



Patient & Community
Partnership for Education

informed and shared decision making



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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Report of Patient and Public Consultations

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REPORT 4

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THE UNIVERSITY OF BRITISH COLUMBIA

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UBC Health



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
Report 5	Synthesis Report and Recommendations	Created by: Angela Towle, Patient & Community Partnership for Education

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Executive Summary

Purpose ‘Bringing Patients and Society Back into the Social Accountability of a Medical School’ is a one-year research project at the University of British Columbia (UBC) to co-create with patients and the public a set of evidence-based 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 <https://meetingofexperts.org/programs-activities/social-accountability/>.

Methods This report summarizes input from 38 patient/public members who took part in focus groups held in April and May 2022, including 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.
- The need for 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 that 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.

Introduction

'Bringing Patients and Society back into the Social Accountability of a Medical School' is a one-year research project 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-based 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. A series of patient/public focus groups were held in April and May 2022 to inform development of guiding principles and recommendations for patient/public engagement.

Methods

The plan for the consultations was developed with input from members of the steering committee, including purpose and scope, guiding principles, criteria for recruitment, recruitment plan, focus group protocol and questions. Guiding principles for the consultation were informed by a literature review and an environmental scan (key informant interviews). The importance of building on existing relationships and ensuring diversity were key principles. Recruitment criteria were based on the priority populations identified by the provincial government of BC and UBC Faculty of Medicine defined populations (<https://mdprogram.med.ubc.ca/about/>) and included individual patients, patient groups, and patient representatives or advocates.

An initial focus group was held with three public members on the project Steering Committee and four members of the UBC Health Patient and Community Advisory committee, all with long-standing involvement in health professional education at UBC, to test out the protocol and questions. Invitations were then sent to 25 people who had been invited to participate in a previous public consultation on the priority health concerns in British Columbia (<https://meetingofexperts.org/programs-activities/priority-health-concerns-in-bc/>) and who met the recruitment criteria. To fill in some identified gaps, invitations to a second round of focus groups were sent to organizations who had not previously been involved in the public consultations who met the recruitment criteria, patients from rural and remote communities who had participated in the UBC health mentors program, and volunteer patients at distributed sites of the medical program identified by program managers.

Eight 90-minute focus groups were conducted over Zoom between April and May of 2022 (see Appendix 2 for the focus group protocol). Recordings of the focus groups were transcribed verbatim. Data were analysed thematically and summarized into a draft report by two medical students and two members of the research team. The research was approved by UBC Behavioural Research Ethics Board.

The draft report was circulated to all participants in the consultation with a request to provide feedback and confirm the listing of their name and affiliation in the Appendix. Responses were received from 19 participants, including 13 who commented that they thought the report was very thorough and reflected the rich input from diverse voices. A few suggested edits were incorporated into the report.

Results

1. Description of Consultation Participants

The eight focus groups were attended by a total of 38 people. Of these, 14 were individual patients (not representing an organization) and 24 were representatives of an organization (17 with a provincial mandate and 7 local to the lower mainland). 28 had previous or current involvement with UBC's distributed medical school, medical students and / or other health professional students. Examples of perspectives represented included: 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. See Appendix 1 for a list of contributors to the consultation.

2. Guiding Principles for Patient/Public Engagement

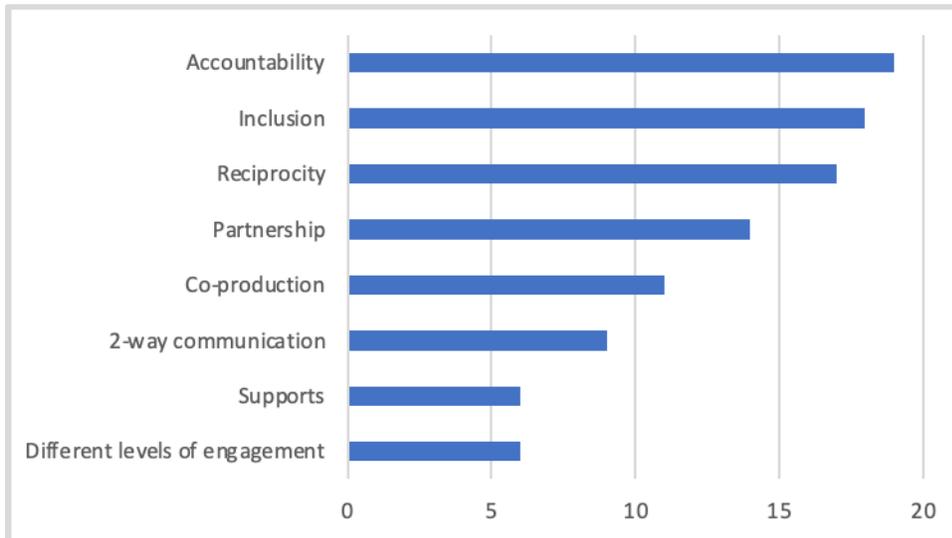
Participants were provided with a list of eight guiding principles drawn from a review of practical guides to patient/public engagement. They were given a link to a Slido poll and asked to identify their top three principles when engaging with a medical school/medical education. When voting was complete the results were displayed on the screen. Participants were then each asked to describe what was in their mind when they made their choices.

