patients at different levels (Consult, Collaborate and Empower) (χ^2= 42.41, p<0.01). Appendix 13 presents frequency of reporting patient partner financial compensation within each subgroup. Conversely, studies originating in Canada, United Kingdom and United States of America were not more likely to report financial compensation of patient partners when compared to studies conducted in other countries (χ^2=1.311, p=0.252217). Similarly, subgroup analysis of studies originating in countries with more than five included studies (i.e., Norway, Netherlands, United States, Australia, Denmark, Canada, United Kingdom) demonstrated that there is no significant difference in reporting patient partner financial compensation (χ^2=4.619, p=0.5936).

Benefits, challenges, barriers and enablers of financial compensation

A total of 32 studies (10%) reported either benefits, challenges, barriers or enablers of financial compensation. The most common reported benefits were that patient partner financial compensation can support “patient partner participation” and “long term engagement across the research project”, since offering financial compensation can enable patient partners to allocate more time to the research project (e.g., attending more team meetings) (Table 3). One identified challenge to patient partner financial compensation was “financial payments can jeopardize disability or social security payments or impact income tax rates” since financial compensation can impact other income sources. Two key reported barriers to offering financial compensation were resource limitations including “budget constraints or the research project did not receive funding” and “lack of an institutional policy or guidance document” to inform compensation strategies.

Justification for and against offering financial compensation

Several studies provided justification for offering financial compensation to patient partners, from which seven themes were generated. The most reported reason to offer financial compensation to patient partners was to “demonstrate that patient partner contributions are valued and respected” (Appendix

14). Commonly reported justification for not offering financial compensation to patient partners include "general inability to compensate patient partners" such as lack of funding or resource limitations.

DISCUSSION

We undertook this systematic review to gain an understanding of reporting patient partner recognition and current compensation practices to further support the research community in navigating compensation. Our findings demonstrate that non-financial methods of compensation (i.e., co-authorship, acknowledgement) are reported more often than financial. We identified methods of non-financial recognition that may uniquely benefit patient partners, namely inviting patient partners to be investigators, covering expenses for patient partners to attend conferences, or providing training opportunities to advance patient partner careers. Ultimately, reporting of patient partner financial compensation was modest (25%) and the majority of studies did not report on financial compensation. Additionally, the monetary value of financial compensation was variable across studies (e.g., $31 to $94 USD for attendance at a half-day meeting), which may be due to utilization of different guidance documents. To the best of our knowledge, this is the first systematic review to focus on reporting recognition of patient partners for their contributions to health research.

The majority of included studies were conducted in the United Kingdom which is likely because patient engagement, better known as patient and public involvement, has a long history in the United Kingdom dating back to the early 2000's.(37) Most studies engaged patient partners at the project level, namely throughout study design. Patient engagement activities at the study design phase of research include informing the project protocol, intervention design and implementation. Similarly, Fergusson and colleagues conducted a systematic review to assess reporting of patient engagement in published randomized controlled trials and non-randomized comparative trials.(21) The authors noted that most studies reported patient engagement at the study design phase of research.(21) Additionally, a recent comparison of patient engagement in primary care research grant applications and published research conducted in the United Kingdom reported the majority of studies and grant applications engaged patients in the study design phase.(38) While there are many facets to patient engagement in research, it's reasonable that research initiatives that engage patient partners at the project level may be more likely to report activities in accordance with the GRIPP checklists. Barriers and enablers to financial compensation identified by the qualitative analysis focus on applying for funding as a key stage in the research process. While this is rather intuitive given that offering financial compensation is easily limited by funding and resource constraints, researchers may require further support or guidance when

budgeting for patient engagement and compensation. In fact, a recent assessment of grant applications for patient engagement in research identified only half budgeted for patient engagement.(38) While many factors may contribute to sub-optimal budgeting, funding agency support and endorsement of guidance may facilitate early consideration of the costs of patient engagement in research.

The results of our subgroup analysis support the association between a greater level of patient engagement (e.g., *Consult, Collaborate, Empower*)(31) and offering of financial compensation. In fact, several patient partner guidance documents recommend different rates of financial compensation depending on patient partner role and are supportive of equal compensation of patient partners in the same role.(11)(12)(39)(40)(41) While it's reasonable to offer higher value financial compensation to patient partners who take on a more involved role, it's important to consider the purpose of financial compensation. In fact, Bélisle-Pipon et al. argue that, if the goal of offering financial compensation is to dissolve barriers to engagement for patient partners who are socioeconomically disadvantaged, then the compensation strategy should be equitable.(42) Using an equity lens, patient partner compensation would be individualistic, and compensation strategies would be informed by unique circumstances. Similarly, for non-financial compensation strategies, patient partner circumstances are crucial to consider. While some researcher team members benefit academically from co-authorship and credit on research outputs, it is important to consider that co-authorship may not directly advance a patient partner's career. In fact, co-authorship can be disadvantageous for patient partners who have lived experience of a condition that is stigmatized. Lessard and colleagues partnered with a panel of patient partners with lived experience of human immunodeficiency virus (HIV) to develop clinical research.(43) When offered co-authorship on research outputs, patient partners opted for team authorship to maintain health anonymity. While guidance documents are helpful in informing patient partner compensation, strategies require consideration of the purpose of financial compensation and patient partners circumstances and preferences.

While there is little evaluative evidence of patient partner financial compensation, the barriers and enablers identified by our review are similar to those previously presented by a group of individuals with patient partner experience. For instance, Richards and colleagues highlighted the pivotal role played by institutions in supporting patient partner compensation, (18) specifically in developing or amending existing contractual agreements to fit patient partner relationships and the logistics of processing payments. Similarly, our qualitative analysis identified institutional processes as a key barrier to researchers offering financial compensation. To date, several funding agencies utilize guidance on how

to compensate external consultants to inform patient partner compensation, yet these documents are not always developed to support the collaborative exchange between researchers and patient partners (e.g. National Institutes of Health – Develop your Budget (44)). This highlights the importance of institutional policies and procedures to support patient partner compensation.

While financial compensation has been proposed as a method to avoid tokenistic patient engagement, it has been discussed that offering compensation may unduly influence patient partner opinions.(7) Two studies in our review reported purposefully not offering financial compensation to ensure patient partners were allowed to speak freely without any pressures associated with payments. This challenge has been detailed in compensation guidance documents including The Change Foundation's Tool for Deciding Whether to Pay Patient-Engagement Participants, specifically the possibility of patient partners losing a sense of independence and biasing opinions in favour of the institution.(16) The impacts of financial incentives on intrinsic motivation have been studied extensively by Deci and colleagues and it is well supported that introducing financial compensation can render a joyful activity insincere.(45) Applying this psychological phenomenon to our findings, offering financial compensation to patient partners may negatively impact patient engagement experiences. While McCarron et al. identified compensation as a key motivator for patient partners to be engaged in research, the stronger motivations were altruistic in nature, namely self-fulfillment, feelings of making a difference, and helping others.(46) Despite possible additive pressures associated with payment, our review identified nominal monetary values being offered to patient partners that are likely incomparable to income. Keeping financial compensation at a level that reflects appreciation and is approved by patient partners may address this challenge.

While our systematic review contributes to an important gap in the literature, limitations are noted. First, our search strategy is limited to studies that cited the GRIPP reporting checklists, thus we are missing published patient engagement research that did not use the GRIPP checklists. As stated, it would not be feasible to conduct a broad literature search given the paucity of reporting patient engagement in health research.(21) Second, journals including Research Involvement and Engagement and Canadian Medical Association Journal endorse reporting in accordance with the GRIPP checklist, while other journals may not have this requirement. Third, the majority of included studies were written by researchers. Because of this, our qualitative analysis findings are likely from the researcher perspective. It is pivotal that the patient partner experience is also taken into consideration to better understand benefits, challenges, barriers and enablers to financial compensation. Finally, it would be ideal to have

partnered with more than one patient partner when developing and conducting the systematic review. Both funding limitations and the scope of the project limited our ability to seek out additional perspectives. However, we will consult a larger panel of patient partners to guide dissemination.

In conclusion, our systematic review findings contribute to an aspect of patient engagement research where little available evidence exists. Of particular emphasis, non-financial compensation is more commonly reported than financial, and where financial compensation is mentioned, details were rarely reported and highly variable when reported. Of note, level of engagement was associated with financial compensation. Findings suggest that funding agencies hold a lot of potential in setting the direction of patient partner compensation practices and should consider arming applicants with resources to guide budgeting for patient partner compensation.

TABLES AND FIGURES

Figure 1. PRISMA flow diagram

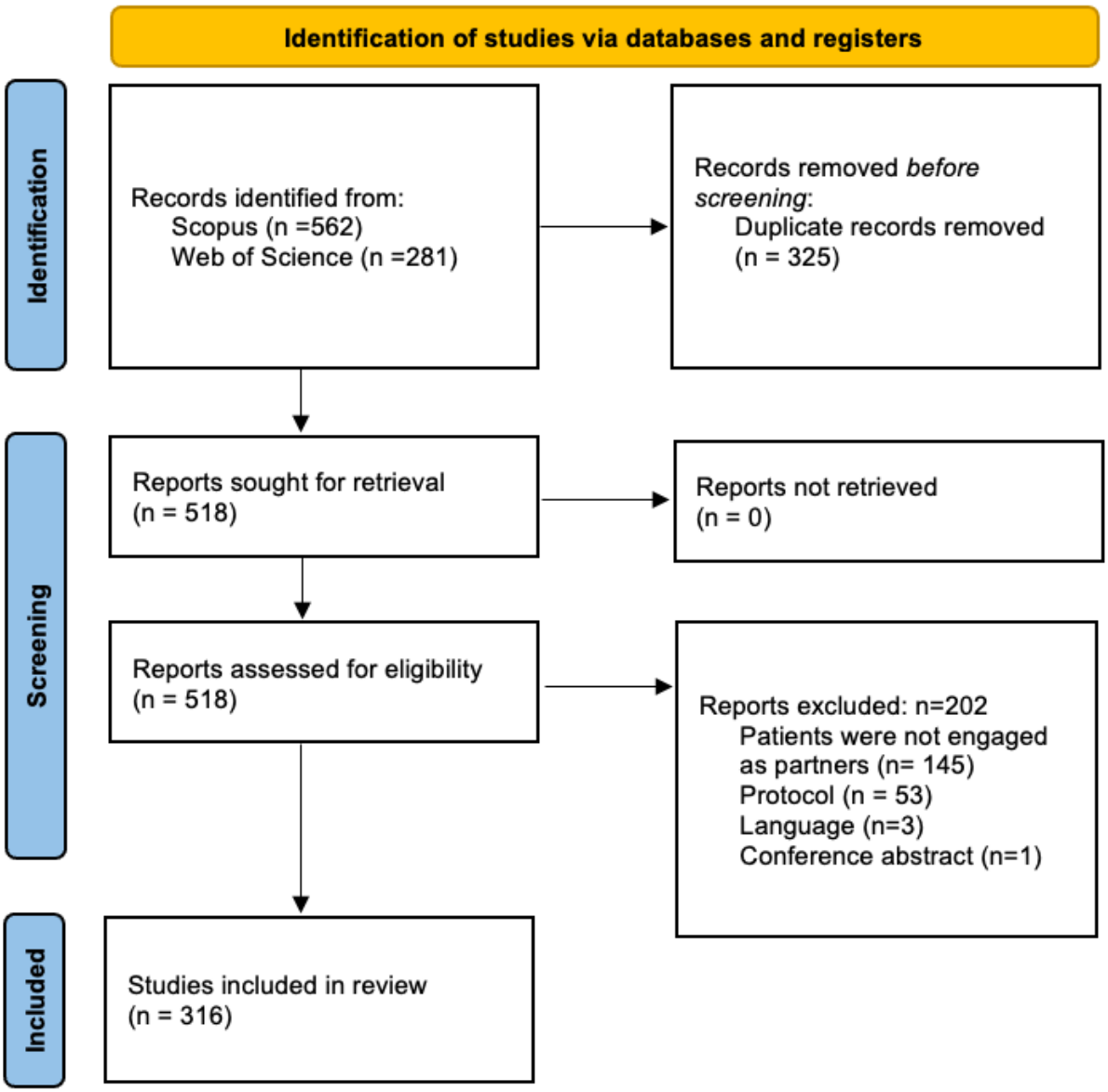

Table 1. Financial compensation details (n=316)

Did the authors offer financial compensation to patient partners?	Number of studies (%)
Yes, financial compensation was offered to all patient partners.	62 (19)
Financial compensation was offered to some patient partners.	17 (5)
No, patient partners were not offered financial compensation	32 (10)
Not reported	205 (65)
Type of financial compensation offered to patient partners (n=79)	
Honoraria or stipend	47 (59)
Salary	4 (5)
Gift card (e.g., fee, voucher)	13 (16)
Scholarship	1 (1)
Not reported	20 (26)
*Amount (rate)	
$12 - 997 per task completed (i.e. attended meeting, review document, video feature)	15 (19)
$31 - 94 per half day meeting	4 (5)
$12 - 42 per hour	7 (9)
0.1 full-time equivalent for the duration of the project	1 (1)
Not reported	57 (73)

*Currency presented in USD (conversions were made based on September 2022 rates)

Table 1. continued.

*Amount (total)	Number of studies (%)
$15 - 77	3 (4)
$77 – 153	5 (6)
$376	1 (1)
Sufficient value to take a friend for dinner	1 (1)
Not reported	68 (87)
Payment frequency	
Annually	1 (1)
One payment	13 (17)
Paid at each meeting	4 (5)
Not reported	61 (77)

*Currency presented in USD (conversions were made based on September 2022 rates)

Table 2. Non-financial methods of compensating patient partners (n=316)

Non-financial compensation	Number of studies (%)
Acknowledgements	206 (65)
Co-authorship on a manuscript	156 (49)
Reimbursement of expenses incurred from engagement	67 (21)
Provided meals	37 (12)
Listed as a co-investigator or co-applicant	33 (10)
Conference presenter	23 (7)
Conference attendance	12 (4)
Provided transportation	9 (3)
Certification or training opportunities	7 (2)
Token of appreciation (i.e., gift)	4 (1)
Gift card	4 (1)
Scholarship	2 (0.6)
Providing babysitting services	1 (0.3)
None	28 (9)

Multiple methods of non-financial compensation can be reported in a single study.

Table 3. Reported benefits, challenges, barriers and enablers of patient partner financial compensation

Theme	Number of studies
Benefits (n=16)	
Facilitates patient partner participation in research activities across the research project and supports long term engagement	7
Tangible method to demonstrate patient partner appreciation and	5
Supports a sense of equality among team members	4
Challenges (n=3)	
Financial payments can jeopardize disability or social security payments or impact income tax rates (United Kingdom, Netherlands)	3
Barriers (n=14)	
Budget constraints or the research project did not receive funding	6
Lack of an institutional policy or guidance document	6
Failing to consider the cost of patient engagement at the study design or funding application phase	2
Enablers (n=9)	
Sufficient resources and funding	6
Institutional and financial support at the pre-funding stage to support engagement at project onset	3

APPENDIX

Appendix 1. PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	17
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	18
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	19
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	20
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	21, 41
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	21
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	21
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	21-22
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	22
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	22, 42
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	22, 42
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	22
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	23
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	23
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	23
	13d	Describe any methods used to synthesize results and provide a rationale	23

Section and Topic	Item #	Checklist item	Location where item is reported
		for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	24
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	31, 43-59
Study characteristics	17	Cite each included study and present its characteristics.	24, 43-59
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	24-27, 32-35
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	24-27, 32-35
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	24-27, 32-35
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	27-29
	23b	Discuss any limitations of the evidence included in the review.	29-30
	23c	Discuss any limitations of the review processes used.	29-30
	23d	Discuss implications of the results for practice, policy, and future research.	30
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	20
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	20

Section and Topic	Item #	Checklist item	Location where item is reported
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	TBD
Competing interests	26	Declare any competing interests of review authors.	TBD
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

Appendix 2. GRIPP II short form reporting checklist

Section and topic	Item
1: Aim	Conduct a systematic review to assess the current landscape of reporting patient partner financial compensation and identifying current compensation practices. To partner with a patient partner throughout the development and conduct of the systematic review.
2: Methods	One patient partner (MS) was recruited to join the research team through personal referral. MS was involved in developing the protocol, defining compensation terms, identifying data items for extraction, analyzing systematic review results and contributed to edits of this paper. MS attended virtual team meetings and continued to meet with GF monthly. MS was offered financial compensation and co-authorship in recognition of her contributions to the research project.
3: Results	Patient engagement contributed to the study in several ways including: - Informing the project proposal with the patient partner experience: MS is well integrated in the patient engagement field and has a wealth of experience being a patient partner for several organizations. MS has experience with various methods of compensation, barriers to financial compensation and the different perspectives that patient partners have on financial compensation. - Defining our primary outcome (financial compensation) - Categorizing methods of compensation as reimbursement, financial or non-financial compensation - Identified opportunities to present the systematic review proposal and findings to larger panels of patient partners
4: Discussion	Overall, patient engagement was successful in informing review development and conduct. Additionally, the research team learned a lot about the patient partner experience with financial compensation and institutions are recognizing patient partners for their expertise through discussions with MS about her unique experiences. It was helpful that MS was familiar with most team

	members before joining the research team and that members of the team had experience with patient engagement. The systematic review was conducted within a year. At the beginning of the project, we co-developed a timeline and budget to reflect the number of hours that MS devoted to the project. In the future, we will refer back to this timeline at the mid-term mark to ensure that the number of hours budgeted for were accurate.
5: Reflections	Engagement was embedded within the research project and MS was a member of the research team. MS connected the research team with groups of patient partners who were interested in the systematic review findings. In turn, these connections yielded opportunities to connect with patient groups and disseminate review findings to an important stakeholder group. This would not have been possible without MS.

Appendix 3. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
- Studies that referenced the GRIPP (Guidance for Reporting Involvement of Patients and the Public) reporting checklists (I or II)(19,25) - Studies that engaged or described engaging patients in health research, in which members of the public or patients are engaged as partners. - Studies that described the patient engagement in research component as part of a larger research project were included. - Studies that engaged patients as research partners and research participants. - All study designs	- Studies that engaged patients as research participants - Studies that interviewed patients about their experiences as patient partners - Conference abstracts and commentaries - Studies written in languages other than English

Appendix 4. Data extraction items

Data item
1. Corresponding author name, e-mail address, country of residence, and institutional affiliation at time of publication 2. Publication title 3. Year of publication 4. Journal/Source of publication 5. Funding details (e.g. source of funding, whether funding was received specifically to support patient engagement) 6. Type of stakeholder engaged (e.g. patients, caregivers, community member etc.) 7. Number of patient partners engaged 8. Length of engagement (i.e. whether patient partners were engaged once or multiple times throughout the project) 9. Research element where patient partners contributed (e.g. funding, priority-setting, governance, study design, data collection, data analysis, dissemination, ethics approval etc.) (2) 10. Level of patient partner engagement (as defined by INVOLVE(29)) 11. Non-financial compensation offered to patient partners (e.g. co-authorship, gifts, refreshments etc.) 12. Did authors report on offering financial compensation to patient partners (patient partners need not accept)? (Yes or No) 13. Where are details of financial compensation reported in the manuscript? (e.g. methods, results, discussion) 13 a) Type of financial compensation (e.g. honoraria, salary, cash etc.) 13 b) Amount (rate and total) 13 c) Payment frequency (e.g. bi-weekly, one-payment etc.) 13 d) Reported guidelines or policies used to guide financial compensation 14. Stated reason for financially compensating patient partners or stated reason for not financially compensating patient partners 15. Reported benefits and challenges to financially compensating patient partners 16. Reported barriers and enablers to financially compensating patient partners

Appendix 5. Included studies (n=316)

