THE UNIVERSITY OF BRITISH COLUMBIA
Office of the Vice-President, Health
UBC Health

POSITION STATEMENT

UBC Health's Commitment to Patient and Community Engagement in Research

UBC Health is committed to facilitating meaningful patient and community engagement in all research endeavours supported by the unit, its partners and collaborators. This position statement outlines our commitment to integrating patient and community voices into our research programs, activities, and initiatives, ensuring they reflect excellence in inclusivity, equity, and reciprocity. We are committed to involving patients in decision-making, priority-setting, and adjudication committees. Our dedication to patient and community engagement is a continuous journey. This document will be updated regularly to reflect new insights and best practices. This document is not intended as formal guidance for patient and community engagement in research; however, we have identified relevant resources and supports.

Why Involving Patients and Community in Research is Important

Patients[1] must be involved in health research to improve health outcomes, equity, and health systems and to ensure that research benefits and can be used by patients. Patients are experts by experience, key informants, and expert observers of the health system. A collaborative approach brings diverse perspectives, particularly of those with lived experience, into all stages of the research process. Collaboration leads to more relevant and impactful health solutions, fosters trust and mutual respect, and ensures that health policies and practices are attuned to patient needs. Engaging patients and community members honours their lived experiences as essential in understanding complex health issues. By incorporating diverse perspectives, health inequities can be more effectively identified and addressed. Understanding the specific needs that different communities face ensures that research initiatives are aligned with the goal of achieving health equity.

UBC Health's dedication to involving patients and community in research is driven by the acknowledgement that meaningful and sustainable health solutions and an inclusive and equitable health system can only be achieved through collaborative efforts that respect and incorporate the voices of all interest holders.

How this Statement was Developed

The development of this position statement was guided by a collaborative process rooted in the insights of UBC Health's Patient and Community Advisory Committee (PAC), who bring rich lived experience and experience as participants and partners in health research. The idea initially arose from discussions with PAC about the need to promote best practices in patient engagement in UBC Health-supported research activities and partnerships. The statement was shaped through input from PAC members, and drafted by staff from UBC Health and the Patient and Community Partnership for Education, reflecting a commitment to inclusivity and best practices and touching on all areas of the IAP2 Spectrum of Public Participation.[2] An informal scoping review of Canadian

---

[1] For brevity we use the word 'patients' as an umbrella term to include people with health conditions, their caregivers, and others with relevant lived experience.

[2] IAP2 Spectrum of Participation

resources, with an emphasis on CIHR's Strategy for Patient Oriented Research, grounded in guiding principles and values of PAC and UBC Health's strategic plan informed the statement. Input from UBC Health's leadership and governance structure contributed to refining the statement, emphasizing accessible, strengths-based language and clarifying the scope. PAC approved the statement at their June 2024 meeting. This document remains a living resource, evolving to incorporate emerging insights and advancing UBC Health's strategic goals in patient and community engagement. UBC Health will keep collaborators and interest holders informed by evaluating and sharing updates on progress and commitments.

Guiding Principles

UBC Health will use the following principles to guide patient engagement in health research:

- **Mutual Respect:** Researchers and patients acknowledge and value each others' knowledge and expertise.
- **Equity & Inclusion:** Diverse and underrepresented patient perspectives are involved. Patients are included as active partners in health research and decision-making (i.e., nothing about us without us) at all stages of the research process to maximize the impact and accessibility of research so it benefits and can be used by patients and communities.
- **Co-creation:** patients and researchers work together in models that support shared leadership and decision-making to design health research, from identifying research questions to sharing results.
- **Support:** appropriate resources, opportunities, supports and accommodations are offered to mitigate barriers to involvement, including flexibility and transparency in how patients are recognized and compensated for their contributions, including opportunities to facilitate their own development and journey toward meaningful partnership in health research.

Our Commitment to Supporting Patient and Community Engagement in Research

UBC Health is committed to embedding principles of patient and community engagement in all aspects of our research programs, from program development and implementation to evaluation, as well as governance and decision-making processes. This includes adjudication processes for funding and awards, and support for scholarly programs that prioritize and facilitate patient and community involvement and capacity building. In practice, our programs, activities, and initiatives will reflect the commitments in this statement, ensuring dedicated support for facilitating, convening and enabling interdisciplinary research and engagement that follow and advance best practices in patient and community engagement.

How to Use this Statement

If you are a recipient of research funding or support or a participant or contributor to UBC Health research programs, activities, or initiatives, it is critical to adhere to principles of meaningful patient and community engagement. This statement outlines UBC Health's position and informs our work. It is not a practical guide to patient and community-engaged research. It should be consulted alongside other guidance, frameworks, and tools (see **Key Resources and Supports**).

