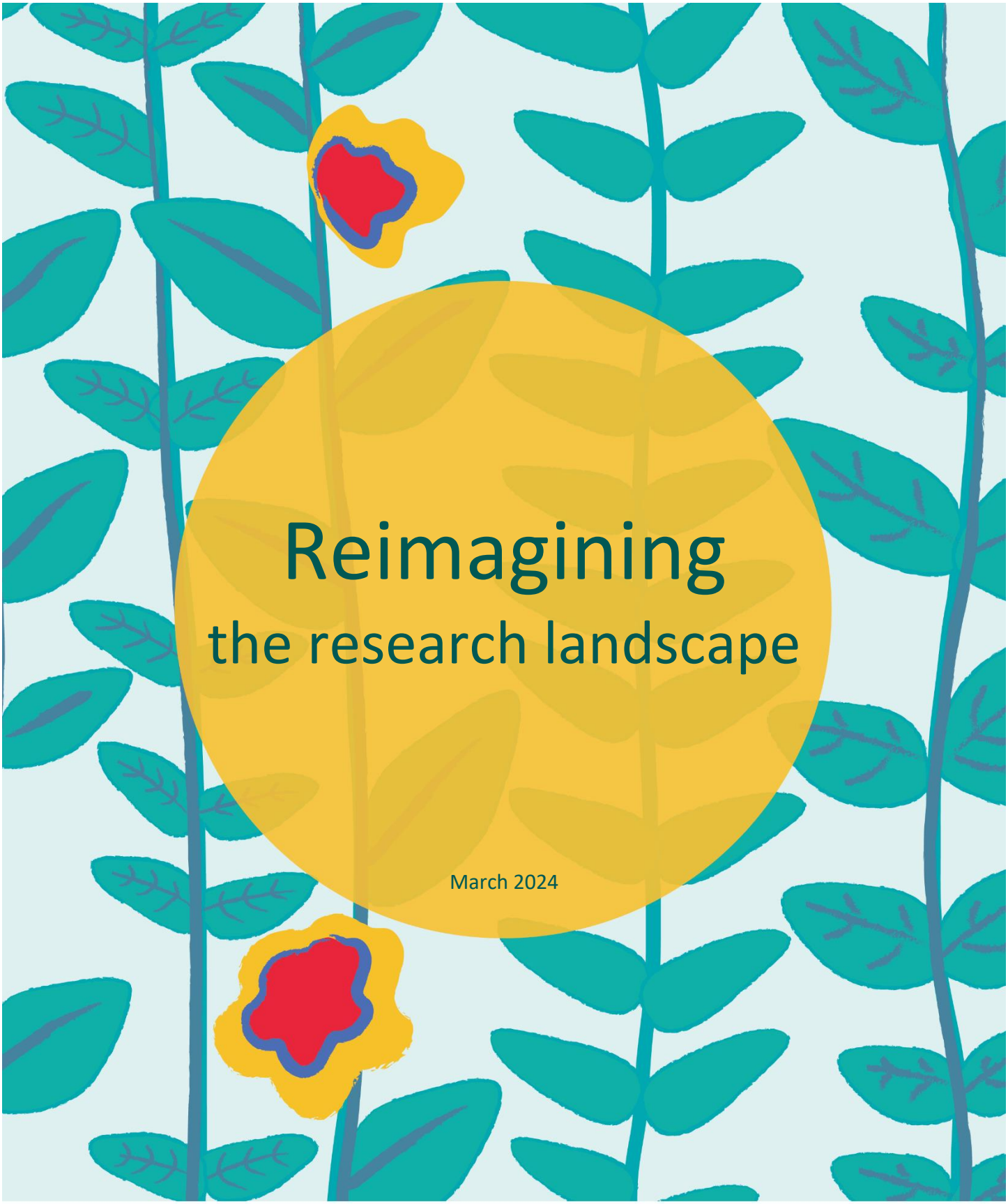


# Reimagining
## the research landscape

March 2024

Patient Advisors Network

Independent
Informed
Connected

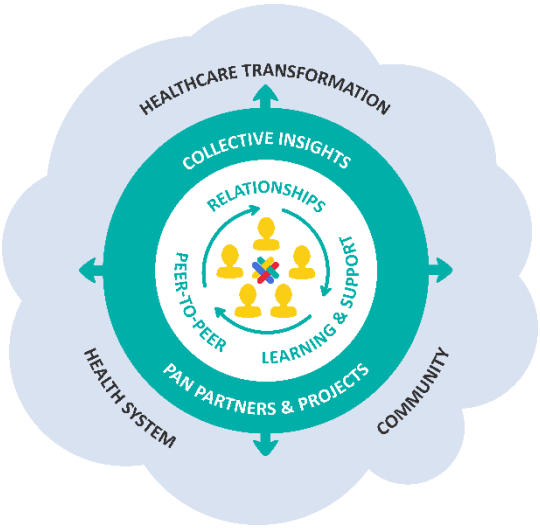
Collective Insights

## About PAN

Patient Advisors Network (PAN) is a community of patient and caregiver partners from across Canada who are committed to help improve healthcare for all.

PAN was formed to provide a community for patient and caregiver partners to get to know each other and learn how to be more effective at partnering.