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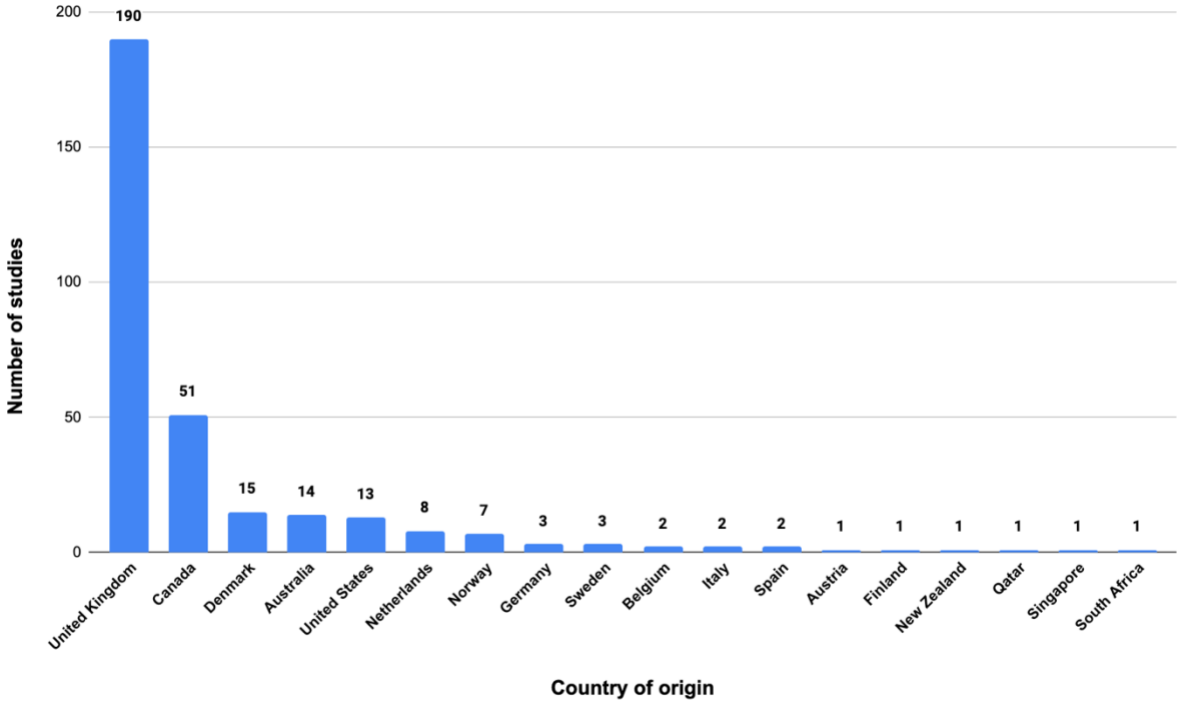
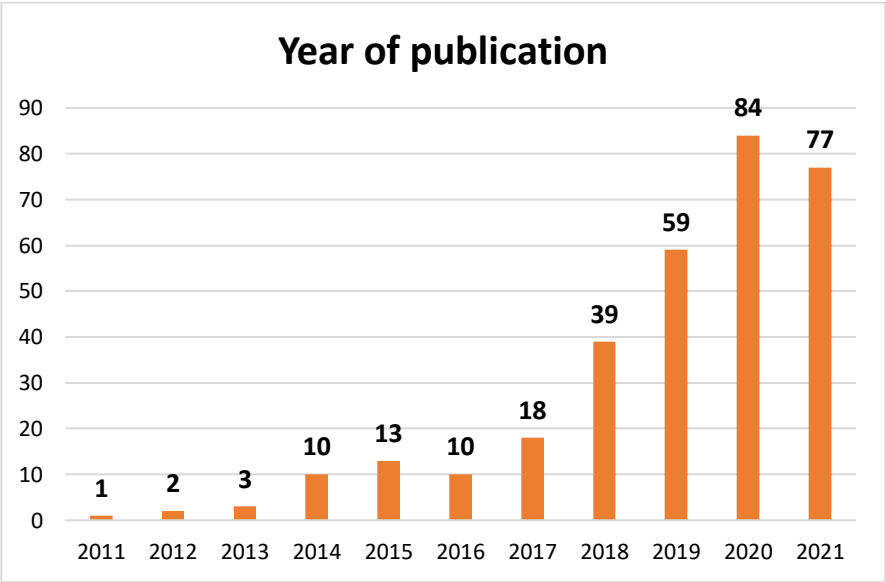
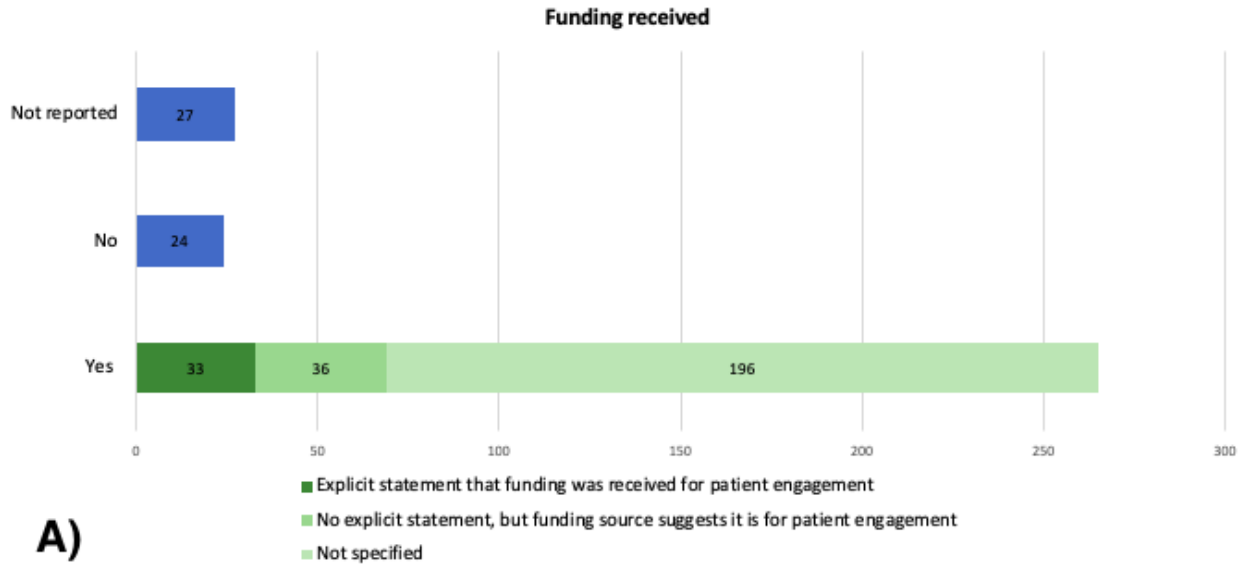
Appendix 6. Geographical Distribution of publications (n=316)

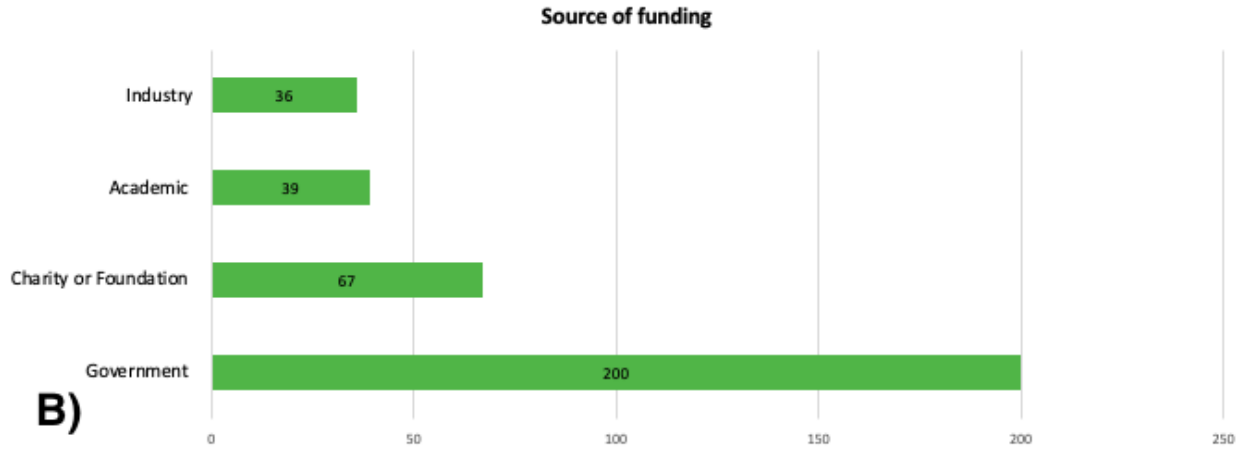


Appendix 7. Year of publication (n=316). The search ended in October 2021.



Appendix 8. A) Funding received (n=316) and B) details of funding (n=265)





Appendix 9. Patient partner characteristics of studies (n=316)

Type of stakeholder engaged	Number of studies (%)
Patient	246 (78)
Caregivers	111 (35)
Member of patient organizations	50 (16)
Community member	46 (15)
Family member	25 (8)
Friends	1 (0.3)
Not specified	25 (8)
Number of patients engaged	
1	31 (10)
2-5	84 (26)
6-10	57 (18)
11-36	72 (23)
40-70	12(4)
100+	13 (4)
Not specified	47 (15)
Were patient partners engaged more than once?	
No	249 (79)
Yes	55 (17)
Unclear	12 (4)

Appendix 10. Patient engagement characteristics of studies (n=316)

Stage of research where patient partners contributed	Number of studies (%)
Project level	
Study design	250 (79)
Dissemination of results	157 (50)
Data analysis	137 (43)
Funding	54 (17)
Priority setting	52 (17)
Data collection	45 (14)
Developing patient engagement strategy	24 (8)
Ethics	11 (3)
Governance	76 (24)
General priority setting	42 (13)
General outcome derivation	16 (5)
Not reported	5 (2)
Level of engagement	
Consult	111 (35)
Collaborate	73 (23)
Empower	19 (6)
Consult and Collaborate	76 (24)
Consult and Empower	11 (3)
Collaborate and Empower	8 (3)
Consult and Collaborate and Empower	6 (2)
Activities are unclear	12 (4)

Appendix 11. Location of reporting patient partner financial compensation

Where are details of patient partner financial compensation reported? (n=79)	Number of studies (%)
Introduction	5 (6)
Methods	43 (54)
Results	12 (15)
Discussion	7 (9)
Funding	3 (4)
Patient and public involvement section	9 (12)
GRIPP checklist	5 (6)
Body of the text	3 (4)
Competing interests	1 (1)
Appendix or Supplementary material	2 (3)

Appendix 12. Guidance documents or policies (n=36)

Guidance document	Number of studies
Guidance documents developed by the National Institute for Health and Care Research or Involve	22
Budgeting for Involvement: Practical Advice on Budgeting for Actively Involving the Public in Research Studies	
National Standards for Public Involvement in Research	
Developing Training and Support for Public Involvement in Research.	
Payment and recognition of public involvement.	
Briefing Notes for Researchers: Involving the Public in NHS, Public Health and Social Care Research.	
What is public involvement in research?	
Reward and Recognition for Children and Young People Involved in Research-Things to Consider	
Policy on payment of fees and expenses for members of the public actively involved with involve.	
Payments and recognition for public involvement	
Centre for Engagement and Dissemination – Recognition payments for public contributors	
Reward and recognition for public contributors - a guide to the payment of fees and expenses	

Greater Manchester Patient Safety Translational Research Centre Guidance on payments and expenses for non-Executive lay-members of Executive Management Board	
Strategies for Patient Oriented Research (SPOR) Evidence Alliance Patient Partner appreciation policy	3
Canadian Institutes for Health Research - Considerations when paying patient partners in research	1
Swansea Clinical Trials Unit (CTU) Standard Operating Practices (SOP)	1
National minimum wage rates or national costs of living	5
Collaborations for Leadership in Applied Health Research (CLAHRC) Patient and Public Involvement Policy	1
SLaM Involvement Register payment rates	1
Staniszewska S, Jones N, Newburn M, Marshall S. User involvement in the development of a research bid: barriers, enablers and impacts. Health Expectations, 2007; 10: 173–183.	1
General patient and public involvement engagement principles	1

Appendix 13: Frequency of reporting patient partner financial compensation within subgroups of highest level of patient engagement in research achieved.

	Highest level of patient engagement achieved		
	Consult	Collaborate	Empower
Financial compensation offered to all or some patient partners	47	49	18
Financial compensation was not offered or not reported	64	24	1
Chi-square value Degrees of freedom p-value	42.41 2 <0.01		

Appendix 14. Stated reasons to financially compensate patient partners and justification for not offering financial compensation

Theme	**Number of studies**
Reasons to financially compensate patient partners (n=22)	
Demonstrate that patient partner contributions are valued and respected	8
Offered financial compensation in accordance with good practice or recommendations outlined in patient engagement guidance documents	4
Support patient partner attendance at research events or team meetings	4
Patient partners that contribute equally to the research project are deserving of financial compensation (i.e. compared to researcher counterparts)	3
Facilitate stronger and sustained engagement	2
Enable patient partners from diverse backgrounds to be engaged	2
Reasons not to financially compensate patient partners (n=7)	
General inability to compensate patient partners (e.g., lack of funding, resource limitations, lack of guidance)	5
Ensures patient partners felt free to express their opinions without the pressures associated with receiving payment	2

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CHAPTER 3: Cross-sectional survey

Recognizing patient partner contributions to health research: a cross-sectional survey of researchers and research institutions

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Preface to Chapter 3

This chapter presents the results of a cross-sectional survey of the corresponding authors of studies included in the systematic review (Chapter 2) and their institutions. Survey results improve our understanding of researcher and institutional leader compensation practices, experienced barriers and challenges to patient partner financial compensation, and stakeholder attitudes of compensation.

ABSTRACT

Background: Offering compensation (i.e., co-authorship, honoraria) to patient partners in research has become increasingly important to demonstrate appreciation and reduce power imbalances. We previously conducted a systematic review to assess the prevalence of patient partner compensation and identify current compensation strategies among a cohort of studies that reported patient engagement in research. Here, we surveyed the corresponding authors (i.e., researchers) of the studies included in the systematic review and their affiliated institutions (i.e., institutional leaders) to gain a better understanding of attitudes around compensation and experienced challenges.

Methods: Survey questions were informed by our systematic review findings and survey procedures were conducted according to validated methods developed by Dillman. Researchers and institutional leaders were asked about their experiences with patient partner compensation, and challenges to financial compensation. Researcher attitudes around compensation were assessed using the Continuing Professional Development (CPD) questionnaire. Participants received the anonymous survey by email.

Results: From 256 researchers, we received 90 responses (35%) and 86 completed surveys (34%). The most commonly reported method of recognition was offering co-authorship (91%,n=81) and 70 (79%) respondents indicated previously offering financial compensation to patient partners (e.g., honoraria, salary). CPD questionnaire responses indicated that researchers are generally positive about their intentions to offer financial compensation and neutral about their abilities to offer compensation. From 236 institutional leaders, we received 26 completed surveys (11%). The majority of respondents indicated that their institution allows financial compensation of patient partners (85%,n=22). Both researcher and institutional leader respondents identified lack of institutional guidance or policy as a key challenge of patient partner financial compensation.

Discussion: Our survey findings present logistical barriers to financial compensation experienced by researchers and institutional leaders, ultimately helping inform implementation strategies to further support patient partner compensation.

INTRODUCTION

Patient engagement in research is defined as active involvement of patients and caregivers, commonly referred to as patient partners, in the research process.(1) The ultimate goal of patient engagement in research is to produce research that is relevant to the ultimate end user. Patient engagement has proven to benefit research in several ways including improved research relevance by aligning with patient priorities, better recruitment in clinical trials, and enhanced readability of research products.(2) As a result, uptake of patient engagement in research is increasing in all areas of health research.(2–5)

Offering compensation to patient partners as a recognition of their contributions, time and effort has become increasingly desirable. Patient partner recognition has been suggested as a method to reduce power imbalances between team members and foster an inclusive environment where patient partners feel comfortable sharing their perspectives.(6,7) Recognition can take on many forms including offering co-authorship, training opportunities, or financial compensation (i.e., offering something of monetary value in exchange for involvement). Financial compensation, in particular, has been proposed as a way of enabling people from diverse socioeconomic backgrounds to be engaged in research.(6,7)

The provision of financial compensation is complex, with benefits and important implications such as increased income tax rates or interfering with patient partner ability to accept disability payments.(8,9) Richards and colleagues compiled a list of additional barriers to financial compensation from the perspectives of the patient partner including institutional barriers.(10) For example, institutions that don't have infrastructure in place to support patient partner financial compensation may repurpose existing contracts to detail compensation. Using this strategy, researchers are providing patient partners with technical legal documents that protect the institution from any risk associated with patient engagement, which can discourage patient partners from being involved.(10) Additionally, another team of patient partners used their experiences to inform a discussion piece detailing the importance of compensation.(6) Missing from this evidence is an understanding of researcher and institutional perceptions of compensating patient partners and experienced barriers and challenges of offering financial compensation. While guidance documents exist to support researchers in navigating patient partner financial compensation (9,11–16), it is unknown what challenges may remain to implementing patient partner compensation practices at the research and institutional levels.

We recently undertook a systematic review to identify a cohort of studies that have engaged patients in research and assessed reporting of patient partner recognition and financial compensation. From the 316 studies included in the review, 79 reported offering financial compensation to patient partners. Moreover, the role played by institutions in guiding and supporting researchers was identified as being crucial. While few studies reported offering financial compensation, it was not clear what is preventing researchers from offering compensation. Here we report a cross-sectional survey of researchers and institutional members identified in our systematic review to address the following objectives: 1) gain an understanding of researcher beliefs about their compensation efforts and 2) identify challenges and barriers experienced by both researchers and institutional members when offering financial compensation to patient partners.

METHODS

Study design

We conducted a cross-sectional survey of researchers and members holding senior leadership positions within institutions (i.e., referred to as institutional leaders hereafter) in accordance with validated methods developed by Dillman (17). This manuscript is reported in accordance with the Checklist for Reporting of Survey Studies (CROSS).(18) The protocol was registered on Open Science Framework (https://osf.io/r46qw/) and published as part of a larger research program.(19) We received ethics approval from the Ottawa Health Science Network Research Ethics Board (OHSN-REB) (Protocol ID#: 20220058-01H).

Sampling frame

Researchers: We recently undertook a systematic review to identify a cohort of studies that have engaged patients in research and assessed reporting of patient partner recognition and financial compensation. The full study is in preparation for submission (19) and we present an overview here to demonstrate how the survey sampling frame was obtained. Original articles were identified using a forward citation search of the Guidance for Reporting Involvement of Patients and Public (GRIPP I/II) (20,21) checklists. This approach offered a highly specific method of identifying published studies with patient engagement. The corresponding authors (i.e., researchers) of the studies included in the systematic review and their affiliated institutions make up the sampling frame for this survey study, thus convenience sampling was used. The systematic review identified 316 published studies that engaged patients, and which included 276 unique corresponding authors.

Institutional leaders: Reviewers searched for the name and email addresses of institutional leaders holding positions within the institutions affiliated with the corresponding authors. For example, contact information for Deans of academic institutions were captured, and Scientific Director contact information for research institutes. In the event that there was more than one institution listed, we prioritized the research institution followed by the academic institution since research institutions likely have better access to potential patient partners and closer relationships. If we identified two publications authored by the same researcher using different affiliations, we extracted information for both affiliations. We identified 246 unique institutions from the 316 published studies.

Survey development

The first draft of the survey questions was informed by the results of our systematic review and existing published guidance around patient partner financial compensation.(6) Both the researcher and institutional surveys were purposefully short (i.e., 5 minutes to complete) to increase response rate. One team member (GF) developed both surveys and circulated to the team for review. After several iterations, all team members approved the final survey drafts. Surveys were hosted on LimeSurvey.

Researcher survey: The survey administered to researchers was divided into four sections (About You, Your Experience with Patient Partner Recognition, Challenges to Financially Compensating Patient Partners, Your Opinions Around Patient Partner Financial Compensation). The researcher survey can be found in Appendix 1. The survey consisted of six multiple choice questions (Appendix 1, Questions 1 – 5b) and asked about respondent research position, gender, previous compensation offered to patient partners, ideal methods of recognition (i.e., in an ideal world with no barriers or resource constraints), and experienced challenges and barriers to financial compensation. Only respondents who indicated that they have experience offering financial compensation to patient partners in previous questions were asked about challenges to offering compensation. The last survey question was a 12-item Likert scale question (Appendix 1, Question 6) guided by the validated Continuing Professional Development (CPD) questionnaire to assess respondents' beliefs and attitudes around patient partner financial compensation and their behaviours.(22) The CPD questionnaire is informed by the Theory of Planned Behaviour and measures respondents behaviour, while taking into consideration four constructs including: their Intention, Social Influence, Beliefs about Capabilities, Moral Norm, and Beliefs about Consequences. Respondents rank each item on a 7-point scale.

Institutional leader survey: The survey administered to institutional leaders was divided into two sections (Your Experience with Patient Partner Recognition, Challenges to Financially Compensating Patient Partners). The survey consisted of four multiple choice questions and asked institutional leaders if they have experience offering financial compensation to patient partners, if their institution allows for patient partner financial compensation, to indicate if they use an institutional policy, and identify experienced challenges to offering financial compensation. Only respondents who indicated that they have experience offering financial compensation to patient partners in the first question were asked about challenges. The institutional leader survey can be found in Appendix 2. The researcher survey was piloted internationally by seven researchers (i.e., Canada, United Kingdom, Australia) with experience of patient engagement in research. The results of the piloting exercise improved question clarity, considering variable terminology between countries, and usability.

Survey administration

Corresponding author contact information and affiliation details were extracted from the systematic review. Institutional leader names and contact information were extracted from institutional web sites. The surveys were sent to researchers and institutional leaders without previous notifications on May 16 and 17 2022 respectively by email invitation. Emails were sent from a team members email (GF) and signed on behalf of three team members (GF, MML, DAF). Unique tokens were assigned to each participant within the survey platform to keep track of submissions. As a result, the survey was closed to participants who received the invitation email and recipients could not make multiple submissions. However, it is possible that recipients forwarded the email invitation to a colleague to respond. In accordance with validated survey administration methods developed by Dillman (17), three separate reminders were sent to non-respondents 1, 3, and 7 weeks after the initial invitation was sent. All survey responses are anonymized within LimeSurvey. Undeliverable emails were removed from the total sample size when calculating response rate.

Statistical analysis

Both partially and fully completed surveys were included in data analysis. Response rates were determined by the number of respondents who answered at least one survey question divided by the total number of email invitations sent (i.e., excluding undeliverable emails). Data were exported from LimeSurvey, stored by question and analyzed in a protected Excel file. Respondent characteristics (e.g.,

demographics) were presented in a table and descriptive data were presented using bar charts. Proportions were generated for responses to multiple choice questions and determined using the total number of responses for each question. Mean and median ranks and standard deviations are presented for each of the five CPD domains and each of the twelve items. Means, medians and standard deviations were calculated in Excel. No subgroup analyses were conducted.

Patient engagement

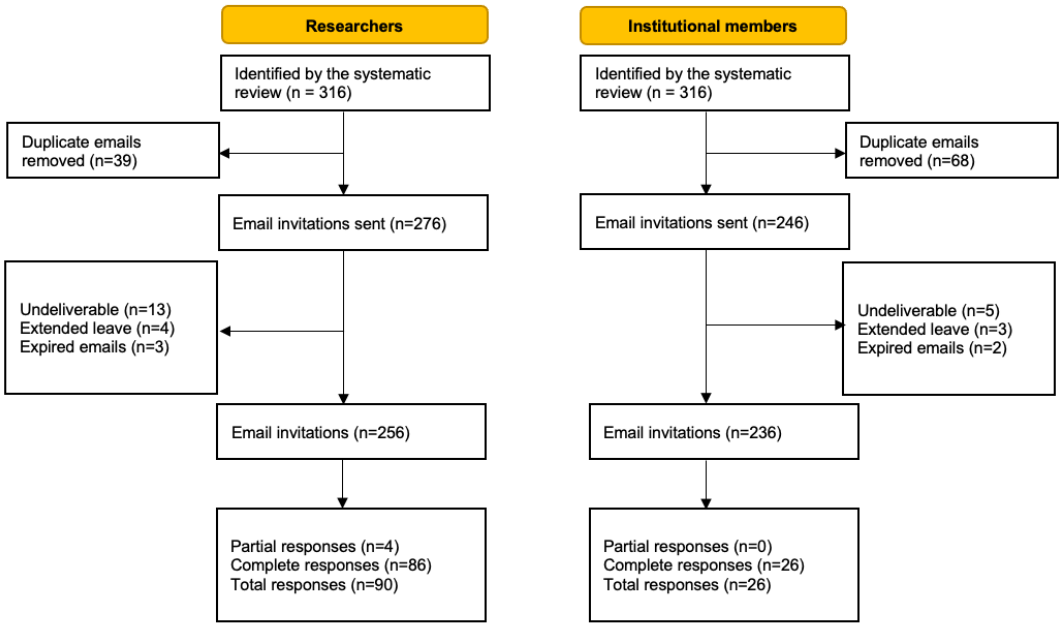
We partnered with a patient partner (MS) throughout the development and conduct of this cross-sectional survey. Maureen Smith has patient engagement in research experience in many capacities both nationally and internationally and at different levels. She has special interest in patient partner recognition. Maureen attended all team meetings and is a recognized member of the research team. In fact, she is a co-author on this manuscript. We offered financial compensation to demonstrate our appreciation for her expertise.(12) Our patient engagement strategy was co-developed a priori using a terms of reference document and informed by INVOLVE's 7 Core Principles of Engagement (23) and the CIHR SPOR Patient Engagement framework.(24) The completed GRIPP II checklist can be found in Appendix 3 and further details of engagement are described in Chapter 5.

