Promoting Patient Engagement in Early Phase Clinical Trials: How Canadian Funding Agencies Can Help

Prepared By: The Blueprint Translational Research Group

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The Blueprint Translational Research Group

The Blueprint Translational Research Group is a preclinical to clinical research team based at the Ottawa Hospital Research Institute working to accelerate bench to bedside translation. The group is multidisciplinary with current interests in knowledge synthesis (i.e., systematic reviews and meta-analysis), patient engagement, and preclinical multicenter studies. For more information, please visit our website at https://www.ohri.ca/blueprint/.

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Executive Summary

Patient engagement

"Patient engagement" in research is the meaningful and active collaboration of research teams with patient partners (i.e., those with lived experiences of a health condition, or their family/friends and/or their representatives). "Patient partners" can include these individuals as well as patient organizations. These partners can contribute at many levels including at the project or study level, governance, priority setting, knowledge translation of research, and longer-term retention of data such as patient values and preferences.

Despite the value of patient engagement in improving the quality and relevance of research, there have been limited initiatives in Canada to involve patients in the earliest phases of clinical research and trials. These earliest phases are often called 'translational' research as they involve moving promising therapies from laboratory experiments to clinical trials in humans.

Barriers to patient engagement

Key barriers include:

- Researchers new to patient engagement have difficulty identifying which guidance documents and best practices to use.
- Lack of appropriate planning can make patient engagement difficult to implement.
- Challenges in achieving equity and diversity in patient partner recruitment. This is an important consideration as it allows for a more representative group of patient perspectives to be incorporated into the research, thereby increasing its potential impact.

How can funders promote patient engagement in early phase clinical trials?

This policy brief will summarize three potential recommendations for **funders** of early phase and 'translational' research to consider.

- *Recommendation 1* – Direct researchers to key patient engagement resources on the funding agency website to highlight expectations, successful practices, and potential frameworks for engagement. Incorporating resources into the existing webpages of Canadian funding agencies is cost effective and will increase exposure of best available resources.

- *Recommendation 2* – Require planning for patient engagement throughout the funding process - start with a checkbox but then move beyond this. Funders can require researchers to demonstrate planning for patient engagement in 'patient engagement' sections of the grant applications (e.g., a detailed explanation of how they plan to recruit and engage patient partners). In addition, funders should consider small seed grants that could support patient engagement in the grant development process. Funders could also ask for updates on planned patient engagement activities in regular progress reports. These approaches may prevent patient engagement from becoming tokenistic or a 'tick-box' exercise.

- *Recommendation 3* – Require researcher training in equity, diversity, and inclusion to equip them with the knowledge required to recruit and retain a representative group of patient partners to work to establish meaningful patient engagement and centricity. Researchers will be able to evaluate the systematic oppressions that are most likely to exist, identify the patient population(s) that would be most affected if the intervention of interest was implemented, and prioritize them for engagement activities

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Background and Context

'Patient engagement' in scientific research refers to a partnership between researchers and patients, patient organizations or members of the public. This approach to research allows the perspectives and feedback from both researchers and patients to be considered throughout the development and execution of a study. Patient engagement embodies the notion of promoting the passenger to co-pilot and replacing "conducting research *about* patients" with "conducting research *with* patients" [1]. We note that, for the purposes of this policy brief, the term 'patient' will be used in reference to individuals with personal experience of health condition (including family, friends, and informal caregivers) as well as patient organizations. Patient organizations can be particular effective partners as their 'institutional memory' allows perspectives to be capitalized over longer periods of time. Important definitions are provided in Box 1.

Engaging patients in clinical research helps to ensure that studies are participant friendly [2, 3], that outcomes studied are important and relevant to patients [4-6] and that research findings are disseminated to patients and the public [4, 7, 8]. There is an ethical imperative to engage patients in clinical research since patients and members of the public are the primary users of the research findings and much of research is publicly funded [8, 9]. Furthermore, it is important to have a diverse group to ensure perspectives are representative of the larger population.

Conducting research guided by the perspectives of patients and members of the public is not a novel concept. In fact, patient engagement practices have been promoted at a national level and led to the development of patient-oriented research agencies. For instance, federal funding bodies, like the Canadian Institute of Health Research (CIHR) [13], have created internal sub-branches that financially support patient-oriented research projects (SPOR - Strategies for Patient-Oriented Research) [14].

