



BRINGING PATIENTS AND SOCIETY BACK INTO THE SOCIAL ACCOUNTABILITY OF A MEDICAL SCHOOL

A project intended to help UBC, and other Canadian medical schools engage directly with the public and patients to fulfill their mandate of social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve.

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Synthesis Report and Recommendations

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REPORT 5

Prepared by: Angela Towle, Co-Director, Patient & Community Partnership for Education

Patient & Community Partnership for Education, UBC Health, The University of British Columbia, IRC #400, 2194 Health Sciences Mall, Vancouver, BC V6T 1Z3

To access the report, visit:

<https://meetingofexperts.org/social-accountability-project-outcomes/>



Bringing Patients and Society Back into the Social Accountability of a Medical School

Project Reports

Report 1	Patient and Public Engagement: A Review of Practical Guides	Created by: Cathy Kline, Patient & Community Partnership for Education
Report 2	An Environmental Scan of Methods for Patient and Public Engagement	Created by: Jordan Williams-Yuen, 4 th Year Medical Student
Report 3	Special Considerations: Bringing Indigenous Patients and Public into the Social Accountability of Our Medical School	Created by: Alicia Liang, 4 th Year Medical Student
Report 4	Patient and Public Consultations	Created by: Angela Towle & Cathy Kline, Patient & Community Partnership for Education and Kenneth Ong & Lucy Wang, 1 st Year Medical Students

Steering Committee Members

Committee Chair: Angela Towle

Medical Students: Emma Swan (NMP), Ishmam Bhuiyan VFMP), Jordan Williams-Yuen (VFMP), Kenneth Ong (VFMP), Naomi Day (SMP), Nilanga (Aki) Bandara (VFMP), Pooja Kadakia (SMP), Simona Bene Watts (IMP), Taylor Sidhu (IMP), Zamina Mithani (VFMP)

Medical Residents: Bavenjit Cheema, Elise Jackson, Veronica Chudzinski

Patient / Public Members: Carolyn Canfield, Darren Lauscher, Sue Macdonald

Faculty: Cary Cuncic, Cathy Kline, Cheryl Holmes, Maria Hubinette, William Godolphin



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Executive Summary

'Bringing Patients and Society Back into the Social Accountability of a Medical School' is a one-year research project (2021-2022) funded by the Royal College of Physicians and Surgeons of Canada. The purpose is to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfil their mandate for social accountability, that is to define and address the priority health concerns of the populations they have a responsibility to serve. The aim is to co-create with patients and the public a set of evidence-informed guiding principles, models and processes for the authentic, ongoing and sustainable engagement of patients and the public in the mission, goals, curriculum and delivery of medical education.

This synthesis report summarizes key findings from data gathered through a literature review of practical guides to engagement, an environmental scan involving expert key informants from different institutions, and a set of patient / public consultations. The detailed findings are to be found in four project reports. The executive summaries from each report are provided as appendices to this report. The full reports can be found at: <https://meetingofexperts.org/social-accountability-project-outcomes/>

Based on the project findings, the following ten recommendations are proposed. These recommendations are not specific to any medical school but are intended to help all medical schools fulfil their mandate for social accountability by involving patients / the public in their mission, goals, curriculum and delivery of medical education.

Recommendations

1. Approve, adopt and evaluate implementation of the eight guiding principles for patient / public engagement.
2. Diversify the opportunities for patient / public involvement in medical education beyond sharing experiences with students.
3. Co-develop institutional infrastructure, policies and processes to widen patient/ public participation in medical education and overcome barriers to involvement.
4. Co-develop, adopt and disseminate a set of best practices for patient / public engagement.
5. Develop processes to increase patient / public awareness of the opportunities for, and benefits of, involvement.
6. Develop materials and processes to prepare, orientate and support patient / public and faculty / staff, and students in their engagement roles.
7. Provide welcoming, flexible, and accessible environments to enable participation by a greater diversity of patients / public.
8. Develop mechanisms by which patients / public know that their contributions are valued and have made a difference (closing the loop).
9. Develop consistent and transparent policies and practices for the compensation and recognition of patient / public participants.
10. Develop and evaluate processes to maintain and sustain ongoing relationships with patients / public.