Many participants said they found it difficult to choose only three principles as all were seen to be relevant and important. They also noted the interrelationship between them, for example:

"I put reciprocity, partnership and accountability, because I think it always starts with relationship so if you have a relationship, that you're building up mutual benefit and trust and respect, it's the best place to jump in to do those other things. And then when you share in that process, having accountability and the ability to have some transparency in sharing the outcomes, and the feedback and maintaining the relationship is really important if you're gonna have a two-way communication, or in essence my third one which was partnership, very similar to a two-way communication in that we make change when we work in partnership and in tandem and there is that back and forth... that it's not rote or orchestrated but you can have that sense of its real connection around whatever topic or area it is that you're dealing with." [S3FG6]

In explaining what motivated their specific choices, participants often extrapolated from their prior experience with the medical system or physicians, or with community engagement more broadly, especially if they had no direct experience with the medical school/medical education. They selected principles that would help balance power and broaden engagement to better address the disparities they observe in society, particularly with respect to the social determinants of health. Figure 1 shows the results of the voting across all focus groups. Accountability (19%), Inclusion (18%) and Reciprocity (17%) were chosen as the most important principles. Participants did not identify any principles that were missing from the list. Table 2 provides a fuller definition of each principle and illustrative quotes that explain their importance to participants.

Figure 1: Guiding Principles in Priority Order (% of votes)



Participants saw Accountability as being transparent with information, goals and intentions, and being able to trust the institution to maintain the relationship, so that the people who are engaged 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. The link between Reciprocity, Two-Way Communication and Accountability was identified.

“I figured that two-way communication and reciprocity went very well so I eliminated two-way and went with reciprocity because it was broader for me. The second thing I was thinking about was feedback loops. Really the evidence is clear that when we get feedback after we’ve done something we’re more interested in maintaining our interest over the long term so by having accountability, the thing that really grabbed me was about sharing outcomes, giving feedback and maintaining a relationship. And if it were paired with reciprocity where the other people involved also felt like they got something out of it then there’s a really good solid foundation for engagement.” [S3FG7]

Participants also noted the linkage between Inclusion and Supports (see also Section 4). As a caution, one participant objected to the inclusion of ‘sharing power’ under the principle of Partnership:

“Power to me is also an abusive word. You know it implies that there’s a hierarchy and so the whole point is to work together. I think the approach would be more of an egalitarian approach. So if we were to rephrase that, I would say something like ‘and have equal engagement and meaningful decision making in policy making’, something like that, instead of power.” [S5FG4]

Table 2: Explanation of guiding principle choices

Principle	Illustrative quote
<p>Accountability: transparency, shared outcomes, feedback, maintaining relationship.</p>	<p><i>“The accountability I think is one of those important things. I’ve participated in a number of these kind of things and you give your input, you give your feedback, and then you hear nothing and so you don’t know what’s happened with this information that you’re, you’ve become attached to when you’ve given, your life view on it and then it goes out into the universe and we don’t know did I do any good? Did anything happen out of this?” [S1FG5]</i></p> <p><i>“For me accountability and transparency was very important to me, especially maintaining the relationship. So many times that we’re invited in, sometimes outcomes aren’t shared and they don’t maintain the relationship, they tend to just use us at the moment.” [S3FG4]</i></p>
<p>Inclusion: diverse perspectives are sought and invited to participate. Engagement processes are accessible.</p>	<p><i>“That stood out for me because I think it’s important to give people a voice and I think that we have in our community, we have heterogeneous community needs, people come from different demographics and therefore based on their gender, their ethnic background, their socioeconomic status, they’re gonna have different needs and have different barriers, have different values. So I think it’s important... to have a diversity of input.” [S5FG4]</i></p> <p><i>“...those that end up participating are often those that are fairly capable or able to get to wherever they need to be, on their own, with minimal support, and that just really is a fraction of the people that could contribute.” [S2FG2]</i></p>
<p>Reciprocity: relationships are mutually beneficial, based on trust and mutual respect.</p>	<p><i>“I chose reciprocity as my top guiding principle because trust and mutual respect are very important within the medical system, all parts of the medical system, even right down to the cleaning staff ... so I would see that as really important within the education components of the medical schools as well.” [S4FG5]</i></p>
<p>Partnership/Shared Decision-Making: university and community partners have equal voices and share power to make decisions.</p>	<p><i>“Partnership was important in the sense that it was shared decision making and not just okay, we had a community consultation but we’re not really using it if it’s not going in the direction that we want to take. And I think that’s maybe sometimes what’s happening and that yes communities can be wonderfully built but they’re just there for kind of representation but actually not really involved in the decision making.” [S1FG4]</i></p>
<p>Co-Production: university and community partners work together to co-develop and co-design engagement processes and activities.</p>	<p><i>“I think the more that we as patients are trusted to speak up and to actively participate in the design of things, and how things are delivered and what the topics are, I think the more enriched the program can be. And the more opportunities that we’re given, the more skills that we build, the more we are able to take risks because we’ve had some success. And I think that helps towards retention but it also helps towards the quality of what you’re receiving from the person who is participating in the program.” [S3FG8]</i></p>

<p>Two-Way Communication: communication is open, honest, with clear expectations on both sides.</p>	<p><i>“Communication, honest, open clear expectations so everybody knows what they’re getting into, including voices that aren’t always heard. And going to them and then having that real understanding of the [principle of reciprocity] which is around the mutually beneficial based on trust and creating that mutual respect to work together.” [S1FG3]</i></p>
<p>Supports: community partners are given the support and information they need to participate fully.</p>	<p><i>“I’m going with supports ‘cause I thought even if you get the inclusion that you want and need, if the groups do not have the financial support, the support of the schools or community or anything else, it’s not gonna help them.” [S1FG5]</i></p>
<p>Different Levels of Engagement: there are multiple opportunities for the community to engage in medical education (from classroom to committee).</p>	<p><i>“The different levels of engagement I thought would recognize the different capacity to engage by players in the community.” [S4FG3]</i></p> <p><i>“I think we have to be creative in different ways in how we do that [include people] and we can’t really be one dimensional in that because, different approaches will appeal to different people and in terms of their level of comfort in participating.” [S5FG4]</i></p>

3. Types and Levels of Engagement (Roles)

Participants were provided with a list of different ways in which patients / public can be involved in medical education organized according to different levels of involvement (see Appendix 3 for details).