Key Resources and Supports

Patient Engagement Frameworks and Guides

- Canada's Strategy for Patient-Oriented Research: https://cihr-irsc.gc.ca/e/44000.html
- Strategy for Patient-Oriented Research – Patient Engagement Framework – Guiding Principles (CIHR) (guiding principles for patient engagement): https://cihr-irsc.gc.ca/e/48413.html#a7
- IKT Guiding Principles (framework for integrated knowledge translation): https://ikt.ok.ubc.ca/
- Ontario SPOR Support Unit's Equity Framework (strategies for equitable engagement): https://ossu.ca/resources/equity-framework-and-curriculum/
- A Guide to Authentic Patient Engagement (Health Quality BC) (practical steps for authentic patient engagement): https://healthqualitybc.ca/wp-content/uploads/FINAL_Guide_to_authentic_patient_engagement_2022-09-09-2-1.pdf
- AAMC Center for Health Justice. The Principles of Trustworthiness Toolkit: https://www.aamchealthjustice.org/our-work/trustworthiness/trustworthiness-toolkit

Evaluation Tools for Patient and Community Engagement in Research

- PPEET
- WE-ENACT
- University of Calgary - Knowledge Engagement Impact Assessment Tool

Resources on Patient Engagement in Research (Planning, Budgeting, Evaluation, Guidelines)

- Child-Bright Network Consultation Service for Researchers: https://www.child-bright.ca/lived-living-experience-consultation-service/
- CIHR Citizen Engagement Resources: https://cihr-irsc.gc.ca/e/41696.html
- CIHR – Institute of Musculoskeletal Health and Arthritis Patient Engagement Training, Resources, and Compensation Guidelines: https://cihr-irsc.gc.ca/e/27297.html
- SPOR Evidence Alliance Patient and Public Partner Engagement in Research: https://sporevidencealliance.ca/wp-content/uploads/2021/08/7.-SPOREA-COVIDEND_Patient-and-Public-Engagement-for-Researchers.pdf
- BC SUPPORT Unit Resource Library: https://healthresearchbc.ca/resource-library/?resource-unit=bc-support-unit
- UBC Library Patient-Oriented Research and Community-Based Health Research: https://guides.library.ubc.ca/por
- UBC Faculty of Medicine – Patient-Oriented Research Repository: https://porr.med.ubc.ca/

Knowledge Translation & Dissemination:

- Guidance for research ethics considerations in patient- and community-oriented knowledge dissemination: A tool for researchers: https://healthresearchbc.ca/wp-content/uploads/2024/04/Guidance-for-Research-Ethics-Tool-for-Researchers---FINAL.pdf
- GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research: https://www.bmj.com/content/358/bmj.j3453
- Jones J, Cowe M, Marks S, McAllister T, Mendoza A, Ponniah C, Wythe H, Mathie E. Reporting on patient and public involvement (PPI) in research publications: using the

- University of Toronto – Family & Community Medicine - Patient Engagement Toolbox: https://dfcm.utoronto.ca/patient-engagement-toolbox - Patient Voices Network – Health Care Partner Resources: https://patientvoicesbc.ca/healthcare-partners/resources/ - Unity Health – Resource Guide: Patient and Community Engagement in the Design and Implementation of Research Studies: https://research.unityhealth.to/patient-and-community-engagement/resource-guide/ - PCORI Engagement Tool and Resource Repository: https://www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository - McMaster University - Patient & Public Engagement Resources: https://ppe.mcmaster.ca/resources/ - Canadian Primary Care Research Network – Patient Engagement Resources: https://cpcrn-rcrsp.ca/resources/patient-engagement/ - Women's Health Research Institute Resources for Patient-Oriented Research: https://whri.org/research-resources/patient-oriented-research/	GRIPP2 checklists with lay co-researchers. Research Involvement and Engagement. 2021 Dec;7:1-3. https://link.springer.com/article/10.1186/s40900-021-00295-w
Key Literature - Hoekstra, F., et al. "A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: a first step in synthesising the research partnership literature." Health Research Policy and Systems 18 (2020): 1-23. https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-020-0544-9 - Arumugam A, Phillips LR, Moore A, Kumaran SD, Sampath KK, Migliorini F, Maffulli N, Ranganadhababu BN, Hegazy F, Botto-van Bemden A. Patient and public involvement in research: a review of practical resources for young investigators. BMC rheumatology. 2023 Mar 9;7(1):2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9996937/ - TLC Study Group. Considerations for patient and public involvement and engagement in health research. Nature Medicine. 2023 Jul 20. https://www.nature.com/articles/s41591-023-02445-x - Williamson C. 'How do we find the right patients to consult?'. Quality in Primary Care. 2007 Aug 1;15(4). https://www.chain-network.org.uk/chain/documents/charlottewilliamson_paper.pdf	**Networking and Engagement** - **Patient and Community Partnership for Education: https://health.ubc.ca/pcpe** - **Patient Voices Network: https://patientvoicesbc.ca/** - **REACH: https://reachbc.ca/** - **BC SUPPORT Unit: https://healthresearchbc.ca/bc-support-unit/about-us/** - **UBC Indigenous Research Support Initiative - Resources for Researchers: https://irsi.ubc.ca/researchers/resources**

Last updated: Nov 2024