RESULTS

Respondent characteristics

Of 256 researchers emailed an invitation to participate in the survey, 90 (35.1% response rate) responded to at least one of the survey questions with 86 (33.5%) completing the entire survey. Of 236 institutional leaders emailed an invitation to participate in the survey, 26 (11% response rate) completed the survey. A flow diagram of survey respondents can be found in Figure 1.

Figure 1. Flow diagram of survey respondents



Researcher demographics

The majority of researcher respondents were academic researchers (82%, n=74), mostly identifying as mid-career researchers (37%, n=33), and self-identified as women (82%, n=74) (Table 1).

Table 1. Researcher respondent demographics (N=90)

Characteristic	**Frequency (%)**
Please select the option(s) that best describes your research position	
Early career researcher (for a period of <5 years)	16 (18)
Mid-career investigator (assumed independent research position 5-15 years ago)	33 (36)
Senior investigator (assumed independent research position >15 years ago)	25 (26)
Post-doctoral fellow	9 (9)
Graduate student (Master's or Doctoral)	5 (6)
Medical resident/registrar	1 (1)
Research personnel (e.g. Research Associate/Assistant/Coordinator)	3 (3)
Other *Consultant Healthcare* *Director at a community interest company* *Service user researcher* *Public involvement practitioner* *Patient partner and patient engagement practitioner*	5 (10)
Please indicate your gender	
Woman	74 (82)
Man	13 (14)
Non-binary person	2 (2)
Prefer not to disclose	1 (1)

Researcher experiences and ideal methods of patient partner compensation

The most commonly reported methods of recognizing patient partner contributions to research were offering co-authorship (91%, n=81), providing reimbursement for out-of-pocket expenses (83%, n=74), and acknowledgement on research outputs (81%, n=72) (Table 2). Sixty-nine (78%) respondents indicated that they have previously offered more than three methods of recognition. Seventy (79%) respondents indicated that they previously offered financial compensation to patient partners in the form of honoraria, salary, or a gift card where the monetary value was determined by a formal conversion. In terms of ideal methods of recognition, there was an observed increase in the number of respondents that would prefer to offer salary (43%, n=38) when compared to the number of respondents that reported offering salary to patient partners (21%, n=19) and an observed decrease for all other methods of recognition (Table 2). Notably, four respondents used the *Other* category to indicate that they would ideally offer whatever patient partners prefer.

Table 2. Researcher experiences with patient partner compensation and ideal methods of recognizing patient partners.

Method of recognition	**[a]Methods of compensation offered to patient partners (n=89)**	**[b]Ideal methods of patient partner compensation (n=89)**
	Frequency (%)	**Frequency (%)**
Co-authorship	81 (91)	60 (67)
Reimbursement for out-of-pocket expenses (e.g. travel, accommodations, parking, meals etc.)	74 (83)	38 (43)
Acknowledgement on manuscripts or other research output/material	72 (81)	16 (18)
Facilitating attendance at a conference or other research event (e.g.,paying attendance fee or other costs, arranging travel or accommodations)	56 (63)	27 (30)
Honoraria, cheque, or cash payment	55 (62)	36 (40)
Gifts or gift cards where the value was determined by a formal conversion for work completed. (e.g. 2 hours of work at $25 per hour = $50 gift or gift card value)	39 (44)	13 (15)
Services (i.e. organizing training/certification opportunities)	30 (34)	13 (15)
Gifts or gift cards where the amount was not determined by a formal conversion	29 (33)	1 (1)
Salary	19 (21)	38 (43)
Other	9 (10)	9 (10)

[a]When thinking about your recent collective experience (e.g. last 2-3 years) of collaborating with patients as partners on your research team, which of the following methods of recognition have you offered to patient partners (patient partners need not accept) ? (Check all that apply)
[b]In an ideal world (i.e. no barriers or resource constraints), what would be your preferred methods of recognizing patient partners? (Check up to 3 choices)

Barriers and challenges of patient partner financial compensation from the researcher perspective

The most commonly reported barriers to offering financial compensation to patient partners were limited project budget (48%, n=43) and institutional barriers (39%, n=35) (Figure 2). Twenty (22%) respondents listed additional barriers including financial implications to patient partners for accepting financial compensation (n=11). Two respondents indicated that it is uncommon in their institution to offer financial compensation to patient partners, while only one respondent indicated that they were not aware that patient partners are being offered financial compensation. Other reported barriers include lack of funding and patient partner refusal.

Sixty-four respondents who offered financial compensation to patient partners, were asked about experienced challenges. The most commonly reported challenges include institutional barriers to compensation (66%, n=42) and financial compensation interfering with patient partner income (e.g., income tax rates, disability payments) (53%, n=34) (Figure 3). One respondent highlighted that, while institutional barriers do not necessarily prevent financial compensation, they slow the process and can be burdensome.

Figure 2. Researcher reported barriers to offering financial compensation to patient partners (n=89)

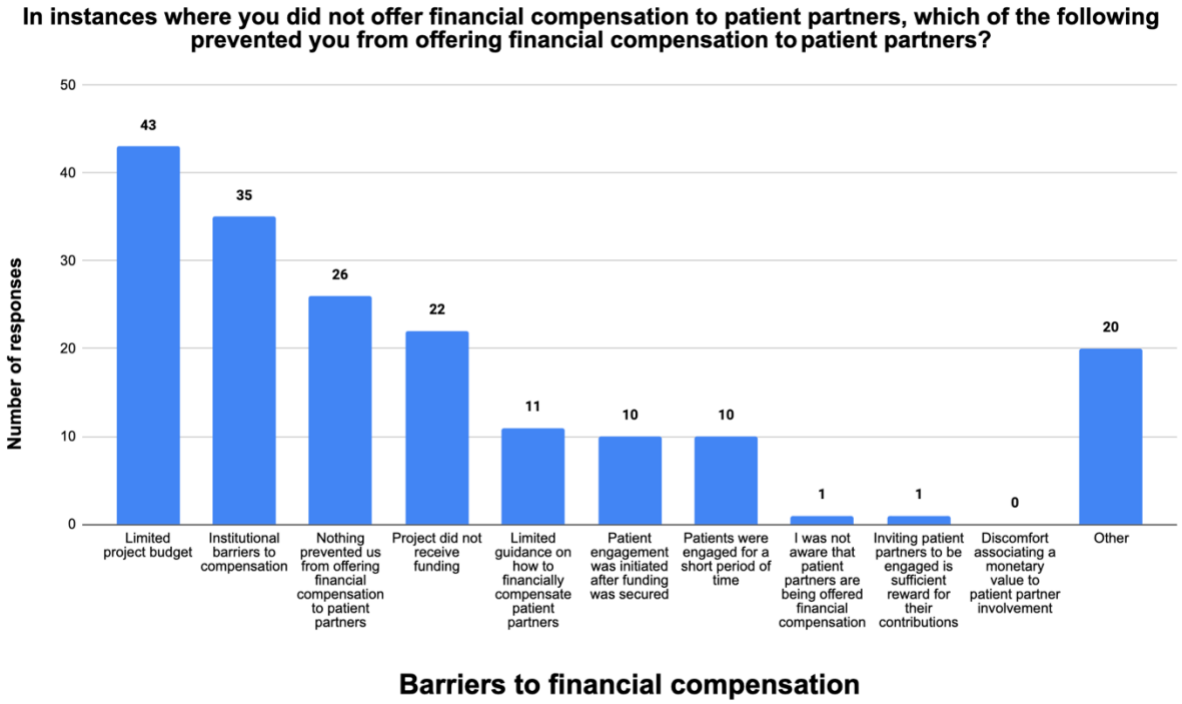
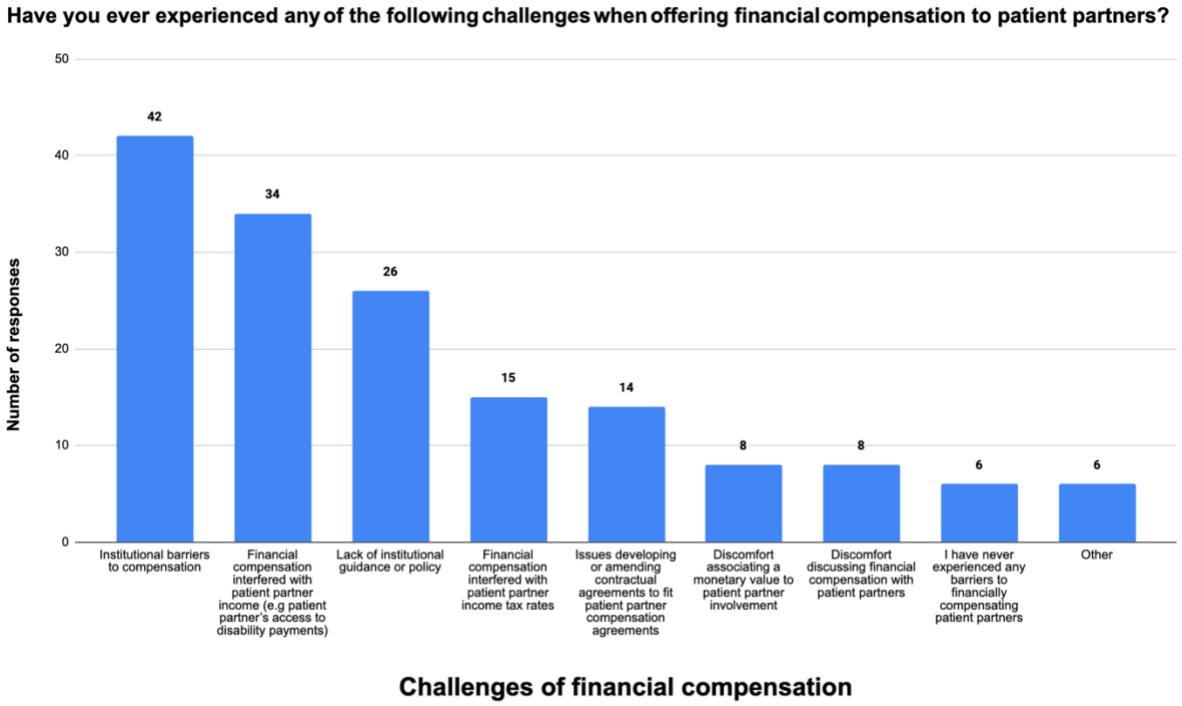


Figure 3. Researcher reported challenges when offering financial compensation to patient partners (n=64)



Researcher beliefs and attitudes around patient partner financial compensation

The final Likert-scale question assessed five domains of behavior (Intention, Social Influence, Beliefs about Capabilities, Moral Norm, and Beliefs about Consequences). Researcher responses indicated that they intended to offer financial compensation to patient partners (6.2±1.6, mean ± standard deviation), were in favour of patient partner compensation (6.3±1.5) when asked about moral norm, and believed that offering financial compensation is useful and beneficial (6.2±1.4). (Table 3) Conversely, researcher respondents were relatively neutral in terms of social influence on their patient partner compensation behaviors (4.8±1.9) and beliefs in their abilities to offer financial compensation (5.0±1.9).

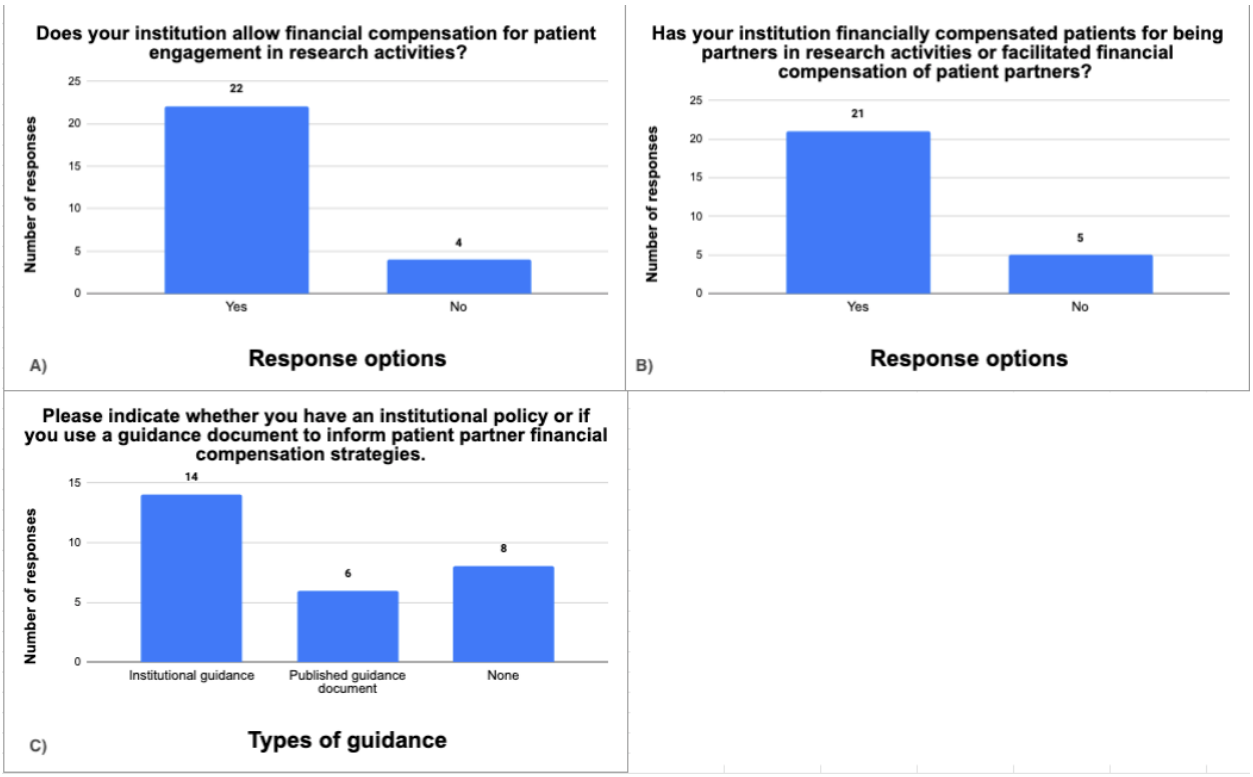
Table 3. Beliefs and attitudes around patient partner financial compensation (n=86)

Construct	Construct mean (SD)	Construct median	Item	Item mean (SD)	Item median	Strongly disagree						Strongly agree
						1	2	3	4	5	6	7
Intention	6.2 (1.6)	7	I intend to financially compensate patient partners.	6.2 (1.6)	7	5	0	0	7	1	15	58
			I plan to financially compensate patient partners.	6.2 (1.6)	7	5	0	0	5	7	12	57
Social influence	4.8 (1.9)	5	Now think about a co-worker whom you respect as a professional. In your opinion, does this person financially compensate patient partners?	5.2 (1.7)	6	4	4	3	19	12	18	26
			Most colleagues financially compensate patient partners.	4.5 (2.0)	5	7	10	14	11	13	11	20
			To the best of my knowledge, the percentage of my research colleagues who financially compensate patient partners is:	4.7 (1.9)	61-80%	0-20%	21-40%		41-60%	61-80%		81-100%
						13	12		15	26		20
Beliefs about capabilities	5.0 (1.9)	5	I believe that I could financially compensate patient partners if I wanted to.	5.4 (1.9)	6	6	3	6	10	12	12	37
			I have the ability (i.e. financial means, institutional support, guidance) to financially compensate patient partners.	4.8 (2.0)	5	6	12	5	10	17	11	25
			For me, financially compensating patient partners would be:	4.8 (1.6)	5	Extremely difficult						Extremely easy
						3	7	5	16	23	19	13
Moral norm	6.3 (1.5)	7	Financially compensating patient partners is the ethical thing to do.	6.3 (1.6)	7	4	2	0	4	2	12	62
			It is acceptable to financially compensate patient partners.	6.3 (1.4)	7	4	0	1	4	1	15	61
Beliefs about consequences	6.22 (1.35)	7	Overall, I think that for me to financially compensate patient partners would be:	6.28 (1.29)	7	Useless						Useful
						2	0	1	6	8	12	57
			Overall, I think that for me to financially compensate patient partners would be:	6.16 (1.40)	7	Harmful						Beneficial
						2	2	1	5	7	17	52

Institutional leader survey responses

Overall, the majority of respondents indicated that their institution allows financial compensation of patient partners (85%, n=22)(Figure 4A) and has experience offering financial compensation to patient partners or facilitating compensation (81%, n=21)(Figure 4B). Six respondents reported the use of published compensation guidance including those developed by the Strategies for Patient Oriented Research (SPOR) Networks (Chronic Diseases and the Primary and Integrated Health Care Innovations Network (n=1), CHILD-BRIGHT Network (n=1))(9)(25), National Institutes for Health Research documents (n=2)(26), and the Centre d'Excellence sur les Partenariats avec les Patients et le Public (n=2)(27)(Figure 4C).

Figure 4. Institutional leader responses regarding institutional practices (n=26)

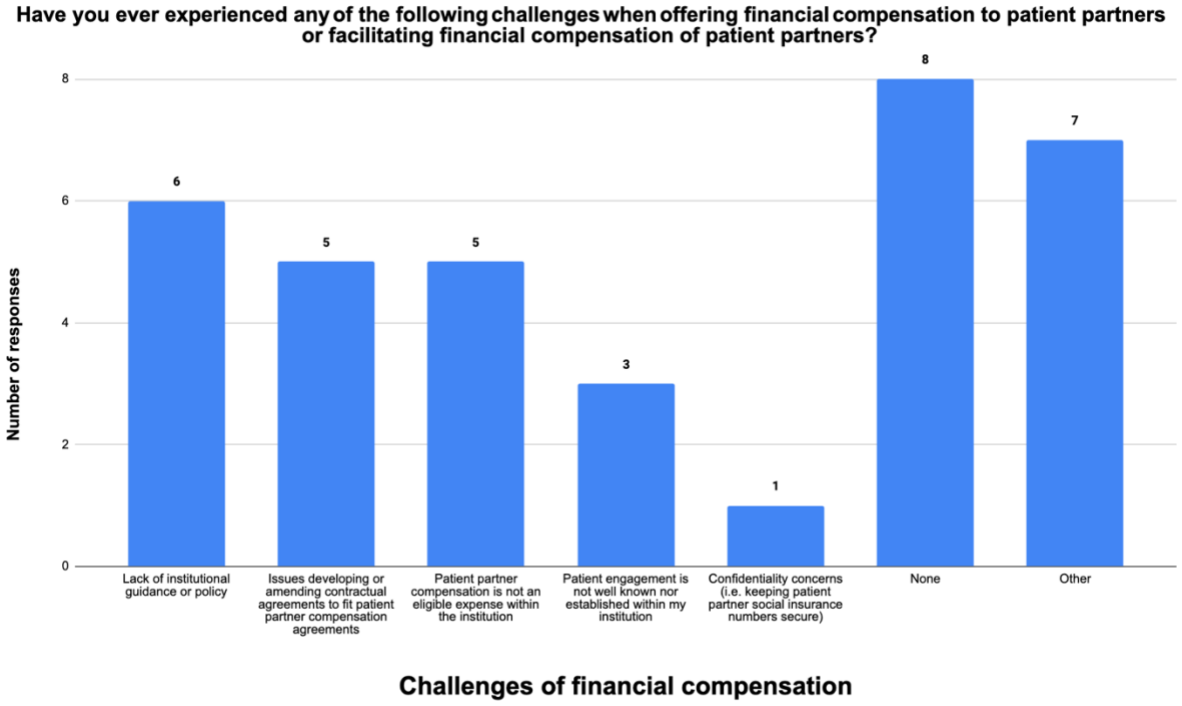


Challenges of offering financial compensation from the institutional perspective

Institutional respondents who indicated that their institution has experience offering financial compensation to patient partners or facilitating compensation were asked about any challenges that they may have encountered. Six respondents noted lack of institutional guidance or policy as a challenge to offering financial compensation (Figure 5). Other identified challenges include patient partner inability to accept financial compensation due to impacts on income streams, issues reporting financial

compensation to national revenue agencies, and lack of funding. Eight respondents indicated that they did not experience any challenges when offering financial compensation.

Figure 5. Challenges of offering financial compensation from the perspectives of institutional leaders (n=21)



DISCUSSION

Our study provides an understanding of how compensation is used to recognize patient partners and the barriers and challenges to financial compensation from the perspectives of researchers who have experience with patient engagement in research and their institutions. We sampled a group of researchers who have published patient engagement research and referenced the GRIPP checklists (20,21) and found that the majority of respondents, both researchers and institutional members, have experience offering financial compensation to patient partners. Additionally, we identified institutional procedures (e.g., lack of institutional policy or support) as a key challenge of financial compensation from the perspectives of all survey respondents. Overall, researchers are generally positive about their abilities to offer financial compensation. Our survey findings highlighted logistical barriers to financial compensation and serve to help inform implementation strategies to further support patient partner compensation.

The majority of researcher respondents reported offering non-financial methods of compensation including co-authorship and acknowledgement. When asked about their ideal method of compensation, there was an observed increase in the number of respondents who would ideally offer salary when compared to the number of respondents who reported using salary to recognize patient partners. Additionally, there was an observed decrease in all other methods of compensation. It is important to note that the majority of respondents (78%) reported utilization of more than three methods of compensation before being limited to selecting only three ideal methods of compensation. However, these results support that lack of financial compensation may be a result of practical barriers rather than ideological barriers. For example, offering a salary to patient partners may have tax implications or interfere with their ability to accept disability payments. In fact, our systematic review identified financial implications of accepting payment as a key challenge to financial compensation(19) and several guidance documents advise researchers to consider the impacts that payment may have on patient partner income streams.(25,28–30) Additionally, eight researcher respondents used the textboxes to clarify that, while they indicated their preferred methods of recognition, they would rely on patient partner preferences to guide decision-making. While survey findings may suggest that researchers intend to offer financial compensation in the form of salary more often, it is important to remember that patient preferences require consideration.