Canadian organizations that financially support early-phase clinical trials may be particularly interested in promoting patient engagement

Box 1. Patient Engagement Terminology

Patient engagement - the meaningful and active collaboration between researchers and patients in governance, priority setting, conducting research and knowledge translation (i.e., education and advocacy)

Patient - in this context refers to an individual with personal experience of a health issue and informal caregivers, including family and friends [10].

Patient Organizations or Patient Groups - a term referring to patient advocacy organizations, disease advocacy organizations, voluntary health services, and non-profit research foundations. It is not meant to refer to individual patients or individual advocates [11].

Note that this definition does not include collecting samples or data from patients and caregivers. Patient engagement is distinct from participation in a clinical study. True engagement requires patients to become members of the research team. This is why patients who are engaged in research are often called **patient partners**.

Patients can be engaged at varying levels. The **Ontario Patient Engagement Framework** [12] does an excellent job of portraying the different levels of engagement and the stages of research at which each can take place. The four levels are outlined below:

- **Share**: One-way communication of research ideas to patient partners to ensure that partners have sufficient background to fully understand the project to form personal opinions. For example, a research group hosting an information session to educate parents on the prevalence of diabetes in children.
- **Consult**: Obtaining and acknowledging feedback from patient partners on various project components. For example, a research group surveying or organizing focus groups to enable discussion between parents and researchers about obesity in children to get the parent perspective and inform the downstream research projects.
- **Deliberate**: working with patients throughout the research process. For example, a research group partners with parents who help shape project deliverables.
- **Collaborate**: Patients are partners and power is shared between all team members. For example, patients are recruited to the research group and involved in informing all aspects of the project, especially decision making.

practices amongst researchers applying for research grants. Although patient engagement has been taken up in many forms of clinical research, it has been rarely applied in early phase clinical research. This type of research is often called 'translational' as it exists at the juncture between basic biomedical laboratory research and the patients' bedsides. Unfortunately, due to high failure rates, early phase clinical research exists in one of the "death valleys" of the research-to-practice continuum. Our research group has recognized the potential for patient engagement to build a translational bridge that strengthens early phase clinical research.

For instance, low recruitment rates or high participant dropout rates play a significant role in premature termination of early phase clinical trials. This may contribute to waste of research resources [15] and ethical issues such as nonpublication of trial results [16-18]. Engaging patients in the development of clinical trials can help improve recruitment and retention to clinical trials [7, 19]. Moreover, patient engagement can help ensure early phase trials are accessible (e.g. equitable inclusion criteria) and study outcomes are relevant to patients (e.g., quality of life and symptom control, patient preferences and values) [2]. These recognized benefits create an ethical imperative to engage patients in the development process of an early-phase clinical trial. However, it is important to consider the fact that patient engagement is currently not a requirement of clinical trials and many funding agencies have not established guidance on this issue. Establishing this guidance in early phase clinical trials may be of interest to funding agencies, considering the reported benefits of patient engagement include increased trial efficiency. This may improve patient access to promising new therapies and ultimately benefit the Canadian healthcare system.

This brief was developed following evidence informed methods which are outlined in Box 2 [20]. It summarizes existing evidence and suggests three recommendations to promote engagement of diverse and representative patients in early phase clinical research. These recommendations may be implemented by Canadian organizations that fund and support early phase clinical research.

Box 2. Background to Evidence Brief

We developed this policy brief to help accomplish two ultimate goals:

- To catalyze discussion amongst researchers, patients, and policy makers.
- To inspire action towards increasing patient engagement in early phase clinical trials.

We prepared this evidence brief using the following steps:

1. We organized and executed a Patient-Researcher Roundtable to identify barriers and enablers to patient engagement in early phase clinical trials. This exercise included patient partners, scientists, and research assistants.
2. Members of our group attended the "Policy Brief Workshop" organized by the Ontario SPOR SUPPORT Unit to become familiar with policy brief development.
3. We identified, reviewed, and assessed current research evidence relevant to identified problems, solutions, and implementation considerations. We also drew upon personal experience.
4. We mobilized feedback from all group members, particularly patient partners, to ensure that evidence presented was accessible.
5. We finalized the policy brief structure and content based on team discussion and feedback of the document.

