



Patient & Community
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informed and shared decision making



PRIORITY HEALTH CONCERNS IN BRITISH COLUMBIA & THE TRAINING OF FUTURE PHYSICIANS

For the UBC Undergraduate
Medical Education
Curriculum Review Working
Group

Report of a consultation with patients, caregivers and community representatives

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Prepared by: Angela Towle, Cathy Kline and William
Godolphin


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

604-822-8002, pcpe.isdm@ubc.ca
<https://health.ubc.ca/pcpe>



THE UNIVERSITY OF BRITISH COLUMBIA

UBC Health



Watch the video commentary by six participants:

***Patient/Community Consultation on the Priority Health Concerns in
British Columbia and How We Should Be Training Future Physicians to
Meet These Needs***

<https://meetingofexperts.org/programs-activities/priority-health-concerns-in-bc/>

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Executive summary

In October 2019 the undergraduate medical program at UBC formed a Curriculum Review Working Group to re-examine the mission and vision of the MD program with the lens of the new social accountability mandate from the Committee on Accreditation of Canadian Medical Schools. The accreditation standard states that: “A medical school is committed to address the priority health concerns of the populations it has a responsibility to serve” and that this commitment is “a) articulated in its mission statement, b) fulfilled in its educational program through admissions, curricular content, and types and locations of educational experiences; c) evidenced by specific outcome measures”.

Patient & Community Partnership for Education (PCPE), a unit in UBC Health, designed and facilitated a consultation process with patients, care givers and community representatives on behalf of the Curriculum Review Working group. Special efforts were made to include the voices of those who are not normally heard by educational decision-makers. This report summarizes input obtained from a forum held on 3 December 2019 attended by 20 people, and a survey completed by an additional 18 people. The report is accompanied by a short video that brings to life some of the priority issues identified by participants.

In the report, the major findings from the consultation are divided into sections that address priority issues at both the health system and individual doctor-patient level. They include both strengths and concerns, and also identify issues that will affect health care in the future. The strengths of health care and the role of physicians in BC are that care is publicly funded and accessible and delivered by skilled health professionals, there are good services and models of care for particular populations, and the system is seen to be responsive to change. The priority health needs are for better care for the under-privileged, as well as better care for everyone in relation to problems such as the fragmentation of care, physician shortages and waitlists, time, and access to care in remote locations. Alternative care models are proposed. Issues for the future include the aging population, other emerging priorities, team-based and holistic care, technology, costs and increasing cultural diversity. The big themes for what make a good doctor-patient relationship are time, trust, communication, relationship, listening and respect. Participants want physicians who treat them as partners in care, treat them holistically, are open to change, practice cultural safety and humility, and work with others. Based on these themes, the most important knowledge, skills and attitudes that should be in the medical curriculum are listed.

In an afterword, PCPE has identified several important implications for medical education arising from the consultation. These relate to the doctor-patient relationship; holistic care; marginalization, diversity and cultural safety; models of care, collaboration and teamwork; changes to the health care system; and Indigenous health.

Copies of the report will be shared with the consultation participants. They look forward to hearing how their input might influence medical education and what changes might be implemented as a consequence in order to address the priority health concerns, and improve care for British Columbians.

Introduction

Undergraduate medical education (UGME) at UBC has formed a Curriculum Review Working Group to re-examine the mission and vision of the MD program with the lens of the new social accountability mandate from the Committee on Accreditation of Canadian Medical Schools (CACMS). The accreditation standard (1.1.1) states that: “A medical school is committed to address the priority health concerns of the populations it has a responsibility to serve” and that this commitment is “a) articulated in its mission statement, b) fulfilled in its educational program through admissions, curricular content, and types and locations of educational experiences; c) evidenced by specific outcome measures”. In October 2019 the co-chairs of the Curriculum Review Working Group, Cheryl Holmes and Adrian Yee, identified the need for patient input into the review process. They approached **Patient & Community Partnership for Education (PCPE)**, a unit in UBC Health, for help in finding patients. PCPE suggested a consultation process based on their patient engagement experience and the literature on effective patient / public involvement. The PCPE proposal was approved at the first meeting of the working group at end of October 2019.

Consultation process

Recruitment

The first step was to gather information through a patient and community forum and survey in December 2019. PCPE drew up an initial list of invitees based on their current contacts (individual patients, caregivers and community-based organizations involved in health professional education at UBC), suggestions from UBC Health Patient & Community Advisory Committee (PAC) and Patients in Education (PIE), an independent community-based, non-profit organization. The list was checked to ensure a diversity of perspectives and gaps were filled through PCPE, PAC and PIE networks and by consulting organization websites to identify leaders (cold calling). Special efforts were made to include the voices of those who are not normally heard by educational decision-makers. A personal e-mail invitation to participate in the forum was sent to 48 individuals; if someone was unable to attend they were given the option of completing a survey or recommending an alternate.

The questions

Questions were developed that would work for both the forum focus groups and as a survey. PCPE began by doing a search to find out if anyone had done a similar patient / public consultation to see if there were questions that had been used that we could borrow or adapt. The only example we could find was the Educating Future Physicians of Ontario consultation (1992). We also asked the Curriculum Review Working Group what they were interested in finding out, looked at the definition of social accountability and reviewed questions PCPE had used in previous consultations. In finalizing the list of questions, we wanted to i) balance both strengths (positives) and concerns (negatives); ii) examine both big picture health priorities as well as ones specific to patient-doctor interactions; iii) to look into the future (given how long it takes to train a doctor); iv) identify implications for the medical curriculum. We ended up with 7 questions used for both the forum and survey. These were:

1. What are the strengths of health care in BC?
2. What are the priority health concerns for you / the people you work with?

