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COMMUNITY AND PATIENT VOICES IN HEALTH PROFESSIONAL EDUCATION

Improving care for vulnerable populations through their participation in the education of health professionals

Research Report 1: Report of Community Key Informant Interviews

December 2013

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THE UNIVERSITY OF BRITISH COLUMBIA

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Contents

Overall CVHEd Project summary

Our health care system has many barriers for people who are vulnerable or marginalized including access to services, communication with health professionals, and receipt of true patient-centred care.

Changes in health professional education can help to reduce these barriers.

We believe that an important change is to draw upon the lived experience of citizens and include their authentic and autonomous voices in an enhanced education for students at the University of British Columbia.

This 3-year community-based participatory action research project will inform i) development of a mechanism for communities to engage with the university and ii) development and evaluation of an educational model leading to participation by communities in health professional education.

The research should lead to diverse end-users of the health care system having the power and a mechanism to have sustained influence and participation in the education of health professionals.

Core Project Team

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Community Interviewers

We gratefully acknowledge the following interviewers for their assistance with data collection:

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Summary of Key Findings

CVHEd Community Key Informant summary for community dialogue

June 25, 2013, Roundhouse Community Centre

The following summary is drawn from interviews with 17 key informants (e.g. Executive Directors, CEOs) representing 13 Lower Mainland community-based organizations. Interviews were designed to explore their ideas about how the involvement of community organizations, patients and citizens in the education of health professionals could be made a core part of health professional education at UBC.

1. **Community organizations provide a range of educational activities for patients / clients.**

   Key informants described a wide range of educational programs for patients/clients. Peer support, adult learning, health education/promotion and social inclusion underpin many of these programs. Many have developed programs that engage vulnerable / marginalized members of their community.

2. **The involvement of community organizations in the education of health professionals is episodic.**

   Many organizations are involved in the education of health professionals. While there were some examples of longer term engagement with health professionals (e.g. certification programs, fellowships), educational activities for health professionals were typically in the form of guest lectures, workshops and practicum placements for students.

3. **Health professionals need to be better at working in partnership.**

   Discussions of how health professionals should behave differently largely focused on the need for health professionals to work in partnership with patients and other health professionals. For our key informants, this meant that health professionals recognize the expertise of others, understand patient's lived experiences, take a holistic approach, be non-judgmental and more sensitive to cultural and language barriers in health care.

4. **Patients and community members could be involved in many different educational activities.**

   Organizations identified different ways in which their members could participate in the education of health professionals along a spectrum of involvement. The creation of learning materials and sharing personal experiences were identified as the most obvious and easiest ways in which they could be involved, at least initially.

5. **Training and mentorship are needed for some levels of involvement in education.**

   Many key informants thought that there would be few people who would have the skills and confidence for involvement in activities such as assessment of students, curriculum development or sustained involvement in decision making at the institutional level. Gradual entry into the education process could begin with preparation in the community by community organizations, leading to a step-wise progression of increasing involvement beyond curriculum delivery. Higher levels of involvement would require some mentorship from the university.

6. **Avoid "academic projectitis" and invite on-going, mutually beneficial relationships with community organizations and their members that support their involvement in educating students.**

   Long-term buy in from the community and affecting long-term change requires deep commitment to building on-going partnerships. One informant referred to the revolving door of students and university projects that flow in and out of her organization as "academic projectitis." While seen as important obligations for some, these sorts of relationships are taxing to the tight resources of community organizations.

7. **Develop staff liaisons based in community organizations to broker relationships between the university and community educators.**

   On the ground staff members within community organizations are best situated to recruit and support patient educators. They have established trusting relationships in the community and are in the best position to know their members' skills and abilities, special needs, individual circumstances, when they are ready to participate or not, etc. A dedicated staff member within the community organization also helps to create institutional commitment within the organization.

8. **Create a mechanism for the community to communicate with the university.**

   There needs to be a mechanism for efficient sharing of information, reporting and solving problems. Dedicated liaisons who can work effectively between the community and university to resolve issues in a timely manner are needed.

9. **Provide appropriate training and support for community educators.**

   Many individuals will need training and support to acquire the skills and confidence to be effective teachers. For example, training on how to tell their story in ways that are helpful to students should be offered.

10. **Recognize and honour patient and community expertise.**

    Patients and community members have important contributions to make to the education of health professionals. Sharing one's lived experience can be emotionally taxing and risky because of the uncertainty about how it will be received. If they do not feel valued and their contributions are not recognized and rewarded appropriately, they could feel exploited and/or become unvested in the process. For some this may mean monetary compensation. Others need to see that their contributions are making a difference. Systems of acknowledgement and recognition need to be developed that are commensurate with their contributions. Mechanisms for sharing the value (e.g. outcomes) of their contributions also need to be developed.

11. **Prepare students for a different kind of learning.**

    Learning opportunities that involve vulnerable citizens will naturally be a very different learning experience from the ways of learning that are familiar to students. According to our informants, students need to be prepared to "get their hands dirty" and respect the opportunity to learn from vulnerable citizens as a privilege not to be taken lightly. Some organizations have had bad experiences with students who did not see the value in some of the work they were doing in community-based organizations.

12. **Learning activities that involve vulnerable citizens need to be based in the community.**

    Informants were unanimous that in order to access truly marginalized voices, students would have to come to them. While many liked the idea of creating opportunities for their members to come to campus, the university is seen as largely inaccessible for the most vulnerable and marginalized. The most authentic learning about people's lived experiences would take place in the community.

13. **Develop mechanisms to accommodate special needs and vulnerabilities of community educators.**

    Vulnerable people and people with chronic conditions / disabilities have significant burdens that will compete with their ability to participate in education. Conditions need to be created to facilitate their involvement when they are ready and able yet, account for times when they will be unable to take part. The special needs will vary across individuals. Mechanisms will also need to attend to issues of power, confidence, self-efficacy, varying levels of literacy, level of comfort, etc. Opportunities to participate will need to consider each individual's specific circumstances.

14. **People from the community have a variety of expertise to share with health professionals.**

    Key informants thought that people from their communities have much to offer health professional education including teaching students about patient's lived experience, stigma, advocacy, communication skills and cultural knowledge.

15. **A partnership with the university is beneficial to the community.**

    A community-university partnership was seen to have both short and long-term benefits for the community. In the short-term, it validates the work of community organizations, is seen favorably by funders and has direct benefits for the community members who participate (e.g. empowerment, personal growth). In the long-term, key informants envisioned better health care by health professionals more responsive to community needs.

Key informant selection and recruitment

Using an asset mapping approach, the core project team developed a list of approximately 60 contacts within community-based organizations known to work with vulnerable / marginalized populations in BC. From this reference group, a short-list was created that narrowed the list to approximately 30 contacts known to be involved in education and thought to be potential educational partners who could contribute to health professional education at UBC. In consultation with the Research Advisory Committee this list was further revised and refined to identify key informants who are well-connected in the community.

An invitation letter was emailed to 20 selected key informants (e.g. Executive Directors, CEOs) of organizations from the short-list. The invited key informants were from organizations that serve the following vulnerable populations: chronic disease, disabilities, Aboriginal, mental health, HIV/AIDS, immigrants, women, seniors, youth and families. The letter invited them take part in an interview to explore their ideas about how to involve community organizations and individual patients / clients in the education of health professionals at UBC. 16 agreed to be interviewed. Four did not respond to the invitation. Three identified others in their organizations who would be better suited to answer the interview questions. Three who initially agreed to be interviewed did not respond to attempts to schedule an interview. A total of 17 people representing 13 organizations were interviewed.