The Problem

Despite the inherent value in implementing patient engagement strategies in clinical research, the quantity and quality of these initiatives in Canadian early phase clinical trials remain limited [21]. The following barriers were identified from the literature as well as our group's experience, including group discussions between clinical researchers and patient partners:

1) researchers new to patient engagement have difficulty identifying which guidance documents and best practices to use, 2) a lack of appropriate planning and training can make patient engagement difficult to implement, and 3) there are challenges in achieving equity and diversity in patient partner recruitment.

Recommendations to Address the Problem

Many options exist to address the underrepresentation of patient engagement in the development, conduct and reporting of early phase clinical trials. We propose three recommendations that are targeted to Canadian funders who support early-phase clinical trials:

1. Direct researchers to key patient engagement resources.
2. Require planning for patient engagement throughout the funding process.
3. Require researcher training in equity, diversity, and inclusion to promote true patient engagement and centricity.

We present strengths and weaknesses of each recommendation to identify those that may be feasible for your organization. The following sections will discuss barriers to implementing patient engagement in early phase clinical trials, followed by suggested strategies to overcome these barriers, and considerations to adopting each recommendation. It is important to note that the three suggested recommendations can be implemented simultaneously, or elements of each recommendation can be combined to generate a novel solution.

Barrier #1: Researchers New to Patient Engagement Have Difficulty Identifying Which Guidance Documents and Best Practices to Use.

Based on our team's experience, it can be difficult for researchers new to patient engagement to know which guidance documents to use [22]. The abundance of guidance, frameworks, and policy can make it difficult to practically initiate and implement patient engagement. Our group experienced this firsthand when we first recruited patient partners to our research team. Initial efforts (e.g., mass circulation of an advertisement), were unsuccessful in finding a partner; however, a subsequent call for partners was successful through direct referrals. After this experience, we identified published guidance that could have optimized our recruitment approach [23]. Having access to this type of information is key to the success of research teams who are new to patient engagement in research.

Indeed, researchers are faced with a very large, perhaps overwhelming, number of resources. A systematic review on patient engagement frameworks identified 65 frameworks that fit within five categories of focus (power, priority-setting, study, report, and partnership) [22]. In addition, the terminology surrounding patient engagement in research domain is inconsistent.

- Interviews conducted with representatives from 10 agencies that fund healthcare research in the UK revealed that 18 different terms are being used interchangeably in the literature to describe patient engagement. This includes terms like patient involvement, public engagement, and knowledge exchange [24].
- On an international level, the term "patient and public involvement" is often used by the United Kingdom's National Institute for Health and Care Research (NIHR) [25], "patient engagement" by SPOR in Canada [10], and Patient-Centered Outcomes Research Institute (PCORI) in the United States of America [26].

This variation can be challenging for researchers. Different terms encompass different elements of patient engagement adding a layer of difficulty to deciphering the best methods of implementation. It is not surprising then that researchers and patients have voiced concerns regarding patient engagement, highlighting the need for researcher and patient education on the meaningfulness, impact and implementation strategies of patient engagement [27].

Recommendation #1: Direct researchers to key patient engagement resources.

Patient engagement guidance documents are ubiquitous but not necessarily accessible or identifiable to researchers conducting early phase clinical trials. Canadian organizations that fund early-phase clinical studies should create and maintain a section of their website dedicated to informing researchers and interested patient partners about patient engagement. A compendium of web-based resources would highlight expectations and understanding of patient engagement

for patients and researchers alike. Resources would highlight successful practices, and potential frameworks for engagement.

These webpages could contain all, or some, of the following resources that members of our group have found useful:

1. The Blueprint Translational Research Group's Educational Videos on Patient Engagement [28-31]
2. Practical guidance for Involving Stakeholders in Health Research [32]
3. Factors to Consider during Identification and Invitation of Individuals in a Multi-stakeholder Research Partnership [33] and What to Include in a Call for Patient & Public Partners[34]
4. Patient Engagement and Canada's SPOR Initiative: A Resource Guide for Research Teams and Networks [35]
5. Patient Engagement in Health Research: A How-to Guide for Researchers [36]
6. Patient Engagement Quality Guidance [37]
7. Information on regional SPOR Support Units [38]
8. SPOR: Evidence Alliance Patient Partner Appreciation Policy and Protocol [39]
9. Identifying helpful groups to consult for diverse, equitable and inclusive patient engagement: Equity-Mobilizing Partnerships in Community (EMPaCT) [40]
10. Available training sessions and tools: For example, Saskatchewan Centre for Patient Oriented Research offers SPOR training modules [41], the CIHR IMHA Patient Engagement Training [42], and (when available as currently in development) the CANTRAIN Clinical Trials Training Program[43].