**P**AN, a Canadian not-for-profit organization, collaborates with healthcare partners on projects that align with our mission.




**PAN, the value of community**

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## Acknowledgements

Patient Advisors Network (PAN) would like to thank the Canadian Institutes of Health Research (CIHR) for funding our opportunity to reach out to the patient and caregiver partner community to gather insights for this contribution to the SPOR Refresh Strategy and process.

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

We would like to also acknowledge all from the PAN Community and the larger network of patient/caregiver partners who took the time and effort to share their experiences and insights through their PAN survey responses and participation in the PAN focus groups. It is our sincere hope that your contributions will help shape health research and how we partner in research in the future.

We are grateful to Mariel Kelly, graphic designer, whose wonderful illustrations bring the report to life and Jennifer Wilkie who generously contributed to the look and presentation of the content.

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# Introduction

**Patient Advisors Network (PAN)** is a Community of patient and caregiver partners and a centre from where we can share our collective insights.

PAN was asked by the Canadian Institutes for Health Research (CIHR) to contribute insights from the unique perspective of patient and caregiver partners (or persons with lived and living experience - PWLLEs) to the Strategy for Patient-Oriented Research (SPOR) Refresh process.

As part of our collaboration with CIHR, we:

- provided Diana Ermel as the PAN Representative and co-chair of the SPOR Refresh Steering Committee;
  She is supported by our PAN SPOR Council members who are co-authors of this work;
- surveyed the PAN Community and beyond about people's knowledge and experience of health research in December 2023 and January 2024;
- held two focus groups with 15 members of our PAN Community to discuss future directions of research in February 2024.

### Key Term

There are many terms for who we are. In this report, we will use the CIHR term and acronym:

**Persons with lived and living experience (PWLLEs)**

### *Who provided the input to this report?*

The 262 survey respondents come from every province plus the Northwest Territories.

There are some respondents who are younger (20%), rural, reserve and remote (18%), born outside Canada (18%), male (23%), transgender, non-binary or two-spirit (3%), non-white (16%) and who find covering costs for the basics challenging (35%). The majority (77%) have no healthcare work experience while some (20%) worked in healthcare or are still doing so. Despite offering the survey in both languages, the response from Quebec is disappointing (>6%). Mainly respondents reflect the wider patient/caregiver partner community -- mostly older, urban, white, female, well-educated, comfortable financially and Canadian born. While published demographic data is limited, this is consistent with a Pan-Canadian study profiling patient partners in health.[i]

### *How our views contribute value to the SPOR Refresh*

While CIHR has conducted an outreach to all parties interested and involved in SPOR, PAN feels we can contribute uniquely by:

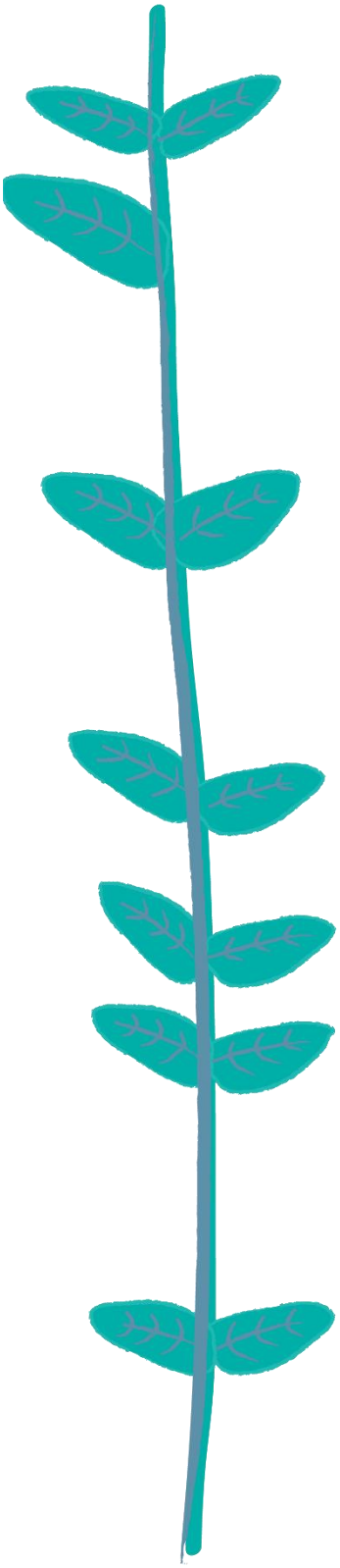
reaching PWLLEs who are not engaged in SPOR research teams (29%) but are interested in health research. This helped us explore aspects of awareness and motivation.

receiving, as a group of peers, people's frank input both through the survey and the focus groups. PWLLEs may protect themselves by self-editing when sharing within groups that include the people who decide whether to engage them or the clinicians who care for them or their loved ones.

PAN is very pleased to contribute to maturing PWLLE involvement in research building on the base provided by SPOR which has done so much to engage us in the research enterprise so far.

# Overview

This is the story of research from the people who have chosen to share their lived and living experiences to impact research for the betterment of all as partners rather than as study participants.



We are telling this story in hopes of realizing the promise of partnering in research from governance to research teams.