Invited Organizations	Sector	Response	No. interviewed
Developmental Disabilities Association	Disabilities	Yes, then no response	0
Spinal Cord BC	Disabilities	Yes	1
Inclusion BC	Disabilities	Yes, then no response	0
IBC Coalition for People with Disabilities	Disabilities	Yes	1
Community Living BC	Disabilities	Yes	2
Reach Multicultural Family Centre	Immigrant	Yes	1
Resosante	Immigrant	Yes	1
Immigrant Services Society	Immigrant	No response	0
Canadian Mental Health Association	Mental health	No response	0
The Kettle Friendship Society	Mental health	Yes	1
Vancouver Community Mental Health	Mental health	Yes	1
Positive Living BC	HIV / AIDS	Yes	3
Youth Co AIDS Society	HIV/AIDS, Youth	No response	0
WISH drop-in Centre Society	Women, Sexual health	Yes	1
Options for Sexual Health	Youth, sexual health	Yes	1
Alzheimer's Society	Chronic disease	Yes	1
Multiple Sclerosis Society	Chronic disease	Yes	2
Family Services of Greater Vancouver	Family services	Yes, then no response	0
Native Health	Aboriginal	No response	0
United Way	Seniors	Yes	1
Total participants		**20**	**17**

Interview design

The interview schedule was developed by the project team. It was reviewed and revised after consultation with the Research Advisory Committee and pilot testing. The interview questions were designed to lead participants from describing concrete aspects of their work (e.g. their organization's educational activities, philosophy, etc.), to their ideas for how health professionals should behave differently and concluding with more abstract thinking about processes and structures that would be required to involve vulnerable people in health professional education at UBC (see Appendix A for the interview protocol). An information sheet with examples of patient roles in health professional education along a spectrum of involvement was emailed in advance of and referred to during the interview to help participants identify aspects of patient involvement in education that were of most interest / relevance to them (see Appendix B). Subsequent questioning focused on the supports, barriers, processes and structures required for authentic participation of patients in health professional education. Interviews were conducted by a graduate student and two individuals with prior interview experience and/or experience working in a community-based organization serving vulnerable populations. Interviewers received two half day training sessions to become familiar with the interview protocol and techniques. The training included a video-taped practice interview with a volunteer from a community-based organization.

Analysis

Interviews were audio recorded and transcribed verbatim. Transcripts were reviewed using an appreciative inquiry approach to identify key themes for each topic area covered in the interviews. Selections of narrative from the transcripts were organized by themes in each of the following topic areas: 1) What educational activities are being done/ have been done that can be built upon? (Interview Question 2); 2) How should health professionals behave differently? (Interview Question 3); 3) What levels of involvement are of most interest / relevance? (Interview Question 5); 4) What needs to happen to support community involvement? (Interview Questions 6 & 7); 5) What community processes and structures are needed? (Interview Question 8) 6) What university processes / structures needed? (Interview Question 8); 6) What can patients/citizens teach? (Interview Questions 4 & 9); and 7) What are the benefits to community? (Interview Question 9).

Key Findings

The findings section of the report is organized by the interview topic areas. Each topic area includes a high level summary of the data and an inventory of relevant narrative organized by themes.

1.What's being done / has been done that can be built upon? (Interview Questions 2)

Patient Education

The community organizations we interviewed are involved in a wide range of patient / community education activities. Programs range from workshops and healing retreats where 30-40 people learn self-care/self-management skills from each other and invited experts to a drop-in learning centre where women in the sex trade learn literacy and numeracy skills. A field trip program that brings Aboriginal women in the sex trade to visit the Museum of Anthropology and public library is good example of how to set up a program to engage women from this community. In addition to providing the obvious necessities of transportation, food, and assigning staff to assist the women find what interests them, the library has a display of things that have been made by the women. Peer support, adult learning, social inclusion and health education/promotion underpin much of community-based programs. Table 1a shows the types of patient education done by community organizations.

Table 1a. Types of patient education done by community organizations

Type	Program / topic	Teachers	Students	Quote
Workshops / seminars	Askable Adult program	Staff	Parents, teachers	1. We also offer something called the Askable Adult program which is a workshop put on for parents, teachers, to be that adult that young people can go to with questions about sex. [CVHEdC01,p.2]
	Diabetes, HIV, STD's	Nurse	Mental health clients	2. The self advocates used to offer educational workshops. They would organize them, they would talk to people about what topics they would like and have speakers come in and usually do it at a speaker forum kind of way. And we have a medical clinic on site. We have a part-time RN from Coastal Health and she does education groups around diabetes, HIV, STD's, those sorts of things. [CVHEdC03,p.2]
	Newly diagnosed workshops	Professionals & patients	Newly diagnosed (Multiple Sclerosis)	3. We have educational workshops throughout the Lower Mainland and it really depends on funding. So our, if we don't have funding then we're not really able to put on the workshops, right, so for example last year we had one workshop in Richmond on research updates in MS and then we had another one in North Van on pain and MS. This year, and we also have two newly diagnosed sessions that we hold andhose are really community effort so we work with the UBC MS Clinic or the Burnaby MS Clinic. We have a psychologist and we have a panel of people living with MS. So what we usually do when we're going to hold an educational workshop is we try and rotate them because our geographical area is so large so we try and move them from community to community and we send a poll out so we ask our members, here's a list of five potential topics and they can also add, you know, topics to that if they have some suggestions and then we take that information and then from there we deliver our workshops. So it is really dependent on funding and we also have one where we've had our annual general meeting which is one of our larger, and that's pared with educational workshop and so that usually will have quite a lot of people attend, usually anywhere from 150 to 300, depending on the topic, so we do do a fair amount of education. [CVHEdC12,p.2]
	Seniors	Trainers	Staff	4. We are often funding workshops so we fund an agency that has something like the elder abuse or another example in law is the representational agreement and that, a representative or representatives from that agency then goes out and holds workshops throughout the region and we have done work with SPARC BC that's identified areas where there's vulnerable seniors and we ask them to target the community organizations or the agencies within those locations on the regional map. [CVHEdC13,p.2]

Type	Program / topic	Teachers	Students	Quote
Healing Retreats / Circles	Loon Lake Retreat	Peers & professionals	Members (HIV)	1. A smaller group of people, approximately between 30 and 40, leave from Vancouver and go out to Loon Lake which is a resort out in the valley and it's there that they learn a skill set on how to live successfully with HIV. We do have, bring in what you might call subject matter experts like doctors and physicians and things like that, but ...a lot of the education that goes on here is by sharing peer to peer. [CVHEdC05,p.2]
	Aboriginal program	Staff / peers	Sex workers	2. Our aboriginal program is in there on Thursday nights and they have healing circles and I think they've got a women who's in there who's going into drumming and talking about drumming and singing and so on and on Friday nights the Carnegie Outreach folks have, they have arts and crafts in there on Friday nights as well. So there's usually something going on in that room and it's all about engagement. [CVHEdC02,p.4]
Support groups /self-management programs / peer support	Advanced planning	Clinical nurse educator	Mental health clients	1. I'm involved with advanced care planning, so advance directives. And again we're looking at that from how do we make sure that patients and clients know that advanced care planning is available to them. We're not talking end of life, we're talking people who are adults and then being empowered to have a voice in how they are treated when they're not able to speak on their own behalf. So it's really empowering people. The other piece that we're working on right now with staff is getting them to think about the decision making piece. So we're doing sort of some initiatives that are, the intent would be that they're empowering individuals to be more assertive in their treatment. [CVHEdCPilot,p.2]
	Diabetes prevention	Staff	Immigrants	2. We have diabetes prevention and health and self management programs which are delivered in the language of the people that are in the program. [CVHEdC04,p.2]
	Resilience	Peers (supervised by lawyer)	HIV	3. ...the last three years have been developing a **one to one coaching program** and resilience education program for people living with HIV and other chronic illnesses. ...we have between six and eight or ten advocates who are people living with disabilities. ...the advocates are highly trained and they're supervised by a lawyer and they provide assistance to people with disabilities in completing forms to access disability benefits, provincial and CPP access, housing, filling in forms for BC Housing and other housing possibilities, accessing various supplements and services they might be entitled to from the government. [CVHEdC07,p.1]
	CARMA	Peers	People with disabilities	4. ...CARMA which is an acronym for **Community And Residence Mentors Association** and that program is a peer support program to help people move out of [Rehabilitation Centre] which is a long-term care facility and rehab facility for people with profound disabilities. So people who've been in car accidents and have multiple physical disability brain injury and so on. So developing the confidence and the supports and the community for those people to be able to move back into the community and live with various supports that they need. [CVHEdC07,p.1-2]

