

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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An Environmental Scan of Methods for Patient and Public Engagement

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REPORT 2

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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, 1st Year Medical Students
Report 5	Synthesis Report and Recommendations	Created by: Angela Towle, Patient & Community Partnership for Education

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Executive Summary

This environmental scan was conducted as part of a 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 project is intended to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfill their mandate for social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve. 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). The report was circulated to all key informants for review and comment before it was finalized. 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

1.1 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.

1.2 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.

1.3 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

2.1 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.

2.2 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.

2.3 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.

2.4 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

3.1 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.

3.2 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.

3.3 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.

3.4 Achieving Inclusion and Diversity

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

Introduction

This environmental scan was conducted as part of a 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 project is intended to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfill their mandate for social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve. 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.

Methods

Key informants were identified by members of the project steering committee as having long-standing expertise in patient / public engagement at institutions in Canada and internationally. Several had contributed their expertise at an international conference 'Where's the Patient's Voice in Health Professional Education?' held in Vancouver in 2015. Additional potential participants were recommended by the initial set of key informants.

Informants who expressed interest in participating in the study were sent a formal invitation letter and consent form. Details from the consent form were reviewed prior to the start of the interview and audio recording, and participants were given the opportunity to ask questions. Consent forms were signed electronically. Interviews were conducted over virtual platforms. Zoom was most commonly used, however some informants requested use of their institution's specific software.

Interviews were 30 to 45 minutes long, and followed a semi-structured format which was informed by an interview guide that had been developed by the project steering committee. Eight of the ten interviews were conducted by a fourth-year medical student (JWY), and the remaining two by the project research coordinator (CK).

JWY transcribed the interviews verbatim, analyzed the data and wrote the summary report. A conventional content analysis approach was used to analyze the transcripts, beginning with a round of open coding to group data into broad categories. The purpose of the Environmental Scan (ES) was used to create initial categories before coding began. New categories were generated iteratively during the first reading of the transcripts. A summary document was created after the first cycle of coding was complete. The described purpose of the ES was used to guide the three sections of the report (i.e. Forms of engagement, Principles of successful engagement, Barriers). Sub-categories were created by identifying high-impact codes (i.e. high frequency of use, or insightful) and also by consolidating codes into more impactful sub-categories. After eight interviews had been conducted, the transcripts were recoded based on these sub-categories. Members of the project steering committee who volunteered to read the first eight transcripts were each given the summary document and invited to provide feedback on the data analysis. The sub-categories were adjusted based on these discussions. The final two interviews were transcribed and coded (no new categories were created) and added to the summary. The summary and full report were reviewed by the key informants and the project steering committee.

1. Patient Engagement Structures

This section describes what patient/community engagement looks like at the different institutions surveyed, including organizational structures, as well as the specific roles of patients or community members.

1.2 Striving for Comprehensive Integration

Informants from both hospital and university settings expressed a desire to integrate community engagement in all aspects of their organization. To conceptualize what this looks like, one researcher distinguished between "domains" of engagement (e.g. education, research) and "level" of engagement (e.g. consultation, partnership). Using this framework, the ideal goal for institutions would be to utilize multiple levels of engagement across each domain of their organization.

The idea of comprehensive engagement was described differently in hospital compared with medical school contexts. When discussing medical schools, informants often framed this concept through the different, discrete stages of training: "It starts [at admissions] and goes all the way through to postgraduate education." [P5] In contrast, informants from hospital settings would describe domains of engagement according to department roles: "Anything that's going to directly affect how services are provided, or how communication is going to happen...how discharges may be occurring...any of those things will likely have patient partners involved in the development." [P4]

The specific roles of patients or community members reflected the principle of deep and varied forms of engagement. Three categories of patient / community member roles were described related to Delivery, Directing and Consultation.