3. What are the current strengths of the role that physicians play in your community? What could be improved?
4. What are the key issues / trends that will affect the role of physicians in the future?
5. What are the characteristics of a good doctor-patient relationship?
6. What ideas do you have about how doctors should behave differently?
7. On the basis of your answers to the questions above, what are the most important knowledge, skills and attitudes that should be emphasized in the medical school curriculum?

The forum

The forum was held from 5.30 to 7.30 p.m. on 3 December 2019 at the Paetzold Multipurpose Room, VGH. It was attended by 20 patient / community members (15 others who were expected or 'maybes' were unable to attend on the day). Participants were pre-arranged into four groups to ensure a diversity of members and perspectives at each table. Each group acted as an independent focus group (with facilitator and note taker) to give each participant time to respond to each question. The group discussions were facilitated by three members of PCPE and a community member; note takers were a member of UBC Health and members of the Curriculum Review Working Group (see Appendix). The small group discussions were audio-recorded for reference. The forum concluded with a brief report-back from the groups, focusing on highlights selected by the facilitator and note taker.

The survey

The survey was e-mailed to 13 people who were unavailable for the forum but indicated willingness to provide input, as well as the 15 people expected at the forum but unable to attend. The survey could be completed as an attached Word document or through Qualtrics, UBC's on-line survey instrument. 15 surveys were completed by 18 individuals (multiple input from some organizations).

The video

We also made a short video to accompany the written report and bring it to life. In our confirmation e-mail we described the video project and asked for expressions of interest. Two participants offered to take part ahead of the forum and another 4 volunteered on the day. Participants could choose which question they wanted to answer.

The report

A total of 38 people provided input into the consultation. All responses were anonymized but respondents chose how they wanted to be acknowledged in the final report (see Appendix for list of participants). PCPE compiled the notes from each of the four groups at the forum and duplicate ideas were condensed. Responses to each question were organized into major themes along with illustrative quotes from the notes or audio recordings. A separate similar analysis was done with the survey data. The themes from the forum data also worked well for analyzing the survey data, so the two data sets were combined. Major points from the data were summarized under each theme. The themes were reorganized to remove overlaps between responses to different questions.

1. Strengths of health care and the roles of physicians in BC

1.1 Publicly funded and accessible

“We have affordable and accessible health care.”

The main strength identified by all participants is that health care is affordable because it is a publicly funded system so that people get the care they need. People have equal access to services regardless of their ability to pay; no-one is turned away and most people have access to a doctor.

Participants identified various efforts that have been made to improve accessibility and reduce wait times. Primary care networks were identified as a great start to accessibility and successful health care for many individuals, and the opening of Urgent Primary Care Centers across BC has reduced wait times. Within large metropolitan areas of BC there are lots of walk in clinics and hospitals that are accessible by transit and have good clinic hours. More physicians are using e-health platforms for simple appointments to reduce the time required for patients to travel to and from and wait in clinics; many specialists, particularly in the lower mainland are accessible through TeleHealth. More MRI machines and appointments have been added so people don't have to wait as long.

1.2 Skilled health professionals

A second strength is that BC benefits from well trained and skilled health care providers – doctors (including a wide range of specialists), nurses and other professionals.

“We know that there are many great care providers in BC who work to ensure that patients receive the best possible care in a system that is overstretched and under supported.”

Physicians are recognized as knowledgeable and trusted healthcare leaders. They care about patients, are highly skilled and always looking to keep up-to-date and improve. Physicians are the gateway to all other health care. They refer, order and interpret tests, diagnose, prescribe, monitor, treat, inform, educate and recommend. They can help patients navigate a system that can be overwhelming and not necessarily transparent or easy to navigate. They have the opportunity to build relationships and trust with their clients, based on mutual respect and shared knowledge. They were perceived to be best at dealing with acute issues. Some physicians are very engaged in patient care and education and do a lot to support their patients and the broader public in their respective fields. Physicians are also becoming more involved in community development (or collaboratives) that enhance quality of care and/or access to care and in developing clinics to meet specific population needs.

“At BC Women’s we have world class physicians, many of whom also contribute to research programs with academic institutions.”

There was especial recognition for the important role of the family doctor as being the first point of contact for any patient. They have knowledge on a vast array of health issues, are able to refer to a specialist when necessary and can follow patients with consistency throughout their life. The family doctor has the opportunity to be team-based, and a coordinator and coach.

1.3 Good services and models of care for particular populations

Participants identified particular parts of the health care system that provide excellent specialist care. Examples given included good emergency and urgent care, health care for children (good early interventions, easy to navigate, respect for child as individual), specialized clinics that address certain health conditions, for example, TransCare BC is a world leader in providing informed care for people previously treated with an un-informed or biased approach. Midwifery services are available for women with trauma. There is a strong network of community organizations in the frontline who work with marginalized populations and practice trauma-informed care. The Rapid Access to Consultative Expertise (RACE) program is also innovative and important to help serve rural communities. The First Nations Health Authority provides great coverage for people with unique needs.