Type	Program / topic	Teachers	Students	Quote
Support groups /self-management programs / peer support	First Link (*partnership with doctors)	Staff / peers	People with dementia and their families (newly diagnosed)	5. …the concept of **First Link** is that we ask physicians, largely physicians, but any health care provider at all, even at residential care. So we build a kind of a partnership in the sense where we say to the health care provider, the physician, would you agree to participate in our First Link program and so what you would have to do is say to anyone who has dementia in your practice or in the work that you're doing or if you're diagnosing them, ask them for their permission to give their name to us so that we can proactively call them and so that, so then that doctor can say I am sorry that the diagnosis that I've come up with is that you do have a form of dementia and but there is some help out there and it's through the Alzheimer Society and would you be willing for me to give them your name… [CVHEdC11,p.7]
Conferences	Positive Gathering			1. Once a year we host a, what is called a positive gathering. It is a two day conference that brings people from around the province into Vancouver, again which where workshops are delivered and information and knowledge transfer occurs. [CVHEdC05,p.2]
	Provincial day conference		Patients, caregivers, family members	2.…up till now and we have to figure out how that will continue next, if it will continue next year not just because of interval changes but there's always been **one big day long conference** that was organized for people affected by MS in conjunction with the Division AGM and we rotated that throughout the chapter so this year we were here in the Lower Mainland but the year before we were in Kelowna, then we were in the Fraser Valley and we were in Victoria, so we target different communities for that. And that's really **aimed at people with MS, caregivers, family members, that's the key target group** for that. [CVHEdC12,p.3]
Newsletters, Websites, social media, videos, webinars, video conference, resources		Peers & professionals (e.g. dieticians & researchers)	Members	1. We have our magazine which is a bi-monthly magazine that comes out every two months in which articles that are written are from community partners like the **dieticians** in AIDS Care or from the **Canadian Trials Network** and we also have a **very large component of what is written by HIV positive members** of the organization who contribute to the magazine. We also have our website which has materials on it. We also re-post and re-tweet things that are of relevance to our membership on our social media. [CVHEdC05, p.1]
	Transition	Staff & peers	Members	2.…we publish a magazine four times a year called Trabsition. [CVHEdC07,p.2]

Type	Program / topic	Teachers	Students	Quote
Newsletters, Websites, social media, videos, webinars, video conference, resources	TeleHealth Travel series	Professionals	People with disabilities	3….we had started a thing quite a few years back called Telehealth which we used around the province. It's a video conferencing system that was in the medical facilities and you could access them by just booking times during the week and then hosting education components where you meet people from all around the province and working with researchers too on studies and getting people and then having them be able to go face to face, go away from the camera and come back to it, things like that. And so we started to really utilize Telehealth in our own directions as far as **bringing professionals in different areas all around medical supplies, sexual health, travelling, bowel and bladder care, nutrition, all these things we were doing province-wide by Telehealth which is now we've evolved into using webinars** just accessed through the computers, right. …We have a big **travel series going on right now where we created a document on how to prepare for travel and just to book flights to thinking about a vacation, getting to the airport, going through the process at the airport, packing, travelling, getting lifted on and off, taking care of yourself and then when you get to the other end** so it's pretty well the whole genre right through. Then we did **videos** for it. We're using a lot of video now and we're working, we had a p**artnership with YVR and West Jet and taking people out there**… [CVHEdC10,p.4]
			Patients (MS)	4. We provide education also through our materials, through our **newsletters**, through people when they call we provide information and education so we do sort of one on one education…The other thing that we do through our National office is we do **webinars,** so we don't organize those but we would, circulate the information …Now those are again primarily geared towards people with MS… [CVHEdC12,p.2&5]
	Self-advocacy booklet			5.…we have a self advocacy booklet on how to advocate for yourself, like how, what do you do when you go to a specialist appointment or a doctor's appointment. These are the things you need to do. So I think we've done some work in that area as well as doing our mail-out to the physicians, you know, providing them with information on MS. [CVHEdC12,p.8]
Community forums, panels	Community forum	Professionals and peers	Members (HIV)	Every few months we hold what is called a community forum which is bringing updates from conferences that may be relevant to our membership or we bring up specific topics like neurological disorders or sleep disorders as they relate to HIV and we present them to the membership. Or we have one doctor present or someone from the medical profession present, a community member present, and we present the material to the population that's in attendance. [CVHEdC05,p.1]

Type	Program / topic	Teachers	Students	Quote
Drop-in centre	In Reach / Out Reach	University instructor (Capilano University)	Sex workers	…with the learning center we have part of, a partnership with Capilano University. They have an **In Reach/Out Reach program** and community development. So we have two instructors, one on Monday, one on Tuesday that come from Capilano University and then we have one of our staff on Wednesdays. So in the learning center they apply, particularly the Monday and Tuesday night women, they really apply I guess what we call adult learning strategies because of course many of the women that come to WISH have varied degrees of education and literacy skills, so and numeracy skills. [CVHEdc02,p.2]
Field trips Museum of Anthropology	Public Library	Staff	Sex workers	The women that are involved in the aboriginal program do two things each year, one of which is go to the **Museum of Anthropology** and one of which is going to the **public library.** But it's all set up so that there's somebody at the museum who knows what the women might want to see or do or talk about and same with the library. And they have somebody who is assigned to them and they really make the afternoon full of things that work for the women. So when they go to the library they might look for books about, you know, cause not all the women come from Vancouver by any means. So whatever their heritage group is and so on and they'll find books about areas and they get library cards and they have this whole really full discussion with that person and **they've actually put a display up in the library of things that they've made here**. … And then with the Museum of course there's lots and lots of beautiful images and masks and **all those kinds of things, regalia, that really are familiar to women** who did grow up with that and so they talk about all those kinds of things, but we also have somebody that goes with them from here so it's organized, it's supported, there's food, there's transportation... [CVHEdC02,p.12]

Health Professional Education (HPE)

Many organizations have extended their work to educating professionals, but most of their involvement with health professionals could be characterized as sporadic / episodic. Educational activities for professionals were typically in the form of guest lectures, workshops and practicum placements. Other ways in which community organizations are involved in professional education included community tours, an 18 month certification program for sex educators, and a specialty fellowship program in dementia funded by the Alzheimer's Society. Examples of the types of professional education done by community organizations are provided in Table 1b.

Table 1b. Examples of health professional education by community organizations

Field Trips / Tours / site visits	1. …tours are arranged for **nurses and other practitioners** in that program [UBC course] to obtain and learn about people living with HIV and their lived realities. The panel that is presenting information is a broad population group. It'll be someone who is a woman living with HIV, someone who is transgendered and living with HIV, someone from within the aboriginal community living with HIV, giving them their cultural and lived experiences to the students. [CVHEdC05,p.2]
	2. …we were talking to medicine, we were talking to **Ph.D. students** on our, you know, some of the things to think about when they get into their profession, you know, **accessible office spaces**, you know, **not touching people or pushing their chair** or, you know, just things around just basic practical education on that which is some people are very afraid of that. … **we got all of those students into manual wheelchairs for a day where they had to go and eat in a restaurant. They had to get on public transit. They had to go into the community. They had to do all the things, they had to ask somebody to open a door for them** and all these sorts of things… [CVHEdC10,p.5]
	3. We may have students that, like nursing students that will book a one hour session and they'll come to the office and learn about the society and learn about MS so we also do that type of education. [CVHEdC12,p.2]
Workshops	1. They do a two day workshop, one would be aimed towards the medical community and then the next day would be towards the HIV positive community. [CVHEdC05p.3]
	2. The other thing that I have done with the BC Center for Disease Control **Street Nurse Program,** was work with **emergency room personnel at St. Paul's**. We did four sessions with them and one with the **ICU folks** at VGH around working with sex workers and sort of identifying key places where they might be able to assist in a better way. [CVHEdC02,p.8]
	3. We've done two workshops this year and two last year with the [Royal] College, the linguistic training and the cultural sensitization. [CVHEdC08,p.24]