Delivery roles involved the direct administration of services. Within a medical school, for example, community members were described as "co-trainers" [P1] who worked alongside nurses, social workers, pharmacists, and doctors in the delivery of medical education. In this way, the role of 'community member' is recognized as a specific role which is being placed alongside, or "around the table" [P1], with other healthcare providers.

Patients who were engaged in directing roles were involved in higher-level institutional decisions. For example, one informant described their organization as having a "smaller strategic group" who were specifically involved in "curriculum planning" [P2]. They described these roles as requiring unique skills different from delivery roles, noting that such community members had "experience already of talking to senior management." [P2]

Finally, community members may occupy consultation roles within different domains of engagement.

One informant described how, within their institution, consultation and partnership were closely linked:

"We bring patients [to the committee] to tell their safety stories and give recommendations to the

board...But we also have members sitting on the committee as well." [P4]

1.2 Having a Centralized Group

Institutions with more developed engagement programs often had a dedicated structure for this work.

From the community perspective, informants saw cohesive infrastructures as a way to gain more autonomy: "why not get one group together, and from that safe, secure group [community members] can choose what direction what want to go in?" [P3]

Benefits for the institution included being able to focus on more specialized areas of engagement and, if possible, having a physical space to facilitate face-to-face engagement work. As an example, one informant described how their Centre supports both the "science and practice of engagement":

"It has three main components...A partnership lab to support engagement evaluation...A school that provides training to people...And a network trying to link various patient partners to communities of researchers, clinicians, etc." [P1]

One structural feature which was shared between a few organizations was the use of a "pool" of volunteers or community members which institutional staff could apply to becoming involved with. "We consistently recruit into that community of patient partners, and we have a process where staff can request a patient partner to be involved in any quality improvement initiative, any committee, any practice change, any strategy that may be going on." [P4]

1.3 Support for Community Members and Staff

Informants described ways in which their organizations support those involved in engagement work. Different forms of support were offered to community members or patients, compared with the resources provided to researchers or members of the institution.

Support for community members most commonly emphasized formal training and practical skills. Informants cited "training packages" [P2] or "e-modules" [P4] which focused on how to give effective presentations, or how to provide constructive feedback. One noted that more targeted support can be provided within medical school contexts:

"The other key thing is not putting someone in blind...They need to understand a little bit about how [medical students] learn, and what kind of things they learn about." [P3]

Informants who worked in research settings often highlighted the need for more nuanced training within patient engagement. Participants often wanted to pass along fundamental research skills to their community partners, a term which one participant described as "capacity building" [P6]. In addition to the practical benefits of having shared knowledge, capacity building was also viewed, in part, as being a moral obligation: "We need to bring people along when they want to come." [P5]

Some forms of support were not related to specific roles of community members. These included monetary compensation, subsidies for travel, as well as career counselling services such as "certificates...job references...and helping [community members] think about how to put [their roles] on a resume." [P8]

Supports provided to researchers or institutional members were often more reflective. For example, some institutions required research or education groups to fill out forms outlining their intentions and

priorities before participating in community engagement. Similarly, some informants emphasized the value of starting with purposeful, exploratory discussions:

"Before a patient sits on a particular committee, we go to that team and actually have a discussion with the team...[We] ask them about their thoughts about having a patient at the table. This allows the team to ask questions, express concerns and talk about the benefits of the partnership." [P4]

2. Principles of Successful Engagement

This section describes some of the values which informants associated with effective engagement work, including what must be present for partnerships to flourish and what lessons they have learnt.

2.1 Success Means Mutual Benefit

When it comes to outcomes and deliverables, successful engagement was commonly defined as having reciprocal gain among all parties involved. Examples of specific benefits were very context-specific, and could include objective measurements such as publication or accreditation, to more subjective outcomes such as a sense of "doing good" [P2] or "mutual learning" [P1].

