

AbSP  RU

Alberta SPOR SUPPORT Unit

# ETHICAL CONSIDERATIONS

for partnering in patient-oriented research

Guidance Document: April 2023

# ACKNOWLEDGEMENTS

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This guidance document has been co-developed by the Albertans4HealthResearch Collaborative Council and the AbSPORU Patient Engagement Team.



# Ethical Considerations

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# INTRODUCTION

# ABOUT THIS GUIDANCE DOCUMENT

This is part of a series of co-developed guidance documents that offer opportunities to reflect on aspects of patient engagement in health research.

Other documents in this series will cover forming a patient advisory council, patient partner compensation, and more.

In this document, we offer guidance for ethical considerations when working on patient-oriented research activities and projects. We also share some resources we think will be helpful to support this.

This guidance document was last updated in April 2023.

# KEY TERMS

## Canadian Institutes of Health Research (CIHR)

The **Canadian Institutes of Health Research (CIHR)** is Canada's federal funding agency for health research. Comprised of 13 Institutes, [CIHR](#) collaborates with partners and researchers to support the discoveries and innovations that improve our health and strengthen our healthcare system.

## Strategy for Patient-Oriented Research (SPOR)

The **Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR)** was designed to facilitate and fund **patient-oriented research (POR)**, and find synergy between stakeholders. You can [read more about SPOR](#) at the CIHR website.

## Patient-Oriented Research (POR)

A continuum of research that engages patients as partners, focuses on patient-identified priorities and seeks to improve patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to provide patient-centred evidence to improve healthcare systems and practices. You can [read more about POR](#) at the CIHR website.

## Patient Engagement

In patient-oriented research, patient engagement describes patients engaged as active and equal research team members collaborating early, actively, and often in as many phases of the research cycle as possible including priority setting, literature review, project design, data collection and analysis, and knowledge mobilization and implementation. Learn more about patient partner roles [at the CIHR website](#), and at the [BC SPOR SUPPORT Unit's website](#).

# KEY TERMS

## Alberta SPOR SUPPORT Unit (AbSPORU)

The **Alberta Strategy for Patient-Oriented Research Unit (AbSPORU)** provides expertise, training, and resources to increase Alberta's capacity for patient-oriented research. Our aim is to bridge the gap between research evidence and health decisions – in other words, to make sure health research has an impact on patients and the health system. Visit the [Alberta SPOR SUPPORT Unit's website](#) for more information.

## Albertans4Health Research.ca (AB4HR.ca)

[Albertans4HealthResearch.ca](#) is an online connection site that connects people with valuable lived experience and expertise of health conditions with academic and clinician researchers. In addition to sharing patient partner research opportunities the site also shares patient engagement resources, episodes of the PEP Talks podcast, and monthly Patient Engagement Journal Club articles and recordings.

## Albertans4Health Research (AB4HR) Collaborative Council

The **Albertans4HealthResearch (AB4HR) Collaborative Council** is comprised of 40 public members and includes patients, caregivers, community partners, patient organizations, clinician and academic researchers, and health policymakers. The Council meets quarterly to discuss issues related to POR, discuss priorities and explore solutions focused on improving health and healthcare for Albertans.

## Patient

An overarching term inclusive of individuals with personal experience of a health issue, or their family members, caregivers, or friends. Read more in [CIHR's Patient Engagement Framework](#). Depending on the context, patient-oriented research can also include specific-affected communities. Read more in [CIHR's Ethics Guidance document](#).

# KEY TERMS

## Patient Partners

People with lived experience(s) who collaborate as active and equal members on patient-oriented research (POR) teams, in any or all of the roles identified in the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) research cycle. Consider [figure 3 in CIHR's Ethics Guidance document](#). As active and equal members of health research teams, this role does not require Research Ethics Board (REB) approval.

## Patient Participants

Patients who are involved in a research study whose data, or responses to interventions, stimuli, or questions by a researcher, are relevant to answering the research question. See also [Glossary](#), Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2nd Edition (TCPS2).

## Tokenism

The practice of making only a symbolic effort to do something. In the context of patient engagement in health research, this can include recruiting a patient research partner to give the appearance of inclusion, without making their role meaningful or valuable. Read this [blog on tokenism](#), Tokenism: Seeing it. Fixing it. Perspectives from IMHA Patient Partners.

## Jargon

Terminology often used by experts that can be confusing or alienating to those who are not experts or familiar with that area. This can include acronyms. Read [CIHR's jargon buster](#).



# KEY TERMS

## Ethics

The moral principles that govern a person's behaviour or the conducting of an activity.

## Research Ethics Board (REB)

A Research Ethics Board (REB) is made up of a group of independent members who act on behalf of a University or Hospital to ensure the ethical conduct of research.

## Research Ethics Board (REB) Approval

Research Ethics Board (REB) members review research proposals, consent forms, recruitment flyers, and other documents to assess submissions to decide whether they meet research ethics guidelines. The board can approve the submission or request amendments. Approval is required to conduct research activities when working with human or animal subjects.

## Cultural Humility

Cultural humility is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience. Read the [First Nations Health Authority Website](#) for more information.