1. Introduction

'Bringing Patients and Society Back into the Social Accountability of a Medical School' is a one-year research project (2021-2022) funded by the Royal College of Physicians and Surgeons of Canada <https://meetingofexperts.org/programs-activities/social-accountability/>. The purpose is to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfil their mandate for social accountability, that is to define and address the priority health concerns of the populations they have a responsibility to serve. The aim is to co-create with patients and the public a set of evidence-informed guiding principles, models and processes for the authentic, ongoing and sustainable engagement of patients and the public in the mission, goals, curriculum and delivery of medical education.

This synthesis report summarizes key findings from data gathered through a literature review of practical guides to engagement, an environmental scan involving expert key informants from different institutions, and a set of patient / public consultations. The synthesis is organized to address the project aim of co-creating a set of evidence-based guiding principles, models and processes for engagement. Based on the data, the project steering committee proposes ten recommendations for medical schools that are also applicable to other health professional education programs or institutions.

The detailed findings are to be found in four project reports:

Report 1: Patient and public engagement: a review of practical guides

Report 2: An environmental scan of methods for patient and public engagement

Report 3: Special considerations: bringing Indigenous patients and public into the social accountability of our medical school

Report 4: Patient and public consultations

The executive summaries from each report are provided as appendices to this report. The full reports can be found at: <https://meetingofexperts.org/social-accountability-project-outcomes/>

2. Evidence-informed guiding principles

- The review of practical guides for patient / public engagement identified shared common guiding principles related to reciprocity, partnership, inclusion, the need for a variety of opportunities for engagement, co-production, communication, supports, and accountability.
- These eight principles were validated and prioritized through the patient / public consultations. No additional principles were proposed.
- Key informants from academic and healthcare institutions identified that successful engagement is based on principles of reciprocity (mutual benefit), community-leadership, equal power and respect, and investment of time and effort into relationships.
- Participants in patient / public consultations identified three main characteristics of successful engagement: meaningful contribution; equitable engagement and inclusivity; feeling valued and respected.

- Principles for Indigenous engagement identified through literature review and key informant interviews included: relationship-first; reciprocity and mutual benefit; Indigenous self-determination; preparation, critical self reflection and cultural safety; indigenizing spaces; collaboration across communities, institutions, sectors and jurisdictions; strengths-based, and diversity-focused.

In summary, we propose the following eight guiding principles for patient / public engagement in the order of priority proposed by patient / public consultants. Additional guiding principles specific to Indigenous engagement should be adopted in consultation with local Indigenous leaders (an example is the document developed by the Northern Ontario School of Medicine, see Appendix 6 reference 6).

Principles for patient / public engagement

- 1. Accountability:** includes transparency, shared outcomes, feedback, maintaining relationships.
- 2. Inclusion:** people with diverse perspectives are sought and invited to participate. Engagement processes are accessible.
- 3. Reciprocity:** relationships are mutually beneficial, based on trust and mutual respect.
- 4. Partnership/Shared Decision-Making:** university and community partners have equal voices and share power to make decisions.
- 5. Co-Production:** university and community partners work together to co-develop and co-design engagement processes and activities.
- 6. Two-Way Communication:** communication is open and honest, with clear expectations on both sides.
- 7. Supports:** community partners receive the support and information they need to participate fully.
- 8. Different Levels of Engagement:** there are diverse opportunities for the community to engage in medical education (from classroom to committee).

Recommendation 1: Approve, adopt and evaluate implementation of the eight guiding principles for patient / public engagement.

3. Model for engagement

Based on the findings of the study, we present aspects of a model for engagement (practices and structure) at the institutional level that permit the authentic, ongoing and sustainable engagement of patients and the public in the activities of the medical school that are consistent with the guiding principles.

3.1 Different levels of engagement

- Most practical guides are designed to support a spectrum of involvement, with the International Association of Public Participation (IAP2) among the most popular frameworks. The IAP2 spectrum of public participation identifies increasing levels of public impact: Inform, Consult, Involve, Collaborate, and Empower.

- Expert informants from model institutions (university and hospital) sought to integrate patient / public involvement in all aspects of their organization, striving for comprehensive engagement. They identified three types of roles: acts of delivery, directing and consultation.
- Patient / public participants were interested in a variety of different ways they might be involved in medical education organized according to levels of involvement (Towle & Godolphin, 2015). Sharing experiences with students was the most rewarding role and foundational to playing other roles. There was interest in helping to develop, not just teach, curriculum, and in being involved at an institutional level to make medical education more responsive to the needs of society by including patients as legitimate partners (a few examples of this level of involvement in decision-making already exist and could be expanded).