While most respondents indicated that they have not encountered any challenges, some indicated unlisted challenges including reporting compensation to national revenue agencies and lack of financial department understanding of how to process payments. The two most commonly indicated researcher experienced barriers to financial compensation were limited project budget and institutional barriers. Similarly, Richards and colleagues highlighted amending or creating contractual agreements to fit the patient partner relationship as a key barrier to financial compensation.(10) Institutions that do not have the infrastructure in place to support financial compensation may repurpose consultation agreements to describe contracting externally for patient partner involvement on a research project. This can be problematic when contracts contain legal jargon and clauses to protect the institution from risks of working with external consultants. Moreover, several researcher respondents noted that funding was secured after the initiation of patient engagement, thus preventing researchers from offering financial compensation. Indeed, "failing to consider the cost of patient engagement in research" was identified as a key barrier in the systematic review conducted by our group.(19) One way to overcome this barrier is to incorporate the costs of patient engagement (e.g., reimbursement for travel, financial compensation) within the research project budget. Indeed, the George & Fay Yee Centre for Healthcare Innovation Public and Patient Engagement team developed a publicly available budget spreadsheet to help researchers financially prepare for patient engagement in research.(31) The budget calculator takes into consideration the costs of engagement activities, compensation, and costs associated with accessibility and inclusivity (e.g., caregiver or childcare costs).(32) Funding agencies should adopt guidance or tools to inform researchers of the importance of budgeting for engagement and guide appropriate budgeting.

Although researcher and institutional perceptions on patient engagement in research have not been thoroughly studied, it is notable that the topic of financial compensation has been highlighted.(33)(34) Beland and colleagues interviewed academic researchers and patient partners to gain an understanding of their experiences with patient engagement.(33) Interviewees noted that offering financial compensation can maximize the benefits of engagement by ensuring that patient partners are actively involved throughout the research project. With that said, the researchers who were interviewed noted that while they are well intentioned to offer financial compensation, they are limited by the capacity of their institutions; for example, when patient engagement is supported by an institution but clear guidance on how to offer financial compensation to patient partners is not established. From the survey results, researchers were generally positive about their intentions to offer financial compensation to patient partners despite being more neutral on their beliefs of capabilities and identifying several

barriers to compensation. It is plausible that offering financial compensation to patient partners is not only driven by intention but highly dependent on external factors like institutional approval and available funding. This finding demonstrates that researchers may be aware of the importance of financial compensation and intend to comply but may not have the support necessary to follow through.

While our survey findings have improved our understanding of researcher and institutional member compensation activities and attitudes, several limitations should be noted. First, our response rate was modest. Since researcher respondents were identified by publications dating back to 2011, they may no longer conduct patient engagement research and thus did not respond to the survey. Similarly, members holding high leadership positions within their institutions may not have oversight or direct experience with patient partner compensation. Additionally, it is likely that those who responded to the survey may have a more positive perspective of patient partner financial compensation.(35,36) Second, our sample population consists of researchers who published research involving patient partners and may be well-versed in patient engagement in research concepts including compensation. This was evident from survey findings as only one respondent indicated that they were unaware of patient partner compensation. While our survey is international, our sample is geographically limited with 69% of the sample population residing in countries that have the infrastructure in place to support patient engagement research (e.g., Canada, United States of America, United Kingdom).(19) A study conducted in Japan found that only 50% of surveyed researchers were familiar with patient engagement concepts and may experience different challenges or barriers to engaging patients.(37). While knowledge gaps were likely overlooked, our survey findings identified logistic and technical barriers and challenges to patient partner compensation experienced by adept patient engagement researchers.

Our survey findings enhance our understanding of researcher and institutional compensation practices, and perceived barriers and challenges of compensation and attitudes around financial compensation. While our study population consists of researchers and institutions who have experience conducting and supporting patient engagement in research, this allowed us to identify logistical hurdles that need to be overcome to facilitate patient partner financial compensation. Overall, there is an emphasis on institutional processes and the role played by institutions in supporting patient partner financial compensation. Assessing opinions and perspectives of both patient partners and researchers who are not familiar with patient engagement in future studies will contribute to our understanding of the entire landscape.

Appendix 1. Researcher survey

Page 2 - About you

1. Please select the option that best describes your research position:

☐ Early career researcher (for a period of <5 years)
☐ Mid-career investigator (assumed independent research position 5-15 years ago)
☐ Senior investigator (assumed independent research position >15 years ago)
☐ Post-doctoral fellow
☐ Graduate student (Master's or Doctoral)
☐ Medical resident/registrar
☐ Undergraduate student
☐ Medical student
☐ Research personnel (e.g. Research Associate/Assistant/Coordinator)
☐ Other: _____ (200-character limit)

2. Please indicate your gender:

☐ Woman
☐ Man
☐ Transgender man
☐ Transgender woman
☐ Non-binary person
☐ Prefer to self-identify _____
☐ Prefer not to disclose

Page 3 - Your Experience with Patient Partner Recognition

3. When thinking about your recent collective experience (e.g. last 2-3 years) of collaborating with patients as partners on your research team, which of the following methods of recognition have you offered to patient partners (patient partners need not accept) ? (Check all that apply)

Type of recognition

☐ Co-authorship
☐ Acknowledgement on manuscripts or other research output/material
☐ Facilitating attendance at a conference or other research event (e.g. paying attendance fee or other costs, arranging travel or accommodations)
☐ Gifts or gift cards where the value was determined by a formal conversion for work completed. (e.g. 2 hours of work at $25 per hour = $50 gift or gift card value)
☐ Gifts or gift cards where the amount was not determined by a formal conversion.
☐ Honoraria, cheque, or cash payment
☐ Salary
☐ Reimbursement for out-of-pocket expenses (e.g. travel, accommodations, parking, meals etc.).
☐ Services (i.e. organizing training/certification opportunities)
☐ Other

Please specify ___

☐ None of the above

4. In an ideal world (i.e., no barriers or resource constraints), what would be your preferred methods of recognizing patient partners? (Check up to 3 choices)

☐ Co-authorship

☐ Acknowledgement on manuscripts or other research output/material

☐ Facilitating attendance at a conference or other research event (i.e. paying attendance fee, arranging travel or accommodations)

☐ Gifts or gift cards where the value was determined by a formal conversion for work completed. (e.g. 2 hours of work at $25 per hour = $50 gift or gift card value)

☐ Gifts or gift cards where the amount was not determined by a formal conversion.

☐ Honoraria

☐ Salary

☐ Reimbursement for out-of-pocket expenses (e.g. travel, accommodations, parking, meals etc.).

☐ Services (i.e. training opportunities, certification)

☐ Other

Please specify ___

Page 4 – Challenges to Financially Compensating Patient Partners

For the purposes of this survey, patient partner financial compensation is defined as:

- Offering monetary means in exchange for patient partner contributions to the research project[1]
- Financial compensation extends beyond reimbursement for out-of-pocket expenses
- For example, honoraria, cheques, cash, or salary (formal payroll). Gifts or gift cards are considered financial compensation if the value of the gift or gift card was determined by using a formal conversion (i.e. 2 hours of work at $25 an hour = $50 gift or gift card) or patient partners decide that they want to receive payment in the form of gifts or gift cards.

[1]Canadian Institutes of Health Research. Consideration when paying patient partners in research 2019 [cited 2021 July 8]. Available from: https://cihr-irsc.gc.ca/e/51466.html.

5.a In instances where you did not offer financial compensation to patient partners, which of the following prevented you from offering financial compensation to patient partners?

☐ Limited project budget

☐ Patient engagement was initiated after funding was secured

☐ Project did not receive funding

☐ I was not aware that patient partners are being offered financial compensation

☐ Limited guidance on how to financially compensate patient partners

☐ Discomfort associating a monetary value to patient partner involvement

☐ Inviting patient partners to be engaged is sufficient reward for their contributions

☐ Patients were engaged for a short period of time

☐ Institutional barriers to compensation

☐ Nothing prevented us from offering financial compensation to patient partners

☐ Other:

Please specify: ___

5.b Have you ever experienced any of the following challenges when offering financial compensation to patient partners?

☐ Discomfort associating a monetary value to patient partner involvement

☐ Discomfort discussing financial compensation with patient partners

☐ Financial compensation interfered with patient partner income (e.g extra income would interfere with patient partner's access to disability payments)

☐ Financial compensation interfered with patient partner income tax rates

☐ Issues developing or amending contractual agreements to fit patient partner compensation agreements

☐ Institutional barriers to compensation

☐ Lack of institutional guidance or policy

☐ I have never experienced any barriers to financially compensating patient partners

☐ Other

Please specify: _____

Page 5 – Your Opinions around Patient Partner Financial Compensation

6. Please answer the following questions by marking the number that best describes your opinion about financially compensating patient partners. Our questions are informed by the Continuing Professional Development (CPD) Reaction Questionnaire, which is a validated tool to assess behaviour. Some of the questions may appear to be similar, but they do address somewhat different aspects of patient partner compensation.

For the purposes of this survey, patient partner financial compensation is defined as:

- Offering monetary means in exchange for patient partner contributions to the research project[1]
- Financial compensation extends beyond reimbursement for out-of-pocket expenses
- For example, honoraria, cheques, cash, or salary (formal payroll). Gifts or gift cards are considered financial compensation if the value of the gift card was determined by using a formal conversion (i.e. 2 hours of work at $25 an hour = $50 gift or gift card) or patient partners decide that they want to receive payment in the form of gifts or gift cards.

[1]Canadian Institutes of Health Research. Consideration when paying patient partners in research 2019 [cited 2021 July 8]. Available from: https://cihr-irsc.gc.ca/e/51466.html

Opinion	**Strongly disagree**						**Strongly agree**
I intend to financially compensate patient partners.	1	2	3	4	5	6	7
I plan to financially compensate patient partners.	1	2	3	4	5	6	7
I believe that I could financially compensate patient partners if I wanted to.	1	2	3	4	5	6	7

I have the ability (i.e. financial means, institutional support, guidance) to financially compensate patient partners.	1	2	3	4	5	6	7
Financially compensating patient partners is the ethical thing to do.	1	2	3	4	5	6	7
It is acceptable to financially compensate patient partners.	1	2	3	4	5	6	7
Most colleagues financially compensate patient partners	1	2	3	4	5	6	7
	Extremely difficult						**Extremely easy**
For me, financially compensating patient partners would be:	1	2	3	4	5	6	7
	Useless						**Useful**
Overall, I think that for me to financially compensate patient partners would be:	1	2	3	4	5	6	7
	Harmful						**Beneficial**
Overall, I think that for me to financially compensate patient partners would be	1	2	3	4	5	6	7
	Never						**Always**
Now think about a co-worker whom you respect as a professional. In your opinion, does this person financially compensate patient partners?	1	2	3	4	5	6	7
To the best of my knowledge, the percentage of my research colleagues who financially compensate patient partners is:	0-20%		21-40%	41-60%	61-80%		81-100%

Appendix 2. Institutional member survey.

Page 2 - Your Experience with Patient Partner Recognition

1.Does your institution allow financial compensation for patient engagement in research activities?
For the purposes of this survey, patient partner financial compensation is defined as:

- Offering monetary means in exchange for patient partner contributions to the research project[1]
- Financial compensation extends beyond reimbursement for out-of-pocket expenses
- For example, honoraria, cheques, cash, or salary (formal payroll). Gifts or gift cards are considered financial compensation if the value of the gift or gift card was determined by using a formal conversion (i.e. 2 hours of work at $25 an hour = $50 gift or gift card) or patient partners decide that they want to receive payment in the form of gifts or gift cards.

[1]Canadian Institutes of Health Research. Consideration when paying patient partners in research 2019 [cited 2021 July 8]. Available from: https://cihr-irsc.gc.ca/e/51466.html.

☐ Yes
☐ No

2.Has your institution financially compensated patients for being partners in research activities or facilitated financial compensation of patient partners?

☐ Yes

☐ No

3.Please indicate whether you have an institutional policy or if you use a guidance document to inform patient partner financial compensation strategies. (Check all that apply)

☐ Institutional guidance

☐ Published guidance document

Please specify or cite the policy/guidance document ____

☐ None

Page 3 – Challenges to Financially Compensating Patient Partners

4. Have you ever experienced any of the following challenges when offering financial compensation to patient partners or facilitating financial compensation of patient partners? (Check all that apply)

☐ Issues developing or amending contractual agreements to fit patient partner compensation agreements

☐ Patient partner compensation is not an eligible expense within the institution

☐ Lack of institutional guidance or policy

☐ Patient engagement is not well known nor established within my institution

☐ Confidentiality concerns (i.e. keeping patient partner social insurance/social security/national insurance numbers secure)

☐ Other

Please specify: ___

☐ No

Appendix 3. GRIPP II short-form.

Section and topic	Item
1: Aim	Survey researchers and their institutions about current patient partner compensation practices, barriers and challenges to compensation, and attitudes around patient partner financial compensation. To partner with a patient partner throughout the development and conduct of the cross-sectional survey.
2: Methods	One patient partner (MS) was recruited to join the research team through personal referral. MS was involved in developing the proposal, drafting the survey questions, identifying response items, analyzing survey results and contributed to edits of this paper. MS attended virtual team meetings and

	continued to meet with GF monthly. MS was offered financial compensation and co-authorship in recognition of her contributions to the research project.
3: Results	Patient engagement contributed to the study in several ways including: - Informing the project proposal with the patient partner experience: MS is well integrated in the patient engagement field and has a wealth of experience being a patient partner for several organizations. MS has experience with various methods of compensation, barriers to financial compensation and the different perspectives that patient partners have on financial compensation. - Informed the development of survey invitation and reminder emails - Pilot tested the survey platform and survey questions. - Interpreted survey findings
4: Discussion	Overall, patient engagement was successful and rewarding. The research team learned a lot about the patient partner experience with financial compensation through discussions with MS about her unique experiences. MS was a formal member of the research team and recognized as a thesis advisory committee member – a unique role. At the beginning of the project, we co-developed a timeline and budget to reflect the number of hours that MS devoted to the project. New opportunities for collaboration arose throughout the last year. In retrospect, we should have referred back to this timeline to ensure that the number of hours budgeted for were accurate.
5: Reflections	Engagement was embedded within the research project and MS was a member of the research team. MS helped inform the responses to the survey question regarding barriers to financial compensation using her unique experiences and provided valuable insight on survey usability.

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CHAPTER 4: Scoping review

Recognizing patient partner contributions in health research: a scoping review of available policies and guidelines

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Preface to Chapter 4

Chapter 2 and Chapter 3 demonstrated that guidance and support play a crucial role in supporting researchers and institutions in offering compensation to patient partners. This chapter presents the results of a scoping review designed to identify publicly available guidelines and policies on compensating patient partners for their contributions on the research team. The results provide a comprehensive overview of recommendations including methods to recognize patient partners, monetary value of financial compensation, and items to consider when offering financial compensation to patient partners.

ABSTRACT

Background: Patient engagement, or the inclusion of patients as partners in the research process, has been observed to benefit research in several ways. One important component of patient engagement is appropriately recognizing patient partners for their contributions to research using compensation (i.e., co-authorship, honoraria). In fact, a recent systematic review and survey study identified guidance as a key enabler for researchers and institutions to offer compensation to patient partners. The aim of this scoping review is to identify available guidance and policy documents for patient partner compensation and provide a comprehensive overview of recommendations.

Methods: Our scoping review was conducted in accordance with updated methodology developed by the Joanna Briggs Institute. We searched Overton (the largest international database of policy documents) and the grey literature (Google, Google Scholar) in April and March 2022, respectively. Guidance documents or policies published after 2000 and were developed to guide compensation of patient partners for their contributions to research were included. Document characteristics and recommendations were extracted and presented descriptively.

Results: After screening 720 documents, 65 guidance or policy documents were included. Most documents were published in Canada (57%, n=37) or the United Kingdom (26%, n=17). The most common recommended method of non-financial compensation was offering training opportunities to patient partners (40%, n=26). The majority of guidance documents (95%) suggested financially recognizing patient partners for their contributions to research. The recommended monetary value of financial compensation varied by organization and depended on the role played by patient partners, the level of engagement, and time commitment. The most common monetary value for obtaining patient partner feedback (i.e., consultation) was $19/hour (USD) (range of $12 - $50/hour (USD)), while the monetary value for patient partners holding positions on advisory committees was $38/hour (USD) (range of $25 - $50/hour (USD)). We identified several documents that guide compensation of unique populations including youth, and Indigenous peoples.

Discussion: Review findings suggest that several publicly available resources exist to support stakeholders in developing patient partner compensation strategies. Our comprehensive overview of recommendations will help researchers identify a guidance document to guide the development of a unique compensation strategy.

INTRODUCTION

The relationship between researchers and patients has recently become collaborative. The term *patient engagement* is used to describe working with patients, defined as any individual with lived experience of a health condition including informal caregivers, family or friends, as patient partners to develop and conduct research.(1) The ultimate aim of engagement in research is to ensure that the patient perspective shapes the development of research outputs and enhances research usability. Patient engagement has been observed to enhance research acceptability and is becoming well-established across health research.(2–4)

The importance of appropriately recognizing patient partners for their contributions to health research may have several benefits .(5–7) First, offering recognition to patient partners demonstrates fairness since other members of the research team are recognized professionally or academically for conducting research.(8–10) Second, offering financial compensation may promote diversity by facilitating involvement of individuals who may not otherwise have the economic means to be engaged in research.(5,9) Third, recognition promotes a sense of equality among all team members and helps reduce power imbalances between researchers and patient partners.(9)(11) Fostering an inclusive environment ultimately encourages patient partners to share their perspectives and maximizes the impacts of engagement.(6) National organizations that aim to support patient engagement in research, namely Canadian Institutes of Health Research (CIHR), Patient-Centered Outcomes Research Institute (PCORI, United States) and the National Institute of Health and Care Research (NIHR, United Kingdom) have developed several compensation guidance documents.(7,12,13) However, it is currently unclear how existing guidance documents complement each other or vary internationally.

We recently conducted a systematic review to assess the current landscape of reporting patient partner compensation and current compensation practices among a cohort of published research that were conducted with patient engagement (Chapter 2). We found only a fraction (25%) of included studies reported offering financial compensation to patient partners.(14) To gain a better understanding of compensation behaviors and experienced barriers or challenges to offering compensation, we surveyed researchers identified by the systematic review and their institutions (Chapter 3). Survey findings highlighted a perceived lack of policies and procedures as key challenges to offering financial compensation to patient partners.(15) Overall, our research suggests that researchers may need further

guidance on why and how to appropriately recognize patient partners for their contributions to research.

To address this gap, we undertook this scoping review of available policies and guidance documents to provide a comprehensive overview of patient partner compensation recommendations. Our broad research question was, '*What guidance or policies exist to guide patient partner compensation in research and how do they compare?*' A synthesis of available guidance and policy documents may help researchers make decisions around methods to recognize patient partners. Additionally, comparing international guidance and policies will enhance our understanding of the similarities and differences across recommendations.

METHODS

This scoping review was conducted in accordance with methods developed by the Joanna Briggs Institute.(16)(17) We followed previous scoping review methodology first defined by Arksey and O'Malley (18) and incorporated a consultation exercise. This was achieved by working with a patient partner and a multidisciplinary research team in developing and conducting this review. This review is prepared in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR).(19) A complete PRISMA-ScR checklist can be found in Appendix 1. The protocol was registered on Open Science Framework (https://osf.io/en8a4/) and has been published as a part of a larger research program.(14)

Eligibility criteria

We used the *Types of Evidence Sources, Population, Concept*, and *Context* framework to define our eligibility criteria.(17) Types of *Evidence Sources* included were guidance documents or policies developed to inform the compensation of patient partners for their contributions to research. Patient partners are individuals with lived experience, including informal caregivers, members of the public, friends and family, who work with researchers to inform, develop or conduct research.(20) Guidance documents developed by any organization were included. We excluded documents produced by organizations where the aim was not to provide guidance (e.g., meeting minutes and annual reports). *Population* was not applicable, however the *Concept* was either compensation of patient partners in their role as research team members, consultants, members of steering/advisory committees, or holding positions on grant review committees. We defined compensation as offering goods or services

in exchange for involvement and inclusive of non-financial and financial methods. We excluded documents that described compensation of patients for their role as research participants. Finally, Context was patient engagement in biomedical research; we excluded other forms of non-health related research. There were no restrictions on the setting of patient engagement in research (e.g., clinical, policy making, preclinical).

Information sources and literature search

An information specialist (Lindsey Sikora, Head of Research Support (Health Sciences, Medicine, STEM), University of Ottawa) developed all search strategies. Overton.io, the largest international database of policy documents, was searched April 5, 2022.(21) The following search strategies were used: "patient partner" AND research AND (compensate* OR remunerat* OR pay* OR reimburse*). Additionally, we used the same strategy to search the grey literature (Google, Google Scholar) in accordance with the Canadian Agency for Drugs and Technologies (CADTH) Grey Matters Tool.(22) We conducted pilot searches of 17 databases (Free, Subscription based, and Search Engines) listed in the Grey Matters Tool and only Google and Google Scholar yielded relevant results. The grey literature searches were conducted on March 29, 2022. Four searches of Google Scholar and Google (8 searches total) were conducted by one team member (GF) and the first 50 hits for each search were collected (200 hits in total) for screening. We limited our searches to guidance documents and policies published after 2000 to identify guidance reflect current patient partner recognition recommendations. We included all documents; however, we extracted data from only English documents. A full list of identified documents can be found in Appendix 3. In the event that we captured a web page or source with vague information about patient partner compensation, an email was sent to the organization asking for further information. In instances where they responded, we included the document that was shared. In addition to the literature searches, we supplemented identified documents with guidance or policy documents identified by a systematic review and survey study previously conducted by our research group (Chapter 2 and Chapter 3).(14)(15)

Study selection

All identified documents were exported, and hyperlinks were stored in a locked Excel file. Following duplicate removal, two independent reviewers (GF, AS) screened documents by full text. The screening process was piloted to ensure reliability between reviewers. Inter-rater agreement for inclusion was calculated after each round of piloting. Once an agreement level of >80% was reached, reviewers

stopped piloting. It took reviewers two piloting exercises (screened 50 documents) to reach 80% agreement. Reasons for exclusion were recorded. Reviewers met to resolve conflicts and a third-party reviewer (MML, DAF) was consulted if the two reviewers could not reach consensus.

Data charting

Eligible documents were uploaded to Distiller, a cloud-based software that supports reproducible work necessary for a scoping review (Evidence Partners Incorporated, Ottawa, Canada). Reviewers searched sources to confirm that the included documents were the most up to date versions prior to commencing data extraction. Data were extracted using a standardized data extraction form by two independent reviewers (GF, AS). Data extraction was piloted for sets of five documents to ensure that extraction was consistent between reviewers and continued until conflicts were below five per document. Reviewers underwent two piloting exercises (10 documents in total) before continuing to data extraction. Reviewers consulted a third-party (MML, DAF) if they could not reach consensus.

Data items

Reviewers extracted document characteristics (year of publication, country of origin, target audience, source organization), recommended methods of compensation (non-financial and financial methods), financial compensation details (monetary amount, payment frequency), reported benefits, challenges, barriers and enablers to patient partner financial compensation, and items to consider when offering financial compensation. A complete list of data items can be found in Appendix 4.

