



PATIENT PARTNER ONBOARDING FOR RESEARCH

**Guidance for Research Teams at
BC Children's Hospital and
BC Women's Hospital + Health Centre**

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The Patient Partner Onboarding for Research Working Group collaborated to review and refine the onboarding guidance document, bringing expertise in patient-oriented and community-based research, and perspectives from research teams and programs from both BC Children's Hospital Research Institute, and the Women's Health Research Institute. In addition to the authors, the Working Group Membership includes:

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Purpose

The purpose of this guidance document is to provide **practical instructions for research teams for how to engage, onboard, and compensate research patient and family partners at BC Children's Hospital and BC Women's Hospital + Health Centre (C&W)**. In addition, these guidelines provide recommendations and resources to support ethical, equitable, and inclusive engagement.

Responsibility

There is no regulatory body that oversees patient engagement in research. Although the following document represents best practice and suggested guidelines for patient partner engagement and onboarding, the ultimate responsibility for patient partners and those who they interact with in a research capacity lies with the Principal Investigator and/or research program.

Language

For the purposes of this document, we refer to patients and families who support, contribute to, or engage in research as partners as '**Patient Partners**'. This term can be broadly used to refer to both patients and families (e.g. in a pediatric setting), and also community partners (e.g. representatives from community who aren't necessarily a patient but represent a related group). It is important to discuss with patient partners how they would like their role on the team to be described. Some alternative options may include:

- Peer Research Associate (PRA)
- Peer Research Consultant
- Community Engagement Advisor
- Community Engagement Consultant
- (Project/Committee name) Committee Member
- Co-investigator

... or other titles that you and the patient partner deem to be the best fit to describe their work.

Overview

BC Children's Hospital Research Institute (BCCHR) and the Women's Health Research Institute (WHRI) recognize the importance of engaging with C&W patients and families as partners throughout all phases of the research process. Patient engagement in research can improve the quality and relevance of health-based research, ultimately leading to better health outcomes for patients and improved healthcare systems. Patient partners can be represented in various roles in research initiatives, including but not limited to:

- As members of a research oversight committee
- Collaborator, Consultant, or Co-Investigator roles on research studies
- As members of a community or patient committee, board, or task force (e.g. advisory board)
- Acting as a study research assistant and supporting data collection and participant recruitment

Patients can be engaged at different levels, including inform, consult, involve, collaborate and empower:

LEVELS OF ENGAGEMENT

Adapted from IAP2
Spectrum of Public
Participation



Additionally, patient partners can take on various tasks within these roles and levels, including but not limited to:

- Prioritizing or establishing research questions and protocol development;
- Reviewing project documentation and methods for appropriate language use and feasibility of methods;
- Co-creating or inform the conduct of ethical research processes;
- Reviewing and interpreting end-of-study findings;
- Supporting knowledge translation activities including conference and community presentations and manuscripts
- Providing letters of support for funding proposals

Planning for Patient Engagement

Within a provincial context there are two primary resources that teams can access to see where and how to initiate patient partner engagement. The first is the BC SUPPORT Unit's "[Road map – Health Research BC: A Journey Through Public & Patient Engagement in Health Research](#).”³ This interactive tool combines the various stages of research when patients can be engaged, what role they can fulfill, and provides resources to facilitate engagement. The second is the BC Patient Safety and Quality Council "[A Guide to Authentic Patient Engagement - Health Quality BC](#)”⁴ which includes diversity, equity, and inclusion, team composition and support, compensation, transparency and expectations, and evaluation.

Table 1. Training/Orientation Resources for Researchers and Research Team Members:

Topic	Resources
Getting Started	<p>Researcher teams can get started by referring to the following guides and resources which offer a foundation for involving patients in research, covering key principles, strategies, and emphasizing the importance of shared decision-making, defining roles and expectations, and fostering a supportive environment: 5-7</p> <ul style="list-style-type: none"> ◦ SPOR: https://albertainnovates.ca/wp-content/uploads/2018/06/How-To-Guide-Researcher-Version-8.0-May-2018.pdf ◦ NHS: https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf ◦ PEIR Plan: http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf ◦ BC Support Unit, free consultations: https://redcap.healthresearchbc.ca/surveys/?s=CAFJNPJJ3C
Language	<p>When engaging patient partners in a research setting, it is important to use plain and inclusive language. The following resources emphasize the use of clear, jargon-free communication, and provide insights and examples for how to use language to bridge the gap between researchers and patients:8-11</p> <ul style="list-style-type: none"> ◦ BCCDC: http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf ◦ CHFI: https://www.cfhi-fcass.ca/docs/default-source/itr/pe-hub/awesome_handbook-fraserhealth.pdf ◦ CIHR Jargon buster: https://cihr-irsc.gc.ca/e/48952.html ◦ BC SUPPORT Unit: https://www.greatminds.studio/lx/Plain-Language/story.html