Our tale starts with the unknown pathways that mark the entrances into research. When inside, we tell of our struggles reconciling the promise of partnership with the reality of the outsider… and we tell of our exemplary partnerships. We tell of our insights about the unconscious exclusions both as individuals and as communities. We look to co-building a research structure that both includes us and reflects our priorities. And finally, we share some directions for building a better future through research.

At its core, this is about building reciprocal and equitable relationships so that research can best serve people.

## Our approach

We draw on the recent work of the **Learning Together Evaluation framework for Patient and Public Engagement (PPE) in research**[ii] to inform our insights about what we learned.

This Framework is rooted in the guiding principles of patient engagement defined by the patient-oriented research community. These were co-developed by PWLLEs with researchers and build on the original four SPOR principles[iii]:

We also draw attention to equity, diversity, and inclusion implications throughout seeing these as cross cutting.

And finally, we offer suggestions throughout.

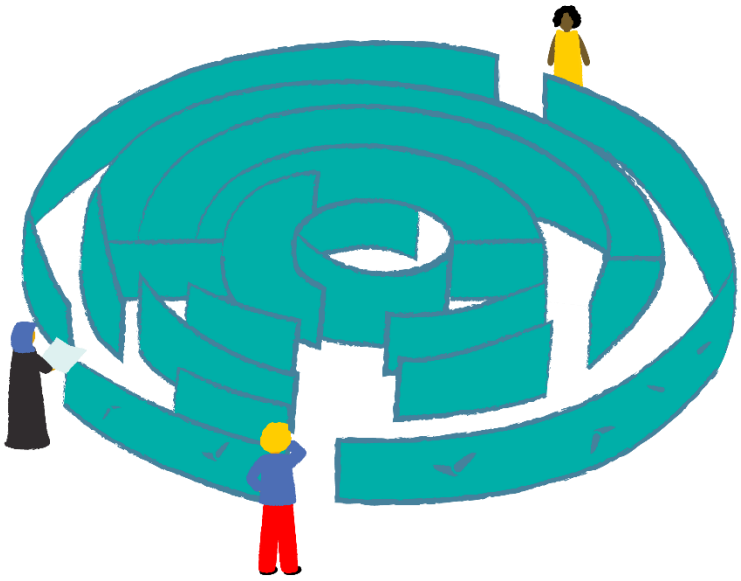
### Learning Together Principles

1. Relationship building
2. Co-building
3. Equity, diversity and inclusion
4. Support and barrier removal
5. Transparency
6. Sustainability
7. Transformation

# Opening the door to research

For many of us, getting into research is not easy.

First, we need to be aware that this option exists for us. Then actually getting involved is often challenging.



**The way into research is not clear**

## BECOMING AWARE

Many of us may not even be aware that research is something we could do.

More than half of all respondents are aware of CIHR and of SPOR at a high level. And about a third of PWLLEs have very little or no understanding of SPOR.

Clearly there is a need to raise awareness.

### *Finding the door*

There is no clear route into research for us. Word of mouth or "who you know" are the main leads to opportunities. Going through SPOR is a less common option for connecting to research.

> "I am very eager to use my learning in patient partner research but fear it is withering without an opportunity."

Many are distressed and frustrated from trying to get involved with research often with no luck…and years of trying.

**INCLUSION IMPLICATION:** Mainly those "in the know" or the researchers' favoured few are participating. The lack of clear routes in, excludes the value of a variety of people and perspectives.

This is not good enough…we can do better.

## WHAT MOTIVATES US

Most of us get involved in healthcare to make positive change. Our primary driver is the same for research. Learning more about our condition is a key secondary motivation for those already involved but not for those of us yet to be involved.

The desire to make an impact is a strong motivator.

> "…how can the system be changed or improved upon for a better Patient and Family Experience and that is what drives me to do

### *How we choose to participate*

We say "yes" when we think our involvement will have an impact on the project and/or the health system. We also seek opportunities that fit with our personal focus and interests.

The practical elements --- understanding expectations, work, schedules and supports and, to a lesser degree, compensation and who is in the group --- also govern our decisions.

**INCLUSION IMPLICATION**: For people with life, work, language and health challenges the expectations and demands of research teams currently make it difficult to become involved.

### *Staying involved*

We stay if we are making an impact and respected… and our health and that of others we care for doesn't pull us away.

> "Presence of other PWLLE, accountable space where, even if have difficulties, team is committed to working through them, feeling of belonging."

> "Would depend on the support received and the resolution of the conflict or issues making participating challenging and unacceptable."

If we have a bad experience on a research team, some of us would stick it out but most are not sure.

> "It depends; generally I would leave, however there are times I would make an effort to address the issue - to prevent it from happening to others; so I might stick it out awhile. I did that once and it made a difference."

## Suggestions

CIHR/SPOR could:

1. Communicate messaging to the existing PWLLE community, community organizations and the broader public about who they are, how PWLLEs can make an impact through research and what doors lead to engagement opportunities.

   We need to understand how we can make a difference, not just what tasks we can perform or how researchers need us to get grants.
2. Reach out to other healthcare organizations with pools of PWLLEs including PAN and tap into existing newsletters as good ways to communicate about SPOR and research opportunities.
3. Accommodate PWLLE preferences for how to learn about opportunities where 85% said by email/newsletter, 83% through PAN, and 58% through SPOR.
4. Include issues management in the training of researchers so that unresolved issues, especially those involving psychological safety, don't drive us away.