Guest speaker / lecture / seminars / presentations	1. …quite often the social work department will ask us, will speak to us about bringing people with dementia to come and speak to the class and some of the professors have relationships now with the people with dementia and ask them directly. But sometimes they might come to us for that and so we've done that for nursing, for social work and not for medicine I don't think yet. And maybe other departments as well. …I'm not aware of every one of them but that's the ones, and it's not a regular thing. [CVHEdC11,p.6]
	2. …at **UBC CPD Faculty of Medicine**. And so this group, so when they're talking about dementia we offer our staff so that they can come and be part of the education for doctors about dementia and so s**ometimes they take us up on it, sometimes they don't.** But I really try and, and you know I've felt like it's been a bit of a fight but eventually the current people who seem to work there, who worked there, and I think sometimes the leadership changes a little bit, they have invited us to come and participate in education which I appreciate. **We haven't heard from them for awhile**… [CVHEdC11,p.5]
	3. We sporadically, like we have been involved in that and I know that in all of our field staff are invited to speak at Sprott College and like Douglas College type of stuff when they were having Licensed Practical Nurses and Home and Support Workers and those kinds of things, Social Support Workers. There's a whole bunch of variety of different terms for these people that I haven't fully grasped and but whatever, like in the programs I educate them a lot of times our staff our asked to come and do a little piece on dementia. So would do it bit but that's very episodic. [CVHEdC11,p.10]
	4. We also sometimes do **inservices** so we might get a call from a **community college** or from a **care aid agency where they're looking for information and training on MS.** So we will go out into the community and do that. We're probably doing less of that now than we have before just because of resources. … Sometimes staff will go into care facilities if they're asked to come in, can you speak about MS and do presentations there. And we have here in the division office one staff person was actually also going out to sort of the unchapter to smaller communities of White Horse or Fort St. John or actually it was just in Cranbrook and again meeting there with health care professionals [CVHEdC12,p.2-3]
	5. …staff education to help make sure that the consumer client voice is fully integrated into staff training experiences. … Actually well recovery oriented services is sort of the keystone of what we're trying to accomplish in mental health and addictions. We're also using trauma informed care and family involvement. So I'm working on a stigma piece right now with a coalition group within our regional body and we're trying to, we're piloting a way of focusing on stigma by changing staff perceptions of mental illness and addictions. … part of what I do in my job with staff education is to talk about client voice and I work very closely with the family voice. So we're helping people see that the health care is not just the clinical piece but the people, person receiving services and their natural support working collectively to help the individual be more independent. [CVHEdCPilot,p.1-2]

Special events / info fairs	1. I've been involved with the Division of Health Care Communication… we were invited to go to the information **fair** that they have in October typically. Yeah, so we've been going to that for a few years. [CVHEd,C07,p.4]
	2. We've done a number of things with the **Alzheimer Clinic at UBC** and they do an education program every January which is awareness month for **Alzheimer Awareness Month** and we do it in conjunction with them. [CVHEdC11,p.6]
	3. We also participate in a big fair which is usually in October. I forget the name of it but we participate there. We have a staff person with our information and usually that person living with MS comes and it's the OT's, the PT's and medical students… Actually the other thing just thinking about health care professionals, we have an equipment provisional program here out of the division office and some of the chapters do a little bit of that. But we require occupational therapy referrals for that and so someone on the Board was managing that program is very regularly in contact one on one with occupational therapists. I think she also does sometimes sort of a newsletter style or something like indication to groups up to OT's that she has email contact with and she also attends yearly equipment fair, equipment ...**Forum where occupational therapists particularly participate and she also usually participates in that with a booth for the MS Society. And again so there's the education about MS and working together to provide equipment.** [CVHEdC12,p.4-5]
	4. We have every couple of years, it looks like it might be every three now, major, and by that I mean three and four hundred people attending from across the community. You've been hearing I think how I define the community, really broad, in November and they're big seniors forums. We held the most recent one was on vulnerable seniors and so there would be learning in that context by the audience from public health officials and then there would be students in attendance…[CVHEdC13,p.5]
Advisory Boards / community consultations / planning tables	1. …other ways that we participate really at UBC is the, when we're asked to sit on advisory boards or community consultations. I'm currently sitting on a prison health initiative that's going on about UBC. [CVHEdC05,p.4]
	2. I was invited to join the DPAS Advisory Committee. [CVHEdC07,p.4]
	3. …the pharmacists themselves have in turn come to these senior led planning tables and they come once a month or once every two months in the case of a couple of our 10 seniors led planning tables. So this to me is an ideal set-up where a health professional is embedded quite deeply in the community and recognizes the advantage of coming out to the planning table where things beyond the seniors health and well-being are discussed, how they participate in the community, what actions they're undertaking, what they're asking of city council in terms of improvements in housing and so general as that and transportation for example. So that is way up there in terms of sort of the embeddedness of the health professionals. Another one …seniors are having a really bad time with hospital discharge, that they're going home and they're really failing to undertake all the instructions that were given them. So they're, um, so they again met with the senior led planning table out in Maple Ridge and worked with the Fraser Health Authority in that case and they got a new hospital discharge system up and working in Fraser Health we understand is using it elsewhere. But, um, I don't know where the direction came, the initial direction came off the planning table or the physicians had heard about it and went. But again that to me is a real nice example of the embeddedness of, um, and the learning and then they of course went on to fix it. [CVHEdC13,p.3]
	4. There are several cases now where grad students have come out and done their research in the context of the planning tables. … invited them to use the planning tables as a portal into the community to get the number of people they need for their studies. And so I think there's a lot of learning by a student that goes on on an individual basis there and they of course have advanced work. [CVHEdC13,p.4]

Programs, certificates	1. …our **SHEC program,** which is **Sexual Health Educator Certification** is an 18 month program in which people who are teachers, nurses, counsellors, trained to become sex ed people and then the completion of their 18 month program and then after successful completion of their practicum they then are certified to be able to go out into schools, either freelance or working for us and offer sex ed in elementary and secondary schools. [CVHEdC01,p.1-2]
	2. We have an **Emergency Preparedness Program** for people with Disabilities which is a reasonably new program. [Name] runs that program and works with the provincial government and with First Responders and so on across Canada to ensure that Emergency Preparedness Plans for organizations and individuals take into account the special needs of people with disabilities in an earthquake or whatever kind of emergency… [CVHEdC07,p.2]
	3. …we do that kind of training [linguistic / cultural], it exists online, it's a 15 module with fake patients and there's one on the assessment of pain and one on the interview and one on heart disease and one on the health promotion… [CVHEdC08,p.25]
Practicum placements Nursing practicum placements (e.g. Langara, Douglas College)	1. …we take a lot of practicum students from Kwantlen and Douglas and I suppose Langara. I'm not, you know, we have had, this term I think we've had 14 practicum students. So people, I mean obviously we have an environment at WISH that is not something that is mainstream and which is sort of difficult for people to access unless they come to us as practicum students. So with practicum students **I'm always very clear that really a practicum student, I personally think it's a privilege for them to be able to come there and interact with the women and learn a little bit about WISH and the downtown eastside, but also very much about the women. And how you actually respectfully interact with people who are marginalized.** [CVHEdC02,p.4]
	2. But I think with the nursing students who have come to us, what's been really great is these group that used to be affiliated with the University of Victoria but went to Langara. ...those women would come to us but they also, part of their work was to go back to their classes and say this is what we did and present about what they did and what they found about, cause obviously working in the downtown eastside and working with women engaging in sex work is gonna be somewhat different than working with children or seniors or you know whomever…. So I think that whole dissemination of information is key to making it so that people actually want to work in this neighbourhood, want to work, not just this neighbourhood but for example, or work with marginalized individuals and **there's only one way to get the experience and that's to be here.** [CVHEdC02,p.6]
Dietetics	3. Well do you know UBC's used to also have, we had **dieticians that came to us through Food Science** or whatever department dieticians come from, and they were also great because they would come, this was some years ago and I think that UBC used to have something where if you went somewhere for a semester, for the three months or whatever, that you would also get credits for that. And so we had dieticians come to us when we used to be at First United Church, and **they helped with the food prep, they helped with menu planning, they did all kinds of stuff.** And I thought that that was fantastic. [CVHEdC02,p.7]
Nursing students (Health Nights)	4. The practicum students as I said before is that they usually, **they just do the work of WISH.** …they did manicures and all that kind of stuff. So they can sit and talk to the women. You know, it's, t**hey don't have to just sit down and be in somebody's face. You can do something. So that was what they did. I think the last nursing students did, they had sort of health nights and they'd pick a topic and then they'd do all this stuff and the women could engage with them. I think it's that, it's, again it's that engagement. It's being able to do something to engage yourself with the women**… [CVHEdC02,p.9]