Notably, informants did not feel that achieving mutual gain required having shared goals. In other words, institutions and communities can create successful partnerships even if their motivations in a project are dissimilar:

"I personally think that it is possible for the goals to be complementary and not the exact same. But they have to be achievable by the same methods." [P5]

Mutual benefit can also mean that the degree of gain between parties is equal, or that communities are "getting as much from us as we're getting from them." [P7]. Having clearly defined goals for the community and institution was described as one way to facilitate equal benefit, as it can clarify differences between community and institutional perspectives:

"The goals need to be explicit because there is often a gap between the explicit goal, like empower people, with the implicit goal, which is oftentimes symbolic [i.e. tokenistic] and needs to be made explicit.

That's how you understand the gaps." [P1]

2.2 Community Leadership

Informants often emphasized the benefits of having communities direct the design, implementation, and evaluation of projects. When communities take on leadership roles, the role of institutions becomes that of support: "The institution has a great power to serve...Research can be incredibly pragmatic, helpful, and useful, if we get out of our own way." [P9] This form of partnership was often seen as an ideal state of engagement:

"I think it is something to aspire to - where our patients and families are actually driving the strategy and the changes made in an organization...And the organization then is fully listening to sort of say yes, we're going to focus on that." [P4]

For many informants, community leadership was a goal which they wanted their institutions to eventually achieve, but which was not currently being enacted. One noted that often leadership must be developed over time between institutions and the community, saying "it isn't just instant leadership,

I think it starts as partnership." [P3] Another informant expressed that the model of community leadership has not been normalized, and hence communication of that goal may not be clear; "do [community members] know what is available to them? Do they know what we are willing to do?" [P5b]

Community leadership was described as the form of engagement which would produce the most practical results. Within a research context, one informant felt that if communities can "[determine] the question that we are going to ask" then the work will have "the best chance of actually being implemented, and being useful." [P6] Within medical schools, a different informant described how the relationships demonstrated within medical education can have parallel impacts to the clinical setting: "If you model that patients can be involved in their own care, as they can in their own involvement in medical education, then it's a much stronger experience for the student. It's partnership, it's an ownership, and ultimately leadership." [P3]

2.3 Equal Power, Equal Respect

Informants emphasized that the contributions of patients, community members, physicians, and researchers must be seen as equally valuable. One summarized the different forms of knowledge contributed by each group, saying:

"It's that mutual exchange of expert knowledge between staff and patients. For patients – their expert knowledge of knowing themselves, knowing their disease, and knowing their experience. Staff have the expert knowledge with respect to clinical aspects of the science, those best practices, and evidence and objectivity." [P4]

Informants expanded on what it means to have experiential knowledge "be treated the same as you would expert knowledge" [P6]. Most notably, they expressed that the views and opinions of community members need to be legitimately considered in decision-making: "It's not just about asking people what they think and then you do something else anyways." [P7] Giving communities decision-making power was seen as one way to avoid tokenism, or "representation without agency" [P9], and requires ongoing dialogue between those in partnerships:

"It's not that because you're the partner what you say goes, or because I'm the researcher what I say goes. It's that we both provide our opinions, and then ideally, we come to some sort of agreement that works for both of us. That is meaningful to both of us." [P9]

Many informants reflected on actionable ways in which power equity could be promoted. For example, one emphasized the importance of choosing "meaningful" topics or questions which would allow "both sides to add value to a conversation." Another emphasized structural approaches, citing a "decentralized model" of engagement where there is more "shared resources, shared funding, and shared money" between communities and institutions [P8]. However, overall informants expressed a sentiment that the best ways to promote power equity are not obvious:

"We want to get to put power in the hands of our patients, but what does that look like? And what does it feel like? ...It's important not to just say the words of empowerment and 'give power to patients' – we have to actually understand what it looks and feels like, and how it rolls out." [P4]

2.4 Relationships Require Work

A common sentiment across interviews was that healthy partnerships require time and intentionality to be successful. Informants cited honesty, humility, and trust as key characteristics of partnerships, with one noting that many of the principles we hold in our personal relationships apply equally to professional ones:

"Did you give appropriate time to nurture, and develop, and build the relationship? Have you been able to navigate through conflicts and misunderstandings? ...It can't be about two experts working alongside each other, you have to work on the relationship with patients just like you need to work on relationships with your life partner or with your co-workers." [P1]

Although informants recognized that conflicts can arise within engagement work, they also emphasized that strong partnerships are resilient: "they are fragile, but there are opportunities for repair." [P6] Recognizing the dynamic nature of partnerships was hence another important sentiment: "If we have gotten to the stage where we think we had [community engagement] cracked, then we had probably gotten it wrong. I think that's a lesson I've learned. That it's a process, and not a destination."

[P7]

Although the above concepts were mostly described in the context of interpersonal relationships, some informants did discuss the idea of trust within broader relationships between institutions and communities. Specifically, it was recognized that organizations may have to invest a great deal of time and effort into building trust within historically marginalized communities.

3. Barriers to Engagement

Given this understanding of successful engagement, this section describes challenges to engagement, from both practical and philosophical perspectives.

3.1 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, if communities and institutions have dissimilar goals within a partnership, then power inequities can shape how those differences play out:

"Where the breakdown happens is if some goals are seen as more important than others...Because in and of themselves, [goals] have inherent power. Which ones are the most privileged, and also given more weight?" [P5]

Funding deadlines, and the academic concept of 'publish or perish', were examples of institutional goals which can be prioritized above those of the community. These goals were described as external forces which may apply pressure to researchers who are otherwise committed to pursuing ethical engagement. One informant described this tension as feeling like "the system is pushing back on you." [P9] For another, these contextual power dynamics and institutional structures were equally important, or more important, than the attitudes of individuals:

"Because the individuals only have so much power, you know, in the environment. You can have individual matches of people who are very committed, but if you want this to grow and be successful and sustain, you need to have what is called engagement favorable environments." [P1]

On an individual level, academic or medical titles were seen as fostering similar power contexts within interpersonal relationships. In this context, it was felt that power inequities may cause community members to be less likely to express their needs, feel inadequate, or censor their feedback out of a belief that "they can't say anything different." [P7]

"As much as I think I am a non-threatening person, and very approachable - to some people, because of my position and because of my title, because of the way I talk, it is seen as intimidating." [P6]

3.2 Resource Management

Whether it was money, time, or access to physical spaces, informants identified managing practical resources as a constant challenge within engagement work. One informant succinctly summarized an often-cited challenge for communities and institutions alike: "[Engagement] has to be meaningful - and meaningful means time." [P10] From a community perspective, one informant noted that asking people to commit more time to their engagement roles may exclude those with incompatible "working schedules" [P4]. Researchers cited funding deadlines which work against purposeful relationship building, as well as pressures to regularly publish within academia. Adopting a community-centered attitude towards research is one way to address time-related barriers within academic careers:

"They say that partnership takes so much time - I say only if your endpoint is publication. If your endpoint is relevant and useful research, then your quick publications that aren't engaged are taking longer to get to relevant and useful research." [P9]

Although many informants expressed a desire to pay community members for their work, it was recognized that such options were simply not possible without sufficient funding. One suggestion was to invest limited funds into physical spaces rather than directly compensating individuals:

"If you have a really small budget, then you use that budget not to pay people to come in...You use that budget to pay for travel, and to really look after them... We put our money into welcoming people...They're not interested in having a fee to talk about their experience - they're interested in having a good experience." [P3]

Some informants noted that engagement work can be difficult to evaluate, specifically because the outcomes of partnered engagement can be difficult to define and "different for everyone" [P9]. The absence of robust evaluation metrics then makes it challenging to promote engagement practices within a funding system which values objective measurements:

"It is not always easy to measure outcomes using the kinds of measurement strategies that are most familiar to, and adopted by, people who are making decisions about resource allocation." [P8]

Finally, one informant felt that communities were being unduly burdened by continuous requests for engagement. They described a "capacity to engage" which was another resource not always being considered in current partnership work.