# Translating Principles into Action

It is one thing to agree on principles -- it is another to translate those into actions.

Acting on principles is hard within a research culture that does not make it easy.

**So how do we do this?**

**Relationships**. Trusted relationships are the bedrock of patient engagement.

We all commit to understanding, building, and nurturing equitable relationships with the tapestry of diverse peoples and communities.

**Relationships take time and nurturing**

## Building equitable relationships

When we are each trusted for the value we bring, then we have relational equity.

Co-creating relational equity begins with understanding the need to build trusting, reciprocal relationships. From there, the team determines what values govern how we work together to ensure every voice is heard, supported, and equal. The lived experience and the expertise of all team members is recognized.

Relational equity must be carefully and continuously cultivated. It is a critical component in retaining our involvement over time.

### *Welcoming and acting on our insights*

Let's improve how those of us currently involved are welcomed in. This will pave the way for new people of various backgrounds entering into research.

While most PWLLEs feel comfortable speaking up, expressing opinions, or even disagreeing with others on the team, less feel their ideas are listened to and acted on appropriately.

"Best experience involved the researcher getting to know me over a coffee/zoom chat first. We talked about our families, personal interests etc. and then found that we had mutual interest in comments and from there it organically evolved into participating as a lived experience partner."

"All the members … of the research teams were very receptive to answering questions if you knew which questions to ask. For most of them, this was a new experience, and they didn't have the scope to understand what the PWLLE experience was.

They were very helpful if you understood how they could help."

### *Allowing for our whole life perspectives*

As people, we do not exist in isolation of family, work, or life circumstances.

Our context informs our health.

So too the whole of our experiences inform our work in research.

"It is still a difficult process to be accepted as someone that brings anything more than only the lived experience. Many of us (patients and caregivers) are also professionals that have or have had successful careers… and can contribute in other ways to improve outcomes."

I experience "bias that the only thing patients bring to the research project is the personal experience as a patient, ignoring all the other skills and insights we have into patient engagement. "

Too many times we are seen only as the patient or our encounters in the system … a one dimensional view. This forgets that most of our care is self care or care outside the formal healthcare system and loses the unique benefit of a holistic view.

## Suggestions

For funding agencies like CIHR/SPOR, supporting researchers in developing reciprocal, respectful relationships can include ongoing training to:

5. be open to the variety of perspectives coming from PWLLEs;
6. identify their own privilege, identities and contexts;

CIHR/SPOR can also:

7. co-design or source training for PWLLEs on how to present their experiences to the problem being worked on;
8. look at ways to support and fund researchers in developing relationships outside specific projects.

## Supporting relationships

Respect is not merely a feeling but the result of actions that embody respect. The lack of respectful actions can be experienced as tokenism.

On the downside

"Ne pas être consulté après mettre engagé. Ne pas trouver d'espace sécuritaire pour m'exprimer. Ne pas me sentir écouté. Quand les gens acceptent des statuquos. "

On the downside

I was a "… a marketing prop for gaining grants."

Respect is a key element in a successful research partnership at any level. Respect is both an attitude and the result of actions that embody respect.

On the upside

"I'm invited, included and heard from day 1, I am able to raise ideas, questions and challenges without tension; I receive all the same info as the rest of the team, I am consulted on the meeting plans, I can help with some of the work, to earn my recognition as a Co-author, or Co-Investigator. My time is respected equally with others; my ideas are discussed and considered, even if they are not determined to be viable or appropriate, I understand why."

Supporting actions that promote respect can be understood at the team (micro), SPOR and fund-holder (meso) and system (macro) levels to determine where there should be changes and to define accountability.

**MICRO**: The team has responsibility for the practical and procedural supports.

**MESO**: Some supports are specific to SPOR SUPPORT Units and Networks. Financial support is delivered by the fund-holder of the grant – usually a university or hospital – on behalf of the team.

**MACRO**: System-level support may be offered by the funding agency or other entity to PWLLEs with or without sponsorship from the research team.

### MICRO: TEAM-LEVEL SUPPORTS

Since SPOR began, the capability for engaging patients in research has been growing within and outside of SPOR. However, there are significant discrepancies across teams.

"Level of engagement varies by type of research and whim of the PI. More often good than token."

"Each (*experience*) was different. Often respectful and welcoming, some token expectations, one condescending."

We are treated and managed differently from team to team especially in these areas:

- A designated contact person – is assigned about 50% of the time.
- Access to materials is shared with us only slightly more than half the time.
- Effective team communications occurs consistently only about half the time.

- Compensation is offered about a third of the time.
- Expenses are reimbursed only about half the time.

**INCLUSION IMPLICATIONS:** The 49% of us rarely receiving reimbursement may be due in part to the identification of "hidden" expenses. These are expenses like the costs of printing documents at a store, paper and printer ink and the cost of the devices, software and internet access necessary to participate.