- 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

They were asked to identify which ones were most relevant and interesting to them. All roles were of interest but the ones that were mentioned most were Level 3, Level 5 and Level 6. Participants spoke either about the roles they personally play or have played, or roles they imagined would be of most interest or importance to them or appropriate for the populations they serve. Many mentioned their interest in playing a variety of roles and their interconnectedness/progression (the idea of growing into roles). They also noted that people don’t know what roles are available or possible until they have had some experience (often one thing leads to another).

“For me obviously at this point Level 2, standardized or volunteer patient which I have been for the past few years is my involvement. But I was interested by some of the other levels and some of their potentials for even myself or other people with different backgrounds and experiences could get involved.” [S4FG7]

Sharing experiences with students (Level 3) was the role identified as most interesting and rewarding, and foundational to playing other roles.

“Having the one-on-one with students is probably the biggest, the biggest one in the sense of when you see the lightbulbs go on. You’ve said something that resonates with the audience whether it’s an individual or a group and you can see them stopping thinking and going ah ha!” [S1FG1]

“I feel that’s at minimum we need to get to Level 3 involvement. I feel that somehow having patients and families testifying directly and guiding students, and even all kind of healthcare providers who need to keep learning, I feel is of value.” [S1FG4]

“The curriculum is really important but I do think that the curriculum comes to life a lot more if they’re talking directly to people who have that lived experience... You can’t ask a question to the textbook about the experience or ask things about what other factors came into play and I think that’s something that we see a lot of with some curriculum examples. Or that they don’t represent a full person, they represent a health issue, and don’t have the complexities of the person encapsulated within that.” [S4FG2]

Several participants had experience as volunteer or standardized patients (Level 2) but wanted to expand their role and noted the importance of patient feedback.

“In my role as a volunteer patient, I have engaged in Level 2 and Level 3 involvement. I actually found the Level 3 involvement far more interesting because, and I think the students did as well, ‘cause they were able to ask me questions and dig in all deep with information I was able to share... We’re always told going into those sessions, reminded that, as the volunteer patient we’re not to provide feedback or other information and sometimes I find that a little frustrating and quite often the tutor will ask my thoughts or if I have any feedback and that seems to benefit the students as well.” [S4FG5]

Levels 5 and 6 were of also interest but most participants were uncertain or skeptical about whether these roles would actually be available and what they would look like in practice. 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. They saw this as an opportunity to bring about systemic change in the curriculum rather than patient experiences being an add-on.

“Being part of the curriculum development that sounds great because there’s certain things that certain people just aren’t going to say that maybe need to be taught or thought of.” [S2FG8]

“I think we’d have some really interesting and unique perspectives to offer on things that could be added to the curriculum that might not be highlighted right now. For example, just some studies about disability... I think a lot of that is missed in medical school and I think you know it would be a huge benefit to have some basic disability education and some education around ableism. I mean there is systemic ableism in health care and I’ve encountered it myself.” [S3FG8]

“The co-production of curriculum, from the outside I’m like ohhhh that sounds complicated and that means giving up authority that currently exists within the medical school, ceding that to the

public and patients that participate. I'm a bit skeptical that people are at that level of engagement but I do think there's value to maybe tease apart the curriculum and look for avenues or places where best that input could have the most benefit to actually impact what the public and patients are receiving from folks." [S1FG3]

"[Level] 6 kind of got me. I thought, I don't know, some hospitals for example have patient advisors on their faculty." [S3FG7]

"So I can see with accommodations and thoughtful engagement, authentic engagement I guess, people could be involved in all levels. I do think though the Level 6 is really important in that a lot of the first roles, the 1 to 5 are about placing the students in one position and them in others. The patient in that other position sort of separated, like that's them, this is me and I'm different than them... UBC should reflect the diversity of our community. And so students don't see patients as being them and different from me." [S2FG2]

A few participants mentioned their experiences playing roles at levels 5 and 6 and the value they perceived that they brought.

"Just the experience of being in the room when curriculum is being discussed across a spectrum of disciplines... and having a patient in the room or a public in the room forced them to be cordial to one another in many ways and that they actually explored options that they had never considered before because of responses that I gave in the room... and watching that happen where they go, oh we never considered this or we never talked about this because we're in our own silos." [S1FG1]

"I feel so lucky to be involved in the admissions process because my question that I bring to the table there is, so what kind of doctor does UBC want to produce? So then what are we looking for in the candidates?" [S5FG1]

Some spoke of the capacity or supports needed to engage at the higher levels, or that it would require a particular kind of person.

"So what as an organization would we be able to commit to... certainly a Level 1 involvement and a Level 3 are things that we already do. I think we can do that quite easily. I think to get involved at the higher levels would be really challenging for us. I think if roles could be developed for organizations to be involved in some way in curriculum development or those types of things. If there were mechanisms that allowed for periodic contributions I think that would be really, really great." [S1FG8]

"I don't know how I would participate in that [Level 6]. How I would have the knowledge and skills to participate in that with the exception maybe of looking at a person's communication skills and evaluating whether I think they would be a good doctor maybe?" [S5FG7]

These considerations led into the discussion of what supports would be required for patients /public to be engaged in these different roles (see Section 4).

4. 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. Their responses have been 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.