In addition to the resources, the funding agency websites could provide some of the following examples of patient engagement in early phase clinical research:

- Engaging patients in the development of a clinical trial protocol [2];
- Working with patients to develop resources to help improve the informed consent process for trial participants [44]; and
- TransCelerate Patient Protocol Engagement Toolkit (P-PET) [45].
- Patient group engagement across the clinical trial continuum by the Clinical Trials Transformation Initiative[46].

We anticipate that researchers involved in late preclinical, and early-phase clinical studies may face challenges in identifying how to engage patients in meaningful research partnerships. Similarly, members of patient organizations may be unclear on how to get involved in this early stage of research as a patient partner. Recommendation 1 provides a key list of patient engagement guidance documents that may help introduce and shape patient engagement efforts. The emphasis is on making current evidence accessible to both researchers and patients to educate and facilitate meaningful engagement. We would also encourage funding agencies to help researchers and relevant patient organizations connect. Early two-way information sharing can help identify and validate a research study's focus in preparation for funding proposals. A summary of key findings and impacts of directing researchers to patient engagement resources on the funding agency website can be found in Table 1.

In summary, Recommendation 1 will facilitate the operationalization of patient engagement in early phase clinical trials by providing researchers with educational materials on the meaning and methods of engaging patients. Furthermore, it will provide interested patient partners with the appropriate tools to engage.

Table 1. Summary of key findings from studies relevant to Recommendation 1 – Direct Researchers to Existing Patient Engagement Resources on the Funding Agency Website.

Category of Finding	Summary of Key Findings

Benefits	• Electronically delivered health interventions, including educational databases, have been observed to increased awareness and participation in several disease areas because of accessibility and mass distribution of information [27, 47, 48].
	• Increased awareness of patient engagement opportunities may lead to more engagement [49]. Which may in turn impact:
	  ○ Alignment of research objectives with the priorities of the public, improved dissemination of research findings, and improved research effectiveness [50];
	  ○ Better understanding of the disease, a sense of empowerment, and the development of a trusting relationship with researchers [50];
	  ○ Improved trial participant recruitment and retention [7]; and
	  ○ The long-term benefits of patient engagement to Canadian organizations that may promote an overall improvement of the health-care systems cost-effectiveness [50].
	• Incorporating online resources within the existing webpages associated with Canadian organizations will increase coverage compared to the development of a novel standalone webpage [51].
	• Electronic methods of information delivery are convenient for users, can reach isolated individuals, and allows for timely updates and supplier control of the intervention [52].

Potential Harms	• Some possible disadvantages to interventions delivered electronically include a potential disconnect in transmitting information when compared to face-to-face interactions [51].
Costs and/or Cost Effectiveness	• Online delivery is more cost effective than other methods [51]. • Patient engagement is cost-effective. For example, patient engagement in the development of a pre-phase 3 clinical trial protocol has been estimated using economic modelling to increase the expected net present value by $35M [52]
Partners' Views and Experiences	• Directing researchers to existing, useful resources on grant websites will provide information to them at a critical time. This will hopefully promote patient engagement in the early project development. • It is imperative that funding agencies provide resources, information and/or education to researchers on patient engagement to ensure that is done well and not in a tokenistic manner.

Barrier #2: Lack of appropriate planning can make patient engagement difficult to implement.

Commonly reported barriers to patient engagement in clinical research are time and funding limitations. In addition, there are concerns that the patient-researcher partnership can be tokenistic or a "tick-box exercise".