## Suggestions:

Some practical suggestions for funding agencies to support a more consistent PWLLE experience across teams are to:

9. request that a contact person be identified in the grant proposal;
10. build expectations of PWLLE involvement from start to end explicitly in the grant calls;
11. find ways to give PWLLEs access rights to materials behind pay walls or offer workarounds to access the same materials as the rest of the team;
12. identify researchers, new or seasoned, who could benefit from training to improve their project management and communications skills and offer it to them;
13. insist that budgets include expense reimbursement and compensation for PWLLEs that reflects an established national standard;
14. develop and enforce an expense reimbursement policy;
15. explore with a diverse group of PWLLEs to find solutions for the hidden expenses that are barriers to participation for those living on tight budgets or in areas where reliable internet is not the norm or where accepting honoraria jeopardizes their income benefits;
16. support PWLLEs directly or through teams with technology including the provision of devices and software;

### MESO: SPOR SUPPORT UNIT AND NETWORK SUPPORTS

The SPOR SUPPORT Units and Networks are focused on patient-oriented research and should be set up to support us and our involvement. As such, the people working there should be good at patient engagement. This is not always the case.

We learned that there is room to improve awareness and support at this level.

"I had no idea there was a patient engagement staff at SPOR units."

"Anyone in research is considered able to do the job."

"They have a duty of responsibility to patients that I don't feel they understand. Mostly their background seems to be research. We don't need 'wranglers' we need support."

About a third of the patient engagement staff are knowledgeable and helpful with about another third moderately so.

This is not a great record for the logical person to champion patient engagement in the unit or network.

About half the SPOR people engaging PWLLEs on councils and/or projects within the units or networks are knowledgeable and helpful.

"J'ai rencontré plusieurs personnes très compétentes et inspirantes. C'est personnes ont un impact déterminant dans ma trajectoire."

Interestingly, more SPOR non-engagement people were considered knowledgeable and helpful than those whose job is patient engagement.

## Suggestions

Some thoughts on how SPOR can be encouraged to provide more effective support:

17. include accountability in the SPOR renewal contracts to support increasing the knowledge and capacity for all those working in the units and networks;
18. co-identify support gaps and co-build solutions with PWLLEs and those working in the units and networks.

### MESO: FUND-HOLDER SUPPORTS

The team initiates and approves PWLLE compensation and expense reimbursement, but the actual processing is handled by the fund-holder of the grant money – the university or hospital. These processes are often complicated and inflexible. They are not designed to meet the needs of PWLLEs. The researchers are not always able to assist in resolving issues for the PWLLEs.

"It's so tedious to do all the work of tracking time, reporting or invoicing, and then following up."

- It is a burden on us to track time and invoice, provide a SIN and void cheque. Plus, we may have to deal with different processes across many organizations.
- Reimbursement often takes time – longer than 30 days which costs interest charges on our credit cards. Delays can also cause cash flow distress for some of us.

**INCLUSION IMPLICATIONS:** The demands and paperwork to get reimbursed or compensated, impact who can be involved. Compensation for those living on support may cause issues and jeopardize support income and health benefits.

## Suggestions

Funding agencies could work with the fund-holders to:

19. Recognize PWLLEs as a separate category from regular contractors or staff that needs its own policies and procedures.
20. Identify organizations within and outside the academic and healthcare sectors that have good practices for both reimbursement and compensation. This could develop into a standard and be shared with other fund-holders.
21. Review and modify these standards to support more diverse needs of PWLLEs.

## MACRO: SYSTEM SUPPORTS

Both CIHR/SPOR and other groups provide supports that build capacity for researchers and PWLLEs. These supports can be training, communities of practice, conferences and mentoring. Look at the recent study on **Future directions for patient engagement in research** for other areas of system support.[iv]

### *Training*

We can't find training – or not easily. There is no one place to go for all learning opportunities or widely known tools to help assess what is best suited for our needs.

The courses we know about are considered basic only.

"Generalized resources have not proven to be useful for supporting my work on research teams (too general or poor fit with the type of research)."

"little there for more advanced concepts - like specific research activities (eg data analysis); also very dependent on where you live - not equitable"

Many of us want to learn how to be an effective partner on a research team. We also want to learn about the research landscape including the granting process, the research process and activities, the role of universities and hospitals, grant review boards, ethics review boards, priority setting and governance.

### *Community of practice (CoP)*

There is a strong interest in Community of Practice (CoP) to support patient engagement in research though less from those more experienced. As a CoP, the practice itself needs to be clear:

"It would need to be an active, problem-solving forum, not a support group."

> Is it the practice of engaging PWLLEs to be involved on research teams -- the practice of recruiting, placing, onboarding, supporting, and compensating PWLLEs?
>
> or
>
> Is it the practice of partnering on a research team -- the practice of understanding the research process, tailoring experiences to the benefit of the team's work, understanding the partnering role, learning how to handle expenses and compensation, handling being in a token situation?

"If the CoP involves both, the patients can be drowned out.

To be beneficial I think the researchers and PWLLE need to co-design."

In some cases, our healthcare partners, especially researchers, also do the work of engaging us.

The different practices were not clear to respondents. This calls for further investigation.

### *Mentoring program*

Almost half were mentored in the early days of being on a research team and happy about it.

Most see the benefit of being mentored.

"I think until a PWLLE is comfortable … a mentor -- both an experienced peer and an experienced researcher -- would be most helpful and needed depending on the personalities and the synergies at play."