# KEY TERMS

## Cultural Safety

Cultural Safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. Read the [First Nations Health Authority Website](#) for more information.

## Compensation (Patient Partners)

Payment for the time, skills, lived experience, and expertise patient partners bring to a research project or research-related activity. Compensation is offered as recognition of this essential contribution. Patient partners may choose to accept or decline compensation. The Alberta SPOR SUPPORT Unit has [patient partner compensation guidelines](#).

## Token of Appreciation

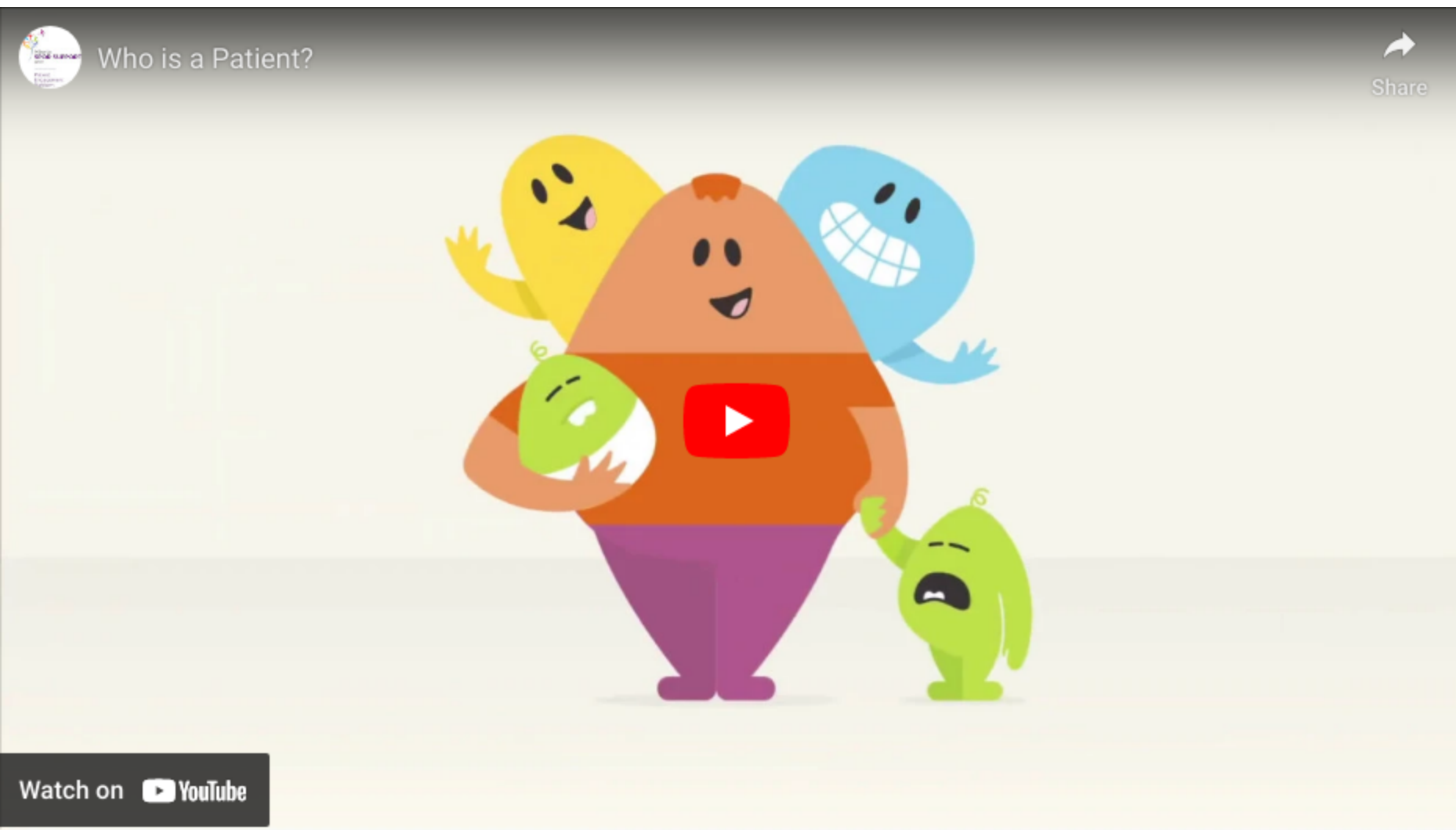
A token of appreciation, usually in the form of a pre-paid gift card or Thank You card given to a patient participant in a study or trial. A token of appreciation is not meant to be a form of compensation for time and expertise.