In summary, patients / the public can play many roles in medical education, such as helping to develop curriculum, teaching and assessing students, and being involved in decision-making processes. Having different opportunities for involvement is one way to widen participation.

Recommendation 2: Diversify the opportunities for patient / public involvement in medical education beyond sharing experiences with students.

3.2 Increasing diversity

- The model of engagement needs not only to increase and provide more inclusive opportunities for engagement, but to increase the diversity of people who are engaged.
- Practical guides emphasize that widening participation is a desirable goal of engagement. However, the barriers are considerable and the specifics of how to engage with groups that have been historically and / or systemically excluded are lacking. An exception is the guide from the Health Issues Centre, Australia (see Appendix 6, reference 4).
- Key informants often described broader representation as an important goal of partnership but achieving diversity was seen as a challenging goal.
- Patient / public consultations identified a lack of diversity among the patients / public who are currently involved, or could get involved, in the medical school, and significant barriers to participation by certain groups.
- There are cost/resource implications for increasing representation/diversity. Institutional infrastructure and processes to support participation are needed (see also 4.4).

In summary, the model of engagement needs to be structured to be inclusive of patients currently under-represented in medical education and support the participation of groups in the population who may have barriers to participation.

Recommendation 3: Co-develop institutional infrastructure, policies and processes to widen patient/ public participation in medical education and overcome barriers to involvement.

3.3 Infrastructure

- Key informants from institutions with developed engagement programs usually have a dedicated infrastructure and support systems for both patient / public members and institution members who participate in engagement work. Benefits to community members include increased autonomy and safety, while benefits to the institution include increased focus on specialized areas of engagement, and support for partnerships.
- UBC has such a central unit: Patient and Community Partnership for Education (PCPE) in the Office of UBC Health. PCPE offers educational experiences for students in the different health professional programs, including medicine, and supports individual instructors and programs to involve patients in a variety of educational activities. For more information see <https://health.ubc.ca/pcpe> and <https://meetingofexperts.org/>.

4. Processes for engagement

4.1 Best practices for engagement

- Study findings revealed many facilitators and barriers to engagement and practical suggestions for enhancing the patient / public experience of engagement. These processes are important in order to operationalize the guiding principles and engagement model.
- The patient / public consultations identified processes for improving the experience of engagement related to: inviting participation; preparing for and supporting participation; increasing and supporting diversity; recognizing participation; institutional buy-in to support sustained participation. The major types of processes that should be developed and / or encouraged, along with specific examples, are summarized in 4.2 to 4.5 below.
- Many wise practices to be followed when engaging with Indigenous peoples were identified through the literature review and environmental scan
- A set of best practices could be generated from the rich data obtained in this study (e.g., ‘Top ten tips for engaging with patients’). These practices could be adopted by the medical school and promoted to faculty and staff wishing to engage with patients / public.

Recommendation 4: Co-develop, adopt and disseminate a set of best practices for patient / public engagement.

4.2 Inviting participation

- In most academic or health care institutions, participation is limited to a restricted subset of the population, often people who are already known to those inside the institution.
- Patients / public are generally unaware of opportunities to participate.
- Recruitment through community organizations, who know their members and can facilitate connections is one important way to widen participation, especially for certain populations such as Indigenous peoples.

- Requests for participation should clearly and concisely describe the commitment required, be realistic in terms of people's time and priorities, and describe the benefits and / or difference that participation is expected to make. This is especially important for people who are managing complex health conditions and interactions with the health care system and need to make decisions about where to put their energies.

Recommendation 5: Develop processes to increase patient / public awareness of the opportunities for, and benefits of, involvement.

4.3 Preparing for and supporting participation

- Patients / public need to be properly prepared for their engagement with the medical school. Faculty and staff also need to be prepared and supported in their engagement work.
- Information and orientation sessions should be offered, and provide the medical education context for patient / public involvement.
- Patients who share their lived experiences authentically make themselves vulnerable. Safety / supports could be in the form of asking people what they need, welcoming introductions, setting boundaries, a follow-up check in, having a familiar person present (e.g. from a partner organization) or creating or facilitating peer group support.
- Instructors facilitating a session should also be prepared for their important role in creating a welcoming and safe environment, as should students.

Recommendation 6: Develop materials and processes to prepare, orientate and support patient / public and faculty / staff, and students in their engagement roles.