Synthesis of results

Document characteristics and recommendations (i.e., source document type, recommended methods of recognition, compensation details) were presented descriptively. Qualitative data for reported benefits, challenges, barriers, enablers to patient partner compensation, and items to consider, were analyzed descriptively. Relevant verbatim statements were extracted from each of the documents by two reviewers independently (GF, AS) and within each of the five domains. Conflicts were resolved between reviewers. Following extraction, each reviewer read verbatim statements independently and generated themes inductively. Reviewers met on a regular basis to combine re-emerging themes and resolve conflicting themes. All themes were tabulated and reviewed by two reviewers. Frequency of reporting each theme was recorded and reviewers named each overarching theme. Overarching themes and

frequency of reporting were presented to the entire team. A narrative synthesis of overarching themes was provided.

Patient engagement

A patient partner (MS) was engaged in this study and details are described using the Guidance for Reporting the Involvement of Patients and the Public (GRIPP II) short form (Appendix 2). She informed development of the scoping review protocol and provided feedback on project conduct (data extraction, interpretation). Meetings with the patient partner occurred monthly to discuss research findings as the scoping review progressed. We co-developed a terms of reference document a priori to document details of engagement (I.e., expectations, project goals etc.). Our patient engagement plan was informed by INVOLVE's seven Core Principles of Engagement (23) and the CIHR SPOR Patient Engagement framework.(1) Co-authorship and financial compensation have been offered as a method of recognition. We followed the SPOR Evidence Alliance Patient Partner Appreciation Policy (24) to inform the development of our financial compensation strategy, which was discussed and approved by the patient partner. Additionally, we presented the larger research program to a patient partner council to get their feedback. The aim of collaboration was to ensure that the patient perspective was considered throughout the project.

RESULTS

Search results

Our searches retrieved 697 documents. Our systematic review and survey study identified an additional 17 documents. Following screening, total of 65 documents met full eligibility criteria (Figure 1). A full list of included documents can be found in Appendix 3 and on Open Science Framework (https://osf.io/en8a4/).

Document characteristics

The earliest document was published in 2012 and the largest proportion of documents were published in 2021 (Figure 2A). The majority of documents were published in Canada (57%, n=37) or the United Kingdom (26%, n=17) (Figure 2B). A large proportion of documents were developed by research networks (45%, n=29) including seven from Canadian provincial Strategies for Patient Oriented Research (SPOR) SUPPORT Units (Figure 2C). Most documents were developed to either guide researchers in offering compensation to patient partners (n=54%, n=35) (Figure 2D). Similarly most were developed by national organizations (51%, n=33)(Figure 2E). Forty-six percent (n=30) focused on patient engagement

and included a section dedicated to patient partner compensation, and 46% (n=30) focused entirely on patient partner compensation (Figure 2F).

Recommended non-financial compensation methods of recognition

The most common reported methods of non-financial compensation were offering training opportunities to further patient partner careers (40%, n=26) and facilitating patient partner attendance at a conference (38%, n=25) (Figure 3A). The majority of documents recommend that patient partners be reimbursed for expenses associated with engagement (77%, n=50) (Figure 3B).

Recommended financial compensation methods of recognition

Of 65 documents, 62 (95%) recommended offering financial compensation to patient partners. Suggested methods of providing financial compensation include honoraria (n=43), gift cards (n=11), salary (n=9) or stipends (n=4) (Figure 4). Nineteen studies (31%) did not suggest a specific method of financial compensation. Recommended monetary value of financial compensation varied and mostly depended on the role played by patient partners or engagement activities (Figure 5). Most guidance documents recommend hourly rates with a range of $12 - $50 (USD). For example, 21 documents recommend that, at a minimum, patient partners should be offered $19/hour (USD) for “one time” engagement of a few hours or participating in consultation exercises (i.e., unidirectional flow of information from patient partners to researchers (25)) including providing feedback on a project proposal. However, offering financial compensation of higher monetary value was associated with higher levels of engagement. For example, the recommended monetary value to compensate patient partners for holding positions on advisory committees ranged between $761 - $1,141 (USD) per annum. Two organizations have capped annual income amounts ($228 and $1,141 USD) that they can offer to patient partners (Appendix 5).(26)(27) One identified guidance document recommended using a Fair Market Calculator to inform monetary value.(28) This tool considers patient partner experience level when recommending a monetary value instead of focusing on patient partner role or time commitment to the project.

Seventeen documents (27%) provided compensation guidance for specific populations including youth (41%, n=7), Indigenous peoples (41%, n=7), and individuals with disabilities (18%, n=3) (Appendix 6). Two guidance documents suggested monetary values to demonstrate appreciation to Indigenous peoples for performing a traditional cultural service (e.g., Opening ceremony prayer, Welcome to Territory etc.). However, the majority of guidance focused on logistical considerations to financial

compensation. For example, children or individuals affected by homelessness may not have bank accounts to deposit honoraria.

Benefits, challenges, barriers and enablers to patient partner financial compensation

A total of 27 documents reported either benefits or challenges of financial compensation (Table 1). The two most commonly reported benefits were that financial compensation can support the inclusion of diverse perspectives (n=18) by enabling individuals from different socioeconomic backgrounds to be engaged in research and offers a tangible method to demonstrate patient partner appreciation (n=8). Two key reported challenges to financial compensation were financial limitations and lack of institutional procedures (n=5). We did not identify reoccurring themes for reported barriers and enablers to patient partner financial compensation.

Items to consider when offering financial compensation to patient partners

The most commonly reported item to consider when offering financial compensation include acknowledging that patient partners can refuse financial compensation or agree to accept less than what is offered (n=19) (Appendix 7). It was crucial to discuss compensation with patient partners at the beginning of the research project (n=17) and financial compensation was considered taxable income (n=15) and therefore can impact income tax rates or jeopardize ability to collect disability payments.

DISCUSSION

Our scoping review synthesizes publicly accessible international recommendations about patient partner compensation. Our findings demonstrate that, at a minimum, current guidance suggests that patient partners need to be reimbursed for any expenses incurred from engagement, including travel or accommodations. The majority of guidance also suggested financially recognizing patient partners for their contributions to research (e.g., through honoraria) and none advised against financial compensation. The recommended monetary value of financial compensation varies by organization with most guidance documents recommending different monetary values depending on the role played by patient partners, the level of engagement, and time commitment.

Overall, researchers are well supported by the considerable amount of available guidance on how and why it is important to offer financial compensation to patient partners and recommendations are relatively consistent across documents. Most guidance documents or policies we identified were developed by Canadian research networks. This may be due to using the term *patient partner* in the

search strategy and the existence of a number of national SPOR disease-oriented networks and 11 SPOR SUPPORT Units, which are located provincially and responsible for supporting stakeholders in developing and conducting patient engagement research. While it is reasonable that different research networks develop unique compensation guidance documents to their local context, there may be benefits to having one comprehensive set of Canadian recommendations. In fact, the negative impact of having too many choices has been supported by "the choice overload hypothesis".(29) This psychological phenomenon argues that, when faced with too many choices, individuals may be less motivated to make a decision and end up making no decisions.(29) Applying this theory here, researchers may choose not to use a guidance document because there exist multiple from which to choose. Nonetheless, the presence of multiple guidance documents improves informational diversity as some documents may guide unique aspects of compensation that are not covered by other guidance. For example, we identified documents that recommend specific methods of compensation for unique populations (e.g., Indigenous peoples, youth). Currently, it is not clear whether one comprehensive set of recommendations is needed.

Although there is wealth of guidance available to support researchers in navigating patient partner financial compensation, previous studies showed that an implementation gap may exist. From our systematic review, we identified a paucity of reporting patient partner financial compensation.(14) Conversely, our cross-sectional survey found that researchers identified lack of policy as an important barrier to compensation.(15) Despite the wealth of guidance identified by our scoping review to support researchers in navigating patient partner financial compensation, researchers and institutional members may not be aware of available guidance or understand how to implement guidance. One way to overcome this implementation barrier is for guidance and policy documents to incorporate details to support implementation. For example, guidance documents should provide information to help finance departments alter institutional procedures to accommodate patient partner financial compensation. Incorporating information about how institutions and researchers can implement guidance and policy recommendations may address this gap and facilitate the uptake of guidance documents by institutions and researchers.

While financial compensation may offer a method to improve accessibility, it is important to alter recognition strategies to better support the population being engaged. Indeed, offering financial compensation may reduce barriers to engagement in research and encourage future engagement of

underrepresented populations. For example, a recent study interviewed Indigenous patient partners and researchers to inquire about their experiences with patient engagement, and valuing patient partner contributions was identified as one of the four key pillars to successful engagement of Indigenous peoples. Specifically, compensation improved patient partner confidence in being involved ultimately encouraging future engagement.(11) While offering financial compensation may encourage members of underrepresented populations to be engaged in research, recognition strategies must account for specific needs and cultural significance.(30) We identified several guidance documents or policies that offer recommendations on how to appropriately recognize members of specific populations. For example, when offering compensation to Indigenous patient partners, it is crucial to clarify that compensation is used to express appreciation instead of exchanged for time because the latter would imply purchasing Indigenous knowledge, which cannot be owned by a person or institution.(32) Additionally, when offering financial compensation to youth or individuals affected by homelessness, it is important to consider that they may not have bank accounts to deposit cheques or honoraria. Overall, it is crucial that researchers consider unique needs and priorities of diverse patient partner populations when developing a recognition strategy.

While several documents reported on benefits of offering financial compensation, very few acknowledged challenges or barriers. As such, organizations may be more focused on addressing knowledge gaps around patient partner financial compensation by convincing researchers of the benefits while overseeing the logistical barriers that may exist. One major item to consider when offering financial compensation to patient partners is the potential impacts that added income from engagement may have on existing income streams. Financial compensation, in the form of cheques or cash, are considered taxable income. Therefore, appropriate tax forms must be supplied, and financial compensation must be declared to National revenue agencies if the monetary amount exceeds a specific value. In Canada, compensation of $500 (CAD) or more per year is considered taxable income.(33) Additionally, if patient partners are accepting disability payments or other forms of payment for sick leave from their employer, accepting additional finances from engagement can prevent them from continuing to collect these types of payments. It is important that researchers understand the implications of compensation in addition to the benefits to avoid putting patient partners at risk or jeopardizing their income.

While our scoping review provides a comprehensive overview of available guidance around patient partner financial compensation, limitations must be noted. First, while comprehensive, Overton is a relatively new database but, despite its novelty, evidence exists to support its validity and value.(34) Additionally, we worked with an information specialist to verify our search strategies and supplemented the systematic search by searching the grey literature and including any guidance documents identified by previously conducted systematic review and survey studies. Second, our search is limited to publicly available guidance and policy documents. Because of this, publicly inaccessible organizational or institutional policies were not identified.

Our review demonstrates that a number of publicly available resources exist to support stakeholders in developing patient partner compensation strategies. Generating a comprehensive overview of documents has enhanced our understanding of the similarities and differences across recommendations and on an international scale. When choosing a guidance document, it is important to consider geography as financial implications vary by location and the population that is being recognized (i.e., youth, Indigenous peoples, etc.). Evaluation of the impact and uptake of patient partner compensation guidance requires further research. Future guidance documents should include information about how institutions can alter internal procedures to facilitate adoption of these guidance documents and provide awareness to members (e.g., researchers, administrators, patient partners).

FIGURES AND TABLES

Figure 1. PRISMA Flow diagram

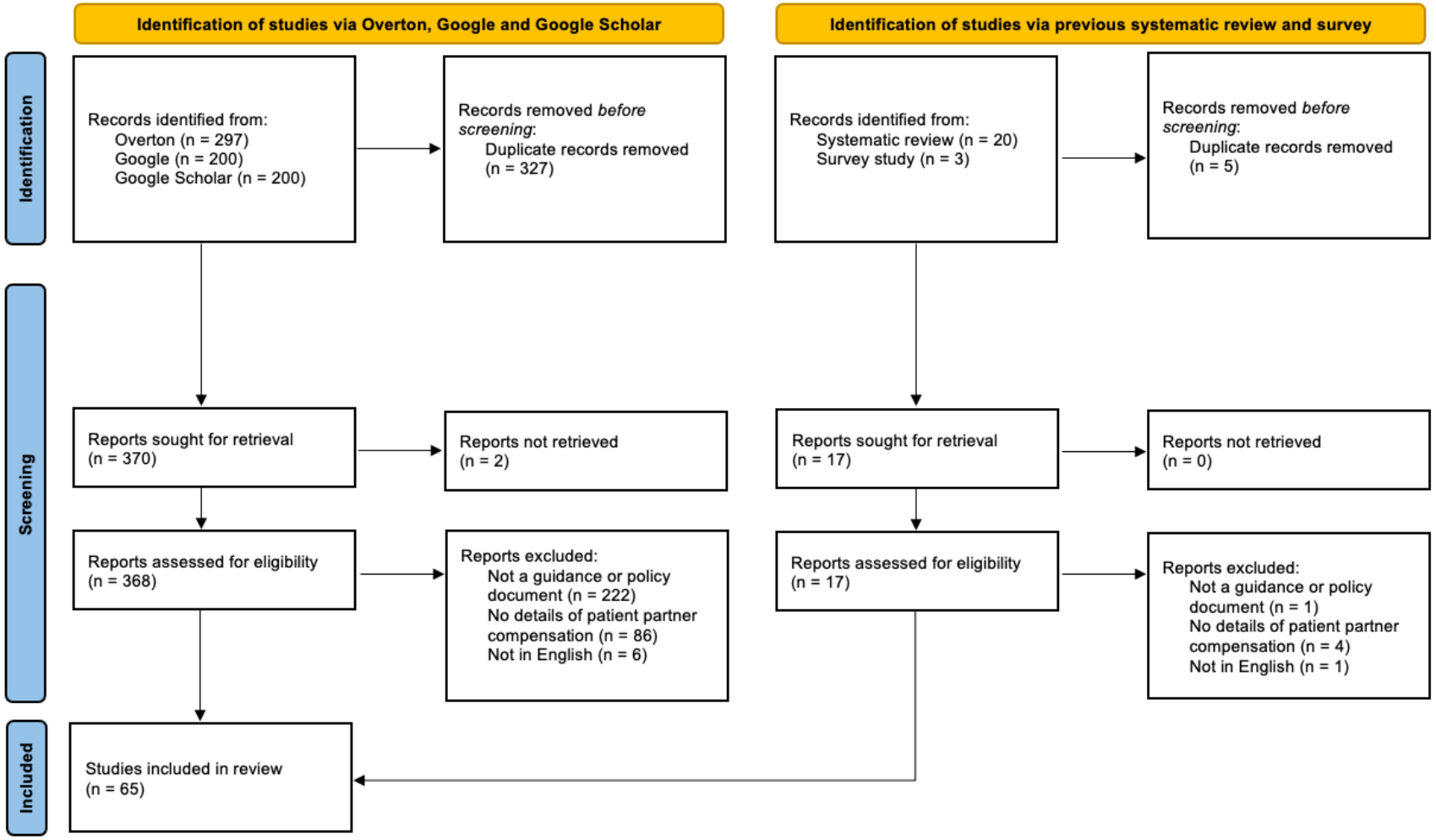
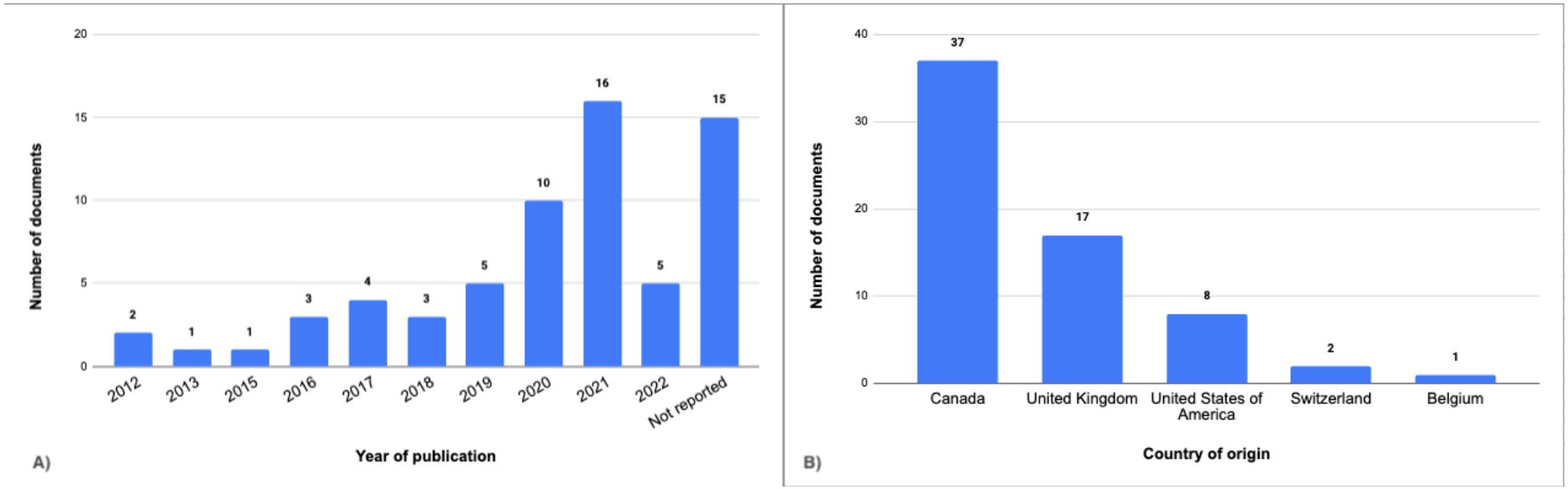
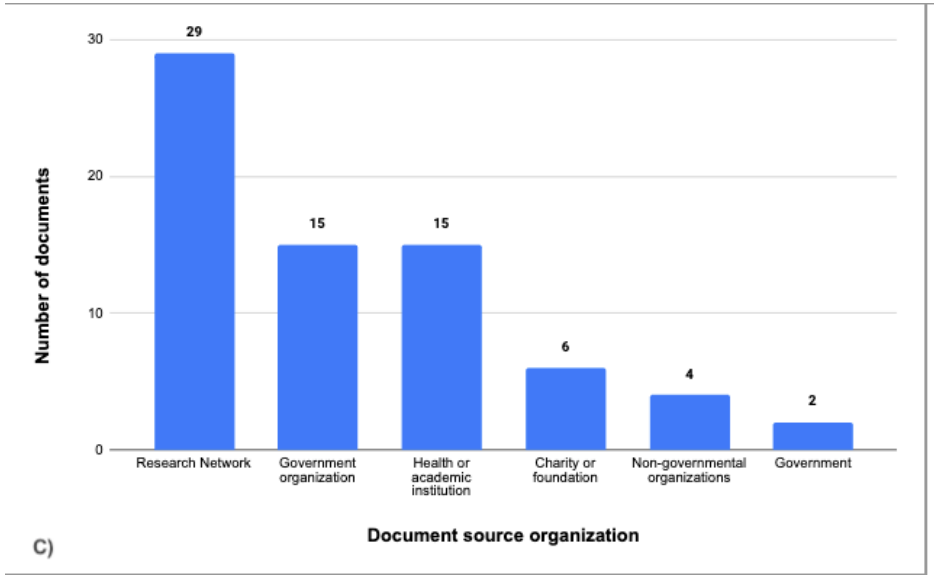


Figure 2. Document characteristics including a) year of publication (literature searches were conducted in March and April 2022), b) country of origin, c) source organization, d) target audience, e) level of policy-making and f) document scope (n=65).