UBC Kinesiology students College social service programs	5. …we feel really strongly about working with students because it's an excellent opportunity to open people's eyes and help people become more aware of disabilities. So we, the various programs we've always got practicum students or I've just finished working with a **team of students from UBC School of Kinesiology** and I have a kind of a **long standing agreement with the prof there so I work with their service learning placement students every term or two** and they do amazing things. I mean I'm just, **I'm so happy to work with students because they can work on a project that we wouldn't be able to do otherwise and by the time they leave here they see things in a bit of a different way.** So we have a lot of students, we have students who are doing the social service programs at colleges and so on. Um, oh boy, you name it, I've been working with kinesiology students. I've worked with **writing students from Douglas College, nursing students,** that kind of thing. [CVHEdC07,p.2-3]
UBC Art Internship program	6. We have a huge art program and an art show and we use students, we have UBC students coming in and helping with the art program and all of that is very important in people's lives and health to be able to do different things, right, so... They come in and do, they're just doing I think 8 weeks or something, 8 or 10 weeks. They come in and they do an art program. They do art at our other site. [CVHEdC03,p.8-9]
BCIT nursing students	7. We also have placements for nursing students from BCIT and they will work with our, they've been working with mostly our Middle Eastern women giving sort of a 10 to 13 week practicum session where they come every week. The women decide what topics they want information on and then they do discussions that sort of fit with the women and not, not sort of informal education lecture style but in discussion and also getting women to give input because they also have the knowledge. [CVHEdC04,p.2]
UBC Law students	8. …the other thing we've done, I've done, in the volunteer legal advocacy program, now that wasn't health care professionals but it's **law students.** They have, there's one course at the Law and every I think two or three years there's one professor who then gets the students connected to one of the agencies who does advocacy work or, yeah, particularly in the area of disability. And the **students come for three weeks, one day a week and sits in and talks with us and then works on a bit of a written project and it's really learning about related to law, issues that people with disabilities face.** [CVHEdC12,p.4]
Public health students	9. I had here a practicum student from the, um, so this is me ranging a bit more broadly, I don't know whether health professionals, public health, she was with the graduate school of Public and Population Health at UBC here for a practicum last summer. [CVHEdC13,p.4]
Health clinics	One of the things I did try to do through St. Paul's was have resident doctors come to us because we have a clinic, a drop-in center. That proved to be very complicated and it's because of, they got to the point where they could have somebody who supervised over the phone. They didn't have to have a supervisor with them to do their whatever supervision piece that is. But then there's all the issues about who has access to the files, you know, the central files for individuals and so on, and it really didn't fly. I think we might have had a couple of student doctors and that was it. But and that, it was positive. I mean the whole, everybody sort of wanted to work in that direction. …I think that when you have a clinic, it would be good if we could have people who came and gained some experience there. So anyway that hasn't worked out but that's not to say that in the future we couldn't make something else work. [CVHEdC02,p.6]

Fellowships, grants for training	1. We funded a professorship for dementia and I hope, I think it has just finished it's term and I'm really hoping that our, that the society will, I mean that's what would love to see is that we continue to support the professorship at UBC but in dementia but we'll see. [CVHEdC11,p.6]
	2. The training that we fund in grants is often oriented towards the social service sector workers. Something that we will be funding, I hope, in the not too distance future is training social service sector workers for seniors who have dementia, early stage dementia so they can use the social and recreational programming offered in the community. We see the wave of dementia coming and we see the social service agencies and their staff being unequipped. Another kind of training our money may go to would be, well what's another example, um, elder abuse right now is getting a lot of attention and deservedly so and there's training around that, the ways to learn to interview and so on. [CVHEdC13,p.2]
Tele-health sessions	[Name] also has done, so she's the staff person who does the division-wide, does the unchaptered areas here at the client service staff person. She also has done some **tele-health sessions with health care professionals** throughout, particularly again **in the more rural areas**. … I've had sessions where for example I was in Dawson Creek a number of years ago presenting to **nurses and care aids** and what we usually do with those kinds of presentations is if a care facility asks us, and we say so who else in the community might benefit from it, help us advertise it. And so when then there were people from the hospital, from the care facility but also from care agencies sometimes would attend or **OT, physio from the local hospitals.** It's sometimes difficult with the timing but that's what we try to do. But then with that session **we also did a live link, video link to Fort Nelson and a group of nurses in Fort Nelson was able to listen in** through that. So **we haven't done that a whole lot. It depends on the community where we've in and the health care professionals how much can they organize on that because our ability to organize that of course is quite limited.** [CVHedC12,p.3-4]
Mail outs / outreach	...we used to do **mail-outs to physicians** ...In our chapter in the Lower Mainland and so we would **target different areas and we would do a mail out, information on MS, difficult questions for health care professionals, how to answer them and information on what the chapter was doing. So sometimes they would include like a magnet**, just different things like that. [CVHEdC12,p.5]

2.How should HP's behave differently? (Interview Question 3)

According to our key informants, health professionals need to be better at working in partnership with patients and other health care providers. Recognizing the expertise of others, especially the patient's, was described as key to being able to work in partnership. They also suggested that health professionals need to take more time, be more holistic in their approach, be non-judgemental, understand patient's lived experiences and be more sensitive to cultural and language barriers in health care. Table 2 presents the main themes for the ways in which health professionals should behave differently.

Table 2. Main themes for how health professionals should behave differently

Work in partnership with patients and families	1.…we've identified as a gap for our current staff would be really nice to see that happening in advance of their employment with us. So if we are able to hire people into our system who are already recovery oriented and already inclusive, see families as a natural part of the team. We see pockets of new staff coming in who are already in the right frame of mind but there's still a lot of people graduating from different health programs and they come in and they're very rigid. Confidentiality, that's another piece I've been involved with. So confidentiality and continuity of care. We did a lot of training last year with new staff and maybe some old staff and the new graduates were probably the strictest around we can't share and part of what we were doing was walking them through the legislation and saying, actually we can and accepting information is not a problem. So if that's a piece that could be addressed earlier on to help people demystify the freedom of information and protection, I think a good thing. [CVHEdCPilot,p.3]
	2. One of the pieces that we are advocating for is that people are approaching the individuals they're working with from a strength based approach. So I think, I think we've institutionalized the people receiving services and I don't think that we've done them any favors and I'm not talking about people who've been in actual institutions. I think anybody who's been receiving treatment in a paternalistic system for more than 10 years has been influenced by a system that is pretty directive and pretty rigid. And now we're trying to be less directive and less rigid and I think it's scary. So, I think if clinicians who are coming in to the system are more collaborative and more focused on what's working well for the individual and how they can support that, I think that would be a huge improvement. [CVHEdCPilot,p.4]
	3. My own experience with a medical professional in the city was one in which I was told what to do and was not invited to be part of the conversation. That I had to change my doctor as a result because it just wasn't working for me. I needed to be, I'm a smart man, I'm not stupid, I know what's going on with me and **I need to be able to have an open discussion, an open-ended discussion, not one where he's presenting solutions to, one in which we arrive at the solutions together. That gives me the opportunity to have a say in my health care and it also it empowers me but it does something else and that it enforces my commitment to whatever we decide because I took a stake, I had a stake in the decision,** right, so that's probably, for me that's probably the single most important piece of that whole thing. [CVHEdC05,p.4]