4.1 Inviting participation

Patient/public members need to be invited to engage with medical schools. Participants told us there are many people who might be interested but don't know about the opportunities. There needs to be better public awareness of the importance of patients in the process of medical training, the different opportunities to participate and the benefits of participating.

"...it's really important to help increase awareness and a lot of people were excited that something like this [First Patient Program] exists and none of them knew about it either. So just even having that awareness that there is a way for us to participate and give back to the medical system and also essentially help others that are like us. I think that's a really important first step." [S4FG6]

Community organizations were identified as potential partners in efforts to find the right people for different engagement opportunities.

"Here's the thing about engaging with people. You're more likely to get them if a trusted person, people or organization introduce the ask first. By leveraging relationships that already exist you might have a better recruitment strategy. ...Organizations can be that pivotal introduction level. It takes a great deal of time to find the person. We handpick them sometimes and then we orient them, we might have a phone call, a follow-up phone call. Because we're playing that intermediary role, people are more likely to say yes to the opportunity versus like a cold call or an email. They don't know you from Adam as the saying goes, but once we get that soft personal touch we get a lot of yesses. ...So for us we would dig deep and we'd look at our volunteers, the people that we know and we'd say wow this sounds like a really good opportunity because if you get in at the education level you change the future." [S3FG7]

Participation needs to be made easy as patients have enough to do already. There need to be realistic time expectations, as well as convenient times of day and locations. Communication needs to be concise. University bureaucratic processes that are slow and require lots of paperwork should be kept to a minimum.

"If it's not easy people have enough on their plate, they're dealing with enough in their lives that if it's not easy it's a major barrier, they're not gonna come through." [S6FG1]

"Try to put the information in a short amount of words as possible. The reading of information can be a lot and it can be daunting and if we think of patients and the amount of paperwork that they have to do on a regular basis, having more paperwork when they just want to give back is additionally daunting and can be confusing." [S2FG1]

“Time is a big deal. I mean things that are set at times that aren’t as accessible for people who want to come forward and support but they’re not gonna do a 7 a.m.” [S7FG1]

“I’m wondering if there would be any thoughts of perhaps setting up ... venues for students to meet the volunteers... so that people don’t have to drive long distance... that’s a long way to drive for three hours in the afternoon to volunteer.” [S2FG6]

Believing that their participation would make a difference is important to getting and staying involved.

“...to know that something tangible is the outcome of the work that they are doing. People don’t love to do things for the sake of just doing them. There needs to be actually something that comes out of the work that people are doing... So what does that mean long-term in the education of those medical students and not just we heard a lovely story this one time from this person and that was great?” [S3FG3]

Opportunities for personal growth and new connections are also incentives for engaging with the medical school.

“There has to be some type of value, so there’s always a value proposition to these types of engagements. ...it could be some form of remuneration for their time. It could be that they received some training or some other educational type benefit where they learnt something. A lot of people really like to do these things because they learn something by participating, so that’s value. [S1FG8]

“You make new friends, you make new connections with people and you hopefully inspire and at the end of the whole year when they’re showing you gratitude it’s one of the best feelings out there and that they’re so grateful you’ve shared your parts of your stories with them.” [S2FG8]

4.2 Preparing for participation

Patients need to be properly prepared for their engagement with medical schools. Participants emphasized the need for clear communication of the purpose, what is expected of volunteers, what they can expect from the medical school in return, and what are the anticipated outcomes. This is especially important for people who are managing chronic health conditions or complex life circumstances and need to make decisions about where to put their energies.

“...having full transparency through the whole process of what is expected of them and who are they talking to and what are their hoped-for outcomes.” [S3FG2]

“If you’re living with chronic illness you have only so much energy that you have available and so I know for myself I think of it as I don’t want to write cheques with my mind that my body can’t cash and so there’s always that fine line between how much can you do and how much is too much.” [S2FG8]

“Having a clear outline of the time commitment that this is gonna be. Like is it gonna be five meetings at two hours each, or is it going to be one meeting, one prep meeting at an hour, and then the day of the event, so that I can gauge like okay I can commit to this or I can’t commit. And to be realistic in what that time commitment is for that engagement.” [S2FG1]

Information and orientation sessions should be offered to prepare patients for what to expect. It is a good idea to give time to answer questions and ask individuals what kinds of specific supports they need so that information can be tailored to different needs. A good orientation might also include an opportunity to observe others and visit the space where the activity will take place.

“I think even almost before an orientation I’d just like to chat with somebody, just sit down one-on-one so I don’t feel any pressure or anything else and just kind of find out what it’s about. And then you could move to the orientation session, but I thought as part of an orientation session it’d be interesting for me to ...watch one of the other volunteers.” [S1FG5]

“One is know what you’re getting into and we’ve talked about a briefing and so on, and time estimates, but also visualizing the setting and maybe even having a chance to go visit the classroom or visit the place in which you’re going to be presenting.” [S5FG1]

Familiarity with the curriculum and the learning context was also deemed to be important preparation for good engagement with students.

“What is my, my audience, where have they been? What have they been exposed to? Where are they in their training in a really specific way, so I can tie what I say to what happened yesterday or last week or in a previous encounter of this topic. And then I can hand off to what’s happening next in their training this afternoon or tomorrow or next week.” [S5FG1]

4.3 Supporting participation

Participants emphasized the need for the medical school to recognize that sharing their personal experiences authentically makes patients vulnerable. Some patients fear that what they really want to say will be deemed too controversial. Others may feel intimidated by the setting. It is important for the medical school to provide safer and welcoming (including culturally safe) spaces, and support. The need for support is especially important for people who are the most vulnerable or marginalized in the health care system or in society more generally. People in rural/remote areas need support to feel connected.