Topic	
Compensation	<p>Patient partners should be compensated for their contributions to the research, and unless otherwise specified, cash or e-transfer payments are recommended over other forms of payment to reduce barriers and burden (see below: Onboarding). Determining rates of payment involve considerations such as the nature of the patient partner's contributions and time commitment, but a minimum rate of \$25/hour is recommended, with rates for Elders/Knowledge Keepers ranging from \$200-400/hour. The following resources help outline suggested fees for payment and guidelines that reinforce the importance of fair, transparent, and equitable compensation:12-17</p> <ul style="list-style-type: none"> o PHSA: https://pod.phsa.ca/workplace-resources/finance/accounts-payable/honorariums-elder-payments o CHILD BRIGHT: https://www.child-bright.ca/compensation-guidelines o BCCDC: http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf o SPOR: https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf o UBC, Indigenous Finance Guidelines: https://iap-2021.sites.olt.ubc.ca/files/2022/02/Indigenous-Finance-Guidelines-12-10-2021_1.pdf o JOSPT: https://www.jospt.org/doi/10.2519/jospt.2020.0106

Topic	Resources
Training	<p>Research teams and patient partners can access the following training platforms and modules, offering a comprehensive resource for learning and patient oriented clinical research:18-20</p> <ul style="list-style-type: none"> ◦ CIHR Training Modules: https://lms.udutu.ca/LMSPortal/Account/Logon?orgCode=IMHA ◦ PCORI Tutorials: https://www.pcori.org/engagement/research-fundamentals ◦ PORCCH Training Modules (child health): https://porcch.ca/

Other considerations for patient engagement:

- If patient partners are joining the research team, consider having at least two. This allows patient partners to support and learn from each other, and helps account for existing medical hierarchy (e.g. researchers perceived as more valuable/senior to members of the public). This also helps decrease the likelihood of tokenism. 5
- Creating and sustaining productive, transparent and meaningful relationships with patient and community partners can be enabled through clear expectations of what you or your research team is asking of the patient partner. This could take the form of:
 - Terms of Reference/Guidelines (e.g. for a Community Advisory Committee)
 - Partnership Agreement
- Engaging patients and communities who have experienced traumatic events or been harmed by the health system can put them at risk of being re-traumatized. Collating self-care resources, and developing clear debriefing workflow plans for patient and community partners are some ways to create a safer space for engagement.

Table 2. Overcoming Challenges

Funding Challenges	Mitigating Strategies
Funding/Resources	<ul style="list-style-type: none"> • Build reimbursement and compensation for patient engagement into budgets and timelines • Incorporate patient engagement training for research staff and research training for patient partners into your grant budgets • Contact your department or patient experience office to inquire about funding opportunities • Account for agility; engagement can take time.
Power	<ul style="list-style-type: none"> • Build in methodological approaches for engagement (Patient-Oriented Research, Community-Based Research, Co-design, etc.) • Engage patient partners as equal members of your study team, early in the research process • Consider the role of equity, diversity, inclusion, accessibility, and Indigenous cultural safety in your approach:^{21,22} <ul style="list-style-type: none"> ◦ CHILD-BRIGHT EDI-DI Framework: https://www.child-bright.ca/edi-di ◦ BC SUPPORT Unit (diverse patient engagement training): https://diversity-tapestry.com/tapestry/bc-support-unit-tapestry-project/#/nodes/1615?sidebar=info • Consider and regularly reflect upon your own positionality as a researcher, in addition to your team members' positions and how decisions are being made • Include patient partners in study knowledge translation outputs (e.g. plain language summaries, posters, videos, co-presenters at a conference, and authorship on study manuscripts for those meeting authorship criteria).²³ • Look to experienced mentors for support