Work in partnership with patients and families	4. …take you into becoming a partner in your health care, it's the only way that it works. And I have fired more than one doctor because they were dictating to me exactly what was going to be done and nobody tells me what to do. You ask me what I want to do, then we'll have a working relationship. [CVHEdC05,p.4-5]
	5. …**the biggest problems that people, including myself, find in interacting with health care professionals is the assumption that they're the expert and they know what I need.** And of course they're the expert, that's why I'm going to see them. But when you live with a chronic illness or a disability you have to become the expert in how it affects you, right, and your life and how it impacts you. So there needs to be some shift of perspective on which will also, which will be evident in listening and a respect for what people have to say about. And I know that it can be difficult because often people who've lived with a disability or a chronic illness become very angry because of loss and being marginalized and poverty and all those things. So if they see that someone is prepared to listen to them they'll take advantage of that. And I say that not in a judgmental way. I understand how it works. So communication and understanding how to manage that while showing that you really do respect what it is that they feel and need and have to say about their own issues. [CVHEdC07,p.4]
	6. I'm just a piece of driftwood kind of floating around letting them push me into different appointments and going here and there and when you come out you don't have that sense of responsibility [CVHEdC10,p.8] …not be talked around like you're, you know, like you're not there… you become a part of the process. Like I'm gonna fix me, you're gonna help me do that. [CVHEdC10,p.16]
	7. Often information is given to them in either a complex language they can't understand or at a pace at which they can't integrate it. And/or if they bring someone along then what typically happens is that the medical professional speaks to the person they bring along. So then it's like they no longer exist. [CVHEdC09,p.7]
	8. …to see the person that's ill that needs help is a partner in their care. …there is a divide in terms of power and the thing is that we're already vulnerable because we have potentially, especially people with dementia, they're already vulnerable because they have the stigma of this disease, the stigma of likely aging that surrounds it. So already they're seen as lesser people because cognitive issues make you less acknowledged in the community and then I think as an older person despite all the platitudes about, you know, the seniors and how much we care about them. In theory, in reality, age isn't really a balance in our community, in our society, so and then when you lay on top of that just the fact that you have to ask for some services or ask for some help, so I feel like we have three strikes against us and for our families and so they go to the care professional and they already feel like kind of beaten down scared and confused and so I think if doctors could, you know, see the person there …I've talked, we've talked to nurses quite a bit who tell us that it's shocking some of the stuff that they get, the lack of it or the skew of it that I think is wrong, so I would say that the education doesn't train health care providers and professionals to be, to see people as human, as equal, to see them as partners in their own care and to see that they actually have a stake in their own health. Right, it's, there's a bit of an attitude shift needed I think. [CVHEdC11,p.8-9]
	9. I think to use always a client centered approach, right. Client centered and I think with that also listening to the clients and when the client wants to educate the physician. Cause GP's can't know everything, they're general practitioners, right. [CVHEdC12,p.7]

Work in partnership with health professionals	1.…**we really need to strip out the hierarchy that is there in that a doctor is above a nurse which is above the patient. That doesn't work for me in many ways because I see anyone who's involved in my health care is an equal to myself and either I'm usually pulling the doctor down to my level or he's pulling the nurse up to his.** One of the two has to happen but it's the doctor nurse relationship that really irks the most, irks me the most is because so many doctors see so many nurses as their go-fetch person and I really dislike that. They're both partners in my health care and I'd rather they be treated as equals to each other and myself. [CVHEdC05,p.22]
	2.…emergency room nurses talked about that that the physicians wouldn't help them out with the folks who really needed some you know intervention in whatever way because they were going to start to detox and that was gonna be a problem. [CVHEdC02,p.8]
	3.…they expect people to paddle their own canoes … be proactive with some outreach and team base … preparing people for community medicine rather than hospital based medicine… outreach and the early intervention piece would make a big difference …the community center that works in the downtown eastside in the Francophone community has outreach workers and they have a psychiatrist part-time and they have a social worker and a couple of other people and they, they don't, they're not a clinic, they're a community center …build that multi-disciplinarity… [CVHEdC08,p.8-9]
	4. …it's really good to involve the various health care professionals or health care disciplines. I also think actually that the different disciplines can learn a lot from each other and so that may very well, that could become a part of this because I'm an occupational therapist by background so I'm trained to look at the connection between symptoms and functioning, illness and functioning and that's something that a lot of physicians completely never get. …they don't learn what's actually the impact of that symptom on the person's day to day life? There's a complete lack of connection with a lot of the physicians. Some acquired over time on their own, but not all of them do, and certain disciplines are worse than others with it. I know certainly from, I worked at VGH for a number of years. The more technical the discipline, the medical discipline, so the orthopedic surgeons were, I mean they saw the joint, the bone and that was it. And that maybe a 90 or 85 year old lady who doesn't have any supports at home after hip replacement can't be sent home quite as quickly as a 70 year old who goes back to a spouse. That is just sometimes, they just never got that kind of thinking. As an OT that's what we're trained for so I think that kind of cross pollination could also be really valuable… [CVHEdC12,p.20]

Understand patient's lived experience **Gap in training about the community lived experience (e.g. classroom to clinic/hospital)**	1. Many of them just have a strict classroom and then they're right into the hospital scenario. **They don't get to see the interim step of what is life like in the community. They see everything coming through sort of the lens of emergency medicine, you need to react now, you need to react quick, you need to do this ...Be a solver. ... these decisions need to be done now.** And there isn't a lot of empathy. [CVHEdC05,p.6]
	2. This is something that I think is essential because I think that **you can't just go to university and graduate.** And I know that there's interns and residents and all that stuff, but **if you never run across folks who have many many talents but are living on the edge, I think that if you never run across that I think that you're really missing something. I realize that people pay a lot to go to medical school but as does the taxpayer. I think we're missing something socially if we don't bring all of these people into the conversation somewhere. …Cause I think that's how we break down the barriers. But the university is pretty removed from here.** I mean I know we have the UBC learning exchange and so on. But it is fairly removed and it could be quite different, you know, and we would embrace it, really. [CVHEdC02,p.18]
	3. …definitely around what it's like to live with mental illness. To have some education around identifying, often people's physical illnesses get missed because people, like I say, healthcare professionals often don't have the time to really explore what those stomach cramps are from and there's assumptions at times, stereotypes around people who've lived on the street are, you know, more vulnerable. There's stereotypes, sometimes symptoms tend to get overlooked. [CVHEdC03,p.3]
	4. Allowing for a bit of leeway on appointments, you know, things like that, not being very cut and dry. There's some people, you know, their attendants maybe showed up late in the morning or they didn't show up and they're getting to an appointment that they've been waiting six months to get to and because Handy Dart shows up late, their attendants were late ...And they get to the appointment and their time's over with, you know. There's, the only thing that can fix that is understanding of who your patient is, right. [CVHEdC10,p.7]
	5. …they don't really understand the systems in which their patients, their patients live in and have to navigate and so, you know, and I could appreciate they have the ability, the physicians have the ability to see what it is that their patients may need in terms of services but the reality is anybody who's worked in the social service system knows that resources aren't there in the same way that there are wait lists for health care, there are wait lists in social service settings and so they end up kind of getting in the way in terms of the health care plans or their orders that they make in the way that is really not very instrumental. And so I think that this is one of the areas I've always wondered whether that could be somehow incorporated into training in a different way. …**the difficulty that they have is they want to be able to say well this is what this person needs, go and do it. But the reality is if they tell their family, especially in the case of children with disabilities or a family member, well this is what you have to do and here's a list of resources and they give it to them, they set the people up for thinking that it's just a matter of walking out the door and it is not that easy.** It's really about being able to work with the family or the individual or the child in a way that's going to somehow support them but within the reality of what lies out there, the context of what lies out there in terms of the social services. [CVHEdC09,p.9]
	6.…a few times during their medical training to actually go and work in a setting as a student. I think it would give them an opportunity to see that there's a human face there. [CVHEdC09,p.16]
	7. I think particularly with physicians more so than with most other disciplines, with the other sort of more the allied health care professionals, it is that, so how does the disease impact the person's life? I think that's a focus that's often really missing in the education. [CVHEdC12,p.21]