4.4. Supporting inclusivity and diversity

- There are significant barriers to participation in the medical school among groups that have traditionally not been well served, or excluded, by powerful institutions.
- Widening participation will require i) dedicated people within the university who have specialized knowledge of under-represented communities, ii) working with organizations, going into the community, iii) commitment to building long-term, mutually beneficial and respectful relationships; iv) having flexibility in the medical program with respect to time and location, and vi) accessibility protocols.
- Technology may help provide more opportunities for engagement of certain populations.

Recommendation 7: Provide welcoming, flexible, and accessible environments to enable participation by a greater diversity of patients / public.

4.5 Recognizing participation

- Patients / public want to know that their contributions are valued by the institution (not just by individual instructors) and that they have made a difference in some way. Ways in which this could be done include personalized thank you cards, letters of appreciation from students, certificates, evaluation / feedback reports, and social gatherings.

Recommendation 8: Develop mechanisms by which patients / public know that their contributions are valued and have made a difference (closing the loop).

- Adequate monetary compensation and other forms of recognition for participation are needed in order to i) recognize the value/expertise that patients bring that so they are not the only people in the room who are there as volunteers; ii) recognize that their contributions are a form of emotional labour; iii) include people who cannot afford to volunteer.

Recommendation 9: Develop consistent and transparent policies and practices for the compensation of and recognition of patients / public participants.

4.6 Institutional commitment to support sustained participation

- Authentic, ongoing and sustainable engagement of a diverse group of patients / public will require the medical school to demonstrate commitment at the institutional level, beyond individual faculty or staff members.
- Ways to move beyond episodic engagement and invest in long-term relationships for mutual benefit are needed.
- Patient / public involvement needs to be valued at the highest levels of the institution, demonstrating that the medical school is committed to ongoing and meaningful engagement, and that patients/public are contributing to systemic change, not only sharing their experiences with students.

Recommendation 10: Develop and evaluate processes to maintain and sustain ongoing relationships with patients / public.

APPENDIX 1. Review of practical guides for patient / public engagement: executive summary

The purpose of the review of practical guides was to identify involvement roles, guiding principles and models for engagement that would be most relevant in the context of medical education and that would form the basis of stakeholder consultations. We reviewed 30 publicly available patient and community engagement practical guides from Canada, USA, Europe, and Australia with content that could be applicable to health professional education. Most of these guides were designed for health care improvement, health care planning, or health research, but included elements that are relevant to health professional education. Three of the resources we reviewed were developed specifically in the context of health professional education.

Most practical guides defined patient engagement as opportunities for patients and families to participate in decisions about health care design and delivery. Guides shared common guiding principles related to reciprocity, partnership, inclusion, the need for a variety of opportunities for engagement, co-production, communication, supports, and accountability. Most were designed to support a spectrum of involvement, with the International Association of Public Participation (IAP2) among the most popular frameworks. A wide range of engagement tools and techniques were put forward to support different kinds of engagement along a continuum of engagement. Although the need to recruit from diverse groups was highlighted, specific ways to engage with vulnerable, marginalized, and seldom-heard/hard to reach groups was scarce. Power was rarely discussed.

Patient and public engagement in medical education could build on the principles of engagement found in these resources and develop frameworks that would support broadening engagement to include perspectives from the full spectrum of communities that medical schools aim to serve. Stakeholder consultations should explore principles and models of engagement that will support the inclusion of hard to reach groups and increase the diversity of patients involved medical education. The outcomes could be used to develop guidelines for patient and public engagement in medical education that would help medical schools fulfill their social accountability mandate.

APPENDIX 2. Environmental Scan: executive summary

The purpose of the environmental scan was to find out what patient / public engagement methods are used by different institutions and organizations, what lessons have been learned, and to collect examples of resources that they have developed and / or use for their engagement work. Thirteen key informants from 10 institutions were interviewed between December 2021 and February 2022.

Information gathered was analyzed thematically and synthesised into key engagement methods and lessons learned (principles of successful engagement and barriers). For the purpose of this report we use the term 'community engagement' as the term informants used most frequently to describe patient / public engagement

1. Structure of Patient / Community Engagement

Striving for Comprehensive Integration

Informants from both hospital and university settings described a desire to integrate community involvement in all aspects of their organization. Three categories emerged to conceptualize the roles of patients or community members in their engagement work: acts of delivery, directing, and consultation.