Number of documents
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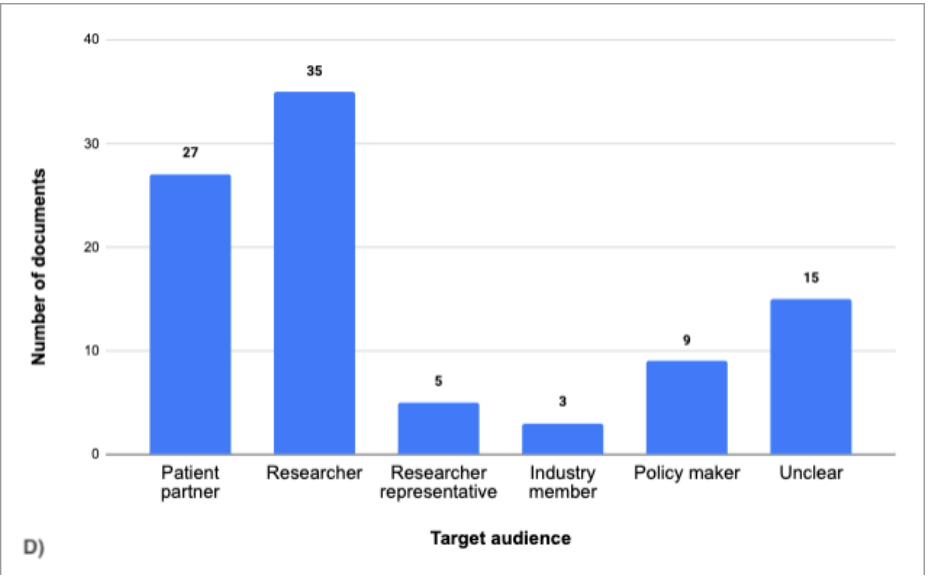
20
10
0
29
15
15
6
4
2
Research Network
Government organization
Health or academic institution
Charity or foundation
Non-governmental organizations
Government
Document source organization

C)


Number of documents
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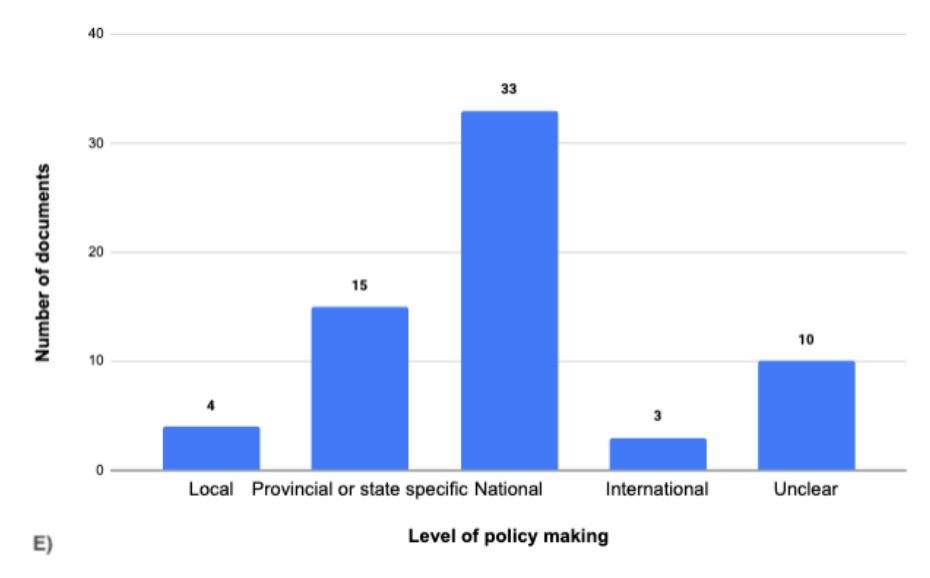
30
20
10
0
27
35
5
3
9
15
Patient partner
Researcher
Researcher representative
Industry member
Policy maker
Unclear
Target audience

D)


Number of documents
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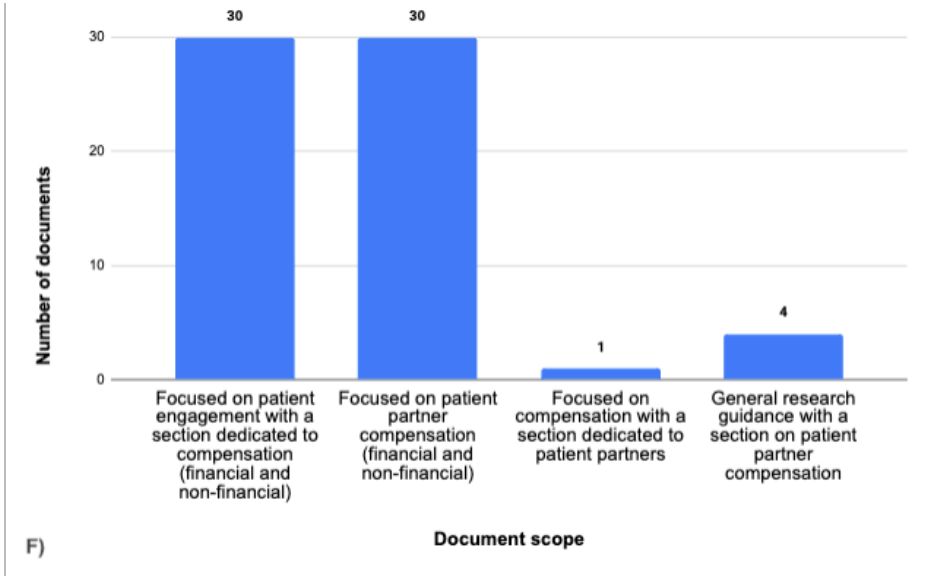
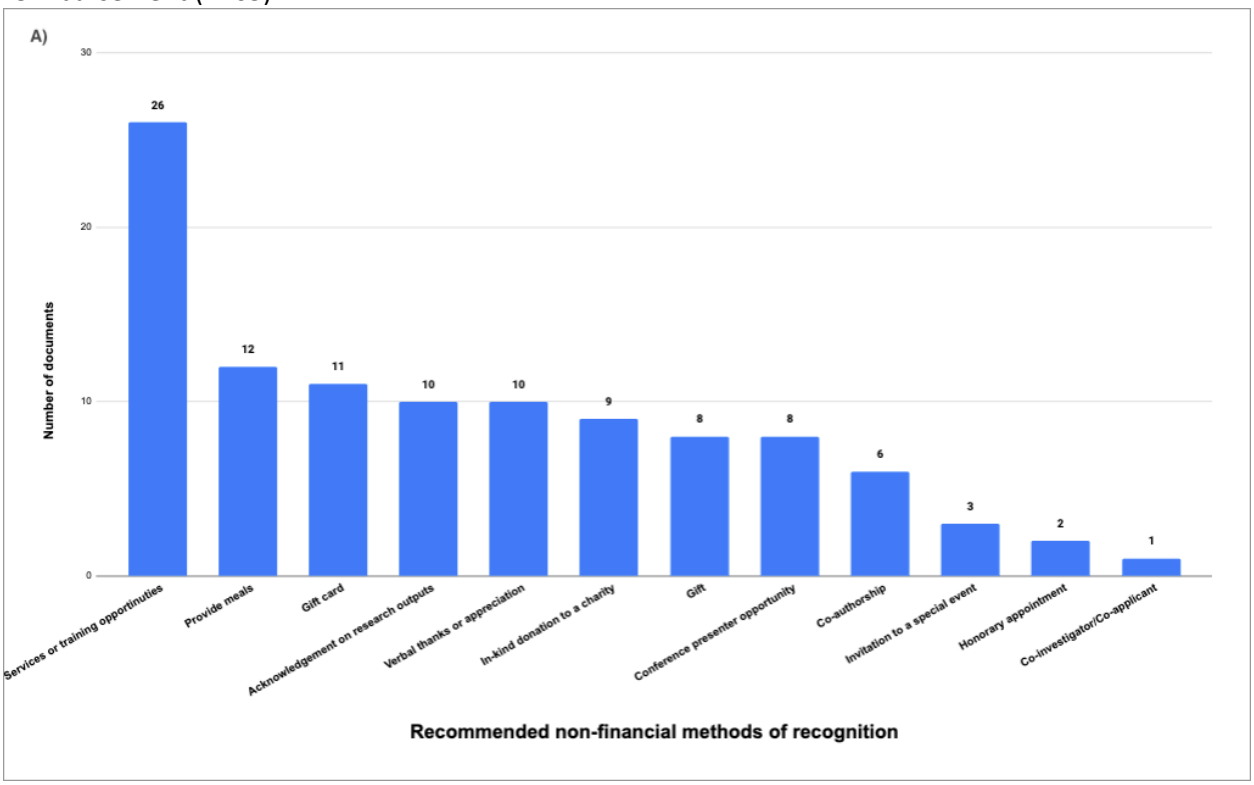
10
0
4
15
33
3
10
Local
Provincial or state specific
National
International
Unclear
Level of policy making

E)


Number of documents
30
20
10
0
30
30
1
4
Focused on patient engagement with a section dedicated to compensation (financial and non-financial)
Focused on patient partner compensation (financial and non-financial)
Focused on compensation with a section dedicated to patient partners
General research guidance with a section on patient partner compensation
Document scope

F)

Figure 3. a) Recommended non-financial methods of compensation and b) recommended methods of reimbursement (n=65)



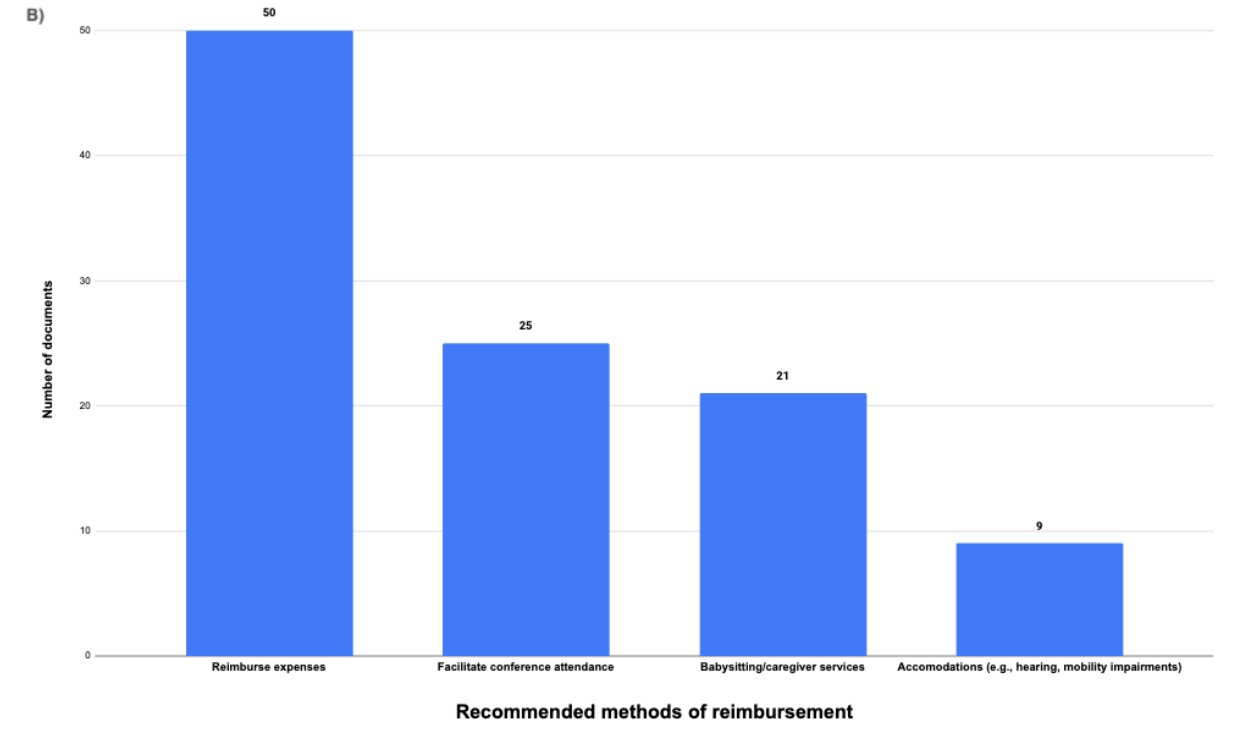


Figure 4. Recommended financial methods of compensation (n=62)

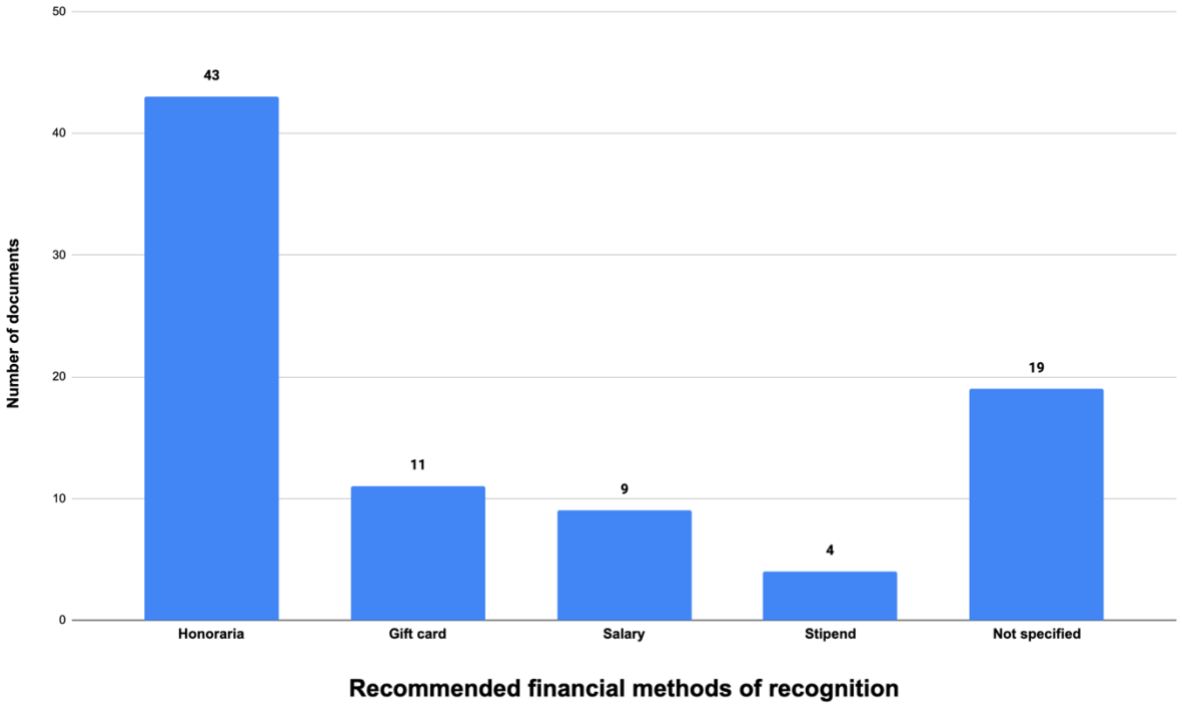
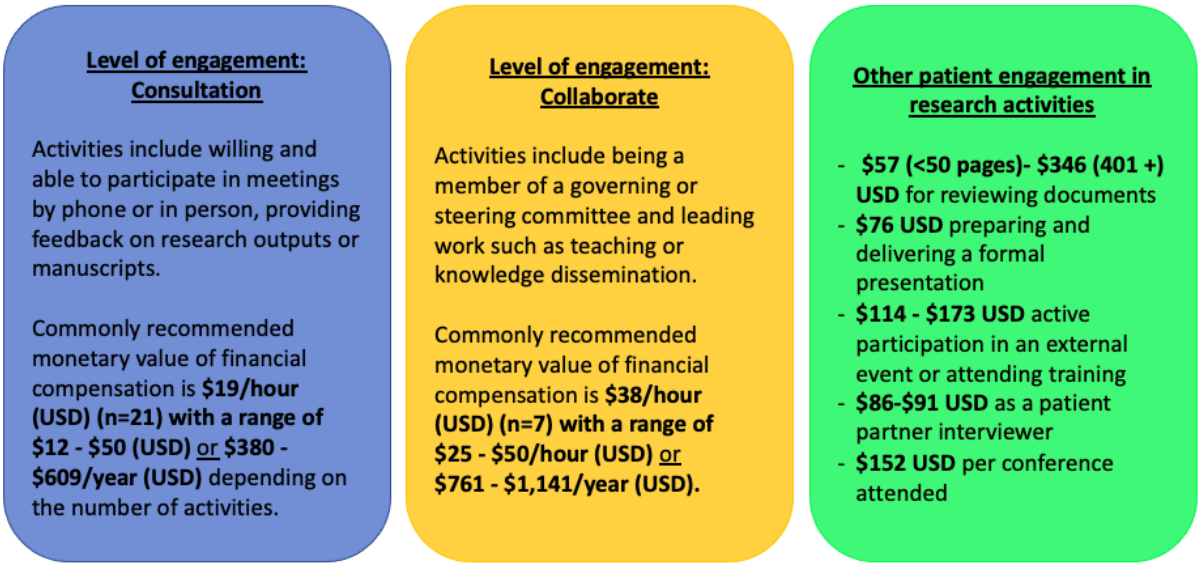


Table 1. Reported benefits, challenges, barriers and enablers of patient partner financial compensation

Theme	**Number of studies**
Benefits (n=23)	
Financial compensation supports the inclusion of diverse perspectives	18
Tangible method to demonstrate patient partner appreciation and supports a sense of equality among team members	8
Removes power imbalances among team members	4
Support patient partner commitment to the project and long-term engagement	2
Benefits patient partners financially	3
Challenges (n=5)	
Financial limitations and institutional procedures (e.g., patient engagement is not an eligible expense) can challenge ability to compensate patient partners	5
Financial payments can jeopardize disability or social security payments or impact income tax rates	3
Loss of autonomy associated with financial compensation	2

Figure 5. Synthesized financial compensation recommendations across guidance and policy documents. Further details can be found in Appendix 6.



APPENDIX

Appendix 1. Complete PRISMA-ScR checklist(35)

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	99
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	100
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	103
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	104
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	102
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	102 - 103
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	103
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	103
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	103 - 104
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	104
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	104
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	104-105
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	111
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	105 – 107, 112- 116
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	105 - 107, 112 – 116
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	105 - 107
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	107 - 109
Limitations	20	Discuss the limitations of the scoping review process.	110
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	110
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

Appendix 2. GRIPP II short-form

Section and topic	Item
1: Aim	Conduct a scoping review to identify guidance and policy documents aiming to guide patient partner compensation (non-financial and financial methods). To partner with a patient partner throughout the development and conduct of the scoping review.
2: Methods	One patient partner (MS) was recruited to join the research team through personal referral. MS was involved in developing the protocol, defining compensation terms, analyzing scoping review results and contributed to edits of this paper. MS attended virtual team meetings and continued to meet with GF

	monthly. MS was offered financial compensation and co-authorship in recognition of her contributions to the research project.
3: Results	Patient engagement contributed to the study in several ways including: - Informing the project proposal with the patient partner experience: MS is well integrated in the patient engagement field and has a wealth of experience being a patient partner for several organizations. MS has experience with various methods of compensation, barriers to financial compensation and the different perspectives that patient partners have on financial compensation. - Provided insight into experiences working with international institutional institutes and their compensation practices. - Analyzing themes from the thematic analysis - Reviewed and edited this manuscript
4: Discussion	Overall, patient engagement was successful in informing scoping review development and conduct. Additionally, the research team learned a lot about the patient partner experience with financial compensation and institutions are recognizing patient partners for their expertise through discussions with MS about her unique experiences. It was helpful that MS was familiar with most team members before joining the research team and that members of the team had experience with patient engagement. The scoping review was conducted within a year and alongside two additional research projects. At the beginning of the project, we co-developed a timeline and budget to reflect the number of hours that MS devoted to the project. In the future, we will refer back to this timeline at the mid-term mark to ensure that the number of hours budgeted for were accurate.
5: Reflections	Engagement was embedded within the research project and MS was a member of the research team. Not only was engagement successful in shaping the scoping review, but it was also personally rewarding to have the opportunity to work closely with lived experience.

Appendix 3. Full list of included documents

1. Center for Patient Partnerships, Wisconsin CYSHCN Program and Partners. Team Engagement for Quality Improvement Welcome Booklet [Internet]. 2018. Available from: https://www.dhs.wisconsin.gov/publications/p02349.pdf

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3. University of Calgary. Travel and Expense Reimbursement Handbook [Internet]. Available from: https://www.ucalgary.ca/finance/sites/default/files/teams/5/ap-travel-and-expense-reimbursement-handbook.pdf

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Appendix 4. Data items

Data item
1. Organization/author name and contact information 2. Type of organization (Government, Government organization, Research Network, Health or Academic institution, Charity or Foundation, Industry, Non-governmental organization) 3. Year of publication 4. Geographical location 5. Publication title 6. Target audience (researchers, patient partners, researcher representative, industry member, policy maker) 7. Population specifics (individuals with chronic conditions, youth and children, individuals with disabilities, seldom heard populations, Indigenous peoples) 8. What level of policymaking is the document supporting? (local, provincial/state, national supra-national) 9. Scope of the document (focused on patient partner compensation, Focused on patient engagement with a section dedicated to compensation, Focused on compensation with a section dedicated to patient partners, Focused on research guidance with a section on patient partner compensation) 10. Recommended methods of recognition (non-financial and financial) 11. Details of financial compensation (e.g., type of payment, frequency, amount etc.) 12. Reported benefits or challenges of patient partner compensation 13. Reported barriers or enablers to guidance document implementation 14. Special considerations when compensating patient partners

Appendix 5. Recommended monetary values and frequency of financial compensation payments

Organization name	Monetary amount	Payment frequency
Alberta Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit (AbSPORU) and the Patient Engagement Platform Compensation Working Group.	$25/hour (CAD) ($19/hour (USD)) (Consult-Level)] < 4 meetings/yr between $100-$200 (CAD) ($76 - $152 (USD)) [Committee members on a standing working group (Involve-Level)] > 4 meetings/yr between $200-$400 (CAD) ($152 – $305 (USD)) [Committee members on a standing working group (Involve-Level)]	Pay per activity completed or meeting attended One payment per year
BC Mental Health & Substance Use Services (BCMHSUS)	$25.00/hour (CAD) ($19/hour (USD)) [serving in an advisory and consultative role.] $30.00/hour (CAD) ($23/hour (USD)) [developing literature based on their lived experience.] $50.00/hour(CAD) ($38/hour (USD)) [leading work, such as teaching and knowledge dissemination.]	N/R
BC SUPPORT Unit	Studies awarded funding can allocate $500 (CAD) ($380 (USD)) to cover patient engagement expenses.	N/R
British Columbia Academic Health Science Network (BC AHSN)	$25-75 (CAD) ($19 - $57 (USD)) [One-time engagement of less than half-day] $50-75 (CAD) ($38 - $57 (USD)) [One-time engagement of half day (+/- 4 hours)] $75-150 (CAD) ($57 - $114 (USD)) [One-time engagement of full day (+/- 8 hours)] $150-300 (CAD) ($114 - $228 (USD)) [Committee or working group that meets <= 6 times per year] $ 300-500 (CAD) ($228 - $380 (USD)) [Committee or working group that meets between 7 and 12 times per year] $500-1000 ($380 - $761 (USD)) [Committee or working group that meets > 12 times per year]	Pay per activity completed or meeting attended One payment per year
Canadian Venous Thromboembolism Research Network (CanVECTOR)	$50/hour (CAD) ($38/hour (USD) [1 to 4 total hour commitments] $200 per conference attended (CAD) ($152 (USD))	Quarterly
CHILD-BRIGHT	$500.00 per year (CAD) ($380 per year (USD)) [Availability by email; willing and able to participate in a few meetings by phone or in person] $1,000.00 per year (CAD) ($761 per year (USD)) [Commitment to a committee (includes meetings, follow-up actions, etc.)] $1,000.00 - $1,500.00 per year (CAD) ($761 - $1,141 (USD)) [Contributing member in a governing committee (includes meetings, follow-up actions, etc.)] $100.00 per event (CAD) ($76 per event (USD)) [Preparation and delivery of formal presentation, either in person or via webinar after working with network organizers to ensure alignment with meeting's or webinar's objectives] $50.00 per event (CAD) ($38 per event (USD)) [Participation in informal panel or facilitation of small group] $75.00 per ½ day, $150.00 per day (CAD) ($57 per ½ day, $114 per day (USD)) [Active participation at external event as a patient- partner] $75.00 per ½ day, $150.00 per day (CAD) ($57 per ½ day, $114 per day (USD)) [Attendance or Attendance and Completion of training] Patient partners will receive compensation of $100 per year (CAD) ($76 per year (USD)) in addition to the compensation they receive for their contributions as members of research teams or network committees.	Semi-annual payments
Clinical Trials Ontario	$25/hour (CAD) ($19/hour (USD)) $500 to $800 per year (CAD) ($380 to $609 per year (USD)), depending on number of meetings and other requirements	N/R
Children and Youth with Special Health Care Needs National Research Network (CYSHCNet)	Payments begin at a rate of $25 per hour (CAD) ($19/hour (USD)) with a $100 (CAD) minimum payment. ($76 (USD))	N/R
IMAGINE	$25/hr (CAD) ($19/hour (USD))	N/R