Funding Challenges	Mitigating Strategies
<p>Tokenism</p>	<ul style="list-style-type: none"> • Consider WHY you are engaging patients and community partners • Approach engagement as an opportunity for mutual learning and collaboration • Consider having at least 2 patient partners on the team • Be conscious of meaningful, culturally safe, representative engagement • Consider evaluating your patient engagement approach regularly to ensure meaningful engagement <ul style="list-style-type: none"> ◦ Schedule regular informal check-ins ◦ Utilize meaningful practice evaluation tools (see Table 1: PEIR plan)

Identifying Patient Partners

Contrary to recruiting patients as participants in research, it is appropriate for Investigators to approach patients within their circle of care and invite them to engage as a patient partner (see Appendix A: Template Physician Recruitment Script). For some patient partner opportunities, you might have multiple candidates in mind and it could be appropriate to host an informal discussion/interview with candidates to help determine who will be a good fit for your project (sample questions to guide this discussion can be found at: <https://patientvoicesbc.ca/wp-content/uploads/2021/03/Sample-Selection-Questions-Final.pdf>).²⁴

In addition to engaging your own patients, the following groups have networks of individuals who have already indicated interest in being engaged as a patient partner:

- BC SUPPORT Unit: <https://healthresearchbc.ca/bc-support-unit/about-us/>
- REACHBC: <https://reachbc.ca>
- Patient Voices Network (PVN): <https://patientvoicesbc.ca/>

- BCCH Mental Health Patient Registry: contact Gordan Andjelic, Gordan.Andjelic@bcchr.ca
- C&W Patient Experience Office: <http://www.bcchildrens.ca/about/accountability/patient-experience>
- For Elder engagement please contact the Indigenous Health team at C&W: indigenoushealthreferral@cw.bc.ca

Confidentiality

It is important to have transparent discussions early regarding confidentiality with the patient partners you are engaging; specifically, that patient partners feel comfortable sharing their lived/living experiences with the study team and larger scientific community. The role of a patient partner differs significantly from a research study participant, and accordingly their identity/confidentiality does not fall under the same research participant rights to confidentiality. As a patient partner is an embedded member of the research team, patient partners can expect their name and role with the study team to be shared, similar to the way a study Co-Investigator could expect their name and role to be shared. For example, it is acceptable (and encouraged!) for a patient partner's full name and role with the study to appear on a grant application, research ethics board application, manuscript, presentation, etc.

Some patient partners may prefer to have specific details regarding their lived experience/health condition/journey within the healthcare system shared only within the study team, or specific groups. We recommend having these conversations early on to help determine if your project will be a good fit for the patient partner, suggest collaboration on what aspects require identification and what aspects could be kept confidential, and documenting these discussions and decisions in your study Terms of Reference/Guidelines (see: Training/Orientation).

Onboarding Processes

Onboarding requirements are largely dependent upon the role of the patient partner; some considerations include: level of engagement, level of interaction with study participants, and where the work is taking place (remotely vs. on-site at C&W). Depending on these factors, your team should consider the following onboarding tasks for research patient partners:

1. Pledge/Waiver of confidentiality

- Have patient partner(s) sign a pledge or waiver of confidentiality, noting that the information/data they review as part of their role is to be kept confidential
- This is recommended for all patient partners engaged in research at C&W (**see Appendix B: Pledge/Waiver of Confidentiality**)

2. Criminal Record Check (CRC)

It is important to note that Criminal Record Checks (CRCs) may be stigmatizing, and in some cases, having a criminal record may actually be preferable as it enriches the individual's lived experiences and therefore contributions to the research. If the patient partner needs to complete a CRC as part of their onboarding requirements, it should be discussed in a trauma-informed way and embedded as part of a wholesome onboarding process (**see Appendix C: Template CRC Script**).

- If the patient partner does not have contact with children/vulnerable adults, AND they are not working onsite then a Criminal Record Check **(CRC) is not required**
- If the patient partner will have contact with children/vulnerable adults (e.g. is co-leading focus groups via Zoom, is working in community directly engaging with patients in the DTES) then a **CRC is required**
- If the patient partner will be regularly working onsite at C&W, then a **CRC is required**

- It is important to note that a patient partner's role may change or evolve over time; it is the responsibility of the Principal Investigator to re-evaluate the need for a CRC prior to any/all changes in engagement/responsibilities
- The study team (and not the patient partner) is responsible for paying for the CRC
- These guidelines are aligned with the [Provincial Practice Education Guideline for Criminal Record Check](#),²⁵ based on the [Criminal Records Review Act](#),²⁶ and were developed in collaboration with the Patient Voices Network (PVN) and the C&W Patient Experience Office.
- If there are any uncertainties, please liaise directly with your Department's Human Resources representative, and/or contact your research institute