“The HIV community is, in many ways, privileged in the health care system. Yes, it has its faults but because a group of doctors got together decades ago and realized that if they were going to tackle that issue as a disease coming into the province they had to work together collectively, take control of the drug supply as drugs became available and everything comes out of St. Paul’s Centre for Excellence. As the years have gone by they’ve trained up more doctors to go rural than just stay urbanized. That is certainly a success because the world comes to BC to learn what we did right. I’ve had gold plated health care service.”

“We have an Arthritis Centre and I was fortunate with navigating the system. I was provided a social worker that was able to give me resources and let me know what I was eligible for and apply for. Why doesn’t that happen in all disease groups? It’s a really great example of a health care hub.”

There is also recognition that some exemplary models of care, especially for people who are more marginalized, are stretched to capacity, underfunded and not available throughout the province (see section 2.1).

“There is excellent leadership happening in youth health care, however they are underfunded and over worked. Models such as the Foundry provide an ideal demonstration of how to support youth with their healthcare needs - yet the staff are stretched thinly working long hours to meet the needs of the youth. TransCare BC is also delivering incredible support to Trans youth and yet is consistently underfunded and lacks the ability to increase impact in rural spaces, which require more resources simply as a result of the demands of the geographical region.”

1.4 Responsive to change

Participants had a sense that genuine efforts are being made to improve the health care system and respond to the needs of patients even though there are financial constraints. Policies and practices are changed to meet changing societal needs, health care providers don’t wait to make improvements happen.

“There is a willingness to investigate and implement system improvement, quality improvement and to include patient/consumer voice in those processes.”

2. Priority health needs and improvements

2.1 Better care for the under-privileged

Participants were clear that the health care system works best for privileged people. More needs to be done to reach those marginalized by race, income, culture, or health and to provide specialized and holistic care.

“The further you move away from being privileged, the less accessible care becomes”.

“People making decisions are so many steps removed from people who are using the system. The system was designed this way to work for people with privilege, and keeps marginalized people sick but just well enough to not complain too much and also just afraid enough that they’ll lose the pittance of care that they receive that they won’t complain too much.”

“The further removed you are from privilege and the more exhausted you are by the other types of oppression that you’re experiencing the less capable you are of navigating that system because you’re already tired from the other things in your life. The more privileged you are the more agency you have and the more resources you have and the more energy you have to knock on doors until someone gets you answers. Otherwise you just give up because you’re tired.”

Participants represented a wide range of health conditions and populations, most of which had specific needs for improved services. Examples included: chronic health care, mental health and addictions, services for non-English speakers, respite care, children aging out of the pediatric system, developmental disabilities, dementia, hepatitis C. Many of these conditions disproportionately affect people who are marginalized.

Examples were given of people known to receive sub-optimal care:

- Indigenous people declined services because they are Indigenous.
- People with precarious or no legal status.
- Homeless people who are discharged from hospital back to the street.
- Queer and trans youth.
- Stigma related to addiction and people who use drugs.
- Women’s specific health issues that are repeatedly overlooked.
- People living in remote communities.

“I want to speak about the issue of people with no or precarious legal status who can’t access services at all. We used to be able to refer women living with abusive partners who have Canadian children but they can’t leave this jurisdiction with their children. They are stuck here for 2 or 3 years until they get their legal status and they can’t access any medical services because they can’t afford to pay. So they used to access Pine Free clinic and since that’s been gone there’s no regular place that they can go to get services. The kids have access but they don’t. So that’s a huge issue and we’re seeing an increase of women in that situation because of mobility worldwide.”

“In the Fraser Valley, I see how the health of youth is largely impacted by the lack of accessible health care in addition to the lack of gender affirming and LGBTQ2S knowledgeable care available within the region. Sexual health testing is minimally available and is difficult to access in small communities.”

They also noted that many people living with a chronic illness or disability are low income and therefore do not have access to ongoing therapies (physio, OT, massage, etc.) or support staff, to affordable medical equipment and devices, or to prescriptions that are not covered as they don't have benefits or the money to pay for them. A diagnostic (stigmatizing) label (e.g. autism) may be needed to access funding.

Potential solutions include:

- Specialized models of care (such as the exemplars from 1.3) could better serve people with complex needs and marginalized groups.
- Access to trauma-informed health care (trauma as in having lived through traumatic events) that recognises diversity, such as trans health, Indigenous health, harm reduction, and accessible health care for people without documentation.
- Expansion of and stable funding for services that have been shown to work (e.g. fully funded community-based sexual assault centres like VSAC in Victoria across the province).
- Funding for more online/phone service since many marginalized people do not feel safe in hospitals, walk -in clinics, etc.
- Better housing solutions for people with chronic mental illness (institutionalized or on the street; social housing is not working either).
- Mental health support that is client-centred.
- Access to peers and support workers.

2.2 Better care for everyone

In addition to the specific needs summarized above, participants identified general issues with the system that affect many people, including fragmentation of care, physician shortages and wait lists, unnecessary bureaucracy, time constraints, care for people in remote areas, and physician attitudes. Although these are concerns for everyone, barriers are greater for marginalized people.

Fragmentation of care

Participants gave many examples of fragmented, uncoordinated care such as the lack of transition between hospitals/home/social services in public/community services, and problems with referrals and follow-up. They identified a need for the continuum of care, including access to housing, food security, prescriptions and non-medicinal therapies, and stronger communication amongst disciplines and to work together to understand the system.