"Peer and researcher mentor would play different roles and serve different needs. PEER mentor would have been awesome during the first couple of years. Same for today, however a different relationship"

### *Conferences*

"The more times patients attend, they are a visible reminder of the importance of having patients with lived experience through all aspects of research. This is very beneficial to everyone around them and the conference as a whole."

Conferences are an important part of how PWLLEs learn, develop relationships, and get connected.

Mostly we attend when we are co-presenting and our expenses covered.

"National level funding is critical.

This gives them a peak at the research and then gives researchers the chances to talk to actual patients they might never have the chance to speak with."

Many of us would like to attend conferences outside our involvement on specific projects. This is financially challenging for most of us.

Many respondents feel health research funders and conference sponsors should provide financial support to PWLLEs. Some think either the SPOR Units or individual research teams should provide the funding.

**INCLUSION IMPLICATIONS:** Lack of funding support limits attendance to those with means. In addition, PWLLEs not used to the corporate world or healthcare work world, can find conferences intimidating.

"As the SPOR program evolves, I think there needs to continue to be effort and investment in basic fundamentals of POR, including the ongoing training and support of investigators and PWL."

## Suggestions

For training, CHIR/SPOR could:

22. Recognize that training is infrastructure and should be persistent and consistent.
23. Solidify a one stop shop for all learning information with funding that is infrastructure-based, not grant-based.
24. Sponsor the co-development of training with PWLLEs and others to cover the research landscape.

For a community of practice CIHR/SPOR with PWLLEs could:

25. Co-define the practice of PWLLEs.
26. Co-design a CoP for the PWLLEs that focuses on the practice of partnering.
27. Co-define the way a PWLLE CoP for the practice of partnering and a researchers CoP for the practice of engaging patients can collaborate.

For mentoring, CIHR/SPOR could:

28. Consider co-creating formal national and local mentoring programs.

For conference attendance, both CIHR/SPOR and the conference sponsors could:

29. Waive conference fees for PWLLEs; virtual conferences should be free.
30. Create a bursary to cover transportation and accommodation for PWLLE attendees.
31. Make conference and educational support for PWLLE mandatory items in the budgets for SPOR SUPPORT Units, Networks and project grant applications.

# Making research more inclusive

The culture in research needs opening up…

to fully embrace PWLLEs as partners in the work and

to reach out into the communities it is meant to serve.

**Going beyond for richer variety**

## Shifting culture

As partners we come from two different worlds.

The health research world is a unique culture. Like any workplace culture, it has its own norms, language, and ways of working that form unconscious assumptions -- becoming the **research cultural lens**.

From our part, there is no "patient culture." We all come from various backgrounds, work cultures, family cultures, social environments, ethnic cultures in our own unique blends.

Mixing our many cultures into the existing research culture presents challenges. There is the underlying assumption that we will adapt to the dominant culture. If we cannot, we are seen as "difficult" or dismissed as being out of sync with research practices.

There is an implicit power imbalance between the "in crowd" and us as outsiders.

On the downside

"We were asked to be partners, struggled to be heard, ignored for the most part, did our best to take part, did not appear in the credits either by name or with what we had contributed."

This unease was described as:

"Feeling intimidated".

The "eye rollers"

"Like speaking before an audience with no clothes"

This unease is seen in some of the unfortunate experiences we have as PWLLEs on teams and other aspects of research because of the **unconscious bias of the research cultural lens**.

### *Understanding the research culture*

We all need to become more aware of our assumptions and openly examine them. Most of us are oblivious to the norms of our own unique cultures or ways of doing things…

*like a fish who doesn't know it is swimming in water*.

The onus is on the researchers to understand their assumptions and better bridge to an effective partnership.

"They don't even recognize their views as bias "

On the upside

"Totally engaged, help to develop ongoing funding request, input into REB, engaged in analysis, engaged in writing for publication. Treated as an equal member, all questions responded to in a very timely manner, great support from all team members."

Those of us with similar backgrounds to the researchers and long experience in research, gain cultural knowledge and familiarity. We become the "go to" partners, the favoured few.

For the rest of us, it is foreign territory. We don't know the system, the rules, the players, the culture.

"Not sure whether discrimination as a non-professional on the research team counts as bias.

As a cisgendered white settler with dominant cultural presentation, I'm swept into research teams with presumed advantages made about my suitability and ease in integrating into often much more diverse research teams"

When we asked about the experience of bias or discrimination, overwhelmingly respondents described an insider's often unconscious treatment of an outsider -- welcomed but not taken seriously.

Few of us experience bias based on an aspect of identity – race, age, and so on -- and most feel there is rarely bias as it is commonly understood.

NOTE: Respondents reflect the PWLLE community which is predominantly white, older women and does not represent much diversity. It is difficult to assess from our results how much this is an issue.

**INCLUSION IMPLICATIONS**: If the bulk of us coming from privilege feel like outsiders, imagine how it might be for those having less privilege.

## Suggestions

All research partners from those in governance to those on teams, can increase their own cultural awareness by:

32. openly examining their assumptions;
33. using emerging tools to help understand and address power imbalances[v].

For CIHR/SPOR, developing cultural awareness on research teams can include:

34. working to understand if bias based on identity is an issue on research teams;
35. offering cultural sensitivity and diversity training to researchers – and PWLLEs;
36. training on relationship building and ways to co-problem solve through seemingly conflicting perspectives.