## Reimbursement

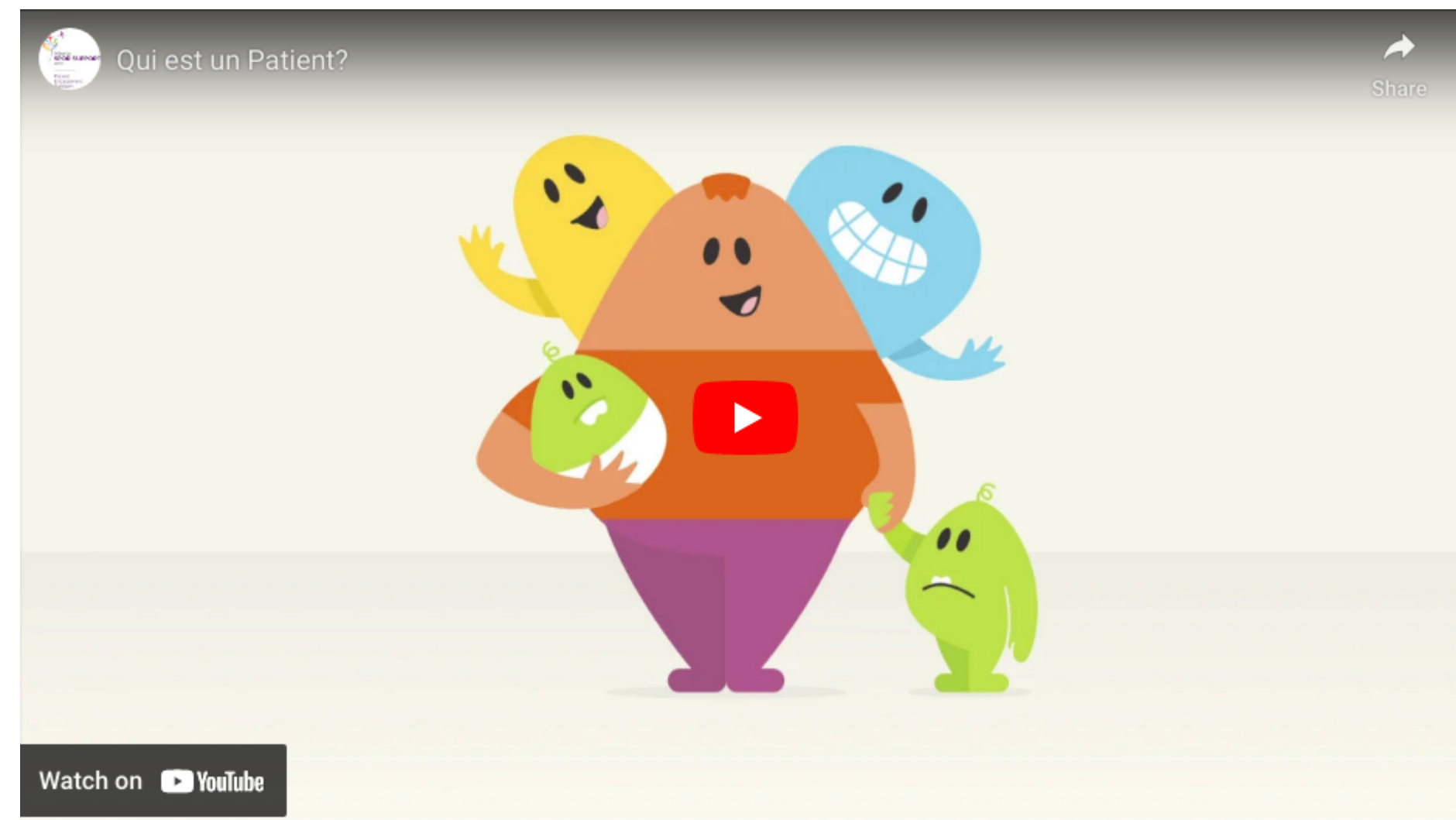
Covering of the direct costs and expenses associated with engaging in research and research-related activities either as a patient partner or a patient participant. These include travel, parking, meals, care giving, digital access and other expenses and should be covered up front whenever possible.

# "WHO IS A PATIENT?"

## English



## French



Link to English video- <https://youtu.be/J8YIQbPDPAM>

Link to French video- <https://youtu.be/hYViaKVLVy4>

**BACKGROUND**

# Ethical Considerations in Research Partnerships

Patient partners are active and equal members of research teams. They collaborate on research processes and activities such as project design, participant recruitment, data collection and analysis, and results dissemination.

In most cases, Research Ethics Board (REB) approval is not required for patient partners as collaborators on a research project. However, REB approval is necessary if patient partners participate in evaluation activities related to understanding if their engagement was meaningful. More about this can be found in Figure 1 of this [article](#).

When partnering with patients in research there are considerations to help build and sustain the trust necessary for effective research partnerships. This document will explore ethical considerations for how academic and clinician researchers and patient partners can work together in respectful and mutually reciprocal research partnerships.

# What are research ethics and research ethics board (REB) approval?

Ethics are the moral principles that govern a person's behaviour or the conduct of an activity. Ethical research gives everyone the opportunity and space to communicate from their terms of reference.

Ethical engagement is an active, ongoing, and consistently reflexive practice.

**Research Ethics Board (REB)** approval is required for any clinical or behavioural study that involves human participants. This helps to ensure the study protects the welfare of study participants.

In Canada, this is governed by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2). Ethical review and approval of a study are given by the institution that holds the grant funding for a study, typically a university or other research organization. Read more [here](#).

# COMMON QUESTIONS

## **Do I need specific ethics training to be a team member on a health research project?**

The conduct of every research team member must be in accordance with the Tri-Council Policy Statement (2010) and the Tri-Agency Framework: Responsible Conduct of Research (2016). This includes patient partners.