“We had to be really careful that we weren’t putting them in a position of... they called it poor, ‘poornography’. We didn’t want them to come into a workshop and to essentially emotionally bleed all over the place for everyone to watch and witness.” [S3FG2]

“I mean often it’s very intimate details about their lives that they’re sharing with people. Like it’s not always easy conversation and so that environment, that space. And I like all the discussion about creating community I think just that’s really important and creating connection and meaningful connection.” [S1FG8]

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 support person present (e.g. from a partner organization), or creating or facilitating peer group support. Technology can be both an asset and a barrier to connectedness. Technical support was identified as being helpful so that patients can focus on sharing their experiences not managing microphones or slide decks.

“So to ask the person that’s coming in, what will help you make this a safer space for you? To have the capacity to have a support person with them if it’s needed.” [S3FG4]

“Welcoming and orientation go hand in hand. If you say don’t worry, we will walk alongside you and we will make sure that you know what to expect at every step, you won’t be left hung out to dry and you’re gonna have somebody to support you... ‘cause so many people in my experience are really intimidated in medical settings, universities, especially if they don’t come from that background themselves.” [S1FG7]

“When we’re talking about keeping people safe and they’re talking about personal things, the things that have happened to them, there needs to be a protection or sort of boundaries set for that individual to feel free what their boundaries are, what they will and will not talk about.” [S6FG1]

“[when] you’re the new kid on the block it would be nice to be able to be like, oh I know that mentor, I’m gonna go sit with them and then I can ask questions a little bit and feel more comfortable.” [S3FG8]

“...focus groups or pods where people feel less isolated, where there are other members of their community so they don’t feel like they’re the only person with a certain lived experience trying to talk about an issue...” [S2FG7]

“I think having a mentor, having a coach, that kind of companion for preparation and maybe even evaluation and debriefing, if the engagement is going to be periodic and a prolonged basis, if this is a relationship with the university, with the School of Medicine, just having that, someone who’s going to travel with you as you learn how to do this and hopefully learn how to do better.” [S5FG1]

Those leading or facilitating the session also have an important role to play in creating a welcoming environment, as can students.

“The person who’s inviting you in, they need to be prepared... and prepared in a sophisticated way for how to, how to create that relationship with the patient and community person who’s coming into their learning environment.” [S5FG1]

“I wonder if having a person who’s, who has expertise in facilitation present or something like that. I know that resourcing is a problem but, but somebody who has expertise and facilitation, and even culturally or I don’t know, just experience. There’s people who are just able to be really

warm... I'm usually an open book but I did find a couple of times that the people who are on the call with me made me feel like oh I don't, I don't want to tell you anything." [S5FG7]

"Having some of that dialogue with students about how privileged they are to be able to bear witness to someone sharing their story and that they should honor that." [S2FG2]

4.4 Increasing and supporting diversity

Participants perceived a lack of diversity among the patients / public who are involved, or would be able to get involved, in the medical school. They said that members of their communities do not often see themselves represented among the students, faculty, staff, or patients involved at the university which is a barrier to participation. The most likely people to volunteer are those with the most time and money, living in urban areas, and from a narrow demographic. They are the ones who have the time and means to volunteer, e.g. during the day.

"I think that often we have missed opportunities for targeted recruitment, both externally and internally at UBC, and I think that sometimes we have a habit of going back to the same sort of homogenized, majority voices that are not representative of minorities or condition groups." [S3FG1]

Participants identified significant barriers to participation among groups that have traditionally not been well served by institutions.

"But some of the barriers are very, very cultural where you have some groups where there is a very deep seated fear of not just the healthcare system but even the educational part of the healthcare system is very, very intimidating and daunting and they often feel disempowered." [S5FG5]

There is a need for people at the university who are recruiting to understand how to reach different groups. This might include having dedicated people within the university who have specialized knowledge of underrepresented communities and can serve as brokers between the university and community.

"...ensuring that those responsible or those tasked with recruiting that participation have a high, high degree of cultural intelligence so it's not just about our cultural knowledge, it's about our cross-cultural relational skills and also our ability to do those metacognitions, being able to think about the way that we think, and ensuring that when we do that outreach, it's incredibly representative. It's very representative of the LGBTQ2Spirit community, it's representative of Indigenous peoples, other marginalized persons or groups, the youth, the elderly, because how it is that we promote and encourage participation from a youth population or an elderly population is going to be incredibly different." [S5FG5]

One solution is to work with an organization to increase/establish trust and communication (see 4.1) However, there is a risk that the organization may filter certain voices.

"It's also understanding how participants are chosen will affect what participants think about it. So for example there's quite a few non-profits who have approved people that they will put forward for consultation who are kind of the nice kind of people with mental health issues so they're usually post-recovery, they're not currently using substances, and they aren't angry, they aren't, you know, XYZ and so I think that's part of it too because I know that when it's strictly from non-profits who have filtered who is coming into their room, there is less trust in that process." [S4FG2]

Widening participation might also require leaving the ivory tower and going into the community instead of expecting the community to come to the university. Also, having flexibility in the medical program with respect to time and location (e.g. weekends, community settings).