“The system is divided but people don’t know what to do. Patients find it hard to know what their rights are and need assistance navigating the health care system.”

Physician shortages and waitlists

The lack of access to a family physician because there are not enough and time is limited (5-15 minutes / visit) affects all health concerns. Participants were worried about the proliferation of walk-in clinics and lack of coherent primary care.

Participants gave many examples of long wait times to receive care. Many appointments with specialists take months to arrange. Examples included referrals getting delayed and children aging-out before getting care, long wait lists for children who need access to assessments (e.g. for autism), lack of treatment and detox beds ready and available on demand.

“Long waitlists = no services = loss of quality of life and income = increase burden on society.”

Time

A major concern is the limited length of time with doctors and feeling that patients are commodities in the system. Participants are looking for system improvements that would permit general practitioners to be able to spend more time with patients as needed.

“If a family doctor sees 50 patients in one day is a good relationship possible?”

Health care in remote locations

In more remote communities, there is up to a year wait for access to specialist care e.g., paediatrician. Many rural areas do not have certain specialists (e.g., movement disorder neurologists) and therefore require patients to travel long distances. In rural/smaller communities, even if you find a doctor who is safe, you may still deal with oppression from staff.

“The rural-urban divide when it comes to accessing care providers and treatment continues to be a major issue for our community.”

Physician attitudes

Participants perceived many problems to be associated with physician attitudes (see also section 4.2).

“Physicians are hub of the system, and hold all the other parts together and therefore must be able to communicate with the various parts, the patient/client included. I believe communication/cooperation skills could be overall improved.”

Potential solution: alternative care models

Participants advocated for system change and alternative care models to reduce over-reliance on the physician and provide funding for other services that can help just as much/better than medical doctors or surgery (physio/nurse/pharmacist/etc, education programs, access to mental health services).

Reliance on the doctor as the gatekeeper to various types of care and benefits was deemed to create unnecessary bureaucracy and requires physicians to know of services/supports in order to provide accurate information and get the right supports. Doctors are not always best positioned to fill the forms – are rushed, have competing priorities and are not incentivized to fill out the forms accurately and quickly.

“One thing I’ve found frustrating personally as a patient is the gatekeeping role of physicians. It’s important they do that and also it can be misinformed or coloured by stigma or out-dated mores – we’ve had people tell us their doc told them they couldn’t get hep C treatment because it’s really expensive and has lots of side effects. Neither are true”.

“If the systems were better organized and resources better allocated, acute pain could be dealt with faster to reduce long term consequences.”

“Streamline bureaucracy for things like dispensing methadone – does this have to be done by a doctor?”

Participants advocated for team-based, coordinated care to maximize health resources (not all via the doctor) and called for the integration of medicine with expanded scope of practice of nurses, pharmacists, and public health/community services.

They also advocated for alternative funding models. Remuneration disparities make certain specialties less attractive and create shortages. Family physicians are underpaid compared to specialists. The funding of health care needs to allow doctors to spend more time with patients.

3. What are the key issues / trends that will affect the role of physicians in the future?

Aging population

A key issue will be the aging population because not only are people living longer but the baby boomer generation are entering old age. There are major implications related to the diagnosis and care of chronic illness, addressing co-morbidities, increased prevalence of certain conditions such as MS, Parkinson’s and dementia, need for end-of-life care and issues related to assisted dying. Elderly people are more likely to be house-bound and isolated and lack personal and home support to access care.

Other emerging health priorities

Participants noted that the increase in addiction and mental health issues is already impacting how physicians provide care, along with the compounding issues of an aging population. They also identified that climate change / severe weather will affect medical supply systems, food systems, infectious diseases, etc. requiring new and nimble solutions to emerging problems.

Need for team-based / shared care / holistic care

This was a major priority identified by participants in order to provide holistic care, reduce the administrative burden and add capacity. It was noted that the scope of practice of health professionals is changing with an increasing role for nurse practitioners and pharmacists, though the full potential for this has not been realized. They highlighted the potential for an expanded role for nurses, but a lack of uptake system-wide. Participants identified physicians as working in silos, instead of being part of multi-disciplinary teams and perceived a resistance on the part of physicians to give up control, share

leadership and develop collaborative working relationships, and adapt to a multidisciplinary team model of care.

Technology

“E-health will continue to grow and develop; the system and care providers need to adapt to ensuring that patients are able to connect with care providers in ways that work for them.”

This was identified as another major issue that will affect health care, with both positive and negative consequences. Technology could streamline the system and facilitate many aspects of health care through virtual clinics (for pre-diagnosis, medical advice), telehealth / videoconferencing (for patients in remote communities), on-line systems that can provide anonymous advice and support for vulnerable or stigmatized people (e.g. advice on sexual behaviour, domestic violence), and electronic medical records and reports that can be accessed by patients (e.g. my ehealth). Patients are already using technology (Internet, social media) to find health information, keep up-to-date with new treatments and find support groups. Technology has the potential to expand practice and intersections of health care providers across disciplines. On the downside, telehealth may not be the best thing for complex needs, and the elderly, people with limited English and certain other populations may not be able to access technology. Other concerns include the lack of social and emotional contact with health care providers, concerns about privacy, and the need to empower / educate patients to manage information.