"We are exhausting community members by going about [engagement work] in a very uncoordinated fashion. Meaning that I am calling upon community partners at the same time that Pediatrics is calling upon them, at the same time that ObGyn is, at the same time that the medical school is...The medical school has not figured out a way to strategically develop a program that does not burden the community." [P8]

3.3 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.

Having a "paternalistic mentality" [P4] was an often-cited barrier to engagement. Many informants felt that being closed-minded to different forms of knowledge betrays fundamental principles of partnership: "If you believe you know the truth, then there is not much to gain by engaging with others, other than trying to convince them to do something." [P1]

The use of jargon, as well as a lack of humility, were seen as harmful qualities associated with the culture of academia medicine. Many informants described these qualities as intrinsic to the roles of researchers or physicians, such that the qualities fostered in these roles must be unlearned within engagement spaces:

"You actually have to listen. And I know this sounds fundamental, but a lot of people have a hard time doing that. Especially researchers, especially PIs, especially healthcare providers who are used to being the knowers of knowledge...We are used to being in charge...There's all kinds of things that we are so used to doing that make it really hard." [P6]

Finally, multiple informants expressed that a barrier to successful engagement work is simply lack of experience from staff, physicians, or researchers. Those with less experience were described as often being "more nervous" [P2], or more likely to hold counterproductive attitudes. However, informants also emphasized each person's capacity to move through their inexperience, and adopt productive attitudes in the place of old ones.

3.4 Achieving Inclusion and Diversity

Informants often described inclusion and diversity as important goals of partnership: "it's not only the patient's voice, but it's which patients as well?" [P8b] However, actually achieving diversity within a partnership was viewed as exceedingly difficult. Informants noted that the time and financial barriers associated with engagement work would favor dominant demographics:

"The challenge is to get a broad demographic of people, isn't it? People who are working, people who are frail, people from minority ethnicities, people that speak a different language, those are the questions that we have, and that I'm sure every university has." [P2]

Many informants expressed uncertainty as to the best way of "accessing groups that, by definition, you can't access as easily as others." [P7] Outreach methods were cited by a few informants as one way to achieve greater diversity. One informant expressed the need to explore new ways of engagement, while also noting that "there's no real right answer" to addressing representation within partnerships:

"In order to hear from all of the patients that we serve, and our populations that we serve - we have to think outside the box...That means going outside our walls and partnering with communities that we serve, and building trusting relationships." [P4]

Resources

The following resources related to engagement work were recommended or provided by informants.

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- 2. Marjadi B, Scobie J, Doyle K, Tobin S, Whitton G, Rollinson N, Haque S, Fava G, Smith M, Spannenberg J, Micheal S. Twelve tips for engaging students and community partners in medical education. Med Teacher. 2021. https://doi.org/10.1080/0142159X.2021.1986625
- 3. Leeds Institute: Patient Carer Community (PCC) Rules of Engagement and PCC Pledge.
- 4. Devaney J, Costa L, Raju P. More than Paint Colors: Dialogue about Power and Process in Patient Engagement. The Empowerment Council, 2017.

 https://www.empowermentcouncil.ca/wp-content/uploads/2021/02/More-Than-Paint-Colours-Dialogue-Power-Process-1.pdf
- 5. Centre for Addiction and Mental Health. Patient Partner Declaration of Values.
- 6. Integrated Knowledge translation (IKT) Guiding Principles. UBC Okanagan. www.IKTprinciples.com
- 7. Association of American Medical Colleges Center for Health Justice. The Principles of Trustworthiness. https://www.aamchealthjustice.org/resources/trustworthiness-toolkit

List of key informants

University of Montreal: **Antoine Boivin**, Centre of Excellence on Partnerships with Patients and the Public

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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