Maritime SPOR SUPPORT Unit (MSSU)	$25 - $50 (CAD) ($19 - $57 (USD)) [One time engagement of less than one half- day (less than 4 hours) $50 - $75 (CAD) ($38 - $57 (USD)) [One time engagement of a half day (4 - 5 hours)] $75 - $100 (CAD) ($57 - $76 (USD)) [Full day engagement (approximately 8 hours)] $300 - $400 (CAD) ($228 - $304 (USD)) [Standing committee or working group that meets 8-12 times per year] $100 - $300 (CAD) ($57 - $228 (USD)) [Standing committee or working group that meets less than 8 times per year.]	Pay per activity completed or meeting attended One payment per year Semi-annual payments
Richards, D	$25/hour (CAD) ($19/hour (USD)) $50/meeting per month (CAD) ($38/meeting per month (USD)) [personal experience] $250 (CAD) ($190 (USD)) [a daily committee fee or daily research work fee] $500-800/year (CAD) ($380 – $609/year (USD)) [partner in a specific research project] $1,000-1,200/year (CAD) ($761 – $913/year (USD)) [member of a committee with a network-wide mandate that includes more meetings/commitment than a research project] $1,500/year (CAD) ($1,141/year (USD)) [member of a network steering or executive committee] $2,000/year ($1,522/year (USD)) [for a 2-3 year project to participate in monthly meetings, to provide project input frequently, and to review work plans, papers, etc. (personal experience of the authors)]	Pay per activity completed or meeting attended
Smith, E	$50 (USD)/ hourly When patient partners occupy more stable and long-term positions within a research team and/or their involvement is related to specific research tasks (e.g., recruitment, data analysis), their salary has to follow established university pay standards	N/R
National Institute for Health and Care Research UCL Partners	£12.50 ($19 (USD)) For involvement in a task or activity such as reading and commenting on an abstract which equates to less than half an hour. For example, reviewing papers for the development of Alerts. £25 ($38 (USD)) For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less. For example, participating in a focus group to provide feedback on a proposal. £50 ($76 (USD)) For involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity. For example, a teleconference with related papers to read or review a few short documents. £60-75 per interview ($91 - $86 per interview (USD)) [Peer researchers/interviewers] £75 ($86 (USD)) For involvement in a task or activity where preparation is required and which equates to approximately half a day's activity. For example, participating in a meeting to interview a small number of candidates who have applied to join a committee or panel, participating in a focus group, or delivering training. £150 ($173 (USD)) For involvement in all-day meetings. For example, attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel. £300 ($346 (USD)) For involvement in all-day meetings that require substantial preparation. For example, when chairing or co-chairing a meeting or when carrying out other discretionary work, which requires additional responsibilities. £150.00 ($173 (USD)) For attending a full day of training or event organized by NIHR programs. £50 ($57 (USD)) (document review <50 pages), £125 ($144 (USD)) [51-200 pages], £200 ($230 (USD)) {201-400], £300 ($346 (USD)) [401+] document reviewal 'Budgeting for Involvement' from INVOLVE, which includes an online cost-calculator https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/#1	Pay per activity completed or meeting attended

Newfoundland and Labrador's Support for People and Patient-Oriented Research and Trials Unit	$ 200 per annum (CAD) ($152 per annum (USD)) [This is the standard honorarium offered for preparation, attendance at and follow up activities from the Patient Advisory Council meetings and/or Indigenous Council meetings.] $50 per half day (CAD) (up to 3 hours) ($38 per half day (USD)), $100 per full day (CAD) (3 hours and up) ($57 (USD)) up to max $300 per annum (CAD) ($228 per annum) (USD))	One payment per year
NHS England	£150 per day (more than four hours) ($173 per day (USD)) or £75 per half day (four hours or less) ($86 per half day (USD)).	N/R
Rising Tide Foundation	55-100 (EUR) as compensation for the work of patient experts on review panels or clinical research projects. ($55 - $99 (USD))	N/R
Saskatchewan Centre for Patient-Oriented Research (SCPOR)	$25/hour (CAD) ($19/hour (USD))	N/R
Sepsis Canada	$25/hour (CAD) ($19/hour (USD))	N/R
SPOR Evidence Alliance	$25/ hour (CAD) ($19/hour (USD))	Pay per activity completed or meeting attended
SPOR Networks in Chronic Diseases and the PICHI Network	$25.00 (CAD) ($19 (USD)) $500 to $800 per year (CAD) ($380 to $609 per year (USD)) depending on frequency and numbers of meetings and other factors deemed important by the team (Availability by email; willing and able to participate in a few meetings by phone or in person) $1000 to $1200 per year (CAD) ($761 – $913/year (USD)) depending on frequency and numbers of meetings and other factors deemed important by the team (Commitment to a committee or group (includes meetings, follow- up actions, etc.)) $1500/year (CAD) ($1,141/year (USD)) Contributing member in a governing committee (includes meetings, follow-up actions, etc.)	Pay per activity completed or meeting attended Quarterly
The Canadian Donation and Transplantation Research Program (CDTRP)	$50 per hour (CAD) ($38/hour (USD)) maximum remuneration is $1500 per year (CAD) ($1,141/year (USD))	Quarterly
The Change Foundation	Minimum wage in Ontario ($15.50/hour (CAD))[a] ($12/hour (USD))	N/R
The National Health Council	Fair Market Value calculator: https://nationalhealthcouncil.org/fair-market-value-calculator/	N/R
University of Calgary	$25/hour (CAD) ($19/hour (USD))	N/R
US Department of Veteran Affairs	Veteran Consultant Network, $25/hour (USD) Veteran Engagement Group member, $50/meeting (USD), Veteran Engagement Group member, $599/yearly (USD)	Quarterly Monthly

Currency conversions are based on rates in September 2022

[a]Minimum wage in Ontario in September 2022

Appendix 6. Population specific compensation details

Population	Important compensation considerations
Indigenous peoples including Elders, Knowledge Keepers, and other traditional leaders and gatherers	- Performing a traditional cultural service (i.e., opening and closing prayers, Welcome to Territory, Smudging, facilitating a Sharing/Talking/Healing Circle and other ceremonies): $150-200 per service (CAD) ($114 - $152 per service (USD)) - Attendance at a whole day event $400-500 per whole day event (CAD) ($304 - $380 per whole day event (USD)). - When offering honoraria, it should not be viewed as a payment for service, but rather as a gift exchange for knowledge, ceremonies, or blessings. Traditional Indigenous and cultural knowledge is not and cannot be purchased or owned by an individual or institution. - It is particularly important that the honorarium is available at the time of the event and presented prior to the activity in which the Elder has been invited to conduct or participate. - Elders must never be asked to sign a "receipt" as acknowledgement of their gift even if it is financial nor should they be asked for their Social Insurance Number (SIN), or their birth dates. - Additional costs incurred by the Elder, such as parking, mileage, meals and accommodations, must be reimbursed. - Appropriate gifts include tea, blanket, or scarf.
Youth and children	- Proxy payment such as vouchers can be offered as recognition for involvement, especially for one-off events or consultations instead of cash payments. - Authorship is highly valued by some youth patient partners. - Cover expenses in advance (such as to a travel company for rail tickets) to avoid young people having to claim reimbursement. If youth partners need to be reimbursed, ensure that any reimbursed expenses are processed quickly and easily. - Consider the costs incurred by an accompanying adult or family member, or those of a support worker, when appropriate - Be mindful of the legal restrictions that limit the times and number of hours that children and young people aged under 16 can undertake as paid activity. - Be aware that young people of working age may be in paid employment, or in receipt of welfare benefits. In these circumstances, the same considerations apply as for adults with regards to tax and benefits.
Seldom heard and marginalized populations (i.e., members of LGBTQ+, homeless people, sex workers, individuals living with mental health and/or substance abuse, Traveller communities)	- For people who face multiple barriers caused by marginalization, stigma, and criminalization, equitable compensation ensures that participating in engagement is as barrier-free and inclusive as possible. - When offering co-authorship, consider that patient partners may have more sensitivity about being known publicly as having a health condition or health experience - Particular care should be taken to understand patient partner circumstances for example, pre-booking travel on their behalf so that they are not out-of-pocket. - Consider reimbursing expenses or offering financial compensation in cash as some individuals may not have a bank account
Individuals with disabilities	- Monetary value of financial compensation may be increased for patient partners with disabilities - Some people living with disabilities may have a personal assistant to support them to get actively involved in research. Consider the cost of personal assistant attendance. - Recognize that patient partners may be in receipt of state benefits and accepting financial compensation may put their benefit entitlement in jeopardy.
Individuals with chronic conditions	- Consider offering financial compensation to patient partners living with chronic disease. They may have to stop paid work and may have increased costs due to additional medical care, childcare or other support needs. If only travel costs and some other expenses are reimbursed for patient involvement, this is usually insufficient and will lead to a very limited availability of patients who may be able to contribute.

Currency conversions are based on rates in September 2022

Appendix 7. Items to consider when offering financial compensation to patient partners

Item to consider	Number of studies
Patient partners can refuse financial compensation payments or choose to accept less than what is offered.	19
Organize one-on-one meetings with patient partners to discuss financial compensation at the beginning of the project. - It is the researcher's responsibility to initiate the conversation around financial compensation. - Be open and transparent about compensation during this meeting and be sure to continue communication throughout the project. - Use the discussion to guide drafting a budget with anticipated hours and financial compensation details. - Patient partners must approve the final budget.	17
Payment frequency, monetary value and compensation method (i.e., cheque, direct deposit, gift card etc.) should be informed by patient partner preferences. - Ensure payments are made on time as late payments can undermine respect - If paying cash, offer $20 bills as some businesses don't accept higher - Cheques can take a long time to process and can only be accepted by people with bank accounts. - Offering gift cards without that being the patient partners preference can be patronizing (i.e., dictating where they can spend the money)	16
Financial compensation is considered taxable income. Thus, payments for involvement are subject to income tax - In Canada, a T4 is issued for honoraria of $500 (CAD) per year or more. Canada Pension Disability requires disclosure of compensation above a specific amount (recently $5,500). - You may need to collect patient partner social security numbers. Confidentiality measures may be necessary to store this information. - Patient partners who are in receipt of income from medical insurance or as disability payments should be aware that accepting additional compensation can jeopardize future payments.	15
Budget adequately for compensation before engagement starts - If engagement is more than budgeted, prepare to pay more. - If engagement is less than budgeted, pay what you promised. - INVOLVE recommends 5% of the project budget should go towards supporting patient engagement.	10
The value of financial compensation should not reflect the "market value" of patient contributions rather the level of responsibility, type of work, degree of participation, expertise and time committed to the research project - Although different levels of engagement may require different rates, payments are additive. For example, if a patient partner is engaged at two levels, they should receive both payments.	8
Compensation rates should be consistent within an institution. For example, patient partners in the same role are compensated the same amount.	6

Developing a contract or policy a priori can be helpful in outlining engagement activities, expectations, and compensation details.	3
Review your organizations policy or procedure for financial compensation payments before you develop a contract or budget. - For example, some organizations cap compensation amounts and anything that exceeds this value will require a contract/salary.	2

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CHAPTER 5: Patient engagement in graduate research

Preface to Chapter 5:

This chapter is a reflection piece about patient engagement in graduate research and discusses how I navigated patient engagement in developing and conducting my graduate research. While this is not a manuscript, a patient partner and I plan to publish a more detailed reflection piece about our experiences.

5.1 INTRODUCTION

My experiences with patient engagement in research as a summer student and research assistant (1–4) led me to pursue graduate research in the area of patient engagement, and, of course, doing so with a patient partner throughout the development and conduct of my thesis. Notably, there is very little available guidance on how to navigate patient engagement within a thesis and evidence advocating or supporting patient engagement in graduate research. Quickly in my graduate studies, I came to realize that patient engagement in graduate research is relatively novel. Indeed, a recent assessment of the prevalence of patient engagement among a cohort of trainees conducting pain research in Canada identified only a fraction of respondents previously partnered with patients in their research and even fewer reported feeling very or extremely confident about implementing patient engagement in their research.(5) In fact, trainee respondents identified "support from their supervisors, departments and institutions" and "knowledge of how to practically implement patient engagement" as key facilitators to improve uptake of patient engagement by trainees.(5) The aim of this chapter is to contribute to the lack of knowledge of patient engagement in graduate research. Here, I will describe my experiences, logistical processes of engagement, and the benefits and lessons learned of incorporating the patient perspective in the development and conduct of a master's thesis project.

Despite its novelty, there are several reasons to support the importance (and need) of patient engagement in graduate research. First, supporting trainees and early career researchers in partnering with patients may facilitate future commitment and incorporation of patient engagement in graduate research. Second, working alongside patient partners can help trainees develop crucial communication and interpersonal skills (i.e., communicating scientific ideas accessible, discussing and navigating sensitive topics) that are not otherwise taught in graduate school courses. At the University of Ottawa, candidates in the Masters of Epidemiology program conduct their research under the supervision of

supervisors and a thesis advisory committee generally consisting of three to five academic members. The roles of the thesis advisory committee are to provide advice on the conduct of the research project, approve the student's Thesis Proposal, and evaluate student progress and performance.(6) To meet these goals, it is recommended that the thesis advisory committee consist of members who are knowledgeable in the research areas of interest.(6) By this definition, a patient partner would make an exceptional addition to a thesis advisory committee as they are experts in lived experience and that they bring a novel perspective to research. Given the nature of my thesis topic, financial compensation of patient partners, we invited a patient partner to join my thesis advisory committee.

5.2 RECRUITMENT AND ONBOARDING

A patient partner was nominated by several team members (DS, DAF, SN) as she had a history working together on various research projects. She has a wealth of experience being a patient partner in many capacities, both local and internationally, and at different levels (i.e., research project specific, governance etc.). As a result of her experience, she is extremely knowledgeable in patient engagement practices and advances in the field. Furthermore, she has lived experience in patient partner compensation. These experiences made this patient partner an asset to the research team and thesis advisory committee. A team member connected the patient partner and me by email where I introduced myself, provided a brief overview of the thesis topic, and she accepted an invitation to attend an onboarding meeting to further discuss the thesis proposal. The purpose of our onboarding meeting was to discuss the patient partner's interest in the project and to assess her willingness to join the committee. At this meeting we discussed our previous research experience (i.e., personal experiences with patient engagement in research and compensation), the role of the thesis advisory committee, presented an overview of the thesis plan, and discussed our expectations and availability. She was optimistic about the general thesis plan and expressed her willingness to be a thesis advisory committee member.

Over email and further conversations, we co-developed a terms of reference document to outline the project plan, team member expectations and roles (Appendix 1). The terms of reference was referred to throughout the thesis research. In the terms of reference, we outlined our patient engagement strategy in accordance with the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework and the 7 Core Principles for Public Engagement.(7,8) For instance, in terms of demonstrating 'patient partner contributions are valued', the patient partner and I discussed how her contributions could be best recognized. We decided that co-authorship and financial compensation (in

accordance with guidance developed by the SPOR Evidence Alliance recommending $25/hour (9)) would be offered in appreciation for her time and work.

5.3 PATIENT ENGAGEMENT RESEARCH ACTIVITIES

After our onboarding meeting, the patient partner was invited to attend a formal thesis advisory committee meeting (June 2021) where I presented my thesis proposal. The aims of this meeting were to receive feedback and direction on the proposal from committee members. This evaluation is a requirement of the program and was submitted to the University of Ottawa School of Epidemiology and Public Health to ensure that candidates are meeting program expectations. After receiving approval of my thesis proposal from all thesis advisory committee members, I started conducting my thesis research. Throughout the conduct of the thesis, from September 2021 to September 2022, the full thesis committee (including a patient partner) met twice and I met with the patient partner monthly to discuss project progress with more frequent email communication as needed. The patient partner was a member of my thesis advisory committee and participated in all of the following research activities with other committee members:

- Reviewed and approved the thesis proposal and she was named as a co-author on the published version(10)
- Co-developed definitions for patient partner compensation (i.e., financial compensation, non-financial compensation)
- Participated in jointly interpreting compensation practices identified in the findings from the systematic review (Chapter 2), survey (Chapter 3), and scoping review (Chapter 4)
- Informed the response to reviewer comments on the published research program protocol (10)
- Reviewed and approved the final thesis for submission
- Reviewed student applications for grants and awards
- Provided feedback on a presentation of thesis findings to the Children's Hospital of Eastern Ontario (CHEO) Patient and Family Advisory Council and co-developed discussion questions for the meeting
- Connected the research team with the Ontario SPOR Support Unit Patient Partner Working Group to get feedback on the thesis projects including systematic review findings
- Co-developed a plain language summary of the thesis to be shared on Twitter

5.4 SUCCESSES OF PATIENT ENGAGEMENT IN GRADUATE RESEARCH

Overall, we demonstrated that having a patient partner on the research team ensured that the conduct of graduate research about patient engagement in research included the patient voice in the research proposal, interpretation of findings, and knowledge translation activities. First, the patient partner was engaged from proposal development until thesis submission and submission of papers to journals. In my previous experiences with patient engagement in research, it has been challenging to maintain engagement and regular communication with patient partners. I found this even more challenging given the fast-paced nature of graduate level research. By scheduling monthly meetings, I was held accountable to update the patient partner on the direction of each project and these meetings provided the opportunity to ask her questions and regularly get her feedback. Second, the patient partner was integrated as an equal member within the thesis advisory committee. At the beginning of my thesis, I wanted to ensure that the patient partner had the opportunity to provide input and guide the direction just as other committee members and I achieved this goal. On a more personal note, working closely with the patient partner has helped me achieve a more complete understanding of patient partner recognition from the perspective of the patient partner community. I am grateful to have heard her personal experiences with the issues around compensation. Our discussions helped me formulate less biased balanced opinions about patient partner compensation.

5.5 CHALLENGES WITH PATIENT ENGAGEMENT IN GRADUATE RESEARCH

Despite my previous experiences working with patient partners in research, patient engagement in graduate research was new territory, and navigating engagement processes posed unique challenges. First, it was challenging to estimate the number of hours that a patient partner would allocate as a thesis advisory committee member. At project inception, the patient partner and I budgeted for engagement and estimated the number of hours she would allocate to the various projects to ensure that she had the capacity to take on the role of a thesis advisory committee member. In retrospect, we underestimated the number of hours required of thesis advisory committee members. Throughout the year, new opportunities arose including developing student applications and various presentations of the thesis work. I should have revisited this budget throughout the project and adjusted it accordingly. Second, I believed it was important to formally recognize the patient partner for her contributions to my thesis work by listing her as a thesis advisory committee member on all formal documentation to the University of Ottawa, however institutional barriers prevented this. At the beginning of my thesis, I asked the School of Epidemiology and Public Health about processes required to formally recognize the

patient partner as a thesis advisory committee member. The school responded that it would not be possible to have a patient partner as a thesis advisory committee member since "*key roles of the thesis advisory committee include reviewing and approving the scientific merit of your thesis proposal, doing the same for your written thesis, and evaluating your progress each year.*" While this was disappointing, I understood this barrier. Given that thesis members hold a lot of responsibility in the trajectory of the students' progress, we saw this barrier as protecting students from appointing a member that may not fully understand the research project or the responsibilities of being a thesis advisory committee member. For example, an unsatisfactory score from a committee member may result in the student being withdrawn from the program. Irrespective of this challenge, we continued to list the patient partner on all formal documentation and maintained a high level of engagement and leveraged other methods to formally recognize the patient partner including co-authorship on the final thesis. Third, as a graduate student, my research is not funded, which is a crucial barrier to patient partner reimbursement and financial compensation. Fortunately, all engagement was virtual, and my supervisors were able to leverage discretionary funds to provide financial compensation to the patient partner. Finally, I want to acknowledge that I was very fortunate to have had previous patient engagement in research experience and work with a team of thesis advisory committee members (including the patient partner) who are well-versed in patient engagement in research. Thus, navigating patient engagement in graduate research came second nature. For instance, I had previous experience drafting a terms of reference document and patient partner recruitment was fairly easy provided that my thesis advisory committee members were able to connect me with a patient partner.

5.6 RECOMMENDATIONS

While I am fortunate to have had previous patient engagement in research experience and a committee of researchers with experience partnering with patients in research, this may not be the case for other graduate students. To help guide future initiatives, I have compiled a brief list of recommendations that I believe would have high yield for future graduate student researchers considering patient engagement in their projects:

- Support and patient engagement in research guidance from supervisors and thesis advisory committee members will help overcome barriers to engagement
- Discuss recognition, time commitment and patient partner role before the project begins to ensure that all team member expectations are met

- Create a terms of reference to help guide the development of the patient engagement strategy and ensures that all team members understand the research objectives (an example can be found in Appendix 1)
- Negotiate and schedule regular update meetings (e.g., monthly) with patient partners to discuss project progress and maintain consistent communication
- Seek and use infrastructure/resources available at your institution that may support patient engagement in research
- Review and use publicly available guidance for researchers on patient engagement in research (7,11,12)

5.7 CONCLUSION

Patient engagement in developing and conducting graduate research offers a unique and rewarding opportunity for patient partners to influence trainee research. While I highly support supervisors urging their graduate students to seek patient partner perspectives in developing and conducting their thesis research, I understand that patient engagement can be challenging for researchers and trainees who don't have experience working with patient partners. In my experience, having a patient partner on my thesis advisory committee enhanced my research and contributed to my professional development including developing unique skills in collaborating with a patient partner.

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Appendix 1. Terms of Reference Document.

Terms of Reference: Thesis Advisory Committee

Background

This terms of reference details the expectations of Master's thesis advisory committee (TAC) members. Thesis work is being conducted by Grace Fox at the University of Ottawa between September 2021 to September 2022 in order to meet the requirements necessary for a Maters of Science in Epidemiology. This project is unfunded.

This thesis focuses on patient engagement. Specifically, identifying methods of recognizing patient partners for their contributions to health research. Patient engagement in research refers to the inclusion of patients (individuals with lived experience of a health issue and informal caregivers, including family and friends)(1) as partners in the research process – i.e., research is carried out 'with' patients not 'on', 'about' or 'for' them. (2) One major challenge to patient engagement is to create an environment where all team members are comfortable discussing elements of the research program and avoiding tokenistic patient engagement (I.e. engagement that is insincere). (3) A key aspect of genuine engagement is recognition of contributions, since this can support how patient partners are valued and acknowledged, ultimately discouraging tokenism. (3) (4)
Indeed, there has been much debate regarding the appropriate ways in which patient partner contributions can and should be acknowledged, including need for financial compensation. (4) (5) (6) Without compensation, patient partners are considered volunteers which are defined as individuals who donate their time and energy to benefit others without motivations of financial gain. (7) While volunteerism is personally rewarding and highly impactful, it may be challenging for people without the financial means to volunteer their time to research. (4) (7) Thus, offering financial compensation allows patient partners to decide whether they want to volunteer their time or accept remuneration. This may enable members from different socioeconomic populations to be engaged in research and thereby encourage the inclusion of diverse perspectives. (4) Although there are arguments in support of patient partner compensation, some barriers to compensation exist. For example, it can be challenging to assign a monetary value to a unique skill set and lived experience in a respectful manner and compensation may have legal implications (taxable income). (5) (8) (9)

Despite the discussion of principles regarding patient partner compensation and available resources, there remains little empirical data with regards to actual practices of patient partner compensation. To guide financial remuneration, we need to enhance our understanding of current practices for compensating patient partners and identify available guidance that is used to inform these decisions. This thesis will address the lack of research in this area, in addition to the following:

1. How prevalent is patient partner compensation (financially compensated for their role as partners in the development and conduct of health research) among a cohort of primary research studies that engaged patients as partners?
2. What are the current practices of patient partner compensation (e.g., amount, method of payment, frequency of payment, use of contracts/agreements etc.)?
3. When is compensation appropriate and impactful from the perspective of researchers and patient partners?
4. What do researchers and patient partners believe are best practices for financially compensating patient partners for their contributions?
5. What are principal investigator, patient partner, institutional, and policy maker attitudes (benefits, challenges, barriers and enablers) around patient partner compensation?