- An interview study surveying researcher perspectives on the challenges of patient engagement revealed that practical considerations, like time and funding, are of utmost concern [27].
- A research group collaborated with patients to develop a research proposal to identify barriers and enablers to engagement. They noted that patient partners reported time and cost as two key barriers to engagement [47].
- An interview study with health researchers about their attitudes towards patient and public involvement in research revealed a cynical perspective of patient engagement. This was particularly prevalent amongst the senior researchers referring to patient engagement as a "box-ticking exercise". They also expressed concern about leading a patient engagement initiative without having the expertise to do so. Those that reported willingness to change their practice emphasized the importance of a culture change within academic structures to facilitate behavioural change [27].
- A systematic review of published patient engagement frameworks reported that nearly all frameworks made mention of the dangers of tokenistic relationships between patient partners and researchers and emphasized the importance of seeing patient engagement as more than a "tick-box" exercise [39].

Current guidance recommends that patients be engaged from the inception of a research project and consistently throughout [53]. This can be challenging, however, when the research project starts before receiving support from funding agencies. Even if engaging patients is accounted for in the proposal budget, engagement activities may not be initiated until a positive decision has been made by the funding agency. Planning for patient engagement may therefore oftentimes be an afterthought, conditional on a successful grant application. Furthermore, once funding is secured, the research proposal is essentially fixed, limiting the capacity in which patient partners can inform protocol development. This eliminates an opportunity to align research and patient priorities.

Lack of planning for patient engagement may ultimately lead to tokenistic relationships if researchers do not have the time or resources to implement meaningful patient engagement.

Consider the following example of repercussions associated with the lack of appropriate planning for patient engagement. A research team was meeting with a grant evaluation panel. The grant included patient engagement as a mandatory prerequisite. The night before the meeting, a member of the research team decided to reach out to a patient organization for the first time. They requested that a member accompany them to the panel meeting and suggested they could pick up the patient partner at 6:30 am the following morning [54]. The patient partner respectfully declined as she saw the invitation as inappropriate and tokenistic.

Recommendation #2: Require planning for patient engagement throughout the funding process - start with a checkbox but then move beyond this.

Planning for patient engagement prior to receiving funding

Canadian organizations that fund early-phase clinical studies can include a mandatory section on grant applications where applicants must indicate the patient engagement initiatives they are adopting within their research. Having this as a mandatory field within the funding application is similar to the approach that CIHR adopted to improve sex- and gender-based analysis in health research [55]. This led to transformative changes in how sex and gender are accounted for throughout research projects funded by the agency. Similar approaches may promote patient engagement in early-phase clinical research.

Within the applications, researchers should be prompted to indicate how they are incorporating patient engagement throughout the research project. Conversely, grant applicants that are not planning on engaging patients would have the opportunity to justify why. Indeed, some funders have begun adopting this approach in their grant applications[56]. A hypothetical example can be found in Box 3.

Planning for patient engagement within the funding period

To avoid simply becoming a “tick-box” exercise, agencies should also request that successful applicants submit a more in-depth report outlining the method of engaging patients through interim and end-of-grant reports, depending on the funding agency. For example, many agencies undergo a grant renewal cycle whereby funded projects must provide a project update. This would be the perfect opportunity to ask researchers whether they are engaging patient partners and to describe the methods of engagement. An elaboration would provide insight into current patient engagement practices, reveal novel strategies that would have otherwise gone unnoticed, and identify research groups that may need assistance in their patient engagement initiatives.

Canadian organizations could recommend that successful applicants include the following items in their report:

1. Method of patient partner recruitment.
2. Roles and responsibilities of patient partners.
3. Duration of engagement
4. Benefits, costs, and lessons learned from the researcher’s perspective.
5. Benefits, costs, and lessons learned from the patient partner’s perspective.

This presents the opportunity for funding agencies to 1) demonstrate that they prioritize patient-oriented research and 2) provide concrete examples of patient engagement in action to guide future applicants. Success stories could also be shared and promoted by the funding agency.

Additionally, funding agencies could prospectively study the overall impact of patient engagement. As an example, the Ontario SPOR SUPPORT Unit (OSSU) evaluated patient engagement through interviews of the research teams who were awarded their OSSU Innovative, Measurable, Patient-Oriented, Appropriate, Collaborative and Transformative (IMPACT) award [57]. By evaluating these reports, defined recommendations for engagement strategies were generated and used as a starting point for planning future engagement activities.