"...get out of UBC and going out into the community and interfacing with what really is going on out there." [S1FG3]

"...meeting people where they're at and what's part of their day and their daily life would make a big difference. ...bring the students to the people instead of having the people moving over to UBC, that's a big dream." [S2FG4]

"if people live in group homes, if somebody can go to the group home instead of expecting them to come to you and knowing things like, if somebody relies on support staff, not having a 9 a.m. meeting. Because they most likely won't have the support person come to their house, be able to get them ready and have the transportation to get there first thing in the morning. [S4FG2]

"Perhaps they have to broaden their base of hours, do it in the evening or weekends. I know that's, people are probably cringing when they think of that, but if you want to involve more people you have to expand the hours and the locations I think of the program." [S2FG6]

"Maybe creating some different types of spaces for people to participate and it doesn't always have to go to a classroom necessarily, like people can meet in a coffee shop or whatever's the mutual convenience to people. So just thinking about how it can be made easy for somebody to actually participate." [S1FG8]

Accessibility protocols could be developed that include a support person, childcare, accessible spaces (parking, washrooms, pee patches for service dogs, etc.), interpreters, special dietary needs, small group settings, etc. There are cost/resource implications for increasing representation/diversity.

"...transportation is important for some individuals, payment to get to and from. Food security is important. If you're gonna ask them to show up are you going to ensure that they have something to eat? ...For some people it's childcare and making sure that the place is actually accessible for them to be in and I'm talking about the physical environment is accessible for them. Many people think that that's an automatic given when they're being invited to participate, but I have witnessed many, many times where it's not a given. I need a bathroom and I need to make sure that it's accessible and is there parking there for people with disabilities

and is it close by? A lot of those things are important even before the person arrived at the destination. Once you're there is there somebody that you can ask questions of or if you need support get support? If you are visually impaired or if you are deaf and hard of hearing, are there services there to support you so that you can fully participate?" [S4FG4]

Technology can increase accessibility through virtual groups or recordings. But access to technology may be a barrier for some.

"I think it's really important to talk about communication needs and what that looks like. So, for example as a neurodivergent person, Zoom is so much better for me than phone calls." [S4FG2]

"When we're looking at encouraging diversified participation you're going to have diversified circumstances and some of that might be that somebody doesn't even have high functioning equipment." [S5FG5]

Many participants linked accessibility with the need to communicate in plain language.

"...the language that's being used is so technical or as she said, the word was academia but she couldn't even say that so she called it 'You're all macadamia nuts.' Cause that's the only word that could come to her mind, but they spoke in a language that was not familiar, it was so above her head." [S3FG4]

4.5 Recognizing participation

A majority of participants spoke to the need for adequate monetary compensation and other forms of recognition for participation. Three points were made: i) recognition of the value/expertise that patients bring that so they are not the only people in the room who are there as volunteers; ii) recognition that their contributions are a form of emotional labour, that making yourself vulnerable is work; iii) the only way to include people who cannot afford to volunteer is to offer payment. No-one should be out of pocket, so costs such as parking and transportation should be covered.

"Sometimes it's been my experience that when you have a person who's in the room and they're in a volunteered or non-paid role, that it is easy to give them the responsibility without the appreciation for their rich contribution... I'm already getting paid but I do know that many, many people that I'm affiliated with give their time and energy and their expertise and their focus and their passion, and there's not that payment. And, many of those individuals there's income security concerns and I think that their expertise should be valued and there should be some financial aspect given to it." [S4FG4]

"I think any time you're getting someone to share a lived experience, they are the expert on the subject matter of their own lived experience and they need to be fairly compensated for the work that they are doing because at the end of the day emotional work is work, so they deserve to be fairly compensated for that." [S3FG3]

"People should be paid as well. I think that's a huge thing from the disability perspective. So many organizations bring in non-disabled people and pay them huge consulting fees and then

they offer a cup of coffee to disabled people who are doing kind of the hard work of opening up their experiences.” [S4FG2]

“There sometimes has to be money involved unfortunately. Like my family we can afford to have me volunteering or giving my time up without a money involvement... There are some folks that, that need that support with money cause maybe they need to get food on the table or they do need someone to look after their kids so that if we’re trying to get a broader base of individuals engaging we need to think about what their barriers are.” [S2FG1]

People need to be offered payment options, e.g. cash or gift cards or a gift, or something else that is of value so that they can choose the type of compensation that best fits their personal circumstances.

“...if they’re being paid, do they have a choice of how they’re being paid. When we think of people that can’t cash a cheque or if they’re going to, Money Mart, they’re going to lose this much money or they freak out because they figure they’ve made too much and Social Services is going to take that amount from them.” [S3FG4]

One participant cautioned that monetary payments can have consequences that need to be mitigated.

“...reminding them partway through that you don’t have to share, you only share as much as you want to, you can stop whenever you want cause often times I remember even myself and other folks that we work with, we get paid to talk somewhere and we feel like we have to answer.” [S3FG2]

Other ways in which contributions can be recognized include thank you cards, feedback reports, certificates and end-of-year appreciations.

“Sometimes all they really need is an email after that just says thank you for coming, we really appreciate this, if there’s a report that comes out of this would you like to get a copy sort of a thing, like they’re not asking for weekly updates or things like that.” [S4FG2]

4.6 Institutional commitment to support sustained participation

Skepticism about whether the medical school is genuinely serious about sustained patient /public engagement was voiced by those who had not been involved (who were generally skeptical about powerful institutions, or feel excluded because they are in more remote areas of the province, or perceive that patient engagement is the flavour of the day in health care) and also by those who had a lot of experience in different roles.