Costs

The aging population and personalized medicine will increase health care costs and raise questions about how funding for health care should be allocated, and pressure to consider alternative models of health care funding such as fee for service.

The rising diversity of culture

“The future is diversity and inclusion and respect of the agency of every person including those with developmental disabilities.”

Participants noted the increase in diversity in our society, from the increased number of youth openly identifying as trans to immigrants and refugees from war-torn areas who do not speak English. Keeping up with emerging identities of patients can be overwhelming and short visits make it difficult to take culture into account, leading to distrust. Trauma-informed and culturally safe care will be needed.

Involving patients

Participants reiterated the need to recognize that patients are knowledgeable and want to be respected and have an active role in their care. Key roles of the physician will be to help patients find good information online, acknowledge and respect patient advocates, and practice a shared decision-making model of care that gives patients more voice and autonomy over their care and treatment pathways.

4. The doctor-patient relationship

4.1 What patients want

A good doctor-patient relationship was characterized by good interpersonal and relationship skills on the part of the physician. At the heart is the need to see patients as people first, and to recognize that the patient experience is a human experience. Participants identified benefits that result from a good doctor-patient relationship as well as problems that result from poor relationships. The following were the most frequently identified characteristics of a good relationship: time and presence, trust, respect, transparency and honesty, continuity of care, non-judgmental understanding, two-way communication, and partnership with the patient (see Figure below). Many of these characteristics are interrelated as shown by the following quotes:

“The biggest thing we hear is either ‘my doctor is awesome, they treat me with respect, they listen to me and they never make me feel stupid’ or the opposite. When people feel comfortable, they’re going to be more engaged and willing to do what needs to be done – take meds, get tests, keep appointments, be engaged and respectful”.

“What builds trust is when doctors are not afraid to admit what they don’t know and ask a colleague for help. Trust builds when a patient feels that they are heard, when they have the opportunity to ask questions and when a follow up appointment is booked.”

“I want doctors to be a co-collaborator in my care. Create space for me to make decisions about my health. Not a one-sided exchange. Not sticking to a formula. If trust hasn’t been built, some questions can be very triggering. It takes time to build trust. I want them to ask how is life, what’s happening in my life.”

“Someone who is respectful and willing to be a partner in health. Kindness is also important. Being a good advocate for the client/patient. Knowing that the patient is the expert in their own health and wants to have all the information to make the best possible decisions for themselves and their families.”

“It’s important that doctors realize that they may need to work to help patients overcome distrust or fear of the health system and to encourage them to use the system as needed rather than avoid.”

Appointments should be conversations between the doctor and patient, rather than lectures or question and answer, with all information shared. Although patients want understanding and compassion, they primarily want to be treated as partners in care and to engage in shared decision-making (physicians should explain all potential outcomes and what the options are). The doctor is not expected to fix the patient or have all the answers, especially in the case of chronic illness or disability. Their role is to empower the patient to manage their health condition and access resources. The doctor and patient need to value each other.



Word cloud showing key words used to describe the good doctor-patient relationship

4.2 What needs to improve

Doctor and patient as partners in care

Participants recognize that doctors work under constraints, have a difficult job and are trying to do what they can with the resources they have. They understand that knowing how to speak to people in the myriad of situations faced by physicians is undoubtedly difficult. However, they also saw the need for major improvements in the way physicians interact with patients. The strongest ideas expressed in relation to people’s actual experience with physicians were not being taken seriously or believed, not being treated like a partner in care, and experiencing culturally unsafe care. Some of the consequences include delayed or missed diagnoses, and people avoiding care because of fear or distrust of the system. There was a great deal of frustration expressed about physician attitudes towards patients and family members, and a need for humility, openness, understanding.

Participants want doctors to communicate information so that patients can be well informed and learn to advocate for their needs. Various practical methods were suggested to promote the informed patient such as doctors writing down what they’re telling their patients, or encouraging patients to find an advocate (who could accompany them to appointments), letting patients see/have records of all their tests, recommending to patients that they keep a journal to keep track of symptoms and side effects, what the doctor says, questions to ask. Physicians should learn from patients and get feedback through asking patients / surveys/focus groups. How did I / we do today? What has been your experience? How do you feel about taking certain medications and the side effects? Participants urged doctors to be accountable for their mistakes, be clear on expectations and what they can do for the patient, and to be okay with uncertainty and not knowing.

“Physicians also need to hear out patients’ concerns without being dismissive, understand that people do know their own bodies and respect them as experts of their own lives. It can take 7+ years to find a diagnosis because doctors don’t trust what patients are saying about their body. People know their own bodies and are the experts”.

“Understanding that physicians work within the constraints of the current system, and that time with patients is limited, we believe that doctors need to acknowledge patients’ lived experiences as valid and important contributions to their appointments and diagnosis and treatment plans. Physicians need to support patients to express concerns about treatment options and offer alternatives or at least take the time to explain why alternatives may not be appropriate. Physicians should also ensure they explain any tests or treatments they prescribe and ensure that the patient understands the reasoning behind it. Encourage patients to take notes or write information for them; many things could be added to regular processes e.g. information for the patient to keep on what is being tested for, and why, could print automatically along with lab requisition forms.”