3. **ID badge/On-site Work Requirements**

- If the patient partner will be regularly working on-site at C&W, or regularly representing your study team in community, an ID badge is required
 - For BCCHR affiliated badges, see: support.bcchr.ca
 - For WHRI affiliated badges, see (must be on a PHSA computer to access):
<https://fhsp2016/sites/PhotoId/Lists/PIDMultipleRequests/NewForm.aspx?Source=https://fhsp2016/sites/PhotoId/Lists/PIDMultipleRequests/Default.aspx&RootFolder=>

- If the patient partner will be working on-site regularly at C&W, and where appropriate (age, literacy, etc.), please support the patient partner to complete the following online onboarding courses through the LearningHub, as required by Facilities (learninghub.phsa.ca):
 - Privacy and Security 101
 - Provincial Code Red – Fire Safety Training
 - Respectful Workplace
- If the patient partner is working primarily remotely (+/- an occasional on-site meeting for orientation, etc.), an ID badge is not required

4. Research Ethics Board Requirements

- As per the C&W Research Ethics Board (REB), patient partners must be added to section 1.5A of the REB applications they will be supporting
 - Patient partners with higher levels of engagement on research projects (e.g. Co-Investigators; Peer research associates) should be added to the appropriate sections of the REB application (e.g. 1.3A; 1.4A)
- Where appropriate, all patient partners should complete the TCPS2 course as part of a onboarding/training: <https://tcps2core.ca/welcome>
 - In cases where it is not appropriate for patient partners to complete TCPS2 (literacy concerns, age, etc.) please still select 'Yes' to section 1.6 of the REB application regarding TCPS2 completion

5. Guidelines for Payment

- Rates and processes for compensation should be discussed in your first conversation with the patient partner
- Based on their role, you may discuss an hourly rate vs. a flat fee for their engagement
- If a flat fee or flat fee per task is agreed upon, the research team should track this to decrease patient partner burden and ensure timely payment
- If an hourly rate is agree upon, it is recommended to have your patient partner track their hours and have them regularly submitted for payment.
 - Ensure that tasks like attending meetings, preparing for meetings, and reviewing documents are included in their hours (and described in your TOR).

- Unless specifically requested by the patient partner, cash or e-transfer payments are recommended over other forms of payment (cheque, gift card, etc.). It is important to make compensation as barrier-free as possible. Consider that other forms of ‘payment’ (e.g. gift cards) can be patronizing or stigmatizing.¹⁴
- Cash honoraria will need to be signed by the patient partner, as proof of payment (see **Appendix D: Receipt of Payment Template**).
- A photo of e-transfer confirmation is sufficient as proof of payment for finance purposes, but you may still consider having the patient partner sign as confirmation of receipt of payment
- Have discussions early on about what payment option and frequency works best for the patient partner. For example, monthly payments via e-transfer; cash payments with half at the beginning of the project and half at the end of the project, etc.
- Be prepared to have a discussion about the impacts on tax situation; honoraria exceeding \$500/calendar year should be reported on line 10400 of an individual’s tax return,²⁷ and may have implications for people enrolled in government assistance programs, such as income and/or disability assistance.¹⁴
- Ensure that any other expenses (e.g. parking, lunch) are covered by the study team

For finance instructions for paying patient partners from UBC or PHSA accounts, see Appendix E: Instructions for Compensating Research Patient Partners.

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If you are unsure which onboarding tasks your patient partner should/should not complete, please complete the **Patient Partner Onboarding Requirements Sorting Tool**

Training/Orientation for Patient Partners

It is important that patient partners understand the aims of the research project, their role, and expectations of the position (for themselves, and the researchers). Accordingly, patient partners should be appropriately trained and oriented to the position, similar to the way you would train and orient a staff or any volunteer member at C&W. It is recommended that Investigators store patient partner course completion certificates, along with other documents (e.g. pledge of confidentiality) in a restricted access folder on the PHSA or BCCHR drives.