Spend more time / Take a more holistic approach to health care	1. …the other piece that we're working on right now is care planning, so getting away from the idea that they have to just fix one thing at a time but really working with the client or service recipient when they come into the, you know, what's most important for them at that moment and thinking about problem solving and the bigger picture rather than getting it right. And I think right now we are still quite medical model we are focusing on fixing. And which becomes a moving target. I think that that is not sustainable so I think helping people come into a system prepared to have it with a moving end point. So I think a lot of people come out of school if for any profession feeling fairly idealized and I think maybe helping people understand that the process is just as important as the end point. [CVHEdCPilot,p.4-5]
	2. And an ability to see through a lens of seeing the whole patient's life beyond the specific condition or issue that's brought them in to a visit. …The various environmental factors around them, their home relationship, work. Sometimes I think doctors, any healthcare professionals get a bit of tunnel vision, so being able to, being able to ask questions that leave a patient feeling that the people want to, that the health care professional wants to know more about them beyond symptoms and specific criteria about an illness. [CVHEdC01,p.3]
	3. …the feedback I get from people too is that **they don't touch enough, they rely too much on technology and not enough on what's going on in your family, what's going on in your life** and I certainly see that myself too. People just, you know, **I go to the doctor and it's like a butterfly flying around and up she goes and I go 'are we finished?'** Um, you know, it is just the way our system is getting to be, that there isn't that time taken. [CVHEdC04,p.4]
	4. …an appreciation for the fact that when people are living with a disability or a chronic illness, um, it impacts every part of their life so they're looking at, you know, they're probably living in poverty or have a very restricted income which impacts self-esteem and ability to, and willingness and capacity to engage with their community which is so important for coping and resilience and whatnot, right. So it's not just a physical thing or a mental health thing, it's, and that's the other thing, if you have a physical issue going on it's going to affect your mental health, right, so it's a huge complex thing and it's obviously I'm not suggesting that people need to take on the whole package but there needs an awareness of that and an appreciation for what the sense of overwhelm that people feel. [CVHEdC07,p.4]
	5. So in my experience, particularly Occupational Therapists, Physiotherapists, tend to be quite knowledgeable about how disease affects people with MS because that's their training. …Whereas, and the neurologists that specialize in MS of course are quite knowledgeable. General neurologists may sometimes not, in my experience, address some of the more difficult to describe symptoms. So I've had clients, and particularly through the VLAP [Volunteer Legal Advocacy Program] program where community neurologist, they recognize the person has MS … The client wouldn't necessarily mention that fatigue or cognitive change cause they're more hidden and there's, they try to adapt, they try to cope with it and so they don't think of mentioning it and the neurologist doesn't ask about it. Although those are key symptoms for people with MS. So there's kind of lack of knowledge, lack of paying attention to those invisible symptoms and with general practitioners it's a real hit and miss how much they know about MS and how much they understand MS. And some are really willing in my experience to learn, whereas others base on at least what the clients tell me seem to resist that to some degree. … it seems to be more often with clients that are just haven't been diagnosed yet or are in the process of being diagnosed and present more with not really clear-cuts or more the hidden difficulty to explain symptoms, like the fatigue or the beginning cognitive changes and may come across as complaining or whining or so because there's, there may not be clear physical and easy to assess physical symptoms that the doctors can latch onto. I think it may be dependent on the relationship that the client has with the doctor. [CVHEdC12,p.6-7]

Be non-judgemental	1. … we use a tag line that we serve all ages, all genders, all orientations so that we're open to seeing our clients in whatever way they're comfortable presenting. So there's issues of gender identity or sexuality that there's no judgement, that but there's also no dismissing. We're not afraid to delve into these issues with our clients and sometimes we've heard that some health care professionals just don't want to hear about some of those issues. [CVHEdC01,p.3]
	2. ...it's how long do you keep somebody waiting in a waiting room. Maybe you could identify that somebody could possibly have an addiction problem and that you know their length of time that they could actually be there is limited because you know the health professionals aren't about to assist somebody who is going into withdrawal. …So I think that it is that sort of alacrity with which they could approach individuals. It's the way that they're spoken to, it's the way that they're addressed and I think also that it's really treating them equally with everyone else and I think that a lot of people feel absolutely further marginalized when they go there because nobody wants them there because whatever, they're, you know, their behavior or their appearance or whatever is a problem for people who are them. And I think that, I think they often feel discriminated against. But one of the nurses also said **what do I do when I'm in Emergency and I have a 73 year old woman who's had a heart attack on this gurney and I have somebody who's standing on their gurney shouting because they're really really high. Now what do I do and who do I pay attention to?** [CVHEdC02,p.8]
	3. We've taken members, clients to emergencies, ER's and found that at times they're not treated well because they're seen as, perhaps seen as someone suffering from an addiction and therefore not treated as seriously as a client. People seeking health care, a lot of our members tend to use the drop-in clinics so they don't have, they don't have a health care professional actually knows them. [CVHEdC03,p.3]
Be more knowledgeable about and comfortable with marginalized people / communities	1. Like not everybody is a white collar worker in a suit and, um, and not that, I'm not saying that people on the medical professions or the helping professionals are awful, it's just that it is, it's not comfortable and so I think you probably have to stretch a bit and I think that the earlier the better. Really, I think that students to come here is fantastic. I think that if there are clinics here or physicians and nurses and social workers and everybody could come once a week that that's just part of their work is that they have four days a week over here and they have one day a week here. Because one of the problems has been for nursing care in this community is to have people who actually want to come into this community and work here. Because **I think people find it really intimidating and I think that the only way to not be intimidated is to be here.** [CVHEdC02,p.9]
	2.…they know about the needs of immigrants and so on… CVHEdC08,p.10]
Understand role of culture / language	…language is a huge barrier for most of the people that we work with. So they often can't even get to a doctor. So either people, you know, making sure that there are representatives from different cultural groups in medical schools but also, um, or the use of health brokers or not just interpretation because we also hear from people that it's not just about straight language interpretation so I think accessing if physicians would have an understanding of the role of language and culture and therefore have people, have the system provide people. [CVHEdC04,p.3]
	… using people first language, people with developmental disabilities are really sensitive about language and the, many of the pejorative terms that have been used to describe them have medical origins so I think there's a need for the medical profession to be cognizant of that and to know that in fact that they continue to have pejorative meanings and that people feel very, um, many people feel very denigrated {I: By use of those} by use of those. So retarded would be an example that's just now making it's way out of the DSM. [CVHEdC09,p.10]

3.Levels of involvement (Interview Question 5)

Most informants thought that levels 1-3 could be easily implemented. Many organizations are involved in educational activities that could be easily adapted for UBC students and identifying patients who could be involved at these levels would not be difficult. While higher levels were appealing, they were seen to be more difficult because the number of people “capable” and “comfortable” to get involved at the institutional and curriculum levels would be much smaller and the nature of involvement at the higher levels excludes the most vulnerable / marginalized. One participant likened this to a “pyramid” with the greatest pool of people at level 1 and decreasing numbers of people as the levels increased.

Table 3. Caveats for lower vs. higher levels of engagement

Levels 1-3 Many organizations are already doing things that could be easily adapted for HPE Lots of people with skills for lower levels	1. I can see an in for how OPT could be involved in creating some learning materials. … use of narratives, something that they [Organization’s Education Department] could do. Probably also both our education department and our Sex Sense line virtual patient cases, the Sex Sense line could probably be helpful with that. Level 3, um, in many of our educational settings we have people come in in panels to talk about aspects of sexuality, whether it’s seniors and sexuality or people involved in the kink community or whatever and we certainly feel that’s really valuable for our students. [CVHEdC01,p.4]
	2. I think patients involving creating learning materials was of great interest to me. We have a lot of people here that write, that are writers, so how people communicate. I think, um, you have down here course materials, videos, scenarios, and I definitely think that people would be open to being involved and talking about how health care could improve. … We do have some individuals when I’ve looked down the levels of involvement that would be willing to come out and talk to groups or talk to classes. [CVHEdC03,p.4]
	3. I like the real patient part, learning to or being, sharing the experience, I like that part too. Actually going into the classroom and talking about it, I think that is a real direct experience for both sides. [CVHEdC04,p.6]
	4. …we don’t do a lot of paper based stuff because there’s so many levels of language and literacy and I think people, it could be more of a thing where video or real life kinds of experiences. Video might work well because then people might be more comfortable and not be kind of face to face. But on the other hand I think it’s still a more genuine experience if people are gonna ask questions and get answers. [CVHEdC04,p.7]
	5. I suspect that the degree of difficulty in securing appropriate patients, at least patients appropriate to these tasks increases as you go down the list. I would think it easier to find people who are willing to participate in the creation of learning materials than it is to find patients involved at the institutional level in the evaluation of education and curriculum development. … The real trick of course would be to find a means of incorporating the concerns of the only marginally effective, socially effective individuals in the more senior levels of this list. How do you go about doing that? I have no idea, but as a goal I would think that would be most helpful. And as an example if you could find a way, and there are ways, it has been done, to turn an HIV positive aboriginal sex trade worker into a patient teacher for the purposes of UBC’s health disciplines, I think the enrolled students would benefit greatly by that. But it’s tricky. They’d have to be well supported. They’d have to receive some, something that would incorporate both the elements of training and guidance in a supportive setting that would not have the effect of smoothing off the rough edges. If anything it’s those rough edges you want to convey because that’s what’s going to be confronting these people in the real world. [CVHEdC06,p.5]