Adopt a more holistic approach

There is a feeling that doctors don’t appreciate the link between mental and physical health. They don’t evaluate what they can’t see and they over-evaluate what they can see. They need a more holistic approach to the visible plus invisible. Look at the patient's overall health and wellbeing and suggest other practitioners if applicable. More follow up / follow through and checking that patients have the resources and supports to implement the recommended treatment plan.

“They are unaware of the body/mind connection and see my body parts in isolation not as part of a whole. Allied health workers are much more aware of that and have more success helping people.”

“Physicians think in silos, only deal with the body, and don't know how to work with the social determinants of health. They are often too removed from the issues of poverty, Indigenous people’s issues, wife assault and sexual assault, refugee issues. These impact greatly on people’s ability to access and participate in their own health solutions.”

Be open to change, alternative ideas (respect / believe the patient)

Physicians should be open to sharing power and working in ways they are not used to working, e.g. writing down instructions, encouraging patients to bring an advocate, engaging in conversations about complementary treatments and alternative therapies. They should respect patient choices that might not be their recommendation, e.g. women in abusive relationships may not be ready to leave and may avoid seeking medical help if pressured to leave partner. They should admit when they don’t know about a specific health concern then say so, don't assume, if they don't know, that the symptoms are not real or valid, and make the effort to learn on their own.

“Don’t be the road block; be the pathway”.

Practice cultural safety

Patients need culturally safe environments. Physicians need to understand the communities they are practicing with and also to connect with the communities that they want to be welcomed to their clinic.

They need to see the people outside of the doctor's office, understand their lives, and cultural, age, belief differences. Doctors should not make assumptions, e.g. about the sexuality of their patients or that their patients are sexually active, about pain tolerance based on race (research shows that women and people of colour are less believed in regards to their physical pain). They need to practice trauma-informed and oppression-informed care – be aware of the triggers that can hinder care. They need to know legal frameworks (immigrants, refugees), and understand the criminal code.

“My experience, both first hand and as an advocate, more compassion, more knowledge on poverty and systems of oppression and how that can be barriers to folks being well or even wanting to be well.”

Work with others

Participants are concerned about the stress that physicians are under that affects their mental health and wellness and, in turn, affects patient care. Physicians should let go of some of the responsibilities that are currently on their shoulders and incorporate a more multidisciplinary approach. They should be open to an expanded scope of practice of other health professionals including nurse practitioners and pharmacists. They should be informed about support organizations, especially for patients with a new diagnosis and recognize the therapeutic importance of patients connecting with 'like' others. They should provide guidance and resources for caregivers supporting the patient.

“Other professionals can assist in patient care, you don't have to be all things to all people. Get the work-life balance back.”

5. The most important knowledge, skills and attitudes that should be emphasized in the medical school curriculum

Relationships with patients

- Good communication, engagement and empathy. Make connections with their patients. Patients are people, not diagnoses.
- Ability to hear a patient's point of view and perspective on their symptoms, diagnosis, disease. The patient is a self-expert and active participant in their own health. Don't make assumptions.
- Physicians should be open to having conversations with their patients, as opposed to focusing on a script-like Q&A or back and forth.
- Doctors need to learn how to provide hope to parents and not just grim prognoses.
- Getting to know patient so they recognise if they are not doing well. Getting to know and trust family.
- What quality of life means to each patient - not 'you should be happy it's not so bad' - that devalues your patient and their values and forms cracks in relationships.
- Patient shares personal information – it is difficult to do repeatedly. Help patient feel safe.

Cultural safety

- Students should be taught cultural safety and cultural awareness: what it means to work respectfully, compassionately and client-centered in all communities.
- There needs to be a strong focus on training to understand implicit bias across multiple issues including but not limited to: race, gender, sexual orientation, religion, socio-economic status and disability. This training needs to include how the patriarchal and colonized health care system that exists in BC is inherently hard for many populations to interact with.
- Medical school must have training on social issues and the impact of colonization, male violence against women, refugee issues, and to understand every culture has its own set of beliefs, values and solutions to their bodies and health and that western medicine is often an antithesis to that.
- Reducing stigma towards people living with HIV, involved in sex work, with precarious migration status, with transgender experience, and intergenerational trauma from systemic oppression.
- Bring more Indigenous culture to medical school and teach Indigenous cultural safety so that doctors have a better understanding of inter-generational trauma experienced by the majority of the Indigenous population they serve and how that plays a role in illness and accessibility.”

Holistic approach to diagnosis and care

- Being able to make an accurate and timely diagnosis of an acute or chronic disease and mental illness.
- Look at the person more holistically: its not always the information that people present, its their whole picture.
- Teach how the body is a whole and not separate into little compartments. How people can have many diseases with overlapping symptoms.
- More training in assisting patients with ongoing care related to a chronic illness. More training in identifying and treating cognitive issues and depression/anxiety.
- Know how social determinants of health affect people’s health outcomes and know how to respond to them or at least have appropriate referrals.

Team work

- Ability to co-operate, communicate, co-ordinate with people and administrative systems.
- Learn how to collaborate with other health professionals who are able to support patients in order to provide holistic care. Work with people who have expanded scopes of practice.

Primary and community care

- Emphasis on general practice as a valuable asset to the community.
- Learn what community resources are available and be prepared to become a resource yourself.

Change agents

- Need healthcare leaders to be change agents of our system – to address accessibility, affordability, instead of finding work-arounds for people in the system.