Orientation

Prior to getting started, identify a primary contact for the patient partner to reach out to in the event of any questions/issues (e.g. compensation, IT issues, etc.). The primary contact should meet with the patient partner 1:1 to determine how they want to be involved, discuss more about the project, and confirm commitments and compensation.

After this initial meeting, the primary contact should schedule an orientation meeting with the research team and patient partner(s). Ensure that the patient partner(s) receive an agenda for this meeting ahead of time. Topics to consider discussing at orientation include:

- Introductions
 - Use first names, so that everyone feels welcome
 - Describe everyone's role on the team
 - Make it known that at all meetings you want to hear everyone's perspectives
 - Consider ice-breaker questions and activities to build relationships
 - Consider creating team bios with photos to share
- Project Overview
 - General information about the project should already be shared by the time of orientation

- Share more in-depth details about the project, and if applicable, the project history, research question(s), background, study timelines, project goals and outcomes, and funding details
- Share any study websites or social media accounts so that the patient partners can learn more about your research program
- Explain the research cycle
- Share resources like knowledge translation products or publications for those who want to learn more
- Review training/onboarding requirements
 - Review any training/onboarding requirements, including TCPS2, any LearningHub onboarding courses, protocol-specific training, etc., and leave appropriate time for questions
 - Where appropriate, patient partners engaged in pediatrics/child health research should complete [Research 101 Part 1: What is Health Research and Who is Involved? – PORCCH LMS](#) as part of onboarding/training
- Compensation
 - Compensation should already be agreed upon by the time of orientation, confirm the form and frequency of payment
 - Discuss how additional expenses incurred will be covered by the project, if applicable (e.g. parking)
- Draft and co-create Terms of Reference or “Guidelines”. Include headings such as:
 - *Background* (of the research project)
 - *Guiding Principles/Values* (what are your values/guiding principles in patient engagement? E.g. collaboration, EDI, equal voice for all members).
 - *Confidentiality* (see page 5 above: Confidentiality)
 - *Responsibilities* (what are the expectations and responsibilities of the role?)
 - *Meetings* (format and frequency)
 - *Reporting* (will minutes and action items be documented?)
 - *Payment* (how, when, and at what rate will they be compensated? Who will compensate them?)
 - *Duration* (how long is the “term” for/do you have funding for)

Orientation

- Understand the communication needs and preferences of the patient partners from the beginning. This includes communication preferences (e.g. email versus text messaging) and frequency of communication.
- Schedule regular recurring meetings (remote, or in-person) to address challenges faced by team; avoid having contact with patient partners solely via email
 - When scheduling meetings, ensure the patient partners' schedules are considered in the same way you would consider the Principal Investigator's schedule (i.e. book meetings on dates/times that work best for the patient partner's work/life/school schedule)
- Patient partners are experts sharing their lived/living experience with your study team, and it is important to ensure that patient partners derive benefits from working on a research project. To ensure that patient partners are personally and professionally benefiting from their work on a research project, you might consider:
 - Support the drafting/editing of their resume or cover letter
 - Scheduling 1:1 mentorship check-ins
 - Writing reference letters for further educational or professional development opportunities
 - Invitations for co-authorship on manuscripts/conference presentations
 - Providing access to university libraries or journal articles
 - Invitations to co-present study finding at scientific conferences and the like
- Research projects have defined start and end dates, however, there are ways to continue engaging with patient partners after the project is complete, including knowledge translation activities and planning for future research priorities/projects. Check in with your patient partners, at least annually, to assess their ongoing interest and capacity for involvement.

Contacts

Engage with the BC SUPPORT Unit as an ongoing resource for consultations:

- <https://redcap.healthresearchbc.ca/surveys/?s=CAFJNPJJ3C>

Engage with your Research Institute for support/questions (BCCHR or WHRI)

- There are supports and resources available at the BCCHR and WHRI for budget planning, finance, advice for preparing a grant application, and general consultations/questions regarding meaningful engagement of patient partners in research:
- **BCCHR:**
 - Shanlea Gordon, Senior Research Manager, Clinical Research Support Unit , BCCHR
 - Email: Shanlea.gordon@bcchr.ca
- **WHRI:**
 - Nicole Prestley, Manager, Research and Knowledge Translation, WHRI
 - Email: Nicole.prestley@cw.bc.ca

Engage with your health authority Patient Experience Office:

- C&W Patient Experience Office
 - Email: patientexperience@cw.bc.ca
 - Phone: 1-844-874-3267

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