Funding agencies should also consider seed grant/planning grants that support patient engagement. This type of funding can help support patient engagement from the early stages of the research project planning. Two examples are the Manitoba Primary & Integrated Healthcare Innovation (PIHCI) Network's Primary Healthcare Research Partnership Award [58] and the CIHR's Planning and Dissemination Grants [59]. By providing this funding opportunity, the gap in funding from project start up to securing funding will be removed, allowing researchers the resources required to engage patients from the conceptual stages of study development.

Box 3. Visual representation of the grant application "checkbox" and proof of planning required for patient engagement.

Do you intend to meaningfully engage patients as partners during the proposed research project?

- The term patient refers to an individual with personal experience of a health issue and informal caregivers, including family and friends.
- Patient engagement is meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation (i.e., education and advocacy) whereby patients play the role of partners rather than study subjects.

☐ **Yes**, I am intending to engage patients during this research project.

☐ **No**, I am **not** intending to engage patients during this research project.

Need help?
Visit our website for resources to help shape your patient engagement strategy.

If Yes: Briefly outline the following (max. X words/characters) in the space provided below.

- Intended method of patient partner recruitment and onboarding.
- Expected roles and responsibilities of patient partners (i.e., Terms of Reference document).
- Length of engagement and compensation plans.
- How do you believe patient engagement will benefit the proposed research project?

If No: Briefly explain why you are not intending to engage patients (max. X words/characters) in the space provided below.

- For example, time limitations, feasibility, unfamiliarity with patient engagement etc.

Recommendation 1 and 2 can be implemented simultaneously. For example, grant applicants that intend to engage patients could link to the funding agency website page containing guidance resources. Recommendations 1 and 2 help ensure researchers plan for patient engagement prior to the start of their study. This may help to ensure time and funds are appropriately considered and accounted for in grant budgets. In addition, it may be a starting point to help reduce time and funding pressures, and in turn reduce tokenistic partnerships. A summary of key findings and impacts of planning for patient engagement throughout the funding process can be found in Table 2.

As a supplementary method to demonstrate commitment to patient engagement in research, Canadian funding agencies could lead by example by engaging patients within their organization. Patients can be recruited to scientific advisory boards, grant review committees, or to unique internal patient partner panels. The aim is to ensure that the patient perspective is present within the agency and reflected in their organizational mandates. For example, the Ontario SPOR Support Unit grant review committee includes patient partners to ensure that decision-making is shared, and that different perspectives are

considered. We also saw examples of involving patients within funding agencies in our recent interview study [60]. Allowing patients to review proposed patient engagement strategies and provide feedback may ensure that researchers are adequately preparing for the engagement, from patients' perspectives. For instance, patient partners can indicate if the researchers are taking the necessary steps to learn how to effectively communicate with patients and to reduce the perceived power imbalances; this may diminish the likelihood of the researcher-patient partnership becoming tokenistic.

Table 2. Summary of key findings from systematic reviews and single studies relevant to Recommendation 2 – Proof of planning for patient engagement required in the grant application.

Category of Finding	Summary of Key Findings

Benefits	• After adding a checkbox and free text box to indicate researcher's plans to engage patients in their research on a research ethics board application, the following were observed [60]:
	  ◦ An increase in the number of applicants who intended to engage patients in their research project and appropriate explanations of intended plans of patient engagement; and
	  ◦ A decrease in the number of applicants who did not intend to engage patients in their research project and inappropriate explanations of intended plans of patient engagement.
	• Obtaining the patient perspective when reviewing patient-centered research project proposals can help to ensure appropriateness of planned patient engagement activities [61].

Potential Harms	• Disagreements between committee members due to a lack of understanding. For example, scientific committee members may deem an application ineligible for funding because of a methodological error in the proposal that would go unrecognized by patient committee members unfamiliar with methodological rigor [61].
Costs and/or Cost Effectiveness	• The downstream cost-effectiveness of increased patient engagement in clinical research is financially large. For example, patient engagement in the development of a pre-phase 3 clinical trial protocol has been estimated to increase the expected net present value by $35M [52]. • One study estimated a 180% return on investment when engaging patients and the public in the grant review process. The agency received over $700,000 in extramural funding from community organizations and over $300,000 from academic researchers [61].
Partners' Views and Experiences	• Key informants from 10 funding agencies in the UK suggested that it is highly important for grant applicants to sufficiently describe the impact and intended method of public engagement in health research, albeit the level of detail required for the explanation to be deemed "sufficient" remains unclear [24]. • Some studies reported barriers to partnering with patients and community members in reviewing grant proposals. These include, scientists underestimating the value of patient contributors, patient partners feeling intimated with the jargon and content of grant proposals, and potential differences in committee member perspectives [61].