“To know that there’s a commitment above and beyond just me asking you this one time to provide insight and then never hearing about it again until somebody gets the great idea to ask what the north is doing. Hey, didn’t you ask that five years ago and what did you do with it then?” [S4FG7]

“Co-production or co- is great. However there are some realities to the ability of that to actually happen and from my experience a lot of times we put it out there people that work in the healthcare system that we want to hear from you, we want you involved, we, but the bottom line is there are some boundaries around the ability of patients, families, caregivers to influence the decisions that are being made.” [S1FG3]

“...one of the white elephants would be when senior bureaucracy doesn’t totally believe in the concept and so it is the ‘yeah, yeah’ lip service but the walk isn’t there with the talk. Coming into it you know the person that’s invited you is engaged but you soon figure out the higher-ups are not. That is sometimes a barrier to figure out. Is it worth my time to continue? It’s not so much what I do in the classroom setting cause you’re gonna do your 100 percent there. But when you walk away and you go back to your organizations, you’re like, you know what, it’s not worth our time because this staff person isn’t supported in this mission. That’s an institutional barrier. Where’s the buy-in happen?” [S1FG1]

There was also skepticism about the medical school’s readiness to hear and act on hard truths about health care deficiencies and lived realities of people who have not been well-served by the medical community.

“...often when we share our stories, we have to control our emotions, we have to edit these stories in order to make the people in the room comfortable, in order for them to listen to us... All too often the consultations ask us to divide ourselves and only represent certain parts of ourselves or have a sanitized version of our stories.” [S4FG4]

Participants want to believe that 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.

“Like to say that you had community involvement, to say that you had someone with a disability come talk to the class, to say that you had someone come share their story or you learned about this and you did this, but if none of it is for a purpose, it’s not for an outcome, it’s not going to achieve some kind of end goal, it doesn’t mean anything to me. It becomes pointless if it becomes, for lack of a better word like poverty porn, or a way to say that we did things to make ourselves feel better or to make the medical system feel better, or to make the medical students feel like they did something, or to make the teachers or the people who make the curriculum feel like they’ve checked, ticked off the box that they needed to tick.” [S3FG3]

“But even more, even besides the compensation piece, I’m still in my head going, okay so what, what’s the payoff here? Like I’m gonna go in, talk about my most likely not great experience with the healthcare system, yes that these kids might learn from that and maybe be different when they go out into the world as doctors and that. But I think we’ve done a lot of that in healthcare, asked questions - In Plain Sight is a perfect example of asking lots of questions, getting lots of feedback. People are kind of at the point of okay, yeah, but what’s gonna change?” [S1FG3]

“There needs to be actually something that comes out of the work that people are doing [...] So what does that mean long-term in the education of those medical students and not just we heard a lovely story this one time from this person and that was great.” [S3FG3]

“Most people just want to see, even if it’s minimal changes in the way care is delivered that will support a more person and family centered approach. If it’s specifically about the learning of the students, how does that actually practically apply when they get out into their internships, their practicums and everything else they do in the world? How are they going to spread this? What’s your measurement gonna be around that? Some real stuff that you can point to and say this has made a real difference and this is how it’s made a difference.” [S1FG3]

Participants questioned whether the medical school was ready to provide the kinds of supports needed for systemic and ongoing engagement with the diverse populations they have a mandate to serve.

“...what is the medical school going to invest in ensuring that people are supported well so that it’s not just a come in, share my story and then you go home.” [S2FG3]

Indicators of institutional commitment include support for faculty who want to engage patients, a dedicated staff person to facilitate engagement, preparation for students and follow up communication, as well as the practical supports suggested in sections 4.1 to 4.4.

“I don’t think we can underscore how valuable it is to have a staff person who’s dedicated to doing this type of engagement and I don’t know if that’s something that the medical school has so somebody who’s role is to help facilitate these placements and answer questions.” [S7FG1]

“I think another big one is follow-up communication. There is so much, like our communities are consulted all the time and it is truly exhausting how often we are consulted... I also know that a lot of our members are done because they’ve been to so much consultation and nothing comes from it... but so often people are asked to perform their trauma and then nothing else is given back to them.” [S4FG2]

5. What Does Successful Engagement Look Like?

As a concluding wrap-up question, participants were asked to briefly describe what successful engagement looked like from their perspective. Responses fell into three main categories: meaningful contribution; equitable engagement and inclusivity; feeling valued and respected. Other ways in which participants spoke of success included having a positive experience, opportunities for growth (learning from others) or being able to connect with people they would not normally connect with.

Meaningful contribution

The predominant theme was that participants wanted to know that their involvement had made a difference to students (short term) and, ideally, to health care (longer term). This also meant that there would be a mechanism by which they knew their contributions had made an impact (principle of accountability).

“When I hear that they’ve learned something that they could put into practice for themselves or that will influence their practice in some way, it just feels like I’ve done my job.” [S3FG8]

“I do see a lot of people that are sharing information time and time again and they’re asked to come to the table but they don’t see the outcome and they don’t see themselves within that outcome.” [SFG44]

“The experience of reciprocity that it is felt that the students and the patient have had that experience that we have, we have benefitted in a positive way, we’ve created a shared experience. [...] And in that comes a lot of closing loops or closing the conversations, giving some feedback. For example from your participation the students learned this, right. You’re, you contributed with, by your participation you contributed in these ways or these are some of the comments from the students... That is such a feeling of, it’s that internal satisfaction and oh wow, I contributed this and there’s a tiny bit that maybe that doctor will have an addition – in the future will remember my story and that will have contributed to having better doctors.” [S2FG5]

Equitable engagement and inclusivity

A second important theme was the need for successful engagement to be inclusive of diverse perspectives, and for this engagement to be genuine and authentic.

“Successful engagement for me is to be able to see the voices that are currently underrepresented or unheard.” [S4FG7]

“Successful engagement, what it looks like, is one that is very inclusive, one that is, and I can’t say this enough, one that is based on the strength-based approach and a decolonization approach.” [S5FG4]

“I think one of the biggest things is about a really, really genuine and authentic way of looking at how it is that you’re gonna meet your mandate, your principle of inclusion, rather than, and I’m not saying that the schools do, but rather than just ticking that box.” [S6FG5]

Feeling valued and respected

Participants identified not only the need to feel that they had made a meaningful contribution, but that their skills and expertise had been heard, recognized, respected and valued by the medical school.