- Teach how to change the social structures that promote an exclusionary environment. The system is slow to change but society has moved passed it and we don't have time for petty egos.

Work-life balance

- Work life balance for physicians. Recognize mental health issues in themselves and other healthcare professionals.
- Critical incident stress management, stigma-free care for healthcare workers.

Attitudes

- Curiosity and dedication, understanding / empathy. Humility, openness, ability to listen.
- Teach them to manage their practice and their attitudes with the patient in mind. What accountability is and how the lack of accountability in the health care system turns people away.
- You don't need to know everything, you just need to problem-solve.

Knowledge

- Increased education in medical school around chronic health conditions such as Alzheimer's and other dementias, Parkinson's, MS, chronic pain, diabetes.
- Better education about the health concerns of under-served or stigmatized populations, including mental health, and the health concerns of women, youth, seniors, Indigenous people.
- Knowledge of diversity, disability and cultures, trauma-informed care.
- Knowledge of possible alternative care or treatment possibilities that might be considered by the patient.
- Importance of ongoing education to keep up-to-date on the latest clinical guidelines.
- Know what 'fake' news might be readily available from Internet sources, or other – and caution the patient accordingly.

Curriculum design

- Less emphasis on grades. Patients don't ask about grades they want compassionate people who want to deliver care.
- More work with marginalized communities from the get-go. Get out to communities, shadow in clinics in DTES. More commitment to public health and open access. Students should have placements in community health centres so they are exposed to diverse, multicultural communities.

Medical school admissions

- Selection criteria have to change to ensure admission processes result in students who reflect the diversity of the community.
- Tuition model has to change. Need more people from marginalized backgrounds into med schools.

Implications of the consultation for medical education: afterword from PCPE

Based on the major themes and specific examples given by participants in the consultation, we highlight the following implications for the formal, informal and hidden curriculum to be considered by the Curriculum Review Working Group. Most of the implications involve physician attitudes and what are commonly referred to, and thought of, as the 'soft skills'. It is well known that these are often dismissed by students as unimportant, under-emphasized by preceptors in favour of 'medical' expertise, and inadequately assessed. The changes required to address the concerns expressed in this report are not necessarily solved by adding more content to the curriculum but may require a re-evaluation of the culture of medical education, including admission into medical school.

The doctor-patient relationship. Improving the doctor-patient relationship was the major concern of all participants. We recognize the efforts made in medical schools to improve communication skills and promote caring and compassion. However, patients are looking for more than empathy. They want to be treated as experts in their own lives and partners in care.

Holistic care. Patients are concerned about the fragmentation of care at both the systems and individual level, concerns exacerbated by the increase in complex chronic conditions among a diverse population. Fragmentation underpins the way medical education is delivered. Students learn about patients as individual body systems or through discipline-specific clinical experiences in acute care settings.

Marginalization, diversity, cultural safety. Participants are concerned that health care does not work for many, either at a systems or individual level. Those who experience poor health care as a result of marginalization and stigma include people who are Indigenous, refugees and immigrants, youth, women, the homeless or precariously housed, and those with mental health issues. The (publicly funded) health care system should not perpetuate the social structures that cause poor health but provide a safe haven from an unjust society and preferably model/lead change that could contribute to a more just society. Compared with some health professions, medical education has been slow to adopt culturally safe and trauma-informed approaches to care (as distinct from cultural competency) and address systemic stigma, racism, injustice and oppression.

Models of care, collaboration, teamwork. Participants' concerns go beyond the way interprofessional education is normally addressed in the health professions with its focus on learning and working together in a clinical setting and conflict resolution. They want the patient to be part of the team and want a re-evaluation of the role of the physician in the team and scope of practice. They recognize that doctors are overworked and stressed. What expertise do other professions have and what work can be better done by other professions? What community resources and supports are available to patients?

Changes to the health care system. Many of the priority concerns relate to systemic issues and the need for changes to models of care, scopes of practice, funding. Technology is changing the way health care is accessed and delivered which means physicians will need to be prepared to work in models of care that utilize new technologies, particularly to connect with patients and other care providers in remote areas. What is the responsibility of the medical school to address systemic issues? Are students aware of how

the system works, or does not, from the patients' perspective (patient-centred care)? Given that the medical profession is largely seen as a barrier to change, what is the responsibility to encourage students to be change agents, to change the system rather than be made to fit in with the medical status quo?

Indigenous health. Although we included some Indigenous people and perspectives in the consultation, we recommend a direct, separate, culturally appropriate and ongoing process of engagement with Indigenous individuals and communities to address the Truth and Reconciliation Commission Calls to Action.

Engagement as a process. Finally, we encourage the Working Group to continue to find meaningful ways to engage with patients and community representatives as the curriculum review process unfolds, especially those whose voices are not normally heard.

Relevant reports recommended by participants and PCPE

Monitoring Seniors Services. Office of the Seniors Advocate British Columbia, 2019

<https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2019/12/MonitoringReport2019.pdf>

In her Words. Women's experiences with the healthcare system in British Columbia

BC Women's Health Foundation in Partnership with Pacific Blue Cross

[https://www.bcwomensfoundation.org/wp-](https://www.bcwomensfoundation.org/wp-content/uploads/2019/09/BCWHF_InHerWords_Report_8.5x11_Digital_Sept23.pdf)

[content/uploads/2019/09/BCWHF_InHerWords_Report_8.5x11_Digital_Sept23.pdf](https://www.bcwomensfoundation.org/wp-content/uploads/2019/09/BCWHF_InHerWords_Report_8.5x11_Digital_Sept23.pdf)

British Columbia Framework for Accessibility Legislation. Inclusion BC Brief, November 2019.