Having a Centralized Group

Institutions with more developed community engagement programs often had a dedicated structure for this work. Benefits to community members included increased autonomy and safety, while benefits to the institution included increased focus on specialized areas of engagement.

Support for Community Members and Staff

Informants described the importance of having support systems for both community members and institution members who participate in engagement work. Supports provided to community members were diverse, and often focused on practical skills such as public speaking or feedback delivery. Supports provided to institution members were often more reflective, such as exploring the intentions and priorities of engagement work.

2. Principles of Successful Engagement

Success Means Mutual Benefit

The idea of reciprocal gain was commonly cited as an important element of successful partnership. However, aligned goals were not always seen as a necessity. Some informants felt that institutions and communities may have different objectives in a given project, but are connected by common methods which lead towards shared benefit.

Community Leadership

Community leadership was described as occurring when institutions take a supportive role and let communities direct the design, implementation, and evaluation of projects. This form of partnership was often seen as an ideal state of engagement, and one which produces the most practical results for communities.

Equal Power, Equal Respect

Informants emphasized that the contributions of patients, community members, physicians, and researchers must all be seen as equally valuable. Similarly, the views and opinions of community members need to be legitimately considered during decision-making processes.

Relationships Require Work

Informants highlighted the need to be intentional with partnership relationships. They emphasized the importance of investing time and effort into these settings. While conflicts were often viewed as inevitable, participants also expressed that relationships can be repaired.

3. Barriers

Power Shapes the Context of Engagement

Power dynamics were described as an important context to partnerships, and an inevitable barrier which those relationships will have to navigate. On a systemic level, power inequities between institutions and communities can create harmful external pressures. On an individual level, power dynamics can create challenges in communication and trust-building.

Resource Management

Whether it was money, time, or access to physical spaces, informants recognized that managing practical resources was a constant challenge within engagement work.

Attitudes Determine the Course of Engagement

While power dynamics may set the context of relationships, informants emphasized that it is individual attitudes which define how those dynamics are navigated, and ultimately how the engagement work proceeds. Paternalism, reliance on jargon, and a lack of humility were all cited as qualities incompatible with successful engagement.

Achieving Representation

Informants often described representation as an important goal of partnership. Community outreach was suggested as one helpful strategy. However, achieving diversity was seen as a challenging goal.

APPENDIX 3. Special considerations related to engagement with Indigenous patients and communities: executive summary

Indigenous peoples of Canada share a history of colonization that have resulted in significant health inequities between Indigenous and non-Indigenous peoples. As a medical school, engaging Indigenous peoples in a way that supports Indigenous self-determination and Indigenous health and wellness practices is central to healing this legacy of colonization, and is different from our approach to engaging patients and public more generally. Indigenous peoples in BC have expressed interest in being involved in the education of health professionals, recognizing the opportunity such involvement affords to unsettle stereotypes, address systemic racism, and transform the hearts and minds of future physicians to better serve Indigenous peoples. This report aims to identify and discuss wise practices for health professional school engagement with Indigenous patients and public to inform the next phase of our participatory research project, 'Bringing patients and society back into the social accountability of a medical school' funded by the Royal College of Physicians and Surgeons of Canada.

The following wise practices were identified from a targeted review of the academic and grey literature:

1. "Nothing about us without us" – the right to self-determination.
2. Preparation, critical self-reflection and cultural safety.
3. Engagement driven by sincere relationships that humanize, heal and foster trust and understanding.
4. 'Two-eyed seeing' that positions Indigenous and Western knowledges and worldviews as equal.
5. Appropriately incorporating Indigenous culture to make engagement more relevant and relatable.
6. Attention to Indigenous diversity.

The following wise practices were identified from interviews with five key informants with experience and expertise engaging with Indigenous peoples to advance the social accountability of health professional education:

1. Relationship-first
2. Reciprocity and mutual benefit
3. Restoring power; Indigenous self-determination
4. Preparation
5. Indigenizing spaces
6. Collaboration across communities, institutions, sectors and jurisdictions
7. Strengths-based
8. Diversity-focused
9. Recognizing tokenism as a barrier to Indigenous engagement.

APPENDIX 4. Patient / Public Consultations: executive summary

Eight focus groups involving 38 patient/public members were held in April and May 2022. Participants included 14 individual patients and 24 representatives of organizations. 28 participants had previous or current involvement with UBC medical school, medical students and/or other health professional students. Participants brought diverse perspectives, e.g. Indigenous, LGBTQ+, disabilities (physical or intellectual), mental health/substance use, older adults, people living with complex health conditions, rural/remote, non-English speakers, caregivers and low-income women.