“I want to walk away feeling that I’ve been heard, I felt valued, that I felt that my message got across and I felt that I was of value.” [S6FG1]

“Whatever level of involvement, that they say they felt honored and that they felt respected.” [S2FG2]

Conclusions from the Research Team

- There is demonstrated patient/public interest in engaging with the medical school and in playing a variety of different roles beyond direct involvement with students.
- Patients / public want involvement to be based on principles of accountability (transparency, shared outcomes, feedback, maintaining the relationship), inclusion and reciprocity, and to know that their contributions are valued and have made a difference.
- The consultation identified practical suggestions for improving the experience of patient/public members currently engaged with the medical school.
- 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. Building trust takes time.

Appendix 1: Contributors to the Consultation

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 Womens' 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 2: Focus Group Protocol

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

Patient and Public Consultations

Focus group protocol

Purpose: The aim of this participatory action research project is to co-create a set of evidence-based 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. The questions in this focus group will help us develop recommendations and guiding principles for patient/public engagement that can be used for action in the context of our distributed medical school.

Materials to be sent in advance

Consent form with instructions to sign and send it back as an attachment (scanned or photo) to Cathy Kline, or if this is not possible to confirm their consent in an e-mail to Cathy.

Project description and spectrum of involvement.

Participants:

Facilitator:

Observers / notetakers:

Introduction by facilitator

- Introduce self and observers/notetakers. Ask observers/notetakers to turn off their cameras. Participants to introduce themselves when we start the focus group.
- Confirm purpose and structure of focus group and funding from Royal College of Physicians and Surgeons of Canada. Emphasize the focus is on medical education and the medical school, not health professional education more broadly.
- Informed consent – review consent form and confirm everyone has signed (sent out in advance); confidentiality; recording (remind them they can ask to have the recorder turned off at any time, refuse to answer any questions they don't want to answer or withdraw their consent at any time during the focus group).
- Review best practices for virtual focus groups – mute your microphone when you are not speaking. Remind participants they may use a nickname or substitute a name and turn off their camera if they wish to protect their identity and increase the protection of their personal information.
- Inform participants that the focus group will last 90 minutes. There are seven questions in total.
- Inform them I will call upon people to speak by name to ensure that everyone has a chance to contribute and to aid the transcription process. For each question I will ask everyone once in

turn but if you have additional comments after your turn please use the raise hand feature. You can also add comments in the chat.

- Ask if they have any questions before you turn on the recording and get started.

START RECORDING

Questions

1. Please briefly introduce yourself, the organization you represent / perspective you bring, and your involvement with the UBC medical school (if any).
2. Click link to Slido in the Chat and review the list of guiding principles for patient / public engagement we have gathered from the literature. Please choose the three principles that are most important to you when you are involved with the medical school. After you have voted we will review the results together and have a discussion.
Review the results. Ask each person to say something about the choices they made. Are there any important guiding principles missing from the list?
3. The handout we sent you in advance provided a range of ways in which patient / public have been involved in medical education. Which of these roles are of most relevance / interest to you? Are there other roles that aren't on the list?
4. What needs to happen to enable and support community members to participate in medical education / engage with the medical school?
5. What are the barriers to authentic engagement (real or potential)? How might they be overcome or reduced?
6. This question is specifically for those of you from organizations that have a provincial mandate. The medical program has students in different parts of the province (Prince George, Victoria, Kelowna, Fraser Valley). How might we involve people in those sites? Are there specific considerations in relation to barriers beyond what we have already mentioned?
7. What does successful engagement look like from your perspective?

Closure

- Turn off recording
- Thank them for participating
- Claim for honorarium. Will receive an e-mail from Theresa Pan tomorrow with instructions. If you have any questions she can help you with the process (UBC's process of reimbursement is not very user friendly)
- Let participants know next steps. We expect to have a draft summary report to send out for confirmation/corrections in late June)

Appendix 3: Levels of Involvement

Level 1: Patients are involved in creating learning materials used by faculty (e.g. paper-based or electronic cases or scenarios; course materials; videos). Examples include real patient problems as a basis for case-based learning; virtual patient cases (may involve video of patients); and use of patient narratives.

Level 2: Standardized or volunteer patient in a clinical setting. Examples include standardized patients widely used to teach and assess communication and clinical skills; clinical teachers may encourage volunteer patients to teach and give feedback; and students writing up patients' stories.

Level 3: Patients share their experience with students within a faculty-directed curriculum. Examples include patients being invited into classrooms to share experiences of chronic illness, disability, etc.; community-based patient and family attachment programs.

Level 4: Patient-teacher(s) are involved in teaching or evaluating students. Examples include teaching associates trained to teach and assess specifically clinical skills (e.g. pelvic or breast exam); patients give feedback to students on communication skills; Health Mentors teach students.

Level 5: Patient-teacher(s) as equal partners in student education, evaluation and curriculum development. Examples include patient educators involved in multiple programme areas. Patient educators collaborate in educational decision-making (e.g. curriculum objectives, assessment criteria).

Level 6: Patients are involved at an institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation, and curriculum development. Examples include patients being given a formal position in the institution (e.g. Consumer Academic), patients being involved in institutional decision-making (e.g. student selection, reviewing funding applications), etc.

From: Towle A. Godolphin W. Patients as teachers: promoting their authentic and autonomous voices. *Clinical Teacher* 2015; 12: 149-154.