**A certificate of completion of the [TCPS2 CORE](#) Course is required by all team members working directly with study data collection and analysis, and working directly with study participants or subjects.** This certificate will usually be included with the study Research Ethics Board (REB) application.

# Questions and tensions may arise when partnering in research

It is important for everyone to understand the unique motivations and perspectives each team member brings to the project.

When managed respectfully and responsibly, the resolution of conflicts can provide relationship and team-building opportunities.

Key points and questions for reflection are provided under each of the ethical consideration topics in the following sections.

There are reflexive consideration questions for both, patient partners and researchers. We encourage you to read both. Answers will vary for each person, and for each project.



**PARTNERING  
MEANINGFULLY**

# PARTNERING MEANINGFULLY

Patient engagement fosters meaningful and active collaboration between patient partners and researchers at all stages of the research cycle.

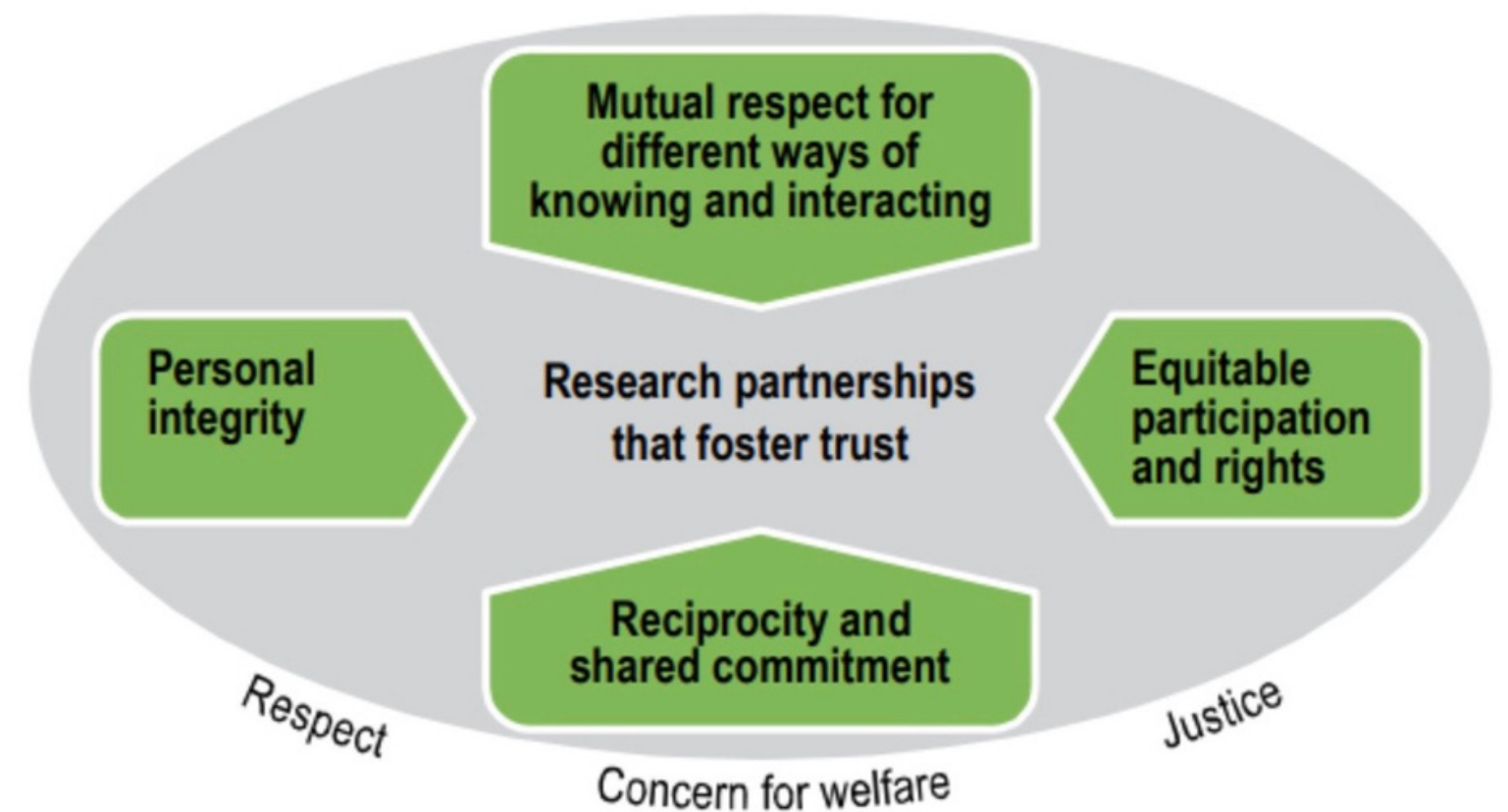
By including those whom research processes impact in the studies that are intended to benefit them, research can be more meaningful and relevant to all users of the Canadian healthcare system.

Research can be implemented sooner in more universal language and formats.