## Being inclusive and engaging widely

### Engaging people with diverse perspectives requires a different approach from the status quo.

Our society's tapestry of diversity is not served by having one or two PWLLEs from different identities on a team unless the work is targeted to a specific group.

Some researchers have taken time and made effort to develop trusting relationships with communities. The transactional nature of research and academic demands make this hard to do. We become inclusive by building relationships within communities and working together on finding the best experiences and outcomes for those in their communities.

Indigenous relationships are introducing researchers and other PWLLEs to other ways of identifying and solving problems and ways of knowing. Much can be learned from them.

Community engagement could form part of the next phase of SPOR.

## Suggestions

For funding agencies like CIHR/SPOR, supporting inclusiveness on research teams can include:

37. learning from those that have built deep, trusting relationships;
38. supporting the establishment of ongoing relationships with communities by researchers;
39. looking at emerging community engagement models;
40. exploring how to involve PWLLEs and communities in governance and decision-making;
41. seeking out cultural knowledge including indigenous cultural training.

# Co-building the future of research

The world is shifting rapidly impacting our health and the care we receive.

The research environment needs to adapt to maintain relevance and become future focused.

**Transforming research takes transforming culture**

## Structuring research for the future

We need our research system to respond to our changing needs.

As people living in Canada, we fund this work through our taxes. We are ready to be involved as PWLLEs in aspects of the health research system like priority setting, reviewing grants, and governance.

We want to be part of the decision-making and have research be accountable to us.

### *Setting priorities*

Priority setting occurs either at the funding agency level or within a SPOR Unit or Network or even at the team level. About a third of us have participated in some sort of priority setting -- a Delphi or James Lind Alliance or other exercise. Many would like to be part of setting priorities.

> "we need to be at the priority setting table."

### *Reviewing grants*

Grant reviews can be both rewarding and taxing.

Despite these challenges, half of the respondents had done grant reviews and many of the others were interested.

> "…most of the work was clustered in a short period of time, so was very time-consuming and stressful."

### *Being on research governance bodies*

Fewer than 15% of us have been involved on various governance committees for CIHR, SPOR or another research organization. Most had a strong interest and felt we should be involved while raising concerns about power imbalances, compensation and accountability.

## Suggestions

CIHR and SPOR can co-design the following with us:

42. Setting priorities;
43. Revising the grant review process to better support our ability to participate;

44. Develop clear accountability mechanisms for the granting process;
45. Training to prepare us for priority setting, grant reviews, and for participating on governance bodies;
46. Mentoring program for PWLLEs involved in grant reviews and governance bodies.

## Collaborating on teams for the future

Our collaboration enriches the research for more beneficial outcomes.

Meaningful participation for us:

- starts from the twinkle in the eye of the person with the research idea
- moves through collaboration on developing the research question and designing the research
- to sharing the knowledge gained from the research.

We are rarely involved in co-planning for the patient engagement budget. And even compensation discussions were held with us only about half the time.

When we collaborate from the beginning on a team, it is a more satisfying engagement experience for all.

The foundation for this is the relationship between the PWLLE and the researcher as we noted earlier.

> "**I'm invited, included and heard from day 1**, I am able to raise ideas, questions and challenges without tension; I receive all the same info as the rest of the team, I am consulted on the meeting plans, I can help with some of the work, to earn my recognition as a Co-author, or Co-Investigator.
>
> My time is respected equally with others; my ideas are discussed and considered, even if they are not determined to be viable or appropriate, I understand why."

Many suggested we be compensated beyond the main work of meetings and document reviews for our work as a co-author, our training and education, our conference attendance when co-presenting as well as when we don't present.

### Suggestions

Within teams, researchers can be encouraged by CIHR/SPOR to co-build with us to:

47. develop relationships at the idea stage and then co-design the proposal and project;
48. design the PWLLE role together keeping it flexible and revisiting it during the project;
49. involve us in discussions and decisions about the engagement budget and plan.

Separately, CIHR/SPOR could co-design with us to identify:

50. which budget items should be covered by the grant budget and which are the responsibility of the granting agency.

# Researching to create a better future

## Patient priorities should drive research.

PWLLEs are deeply invested in the future of healthcare and in health research. And so we also want at least some research to be patient-led.

> "We worry about the future and are concerned about the focus on disease.
>
> We need to look at the social determinants of health not just the emergency department but make sure of support when we are in the community."

> "We see unfilled research gaps in skewed evidence which signifies a bias."

### AREAS OF RESEARCH OPPORTUNITIES

We heard interest in the following areas for exploration:

**Climate change and its impact on health**: Specifically let's learn about the impact of forest fires on people living in fire areas and the impact on healthcare systems. This is not a surprising concern after the last few summers.

**Conditions with hard to manage symptoms and growing prevalence**: These were given as examples: Chronic fatigue syndrome, Fibromyalgia, Alzheimer's, and Long COVID.

**Prevention and whole person focus**: We want a more holistic or whole person focus rather than only a disease or condition-based focus. This would include looking at the social determinants of health and focusing on prevention, learning how to get ahead of disease.