Guiding Principles for Engagement Participants were given a list of eight guiding principles drawn from a review of practical guides to patient/public engagement. They identified the most important principles for engaging with a medical school/medical education to be Accountability (19%), Inclusion (18%) and Reciprocity (17%). Accountability was chosen because of the need to be transparent with information, goals and intentions, and being able to trust the institution to maintain the relationship, so that people feel involved in a way that is longitudinal and consistent, and are able to see the end-results of their involvement. Inclusion was chosen because of the diverse needs, perspectives and geographical locations that need to be brought into the medical school. Reciprocity was chosen because the concepts of trust and respect were seen as foundational to all relationships in health care.

Types and Levels of Engagement (Roles) Participants were given a list of different ways in which patients/public can be involved in medical education organized according to levels of involvement. Level 1: Creating learning materials; Level 2: Standardized or volunteer clinical patient; Level 3: Sharing experience with students; Level 4: Teaching and evaluating students; Level 5: Equal partners in student education; Level 6: At an institutional level. All roles were relevant and of interest to participants or the people they serve. Sharing experiences with students (Level 3) was the most rewarding role and foundational to playing other roles. Level 5 was of interest from the perspective of helping to develop, not just teach, curriculum. Level 6 was of interest in making medical education more responsive to the needs of society and in including patients as legitimate partners (an opportunity to bring about systemic change in the curriculum rather than patient experiences being an add-on). Participants were uncertain whether Level 5 and 6 roles would be available and what they would look like in practice.

Practical Considerations: Facilitators and Barriers to Patient/Public Engagement Participants were asked what needs to happen to enable and support patient/public engagement with the medical school. Responses were categorized into six major themes: inviting participation; preparing for participation; supporting participation; increasing and supporting diversity; recognizing participation; institutional buy-in to support sustained participation. Key points participants made are as follows.

- There needs to be better public awareness of the importance of patients in the process of medical training, different opportunities to participate and benefits of participating. Community organizations can help with recruitment. Participation needs to be made easy, e.g. realistic time expectations, convenient times of day and locations, concise communication, and minimal university bureaucracy. Incentives for engagement include believing that participation will make a difference, and opportunities for personal growth and new connections.

- Patients need to be properly prepared for their engagement, including clear communication of the purpose, what is expected of volunteers, what they can expect from the medical school, and anticipated outcomes. Information and orientation sessions should be offered.
- Sharing their personal experiences authentically makes patients vulnerable, so the medical school needs to provide safer and welcoming spaces, and support. For example: asking people what they need, welcoming introductions, setting boundaries, follow-up check-in, having a familiar support person present, or peer group support. Instructors facilitating a session also have an important role to play in creating a welcoming environment, as do students.
- The lack of diversity among the people who are involved, or could get involved, in the medical school was a major concern. The most likely people to volunteer are those with the most time and money, living in urban areas, and from a narrow demographic. Widening participation will require dedicated people within the university who have specialized knowledge of under-represented communities, working with organizations, going into the community, having flexibility in the medical program with respect to time and location, and accessibility protocols. There are cost/resource implications for increasing representation/diversity.
- Adequate monetary compensation and other forms of recognition for participation are needed in order to i) recognize the value/expertise that patients bring that so they are not the only people in the room who are there as volunteers; ii) recognize that their contributions are a form of emotional labour; iii) include people who cannot afford to volunteer.
- There was skepticism about whether the medical school is genuinely serious about sustained patient/public engagement, its readiness to hear and act on hard truths about health care deficiencies, and provide the kinds of supports needed for systemic and ongoing engagement with the diverse populations the medical school has a mandate to serve. Participants want to believe their involvement is valued at the highest levels of the institution, that the medical school is committed to ongoing and meaningful engagement, and that patients/public are contributing to systemic change, not only sharing their experiences with students.

What Does Successful Engagement Look Like? When asked to describe what successful engagement looked like from their perspective, participants' responses fell into three main categories: meaningful contribution; equitable engagement and inclusivity; feeling valued and respected.

Conclusions from the Research Team Patients and the public are interested in engaging with UBC's distributed medical school and playing a variety of roles beyond direct involvement with students. They want involvement to be based on principles of accountability, inclusion and reciprocity, and to know their contributions are valued and have impact. There are practical ways in which their experience of engaging with the medical school can be improved. Increasing diversity and widening participation will require more effort and resources on the part of the medical school. It is important to continue and build on the relationships that have been developed through this consultation.