CIHR identifies 4 core considerations for ethical research partnerships:

<https://cihr-irsc.gc.ca/e/51910.html>

Figure 1. Core considerations for ethical research partnerships



# COMMON QUESTIONS

**What can I do if I feel my role on the project might be tokenistic or that a research project would not benefit others?**

If you feel that your role on a project might be tokenistic or that a project does not reflect the priorities of the community it aims to benefit, there are some approaches you may consider taking:

- Propose ways to make your role or the project more meaningful
- Share your concerns and problem-solve with the team
- Respectfully decline or withdraw from the research project or activity

Read more about tokenism in this blog ["Tokenism: Seeing It. Fixing It. Perspectives from IMHA Patient Partners"](#)

# COMMON QUESTIONS

## **What can I do to ensure meaningful partnerships?**

You can contribute to meaningful partnerships by:

- Contributing to a welcoming and respectful research environment
- Sharing personal experiences and insights to enhance deeper understanding
- Listening carefully to others as they share their experiences and perspective
- Communicating in plain language, avoiding jargon and acronyms, and using terms that all team members are familiar with
- Working collaboratively and democratically
- Being interested in expanding your knowledge and skills

# Questions for Reflection

## Patient Partner

- Am I sharing my lived experience and insights in a way that is helping others?
- Am I speaking as an individual with lived experience, or am I expected to represent a larger community of people impacted by a health condition?
- Do I represent the community, and does my community see me as acting on its behalf?

## Researcher

- Are we willing to make the ongoing commitment and effort needed to fulfill a trusting relationship including following up after the project has ended?
- If we are asking patients to represent the views of others or their communities, do they have access to opportunities and resources to consult with others?
- Is there support such as training and administrative services to ensure patients can contribute equitably to the research?

**BALANCING POWER  
DYNAMICS**

# BALANCING POWER DYNAMICS

Power imbalances might be influenced by perceived status, control, access to information, economic disparities, and unique cultural backgrounds. Each of these can affect the trust essential to authentic and meaningful patient partnerships.

It is important to check in regularly during the project to assure positive and collaborative engagement of all team members and to confirm all team members are feeling respected and that their voices are heard.

It is also important that all team members are included in any feedback loops after the project is complete. This includes being regularly updated about dissemination and implementation of the results and how the project might have influenced and impacted change in healthcare policy and practice.

# COMMON QUESTIONS

## **What if researchers and patient partners have different motivations and skill sets?**

Patient partners have lived experiences of health condition(s) and can bring a range of relevant skills and expertise to the table.

Patients, researchers, institutions, and funders should consider what skills and experiences will be needed for working together on a research project. They should consider capacity-building opportunities and resources, such as training, mentorship opportunities, education materials, and systems that can support their POR work moving forward.

Researchers may have been drawn to a particular area of research based on personal or professional experiences. They may have their own preconceptions about the experiences of the patients they work with.

It is important for researchers to include patient partners as early as possible in the research cycle to gain insights and understandings that can identify unique recruitment, retention, and dissemination approaches that are more culturally respectful and appropriate for the populations and communities the research is intended to benefit.



# COMMON QUESTIONS

## **How many patient partners should be on a research team?**

Patient partners can be involved at any or all stages of the research lifecycle, though it is best practice to engage patient partners as early as possible and to engage more than one patient partner.

Multiple individuals can offer diverse and unique insights based on their lived experiences of health and health care. This can also help align the research project with a more holistic approach to care. In this way, research results can have more universal applicability and impact.

Multiple patient partners can help prevent tokenism and overburden. Being the only patient partner on a health research team or activity can be intimidating or uncomfortable. Patient partners can provide each other with mutual support.

# QUESTIONS FOR REFLECTION

## Patient Partner

- Do I understand the roles and responsibilities of all research team members?
- Have expectations been discussed and agreed upon within the research team?
- Have the training and supports I need been clearly identified, and have arrangements been made to offer this?
- Do I understand the project's communication processes, and how information will be shared?
- Do I feel that I am being treated equitably and with respect? Will my voice be heard and my contributions valued?

## Researcher

- Am I considering the unique expectations of the patient partners and community?
- Have we included resources and support for patient partners to contribute meaningfully at all stages of the research?
- Are our processes equitable and inclusive supporting all team members to understand meaningful collaboration and responsibilities when working together?

**PRESERVING  
CONFIDENTIALITY  
OF INFORMATION**

# PRESERVING CONFIDENTIALITY

Communities and individuals share personal experiences and insights, both as patient partners and participants, that contribute to better research evidence and care outcomes.

Some information gathered throughout the research process will be confidential and protected by privacy policy; it cannot be shared.

Researchers, institutions, and funders should ensure that all involved can uphold expectations of confidentiality, and that appropriate policies and procedures are in place to support this.

All team members should respect expectations around individual and cultural confidentiality and privacy.

# COMMON QUESTIONS

## **What do I do if I have concerns about confidentiality?**

If you have questions about confidentiality, it is best to talk about them with other team members to help to answer your questions.

For example, if you have questions about how to best store data you have gathered (i.e. interview recordings), the research team will often have established practices for keeping this data safe.

If confidentiality is breached, inform other team members to ensure mitigation strategies can be enacted.