<https://inclusionbc.org/wp-content/uploads/2019/12/InclusionBC-AccessibilityFramework-Nov-27-2019.pdf>

Red Women Rising. Indigenous women survivors in Vancouver's Downtown Eastside. Carol Mureee

Martin & Harsha Walia. Downtown Eastside Women's Centre, 2019.

<http://dewc.ca/resources/redwomenrising>

Creating a climate for change. Cultural safety and humility in health services delivery for First Nations and Aboriginal peoples in British Columbia. First Nations Health Authority.

<https://www.fnha.ca/Documents/FNHA-Creating-a-Climate-For-Change-Cultural-Humility-Resource-Booklet.pdf>

Trauma-informed practice guide. BC Provincial Mental Health & Substance Use Planning Council, 2013.

http://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf

A guide to patient engagement. Patient Voices Network, BC Patient Safety & Quality Council.

https://bcpsqc.ca/wp-content/uploads/2019/07/PVN_Getting-Started-with-Patient-Engagement_WEB.pdf

Edwards L, Monro M, Butterfield Y, *et al.* What matters most to patients about primary healthcare: mixed-methods patient priority setting exercises within the PREFeR (PRioritiEs For Research) project.

BMJ Open 2019; 9:e025954. doi:10.1136/bmjopen-2018-025954

Services recommended by participants as culturally safe models of care

Trans Care BC: <http://www.phsa.ca/our-services/programs-services/trans-care-bc>

Kilala Lelum. Urban Indigenous Health & Healing Co-operative: <https://kilalalelum.ca/>

Victoria Sexual Assault Centre: <https://vsac.ca/>

Rapid Access to Consultative Expertise: <http://www.raceconnect.ca/>

Foundry [province-wide network of integrated health and social service centres for young people aged 12-24]: <https://foundrybc.ca/>

Appendix: Contributors to the consultation

People who provided input into the consultation

Melanie Arnis, Richmond Society for Community Living

Emily Bailey, YouthCo

Brenna Bezanson, Project Coordinator, Trans Health Research Project (CGHSE)

Don Bindon, BC Director Canadian Spondylitis Association

Stacey Bradshaw, MS Society

Hilary Brown, UBC Health Mentor Program & Member of Spinal Cord Injury BC

Jami Brown, Engagement Leader, Patient & Public Engagement, BC Patient Quality & Safety Council

Rhianna Coyle, Richmond Society for Community Living – Self Advocate

Jennifer Campillo, Richmond Mental Health Consumer and Friends' Society

Erika Cedillo, Inclusion BC

Stacey Dawes, Parkinson Society of British Columbia

Sekani Dakelth, Megaphone Speakers Bureau, Community Member and Storyteller

Grant Dustin, Scleroderma Association of BC

Lynsey Hamilton, Manager of Research & Strategy, BC Women's Health Foundation

Cheryl Hewitt, Public Health Care Activist

France-Emmanuelle Joly, Vancouver Women's Health Collective – women and DTES residents

Franca Lattanzio, Diabetes Canada

Darren Lauscher, HIV Community, UBC Health Patient & Community Advisory Committee & Health Council, Patients in Education

Kent Cadogan Loftsgard, UBC Health Patient & Community Advisory Committee

Leslie Louie, Sunny Hill Health Centre for Children, a program of BC Children's Hospital

Justina Loh, Executive Director, Disability Alliance BC

Amy Ma, Parkinson Society of British Columbia

Jim Mann, Living well with Alzheimer's community

Heather McCain, Creating Accessible Neighbourhoods & Chronically Queer

Shanon McQuitty, Arthritis Patient Advisory Board @ Arthritis Research Canada & Patients in Education

Kristie Nicol, Public Health Care Activist

Aimee Nygaard, Principal Giving Officer, BC Women's Health Foundation

Sharon Paulse, Counsellor, Adult Childhood Cancer Survivors Program, Late Effects, Assessment and Follow-up Clinic, BC Cancer

REACH Community Health Centre, Multicultural Family Centre & Spanish speaking cross-cultural health promoter

Melanie Reid

Lisa Rupert, YWCA Metro Vancouver

Deb Schmitz, Executive Director, Pacific Hepatitis C Network

Anne Stoll, Francophone Services of PHSA & member of the community

Tara Taylor, Community Engagement and Development, SpencerCreo Foundation

Sharon Tomlinson, Muscular Dystrophy Canada

Casey Vickers, Vancouver Women's Health Collective – women and DTES residents

Patricia Wallace, Parkinson Society of British Columbia

Mandy Young, Parent, UBC Health Patient & Community Advisory Committee, UBC Health Mentor, Prader-Willi Association.

People who supported the consultation (facilitators, note takers, video)

Patient & Community Partnership for Education

William Godolphin

Cathy Kline

Jen Macdonald

Kurtis So

Angela Towle

UBC Health

Caroline Voisine

MD Undergraduate Program Curriculum Review Working Group

Cary Cuncic

Cheryl Holmes

Ian MacDonald

Barry Mason