APPENDIX 5. Key informants and consultation participants

Key Informants

●University of Montreal: **Antoine Boivin**, Centre of Excellence on Partnerships with Patients and the Public; ●Northern Ontario School of Medicine: **Erin Cameron**, Centre for Social Accountability; **Ghislaine Attema** and **Kirstie Taylor**, Medical Education Research Lab in the North; ●Michener Institute at University Health Networks, Toronto: **Kerseri Scane**, Patient Engagement for Healthcare Improvement / Patient Partnerships; ●Centre for Addiction and Mental Health (CAMH), Toronto: **Sophie Soklaridis**; ●UBC-Okanagan: **Heather Gainforth**, School of Health and Exercise Sciences; ●University of Northern British Columbia: **Paul Winwood**; ●University of Central Lancashire, UK: **Janet Garner**, Community Engagement and Service User Support; ●University of Leeds, UK: **Jools Symons**, Service Users and Carers Initiative, School of Healthcare; ●University of Otago, New Zealand: **Tim Wilkinson**, Education Unit; ●University of Wisconsin, USA: **Rachel Grob** and **Jennifer Edgoose**, School of Medicine & Public Health.

●**Darrel Manitowabi**, Northern Ontario School of Medicine; ●**Derek Thompson**, Indigenous Initiative Advisor, UBC Faculty of Medicine; ●**Larry Leung**, UBC Faculty of Pharmaceutical Sciences; ●**Marion Maar**, Northern Ontario School of Medicine, and ●**Sam Senecal**, Northern Ontario School of Medicine provided expertise and guidance on wise practices for engaging with Indigenous communities.

Patient / Public Consultation Participants

●**Tasia Alexis**, Developmental Disabilities Association; ●**Cindy Bachman**, Health Mentor (rural); ●**Janice Barr**, Community Living Society; ●**Lynn-Ann Baumeister**, Volunteer Patient, Southern Medical Program; ●**Jami Brown**, BC Patient Safety and Quality Council; ●**Jennifer Campillo**, Richmond Mental Health Consumer & Friends Society; ●**Carolyn Canfield**, Citizen Patient; ●**Sue Carabetta**, North Shore Community Resources; ●**Erika Cedillo**, Inclusion BC; ●**Kim(berly) Czotter**, Volunteer Patient, Island Medical Program; ●**Sekani Dakelth**, Community Member and Storyteller; ●**Alex DeForge**, QMUNITY; ●**Alana Dhillon**, Parkinson Society BC; ●**Myryja Friesen**, Health Mentor (rural); ●**Dana Hope**, Volunteer Patient, Southern Medical Program; ●**France-Emmanuelle Joly**, Vancouver Women's Health Collective; ●**Darren Lauscher**, Advocate / Activist / Patient; ●**Lelainia Lloyd**, Health Mentor and MS Society of Canada; ●**Kent Cadogan Loftsgard**, UBC Health Patient & Community Advisory Committee; ●**Leslie Louie**, Ronald McDonald House; ●**Darryl Luster**, BC Hepatitis Network; ●**Sue Macdonald**, Mental Health & Substance Use Services, Vancouver Coastal Health; ●**Barb MacLean**, Family Caregivers of BC; ●**Don Mathewson**, Volunteer Patient, Island Medical Program; ●**Chris McBride**, Spinal Cord Injury BC; ●**Heather McCain**, Creating Accessible Neighbourhoods; ●**LaDonna Miller**, North Shore Stroke Recovery Centre; ●**Valerie Nicholson**, AIDS Vancouver Peer Navigator and BC-CfE Community Researcher; ●**Nancy Pearson**, Volunteer Patient, Island Medical Program, ●**Beverley Pitman**, United Way British Columbia; ●**Doug Robertson**, Volunteer Patient, Northern Medical Program, ●**Sharareh Saremi**, Disability Alliance BC; ●**Anne Stoll**, Provincial Language Service; ●**Gina Switzer**, Health Mentor (rural); ●**Sharon Tomlinson**, Muscular Dystrophy Canada; ●**Jenni Woodcock**, Volunteer Patient Island Medical Program; ●**Mandy Young**, Family Support Institute of BC; ●One anonymous contributor.

APPENDIX 6. Selected references and resources

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