If you have more serious concerns, the research institution you are working in will have its own process and department to hear inquiries.

# QUESTIONS FOR REFLECTION

## Patient Partner

- Do I understand how information will be shared with me and how to access this information? (e.g., emails, shared drives, etc.).
- What are the expectations for confidentiality associated with the kinds of information that I will have access to?
- Am I supported to understand policies and procedures about upholding protections for confidential information?
- Am I able to ask for support or guidance that I may have about my responsibilities regarding confidentiality?

## Researcher

- Have I thought about secure ways information will be shared and accessed?
- Are there policies, procedures, training, and supports in place for respecting expectations of confidentiality?
- Have I included training support for team members to understand the importance of confidentiality?
- Have I considered approaches that I can take if an unintentional confidentiality breach occurs?

**RECOGNIZING  
BENEFITS & HARMS**

# RECOGNIZING BENEFITS & HARMS

Benefits are any positive effects on an individual or group's welfare.

Harms are any negative effects on an individual or group's welfare.

Benefits and harms can be physical, financial, social, and/or emotional. It is important to recognize that benefits and harms may be perceived or experienced differently depending on individual circumstances and experiences and may change over time.

It is the goal of ethical research to “do no harm” and to promote benefits to all communities, both present and in the future.



# COMMON QUESTIONS

**How can patient partners support inclusivity during research processes, knowledge mobilization, and implementation?**

Because of their unique lived experiences, patient partners can help to increase research benefits and make researchers aware of potential harms:

- to participants and research team members during the research processes
- to end-users, due to the ways research results might be communicated, shared, and implemented during the knowledge mobilization processes
- to health care providers by helping to avoid language and approaches that might be perceived as stigmatizing or discriminatory in implementation processes

# COMMON QUESTIONS

## **How can patient partners help to increase research benefits and reduce harm?**

Patient partners can help to increase research benefits and make researchers aware of potential harms:

- Patient partners are well-positioned to advise other research team members about both potential harms and benefits for research partners and participants.
- Patient partners can help to identify potential harm in the way that research processes are conducted and results are communicated and implemented; this can include an awareness of language and approaches that might be perceived as stigmatizing or discriminatory.
- For knowledge translation and exchange, patient partners could suggest ways to share research results using approaches, language, and information formats more accessible to all.

# REFLECTION QUESTIONS

## Patient Partner



- What are the potential impacts of the research activities on my health, and how do my geographic, economic, and social circumstances impact my ability to partner?
- Am I aware of possible unintended harms that might occur during this research project and am I comfortable sharing my concerns with members of the research team?
- Can I safely contribute my insights to the research project?

## Researcher



- Have opportunities been provided for patient partners to discuss the potential benefits and harms of the research?
- Have we collaboratively discussed mechanisms, supports, and resources and implemented them into the project plan and budget to preemptively address potential harms?
- When the research activity ends, how will we recognize and celebrate the contributions of patient partners, e.g. as co-authors?
- Can we help patient partners to find other opportunities for meaningful engagement?

**OVERCOMING  
BARRIERS**

# OVERCOMING BARRIERS

Systemic, structural, or institutional barriers are policies, practices, or procedures that prevent some people from having equal access to research processes and/or research results.

Barriers can be real or perceived and can include language, literacy, and other access to knowledge barriers.

Barriers need to be identified early and addressed and resolved to achieve authentic inclusion and meaningful engagement of all individuals and communities.

# COMMON QUESTIONS

## What are compensation and reimbursement? When should they be offered?

Patient partners provide unique and valuable insights and perspectives [essential to health research priorities and projects](#).

**Compensation** is offered to patient partners for their time, expertise, and contributions to research projects. Compensation should be disbursed in ways that are respectful to the patient partner's unique circumstances. Some patient partners may choose to decline compensation.

**Reimbursement** describes expenses incurred by patients as a direct result of engaging in research activities, including travel, parking, child and elder care, and other expenses. Direct expenses should be covered by research projects, otherwise, they can be a barrier to engagement. These should be paid upfront by the research team where possible.

The eleven SPOR SUPPORT Units have each developed their own patient partner compensation guidelines. These can be found on their respective websites (links to each Unit are on [the CIHR website](#)).

# QUESTIONS FOR REFLECTION

## Patient Partner

- What potential barriers might exist to engaging in this project and am I comfortable sharing them?
- Are partnerships in research accessible to everyone such as scheduled breaks between meetings?
- Does the project budget include compensation as recognition of patient partner time, and reimbursement for the direct financial costs of partnering in the project (including travel, parking, elder and child care)?

## Researcher

- Have I taken the time to explain the objectives and processes of the research project and am I available and open to answering questions in a welcoming and responsive manner?
- Have we explored and addressed potential systemic and/or structural barriers (including compensation) that may inhibit or prevent the collaboration of patient partners?
- Is our training inclusive of all language levels, learning styles, and approaches?

**A C K N O W L E D G I N G  
C O N F L I C T S O F  
I N T E R E S T**



# CONFLICTS OF INTEREST

Conflicts of interest can arise from situations in which there is an incompatibility between two or more of the duties, responsibilities, or personal or work-related interests of individuals or institutions as they relate to the research activity.