**Vulnerable and targeted populations**: We recognize that we need to understand and help the more vulnerable in society, especially populations not traditionally part of research. Several of us made special mention of those with mental health issues, especially children, and those who cannot communicate their needs.

**Home and community care**: We want to learn more about folks at home and to have more data on home care versus long term care.

We discussed what it would take to make system-level changes to support some of the ideas above:

**The caregiver as integral element in the system:** The caregiver is the often unseen and essential piece of care and support for patients within the system. Let's learn more about their role. Let's understand the difference for patients to their health outcomes and experiences if they have a devoted, an inadequate or no caregiver. What can we learn about their stresses, their supports or lack thereof and how these impacts both patients and the system at large.

**Collaborating across systems**: We suggest exploring integrations and collaborations between health and social services but also between health and the education system. Let's demonstrate that this done right could lead to positive outcomes. We have a strong desire to see the physical and mental health systems come together and join with community support systems on behalf of the "whole person".

**Moving across systems**: Another aspect for study is how we navigate the various services we use both within the formal healthcare system and across the allied health services. Many of us use social services as well. We would like to see attention paid to the psychological aspects of

navigating across a barely functional system of services and the impact on our health as a result. For example, one attendee raised the huge challenge of navigating the system on behalf of a child with a rare disease.

Examples of other system-level concerns:

- When doing evaluations and measurement, maintaining humanity – not getting lost in the world of data;
- Responding to the need for health literacy and health data literacy stemming from the need to self-manage;
- Access to all our health data to support our right to our data and enable the model of patients as partners in care;
- escalating the implementation of research.

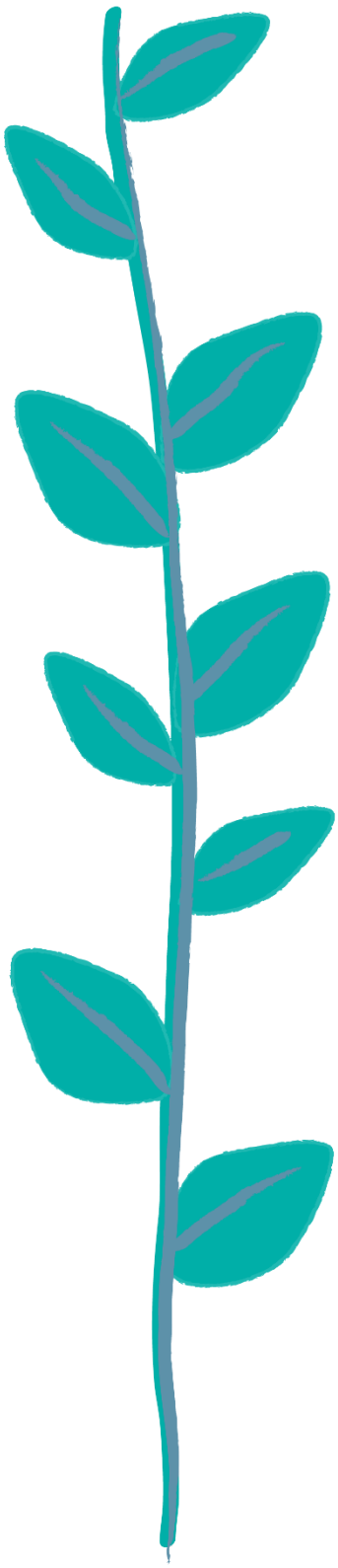
**New technologies**: We have learned about virtual care; now we want to understand how best to merge it with person-facing care for just "care". Most of us find AI both scary and exciting and are concerned about losing the human aspect and the replacement of human contact. Let's learn more about the benefits and pitfalls of artificial intelligence (AI).

We would like to be involved in deciding what will be researched to ensure better health outcomes and experiences in the uncertain and, at times, scary, future.

"We Patient Partners are the 'canary in the coal mine'. We observe poor care and poor experience. Our notes and networks can be a huge resource for improvement. We can be a resource for what needs improvement."

# Summary

## Our story reveals that with reciprocal, equitable relationships at the core, we can together help bring health research into the future.



Our collective insights from the data are informed by those with a wealth of experience as well as those not yet in research. We can make the routes into research known and accessible to all who are interested. We can put wheels under our principles by valuing all perspectives including caregivers and those we have not yet heard from. As a research funding agency, CIHR/SPOR can foster and provide support at all levels.

> Supporting teams at the micro level improving what CIHR currently does.
>
> At the meso level supporting not only SPOR SUPPORT Units and Networks but working with fund-holders to streamline accounting processes.
>
> At the macro level, shifting to provide a sustainable infrastructure for the development and support of long-term relationships including the development of national compensation standards.

We can learn together to better respectfully include existing PWLLE partners removing tokenism by understanding the unconscious research cultural lens and how to be more open. We can co-build how to go out into community instead of requiring communities to bend to the existing ways of working in research.

As PWLLEs, we are keen to help transform the research system for the future through new forms of governance and accountability with definitive roles for us.

> A system to better serve those living in Canada by being agile, responsive, and accountable.
>
> A system that produces timely, relevant and implementable results to respond to the rapidly changing coming challenges.

PAN is excited to continue working for our shared future.

"There's a lot of research that hasn't happened yet."

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