Barrier #3: Challenges in achieving equity and diversity in patient partner recruitment.

Recruiting a diverse and equitable group of patient partners to a research team can be seen as a barrier to patient engagement. There is no gold standard approach to recruitment as it depends heavily on the research project and the patient population of interest. As the current evidence suggests, patient engagement strategies can be implemented in all areas of clinical research pertaining to most disease domains. With that said, it may be more difficult to recruit and engage patient partners to early-phase clinical trials analyzing the effects of certain conditions. Consider a clinical trial that analyzed the effects of varying target oxygen saturations in treating infants admitted to the emergency department with bronchiolitis [63]. The trial participants' caregivers acted as patient partners throughout the trial. Unfortunately, it was reported that this relationship was lost early during the trial and authors suggested that this may have been due to the acute nature of bronchiolitis making it difficult to recruit and retain patient partners [63]. In addition to acute disease states, recruiting patient partners to clinical trials for rare diseases may make it challenging to identify patient partners. An extra layer of difficulty is added when potential patient partners are not local, and communication cannot be face-to-face. This adds another eligibility criterion to

participation as patient partners may need to be relatively technologically savvy to effectively communicate with the research team and to provide feedback in team discussions.

Researchers have also reported difficulty in recruiting members of under-represented groups as patient partners [64]. Specifically, a systematic review assessing patient engagement internationally found that clinical researchers struggled with recruiting and retaining patient partner participation from the elderly, members of minority ethnic groups, and individuals with disabilities [64]. Discrepancies in equity between different patient groups (e.g., different health conditions, young vs. elderly, etc.) may result in underrepresentation of perspectives.

This suggests there is no "one size fits all" approach. Rather, methods of recruitment, and engagement, need to be adapted to the patient population of interest. Consider the example of the Chicago Parent Program [65] – an evidence-based program that addresses behavioural issues through improved parenting skills. As a result of low participation rates of this program, a study was conducted to address concerns, such as motivation for participation and quality of engagement, when a financial incentive was provided to low-income populations. Through surveys, financial honorarium was identified as an important factor for participation in 71% of parents, most of which (73%) had an annual household income of less than $20,000. Although this example was not specifically patient engagement, it highlights that members from under-represented groups may have barriers to participation that should be considered by researchers in order to facilitate engagement [66].

Ensuring that diversity is reflected within the research team can also be challenging. However, it is important to highlight the need for diversity because it is easy for researchers to assume that the recruited patient partner(s) is/are representative of the larger population. This could lead to unnecessary additional pressure put on patient partners to represent all patients. This is an unrealistic assumption considering a clinical researcher sitting around the same table is not expected to be representative of all clinical researchers. With that said, it is important to maintain diversity within the research team but to also appreciate individualism and the unique perspectives that all team members bring.

Recommendation #3: Require researcher training in equity, diversity, and inclusion.

Canadian organizations that fund early-phase clinical studies should include a section on grant applications where applicants are required to upload a training certificate in equity, diversity, and inclusion (EDI). Funding agencies could provide an approved list of third-party training programs in EDI in which the researcher can choose one to complete and encourage researchers to outline how they will incorporate EDI in the recruitment of patient partners and throughout patient engagement. A list of useful resources can be found on the Canadian Institutes of Health Research website [67].

The aim of requiring EDI training is to ensure researchers have considered equity-oriented approaches when recruiting patient partners [66]. Equipped with this knowledge, researchers can evaluate the systematic oppressions that are most likely to exist, identify the patient population(s) that would be most affected if the intervention of interest was implemented, and prioritize them for engagement activities [66]. Having a diverse and inclusive group of patient partners will result in more impactful research as it will better reflect the diverse outlook of the target population. Additionally, it will alleviate some pressure from patient partners to represent the larger target population as everyone has different experiences and perspectives. Patient partners on our team have emphasized the importance of a diverse and equitable group of patient partners: since patient partners in a research project are often only a small group of individuals, it is simply impossible for them to speak on behalf of all patients with their lived experience. Recruiting more than one patient partner and having ways to engage the broader audience at different levels will help to achieve diverse perspectives. This is where engaging patient organizations can be particularly beneficial as they may be able to represent and attract more patient partners with diverse backgrounds, helping to alleviate pressures that would be put on individual patient partners and assisting them throughout the research process.