Conflicts of interest can be potential, actual, or perceived and are severe enough that one's duty, responsibility, or interest cannot be fulfilled without compromising the others.

Conflicts of interest may damage the trust that underlies patient engagement relationships and can also distort a person's judgment without that person being consciously aware of it. Therefore, conflicts of interest and commitments need to be assessed on a case-by-case basis.

Following conflict of interest guidelines and checking with appropriate third parties helps avoid or manage these issues.

# COMMON QUESTIONS

## What kind of conflicts of interest may arise?

Conflicts of interest may arise for both patient partners and researchers while working together in research.

Patient partners and researchers may have relationships or affiliations that could influence or interfere with their roles in research. These may be personal, political, professional, financial, or legal (for example, duties of care, and legal guardianship).

An example of a conflict of interest for both patient partners and researchers would be if invited to take part in a CIHR grant review process and an individual is assigned to review a grant application in which they are also a member of the research team. In this scenario, the reviewer of the grant application would need to declare their conflict of interest to CIHR. This [Canadian Institutes of Health Research \(CIHR\) document](#) provides more information about Conflict of Interest and Confidentiality Agreement for Peer Reviewers and Peer Review Observers.

# QUESTIONS FOR REFLECTIONS

## Patient Partner

- Do I have personal, business, or other relationships in my community that might inhibit me from acting in the interests of sharing insights based on my lived experience?
- Have I disclosed these conflicts to others involved in the research team and, where appropriate, to others in my patient group or community?
- Does the research team, institution, or funding organization have policies and processes for identifying and managing actual and potential conflicts?

## Researcher

- Have fair and transparent policies and processes been established to declare, manage and minimize conflicts of interests for all members of the research team?
- Have we worked to create safe spaces and identified processes for identifying and working through conflicts of interests that might arise?

# PATIENT ENGAGEMENT RESOURCES

## PEP Talks- AbSPORU Patient Engagement Podcasts

Website- <https://soundcloud.com/patientengagement>

## Albertans4Health Research.ca - Online patient partner/researcher connection site

Website- <https://app.betterimpact.com/PublicOrganization/25809ea0-7311-40db-bfac-aaa0e28ba518/1>

## Patient Engagement Journal Club Recordings

2023: <https://vimeo.com/user/148740196/folder/14674584>

2022: <https://vimeo.com/user/148740196/folder/14626312>

2021: <https://vimeo.com/user/148740196/folder/14627053>

## AbSPORU SPOR Northwest Forum Recordings

2022: <https://vimeo.com/showcase/9871850>

2021: <https://vimeo.com/showcase/9372274>

# INDIGENOUS ENGAGEMENT

## Learn more about Indigenous-centred research:

- The Collaborative Indigenous Research Digital Garden can be viewed [here](#). More about the development of this unique digital garden can be found [here](#).
- Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada can be viewed [here](#).

## Online Courses

- First Nations Principals of [OCAP \(Ownership, Control, Access, and Possession\)](#).
- Indigenous Canada, University of Alberta, Faculty of Native Studies, [Massive Open Online Course \(MOOC\)](#).
- [Indigenous Community Research Partnerships](#) (Queen's University).
- [San'yas](#) Anti-Racism Indigenous Cultural Safety Training Program

## Some helpful sites

- [Aboriginal Children's Hurt & Healing \(ACHH\) Initiative](#)
- [British Columbia Network Environment for Indigenous Health Research \(BC NEIHR\)](#)
- [Hotìì ts'eeda \(Northwest Territories SPOR SUPPORT Unit\)](#)
- [Wabanaki-Labrador Indigenous Health Research Network](#)

# REFERENCES

## CIHR Ethics Guidance for Developing Partnerships with Patients and Researchers

**Published-** April 17, 2020

**Prepared by-** Canadian Institutes of Health Research (CIHR)

**Website-** <https://cihr-irsc.gc.ca/e/51910.html>

## CIHR SPOR Patient Engagement Framework

**Published-** May 27, 2019

**Prepared By:** Canadian Institutes of Health Research (CIHR)

**Website-** <https://cihr-irsc.gc.ca/e/48413.html>

## CIHR Considerations when Paying Patient Partners in Research

**Published-** September 29, 2022

**Prepared by-** Canadian Institutes of Health Research (CIHR)

**Website-** <https://cihr-irsc.gc.ca/e/51466.html>

## AbSPORU Patient Partner Appreciation Guidelines: Compensation in Research

**Published-** February 2023

**Prepared by-** AbSPORU Patient Engagement Team

**Website-** [https://absporu.ca/wp-content/uploads/2023/02/AbSPORU-PE\\_Patient-Partner-Compensation-Guidelines\\_February-2023.pdf](https://absporu.ca/wp-content/uploads/2023/02/AbSPORU-PE_Patient-Partner-Compensation-Guidelines_February-2023.pdf)