Definitions

Thesis Advisory Committee (TAC): A committee responsible for informing the development and conduct of an academic thesis.
Ontario SPOR Support Unit (OSSU): A network of health research centres that engage researchers, patients and other partners in patient-oriented research to improve the health of Ontarians and the health case system.
Compensation: The act of awarding something to someone in exchange for a service.
Guidance for Reporting the Involvement of Patients and the Public (GRIPP): A reporting checklist developed to facilitate proper reporting of patient engagement in research. Two versions of this checklist exist.
Patient partner: An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends, and members of the public. http://www.cihr-irsc.gc.ca/e/48413.html#a4

Purpose

This Terms of Reference serves as the guiding document for Thesis Advisory Committee members. The goals for this group are to inform the development and conduct of a graduate level research thesis. Members will engage in:

- Advising study methodology
- Identifying priorities, data extraction items, refining survey questions
- Informing statistical analysis
- Reviewing and providing feedback on documents and protocols
- Connecting with other stakeholders and co-developing dissemination strategies
- Approving activities or documents

Membership

This TAC consists of 5 members:

- Dr. Dean Fergusson and Dr. Manoj Lalu are co-supervisors for this thesis and co-lead the Blueprint Translational Research Group. They have undertaken considerable work in patient engagement in research and have received funding to advance its science and practice. They have developed institutional policy and infrastructure to support patient engagement in research at the Ottawa Hospital. Dr. Fergusson is the Scientific Lead of the Ontario SPOR SUPPORT Unit.
- Dr. Stuart Nicholls is the SPOR Program Facilitator in the Office of Patient Engagement in Research Activities (OPERA) at the Ottawa Methods Centre. Dr. Nicholls is well connected to the current patient engagement practices in Canada and will provide invaluable expertise on how this work will fit in with the current patient engagement landscape.
- Dr. Dawn Stacey is a Senior Scientist in the Clinical Epidemiology Program at the Ottawa Hospital Research Institute and holds a University Research Chair in Knowledge Translation to Patients.
- The patient partner's background is in education, and she has extensive experience as a patient partner, patient engagement advisor and a principal and co-principal investigator on several SPOR funded studies. She is the Chair of the Cochrane Consumer Network Executive and has held positions on advisory committees for several organizations including the steering committee on patient collaboration in research for the Montfort Hospital's Research Institute.

Stepping Down

In the event that team members want to step down, they can email Grace Fox at any time to organize off-boarding or discuss workload. Similarly, if team members wish to take a temporary pause on involvement, they can feel free to reach out to Grace.

Accountability

Grace Fox will be the main contact.

Confidentiality

We do not anticipate any issues with confidentiality. Should any specific confidentiality or copyright issues arise throughout the project, these will be discussed among the group at a team meeting. The terms of reference will be updated to reflect these issues.

Information and resources have been primarily shared via e-mail. Members of the research group will be communicating via their hospital email address which complies with The Ottawa Hospital confidentiality mandates. Members can feel free to reply to emails separately if they wish to keep feedback confidential.

Expectations: Meeting Attendance, Time Commitment, Etc.

- Attendance: Teleconference meetings will be held every 3 months over a 1-year period. Meetings will take place over Microsoft Teams.
- Agenda: Meeting agendas will be circulated 1-week before the meeting. All team members will have the opportunity to suggest additional agenda items.
- Preparation: Minimal preparation for meetings will be necessary. If preparation is required (e.g. review of documents, provide feedback), members will be made aware of this and provided with two-weeks to prepare.
- Conduct of Meeting: Grace Fox is responsible for organizing and leading team meetings.
- Minutes / Notes: Informal meeting minutes will be kept and a high level summary of the meeting will be circulated to members who could not make it. Additionally, a "make-up" meeting will be offered to provide updates to absent members.
- Length of Project: Approximately 4 team meetings over a 1-year period.
- Compensation and Reimbursement: Method of recognition (i.e. compensation) will be discussed with patient partners. Final details will be outlined in a supplementary table within this document. Given that meetings will take place virtually, we do not anticipate reimbursement.

Time commitment is outlined below in *Reimbursement of Expenses and Compensation for Time.*

Decision Making

TAC members will hold significant decision-making power throughout the development and conduct of the thesis. Grace Fox (graduate student), Dean Fergusson and Manoj Lalu (co-supervisors) will have the largest impact on decision-making. With that said, team members will be provided with details of how their suggestions were implemented or justification for why they were not implemented.

Reimbursement of Expenses and Compensation for Time

We used the SPOR Evidence Alliance Patient Partner appreciation policy to inform patient partner compensation strategies. Method of recognition, amount, and frequency of payment will be discussed further with our patient partner.

An outline of the project time commitment is detailed below. We will ask our patient partner for their input and we can amend at any point in time.

Month	Activity	Estimated time commitment (hours)
September	Update meeting	1
	Review SR protocol	1.5
	Review survey protocol	1.5
October	Update meeting	1
	Review ScR protocol	1.5

November	Informal TAC meeting	1
	Review ScR protocol	1.5
December	Update meeting	1
January	Update meeting	1
February	Informal TAC meeting	1
	Consult ScR data extraction	1.5
March	Update meeting	1
April	Update meeting	1
May	Informal TAC meeting	1
June	Update meeting	1
	Review thesis documents	3
July	Informal TAC meeting	1
	Review thesis documents	3
August	Review thesis documents	3
		Total hours:
		27.5
		Total ammount (25$/hour):
		687.5

We do not anticipate patient partner to have “out-of-pocket” expenses (i.e., parking, travel, child care, etc.), but in the event that this happens, we will reimburse such expenses. We will ask that members keep receipts or proof of payment for any expenses related to this project.

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CHAPTER 6: Discussion

Preface to Chapter 6:

In this chapter, I present my central research findings from Chapters 2, 3, and 4, and provide a synthesized discussion. My findings are also contextualized within the broader literature. I also discuss the implications of findings on stakeholder practices, education, and future research.

6.1 SUMMARY OF KEY FINDINGS

The overall aims of my thesis were to provide an understanding of the current landscape of reporting patient partner compensation (with a focus on financial compensation) and identify current practices, assess researcher attitudes and experienced barriers and challenges, and provide a comprehensive overview of available guidance and policy regarding compensation. Chapter 2, a systematic review of published patient engagement research literature referencing the Guidance for Reporting the Involvement of Patients and the Public (GRIPP I and II) reporting checklists, identified a paucity of reporting patient partner financial compensation methods and variation in the monetary amount offered to patient partners. Chapter 3, a cross-sectional survey of researchers and institutional leaders, reported that researchers are generally positive about their intention to offer financial compensation to patient partners, however institutional barriers interfered with doing so. Chapter 4, a scoping review of available guidance and policy documents to guide patient partner compensation, reported a wealth of publicly available compensation guidance and support that organizations highly value patient partner financial compensation. Chapter 5 describes my experience of patient engagement embedded within this thesis and highlights the challenges and successes of incorporating the patient perspective in graduate research.

6.2 INTEGRATED FINDINGS WITH BROADER LITERATURE

At the individual level, researchers and organizations highly value patient partner financial compensation.

Survey findings in Chapter 3 suggested researchers are generally positive about their abilities and intentions to offer financial compensation and the majority of respondents (researchers and institutional leaders) have experience offering financial compensation to patient partners. Similarly, the scoping review thematic analysis, in Chapter 4, revealed that organizations recognise the benefits of financial compensation including providing a tangible method to show appreciation for patient partner efforts and facilitating the inclusion of diverse perspectives on the research team/project. Overall, these

two findings suggest that, at the individual organization and individual researcher level, stakeholders understand the value of offering financial compensation to patient partners. However, the positive attitudes identified from Chapter 3 and 4 may not be reflected in practice since the systematic review (Chapter 2) identified a paucity of reporting patient partner financial compensation. These findings highlight a practice gap as researchers may not be aware of institutional policies or guidance. Sample population characteristics may provide some explanation for the observed discrepancy between intentions and action. Considering that the survey sample consists of researchers and institutions that have experience publishing or supporting patient engagement in research, it is possible that those who have experience offering financial compensation may be more inclined to respond to a survey that is assessing compensation. Indeed, respondents who have a more positive attitude about the topic of interest may be more likely to respond to a survey.(1,2) Therefore, the level of patient engagement in research experienced within our sample may explain the overall positive attitudes identified by the cross-sectional survey.

There is recognized value of reporting patient engagement in research but little guidance on reporting patient partner compensation.

While documents identified by the scoping review (Chapter 4) provided recommendations on how to recognize patient partners for their contributions to research, there was no guidance on how to report compensation in published manuscripts or other research outputs. From the systematic review in Chapter 2, a fraction of studies reported offering financial compensation to patient partners and, of the studies that did report financial compensation, reporting was variable in terms of details of financial compensation (e.g., method of compensation, amount etc.) and where information was reported in the manuscript (e.g., patient involvement section, GRIPP checklist, methods). While the paucity of reporting patient partner financial compensation may be a result of a lack of reporting requirements or standards for recognition strategies, it's important that we consider the value of reporting patient partner recognition in research publications.(3) Indeed, patient partner compensation is only recently being discussed with two influential papers in this area published in 2018 and 2022. (4,5)

In general, it is ethically imperative that researchers are transparent in reporting health research (6,7) and reporting important details of patient engagement in research are no less important. The importance of transparent reporting in newly evolving areas of research is crucial to support further implementation as reporting allows for comparisons to be drawn across published methodology. However, should we strive to increase reporting of patient partner compensation in order to normalise

compensation practices? For instance, researchers interested in engaging patients in their research for the first time may look to previous published examples of patient engagement in research and notice that patient partner recognition is occurring. Thus, enhanced reporting may improve uptake of patient partner recognition practices. Factors that may be influencing the lack of reporting are that financial compensation is not an item on the GRIPP reporting checklists (8,9); widely used for reporting the level of patient engagement on research teams.

While there is a clear evidence in support of reporting guidance to enhance manuscript quality and transparency, it is crucial that the value of reporting patient partner compensation be considered.(10) First, financial compensation is not an item on the GRIPP reporting checklists, and it is not clear from the literature why recognition is excluded. Deciding on the essential patient engagement compensation elements to report in a publication requires further investigation. Second, a prevalent argument in support of financial compensation is to promote equality among team members (Chapter 2). Thus, it could be argued that reporting of patient partner financial compensation should be the same as how we report principal investigator or research personnel salary, which at present is not currently reported. Traditionally, researchers acknowledge financial support from funding agencies or institutions. However, reporting standards for financial support never exceed basic acknowledgement or inclusion of specific monetary values. This makes it difficult to justify reporting patient partner recognition at a higher standard of transparency even if it is well known that complete reporting enhances research transparency and improves researcher accountability. Overall, these issues point to the need for further thought and evaluation to consider the value proposition, beyond simply for research transparency, to incentivize reporting of patient partner recognition.

A major barrier to early patient engagement in research is financial support.

The systematic review and cross-sectional survey (Chapters 2 and 3) identified the lack of financial support as a key barrier to offering financial compensation to patient partners during protocol and grant development. Additionally, our scoping review thematic analyses (Chapter 4) identified important items researchers need to consider when offering financial compensation to patient partners. Two common recommendations reported by guidance documents include discussing financial compensation with patient partners individually at the beginning of engagement in research and accounting for the cost of patient engagement in research (i.e., reimbursement, financial compensation) when assembling the project budget. Several patient engagement in research frameworks recommend that patient partners should be engaged at project inception to ensure that the patient perspective is

considered when developing the project protocol, selecting the research questions, determining the key outcomes, and preparing the funding application.(11)(12) Early patient engagement in research is ideal because patient partners have a unique capacity to assess the acceptability of research products.(12) Despite the benefits of early patient engagement in research, there is typically little funding to support patient engagement at the research question and protocol development stages. As such, there is an important gap between what is recommended from patient engagement in research guidance and what is currently possible in practice since the funding process is not organized in a way to facilitate patient engagement at the protocol development stage. To see the realized benefits of early patient engagement in research, stakeholders may consider leveraging existing organizational support. For example, researchers can utilize discretionary funds to seek guidance or services from organizations within their institutions (e.g., Office for Patient Engagement in Research Activities at the Ottawa Hospital Research Institute) or patient partner networks (e.g., Patient Voices Network). However, challenges persist for researchers who don't have discretionary funds or institutional support. Thus, funding agencies should develop funding calls to support patient engagement in developing research proposals.

Various terms for "patient engagement" may contribute to researcher confusion about what activities are considered engagement in research.

Throughout my thesis, we needed to develop and refine definitions for different types of patient partner recognition to minimize confusion especially since consensus terminology in this space has yet to be established. In fact, inconsistent use of patient engagement terminology across countries (i.e., patient and public involvement in the United Kingdom, patient engagement in Canada) is a key challenge to engagement.(14) While my thesis is concerned with patient engagement in research, the term "patient engagement" has been used broadly in healthcare to describe involving patients in developing policy, informing hospital level procedures, and clinical decision making.(15)(16)(17) Even within research, many terms exist to describe patient engagement in research (i.e., patient and public involvement, patient-oriented, patient-centered).(14) Indeed, one of the GRIPP II reporting checklists items encourages authors to define the term used to describe patient engagement.(9) Heterogenous use of the same term in various contexts can cloud stakeholder understanding of exactly what the term patient engagement means, making it difficult to identify patient engagement in research, especially for systematic reviews. Harrington and colleagues conducted a systematic review to identify published definitions of patient engagement in research.(18) They found 224 distinct definitions used to describe

13 different terms for patient engagement in research and generated a single overarching definition in an attempt to streamline terminology; "*The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their specific experiences, values, and expertise.*"(18)

While conducting my thesis, we used a very broad definition of patient engagement in research, informed by CIHR, to be inclusive of all patient engagement activities and all levels of engagement. Specifically, patient engagement in research occurs when "*members of the public or patients (i.e., an individual with lived experience of a health condition as well as informal caregivers, including family, friends, or members of patient organizations) are engaged as research partners (provided input, guidance, consultation on at least one element of the research process*)".(11) Although we tried to be consistent across all three thesis projects, in the survey we introduced patient engagement as "*referring to activities where patients, caregivers or members of the public are engaged in research as collaborators, not as research participants*" and acknowledged the use of different terms. Given that we were surveying international researchers and institutions, it was possible that using the term patient engagement and providing respondents with a broad definition may have caused confusion. For example, I received an email response from a researcher explaining that they could not respond to the survey because they did not engage patients as partners in their research. Upon revisiting the publication that was captured in the systematic review, it was clear that they consulted a patient panel in developing the intervention, and thus it is evident that our definition of patient engagement in research may not be consistent with other researchers.

6.3 STRENGTHS AND LIMITATIONS

Overall, this thesis provides a comprehensive overview of the current landscape of patient partner financial compensation by assessing reporting, current practices, stakeholder attitudes, barriers and challenges to financial compensation and identifying current guidance and policy. Using this multi-study approach allowed us to conduct unique projects while being consistent in terminology used and its categorization across studies. The relationships between project components provides a comprehensive overview of the current state of patient partner recognition, with each study component having unique stand-alone strengths. First, our systematic review was conducted to a high quality according to the Assessment of Multiple Systematic Reviews (AMSTAR) criteria.(19) Namely: 1) we developed and published our protocol a priori; 2) a comprehensive literature search was performed; 3)

inclusion criteria are clearly detailed; 4) study selection and data extraction was done independently and in duplicate; and 5) a list of included studies was provided. Second, since the systematic review provided the sampling frame for the cross-sectional survey, this provided an opportunity to better understand researcher and institutional leader practices and beliefs around patient partner compensation beyond what is reported in the literature. Third, our scoping review identified a wealth of publicly available guidance to support researchers in navigating compensation. By undertaking a comprehensive synthesis of available guidance and policy, we hope to better support researchers in developing their unique compensation strategies. Finally, we partnered with a patient partner throughout the development and conduct of each thesis project, ensuring the patient perspective was included throughout. The patient partner served as a formal Thesis Advisory Committee member – currently a unique role.

Several limitations should also be noted. First, the systematic review and scoping review qualitative analyses relied heavily on inductive coding which may result in oversight of key concepts. However, both reviews identified a heterogenous cohort of published evidence, and thus it would not have been feasible to use a framework to guide qualitative analysis as there does not exist a single framework to adequately analyze such heterogenous evidence. Of note, inductive coding was conducted in duplicate by two independent reviewers to ensure that codes were generated objectively. Second, our survey population is limited to researchers who have published patient engagement research in accordance with the GRIPP checklists. Therefore, we assessed the experiences of researchers and institutional leaders who are likely more familiar with patient engagement in research. It is clear that researchers new to patient engagement face unique challenges and barriers such as navigating engagement and understanding patient partner roles.(20) This thesis is focused on a subset of patient engagement, patient partner recognition, thus we are limited in addressing broader challenges to engagement in research. Rather, our survey findings focus more on the logistical challenges and barriers to compensation and oversee the educational barriers that may exist for researchers who are new to patient engagement in research. Third, as previously discussed, we used a broad definition of patient engagement in research throughout the development and conduct of each thesis project. As a result, we may have been over inclusive of studies included in the systematic review and may have caused confusion among survey respondents. Finally, we have received criticism about partnering with one patient partner and that this strategy lacks diversity. I think that it is important to reiterate that, while the overall aim of this thesis is to assess the current landscape of reporting patient partner compensation, the focus was on the roles played by researchers and institutional leaders. With that

said, we plan to continue to partner with larger patient panels in developing patient partner specific outputs including plain English summaries of research findings to distribute on social media.

6.4 IMPLICATIONS OF FINDINGS

Implications for researcher and institutional leader practices

Given the benefits of offering financial compensation to patient partners (Chapter 4), researchers and institutional leaders should determine ways to ensure adequate compensation based on available guidance and policy documents. The comprehensive overview of recommended monetary values of financial compensation and population specific compensation details (Chapter 4, Appendix 6 and 7) can help guide researchers in choosing guidance documents when formulating a compensation strategy. Both research outputs will help enhance financial compensation to patient partners through highlighting the benefits of engagement and facilitating decision making. Additionally, funding agencies may adopt guidance highlighted by the scoping review to support researchers in budgeting for patient engagement in research. Ultimately, the scoping review findings may support the uptake of patient partner financial compensation practices by researchers.

Similarly, thesis outputs, including the researcher identified barriers or challenges to financial compensation from the survey study, may improve institutional leader understanding of their role in facilitating patient partner financial compensation. As a result, institutions should implement practices and adopt guidance to support research members. This can be achieved by making guidance identified by our scoping review accessible to members of their institutions or altering the generated list of items to consider when offering financial compensation (Chapter 4, Appendix 8) to reflect institutional procedure, ultimately generating an institutionally specific How-To-Guide to navigating financial compensation.

Implications for funding agencies

Currently most research funding agencies are not set up to support patient partner engagement in the protocol and grant development stages. It is crucial, however, that funding agencies or institutions offer financial support at this stage to encourage researchers in seeking patient perspectives when developing the research project proposal. Strategies may include nominal grants awarded to research teams specifically to support early engagement. Indeed, CIHR has recently organized Planning and Dissemination Grants to help support research planning activities and partnership development meetings.(21) Additionally, pre-funding grants have been recently awarded by the Switzerland based

Rising Tide for Clinical Cancer Research Foundation primarily to close the funding gap.(22) Researchers at the pre-protocol development stages were eligible to apply for funding to support reimbursement of patient partner travel costs (1,000 EUR) and compensation for time (3,000 EUR). While this grant is generous, the recommended monetary values for consulting activities as identified by the scoping review are nominal ($25 CAD/hour). Therefore, pre-funding grants of $1,000 (CAD) would reimburse two patient partners for 20 hours of time, which would likely suffice engagement at protocol/grant development stage for many projects. At this value, the reward of producing a patient partner informed protocol likely exceeds the risk of the proposal failing to receive full project funding. Additionally, funding agencies without unique patient partner compensation policies must adopt existing guidance and make these publicly available for researchers who are applying for funding to encourage and support researchers to budget for patient engagement.

Implications for future research

While the scope of this thesis was focused on researcher and institutional leader compensation practices and experiences, it is clear that patient partner perspectives are necessary to consider. Compensation is a much discussed topic among patient partners themselves and there are varying opinions on aspects such as volunteerism, rates for financial compensation, and its impact on researcher-patient relationships.(4,5) However, we don't know patient partner perspectives on different types of compensation, or experiences with compensation. Thus, future research should focus on assessing patient partner perspectives and experienced with compensation. Similarly, our systematic review and survey study were limited to assessing the perspectives of researchers who have experience publishing patient engagement research. While several studies have assessed challenges to patient engagement in research experienced by early-career researchers, few have specifically discussed challenges of patient partner compensation. (23–25) Subsequent research should investigate early-career researcher perspectives to better understand the landscape of patient partner compensation. Lastly, a wealth of guidance and policy exist to guide researchers in developing patient partner recognition strategies (Chapter 4). However, we did not identify a guidance document including details to facilitate the implementation of guidance at the institutional level. This points to a significant knowledge gap that requires attention from funders and guidance developers for patient engagement in research. Implementation of compensation strategies should be examined at an institutional level, and tools to enhance uptake of suggested compensation methods require further thought.

6.5 CONCLUSION

This thesis details a multi-study approach to assessing the current landscape of patient partner compensation. As a result, we have an improved understanding of the patient partner compensation practices, stakeholder attitudes and experienced challenges and barriers, and available guidance and policy documents to support patient partner financial compensation. Thesis findings identified gaps and inconsistencies in patient partner recognition that require further investigation. Findings from this thesis will serve to inform researchers in offering financial compensation to patient partners and guide implementation of policies and procedures at the institutional level.

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