Similar to Recommendation 2, having researchers elaborate on how they will incorporate EDI into their research requires them to start planning ahead of patient engagement. This allows researchers more time to discover better methodologies in both the recruitment and retention of patient partners. They can also better prepare to work with under-represented groups, ensuring more diversity. Furthermore, at this planning stage, researchers will have the opportunity to seek guidance on their EDI initiatives through programs such as Equity-Mobilizing Partnerships in Community (EMPaCT) that advise researchers on how they can make their project more inclusive and equitable [40]. A summary of findings and impacts of requiring researcher training EDI can be found in Table 3.

A similar approach has been taken by the CIHR for sex and gender-based analysis in health research to make it "more rigorous, more reproducible and more applicable to everyone" [55]. CIHR requires that all principal applicants provide a certificate of training in one of their sex and gender-based analysis training modules, expecting that all researchers will incorporate sex and gender into their research when applicable. Additionally, CIHR requires that their peer reviewers specifically comment on how the researchers have included sex and gender-based analysis within the grant application to ensure that it is incorporated appropriately in all selected proposals.

These different populations are outlined by PROGRESS (place of residence, race/ethnicity, occupation, gender/sex, religion, education, socioeconomic status, and social capital), an acronym used to highlight factors that need to be considered to ensure health equity. Through both personal experience and CIHR's sex and gender-based analysis initiative, we believe that requiring researchers to undergo EDI training and having resources available, such as those through EMPaCT and SPOR, will better prepare them for the recruitment and retention of representative patient partners.

Table 3. Summary of key findings from single studies related to Recommendation #3 – Require researcher training in equity, diversity, and inclusion.

Category of Finding	Summary of Key Findings
Benefits	• Researchers will be better equipped to recruit and retain an equitable and reflective group of patient partners with diverse lived experiences, resulting in more impactful research.
Potential Harms	• Not applicable.
Costs and/or Cost Effectiveness	• High initial costs and time associated with the development of EDI training for researchers.
Partners' Views and Experiences	• CIHR adopted a similar approach for sex and gender analysis to ensure that their funded research is relevant and impactful [66].

Implementation Considerations

Table 4 outlines potential barriers that should be addressed prior to implementation. We would encourage organizations to evaluate and disseminate their own experiences with implementation of these recommendations. Multiple tools exist to evaluate patient engagement in research [69-71]. Further research will help us better understand and optimize the described consideration.

Table 4. Potential Barriers to Implementing the Recommendations.

Levels	Recommendation 1: Direct Researchers to Key Patient Engagement Resources	Recommendation 2: Require Planning for Patient Engagement Throughout the Funding Process	Recommendation 3: Require Researcher Training in Equity, Diversity and Inclusion (EDI)
Individual	• Computer skills and technological ability. • Researchers (particularly older researchers) weariness of the benefits of patient engagement [27].	• Researchers' weariness of the benefits of patient engagement and associating the "Check box" with a check box exercise mentality. • Understanding that it is unfair to assume one perspective is reflective of the entire patient population and appreciating the unique individualistic perspective of patient partners.	• Time to complete and maintain EDI training. • Researchers' weariness of the importance of equity, diversity and inclusion within patient engagement and hesitancy to incorporate it due to its associated challenges.
Organization	• The resources chosen should be specific to the audience and continuously updated.	• Possible discrepancies in patient engagement reporting between industry (e.g., pharmaceutical companies) and non-industry (e.g., government, charities) funding agencies [60]. • Reorganization of committee dynamics and allocation of funds to accommodate involving and compensating patient partners	• The resources and time required for funding agencies to organize and implement EDI training related to patient engagement.
System	• Needs to play a larger role in supporting patient engagement activities [70]	• Increased extramural funding required to support funding agencies prioritizing patient-oriented research.	• Needs to advocate the importance of incorporating EDI in all aspects of research and support agencies that mandate it.

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