# REFERENCES

## Navigating the Ethics of Human Research (TCPS2 2022)

**Published-** February 27, 2023

**Prepared by-** Government of Canada

**Website-** <https://ethics.gc.ca/eng/home.html> or <https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf>

## Onboarding Guide for Patient Partners New to a Patient-Oriented Research Team

**Published-** not available

**Prepared by-** Saskatchewan Centre for Patient-Oriented Research (SCPOR)

**Website-** <https://static1.squarespace.com/static/5c869fd0e666695abe893b3b/t/624dacca5a77250d6e720e92/1649257675822/revise+SCPOR+ONBOARDING+GUIDE+FOR+NEW+POR+TEAMS+Patient+Partner+support+%281%29.pdf>

## Equity, Diversity, and Inclusion: Inclusive Language Guidelines

**Published-** 2021

**Prepared by-** American Psychology Association (APA)

**Website-** <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf>

## Family Engagement in Research (FER): A Glossary

**Published-** 2019

**Prepared by-** Ariel Taylor, Marion Knutson, and Jeff McCrossin

**Website-** [https://canchild.ca/system/tenon/assets/attachments/000/003/539/original/FER\\_Glossary.pdf](https://canchild.ca/system/tenon/assets/attachments/000/003/539/original/FER_Glossary.pdf)



# ABSPORU PE TEAM PUBLICATIONS

## Patient-Identified Priorities for Successful Partnerships in Patient-Oriented Research

**Published-** Res Involv Engagem 8, 49, September 7, 2022

**Authors-** Santana, M.J., Duquette, D., Fairie, P. et al.

**Web URL-** <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-022-00384-4>

## Albertans for Health Research Network: Form, Fit, and Function

**Published-** J Patient Exp. 2020 Dec;7(6):973-977. doi: 10.1177/2374373520925245. Epub 2020 Jun 29. PMID: 33457531; PMCID: PMC7786747.

**Authors-** Rasiah J, Manafò E, Krawec K, Nielssen I, Amirav I, Macphail EC, Lavigne LA, Asis S.

**Web URL-** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7786747/>

## Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: A Qualitative Study of Barriers and Priorities for Patient-Oriented Research

**Published-** BMJ Open 2020;10:e031187. doi:10.1136/bmjopen-2019-031187

**Authors-** Santana M-J, Zelinsky S, Ahmed S, et al

**Web URL-** <https://bmjopen.bmj.com/content/bmjopen/10/2/e031187.full.pdf>



# PUBLICATIONS

## Patient Partner Compensation in Research and Health Care: The Patient Perspective on Why and How

**Published-** Patient Experience Journal. 2018; 5(3):6-12. doi: 10.35680/ 2372-0247.1334

**Authors-** Richards DP, Jordan I, Strain K, Press Z

**Web URL-** <https://pxjournal.org/cgi/viewcontent.cgi?article=1334&context=journal>

## Sharpening the Focus: Differentiating Between Focus Groups for Patient Engagement vs. Qualitative Research

**Published-** Res Involv Engagem 4, 19 (2018). <https://doi.org/10.1186/s40900-018-0102-6>

**Authors-** Doria, N., Condran, B., Boulos, L. et al.

**Web URL-** <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0102-6>

## Guidance on Authorship With and Acknowledgement of Patient Partners in Patient-Oriented Research

**Published-** Res Involv Engagem 6, 38 (2020).

**Authors-** Richards, D.P., Birnie, K.A., Eubanks, K. et al.

**Web URL-** <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00213-6>

# PUBLICATIONS

**Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis.**

**Published-** BMC Health Serv Res 17, 539 (2017). <https://doi.org/10.1186/s12913-017-2463-1>

**Authors-** Shimmin, C., Wittmeier, K.D.M., Lavoie, J.G. et al.

**Web URL-** <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2463-1>

**Partnering with patients in healthcare research: a scoping review of ethical issues, challenges, and recommendations for practice**

**Published-** BMC Med Ethics. 2020 May 11;21(1):34. doi: 10.1186/s12910-020-0460-0. PMID: 32393230; PMCID: PMC7216517.

**Authors-** Martineau JT, Minyaoui A, Boivin A.

**Web URL-** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7216517/>

**The impacts of partnering with cancer patients in palliative care research: a systematic review and meta-synthesis**

**Published-** Palliative Care and Social Practice. 2022;16. doi:10.1177/26323524221131581

**Authors-** Paolucci A, Nielsen I, Tang KL, Sinnarajah A, Simon JE, Santana MJ

**Web URL-** <https://journals.sagepub.com/doi/full/10.1177/26323524221131581>

# THANK YOU!

This is a living document subject to review in collaboration with patient partners to reflect trends and changes in the content and context of health research in Alberta.

This document is an update of a previous version co-developed by the AbSPORU Patient Engagement Team and a working group of diverse stakeholders in 2019. We would also like to acknowledge Kathryn Arnold for her work on these guidelines in 2020.

We look forward to your comments, feedback, or any challenges related to using this document and applying the suggested considerations and guidelines.

# CITING AND COPYRIGHT

**Suggested citation:** Maria J Santana, Paul Fairie, Ingrid Nielsen, Sadia Ahmed, Sumedh Bele, Tiffany Barbosa, and Sandra Zelinsky, Ethical Consideration for partnering in patient-oriented research Guidance Document, April 2023, Available on [www.absporu.ca](http://www.absporu.ca).

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