Levels 1-3 Many organizations are already doing things that could be easily adapted for HPE Lots of people with skills for lower levels	6.…so there are people who are fairly articulate, fairly confident, maybe angry and that may be what's driving them to be confident and articulate, people who have a certain capacity to get themselves to a meeting, be willing to accept whatever unknowns might be there, all of those kinds of things. So if you have, if you invite patients to say go to UBC or go to a setting somewhere to provide their input, you've skimmed off the top of a group of people who are probably fairly adept at communicating their needs to their health care provider in my opinion. [CVHEdC07,p.6]
	7.…the patient involving creating learning materials, um, you know sometimes you read the brochures and it's so poorly done so yes you could provide feedback… Patient invited into classroom to share experience of chronic illness. Okay, that's good, that one. [CVHEdC08,p.15]
	8. I think the in-person contact with seeing the person with the disability is very valuable and hearing the voice of the person with the disability and rather than written material is very valuable. And I mean health care providers it can, they read so much and yes if you read a personal story it has a bit more impact than a basic textbook but I think it drowns in the information they read generally whereas if they're meeting with somebody and hearing a first-hand description of challenges and of what might help, what doesn't help, um, I think is much more impactful. … I could see for example having, um, setting up a meeting somewhere in like anywhere where there's tele-health connecting and I mean and I think probably any of the hospitals have that. So have a meeting at Burnaby Hospital, get people from, with different disabilities there and then have a session that's linked into the classroom at UBC. [CVHEdC12,p.11]
	9. …patients involved in creating learning materials used by faculty. Here's an example. And maybe you can tell me whether this would fit. The seniors funders jointly support a neighbourhood hub, a seniors hub, and they have just with funding from the federal government created digital stories they're called, 17 seniors with transportation or mobility issues of vignette for each of them that really puts their mobility problems in the context of their daily life so I really, you know, so one vignette is just about getting to the grocery store and how difficult that is, what it looks like and coming back the next vignette, getting on the bus in particular or with a scooter and what that looks like and how difficult and so on. And so that would be an example of a group of seniors who would have already created learning materials. I think that would be very helpful. We're planning to use it, maybe it's just useful to understand the parallel ways in which that kind of documentation would be used. We're trying to, gonna be using it for in some forums with Translink and also at city halls trying to bring awareness around transportation and mobility issues. So that would already have been done. Um, I think that the work around the wheelability study, there's been quite a bit written, could be that kind of, so that's experiential when remove in a document form, independent of the person. [CVHEdC13,p.6]
Levels 4-6	1. I like level 4 where the teaching associates were trained to teach and assess specific skills. …we use a lot of tools to screen and categorize and assess and, um, I think having people who've experienced those tests or people who could possibly experience those tests, except there could be some real feedback around how you, I know there's how-to administer tests but I still think that that could be improved by hearing from people who actually experience it. … I think it's harder, harder with mental health but there are pieces of mental health so the metabolic monitoring is an awesome example. I think that would be a piece that I could certainly see clients or people with lived experience saying hey, you know, the way to do metabolic monitoring, this is the best way to do metabolic monitoring, you know, practice on me and I can give you real life feedback on it. [CVHEdCPilot,p.6]
	2. I think program evaluation is a piece I see potential for. So that's probably pushing it into the level 5….Probably on those softer skills. So I think if you're assessing someone's interpersonal skills or their bedside manner, I think a really nice way of assessing that would be to have someone who could be in that role saying yes that would be, I would feel very hurt or no that person still needs some support around this. I think certainly not in the clinical areas but I think in the more humanistic side of work. [CVHEdCPilot,p.7]

Higher levels more difficult	3. I think something like accreditation, we're an accredited organization. We I think have very good intentions of having clients and families involved in that process but it does end up being more mechanized… [CVHEdCPilot,p.8]
Few people qualified to be involved at higher levels	4. There are some of us who will be quite comfortable at levels say 1, 2, and 3, but not be comfortable at the higher levels. I think anybody who's capable of reaching into the higher levels would be comfortable with the lower levels but I think I have to recognize that there are people in the community who are, could share their lived experience but in terms of having a vision to participate in developing curriculum, I'm not so sure that that's, could be said of everybody. No, you'll find that as you progress up these levels there will be a decreasing number of people who would have the knowledge capability, … it's a pyramid obviously and the number of people you would see at level 6 would be, you could count on one hand and I would even think that'd be stretching it for an organization like this. I think that would be stretching it for our community. [CVHEdC05,p.7-8]
Require commitment to learn the "ins and outs" (e.g. Politics takes years to learn)	5. I think those peer support workers could also come out to UBC and be more prepared and confident and trained to come and do some, you know, alongside stuff. [CVHEdC03,p.5]
Waterfall process - Mentorship / train your replacement	6. …if you look at your levels of involvement here, I can see this as sort of a waterfall and you start somebody at these levels and move them up through and as they get sort of, you know, level 3 or 4 you bring somebody in at the bottom and again sort of roll them through. You will find some people who will jump into this with both feet and be good at it and stay with you for four or five years, and that's probably the best from your perspective because it gives you continuity and it gives you, they get the chance to develop expertise in your area which is absolutely key here to being successful. But you're also gonna, other individuals who are gonna be really excited and are gonna want to come on board and they'll get involved for a few months and then they'll find out it's just not working for them and they'll just disappear on you and that's, we know that happens here and I think it's a reality of, the people who become infected with HIV, it is a, it's a disease of the marginalized in many ways today and so that brings with it a whole set of issues and a whole set of problems and some of us still working, struggling with those. [CVHEdC05p.11]
Marginalization and other barriers (time, transportation, self-efficacy)	7. Time commitment is one. Getting to and from wherever these might be held. And respect, being felt, feeling as though you're actually an active participant and that your voice is wanted and encouraged at the table and not one that you're being sort of given lip service, oh great, we've got Positive Living here, we've got Positive Living here and a safe space, absolutely a safe space. I think there's many of us, [Name] and I are pretty out there, we have no qualms about shouting from the highest rafters if need be our status and then the rest of it and we've got pretty broad shoulders that way. But there are many who will get any sort of a flick of stigma, the rest {s/l are only} running and self preservation comes foremost to their minds and that has to be understood and recognized. This disease is a disease of the marginalized, it is becoming a disease of the uneducated, of the poor and of people who are emotionally fragile in many ways. [CVHEdC05p.12]
	8. I think self confidence and language ability might be [barriers]. I know that some people who have all this knowledge, their English might not, even though they communicate well in English, they don't have that confidence in front of a group of people, so that could be a barrier or it could be something that we might have to look like. [CVHEdC04,p.8]
Some are well-positioned to higher levels (e.g. foreign trained health professionals)	9. Looking at the institutional level, um, like 5 and 6, there's a lot of foreign trained health professionals around who aren't practicing and some of them have no intention. We have a fellow who's a physician trained in Columbia who came here as an older person and didn't intend to actually practice because that would have taken years and money, but he is a wealth of information. So people like him being involved at that level at a teaching level would be fabulous, like cause he's just amazing and if he's any example of others that are out there. He's our staff. He's a health, cross cultural health promoter … So I see a role for people like that to talk about you know curriculum and bring some ideas in. And unfortunately there's a belief I think that those other systems are inferior to the Canadian system. Like actually someone from a dietician that we were working with on a project asked him if he knew what protein was, and I thought that well this is implying something, you know, he wouldn't know that. So but there's certainly things going on in other health care systems that could be adapted here… [CVHEdC04,p.5]

Some are well-positioned to higher levels (e.g. foreign trained health professionals)	10. Well it’s an inverse relationship because I mean you will find community members who are themselves high functioning, um, for lack of a better term, although it isn’t what I actually mean presentable person who would, who could slot in in any of these levels fairly easily. Normally you’ll find those people in communities where you would expect to find that. So for example a high functioning gay west end living HIV positive person is hardly an odd thing. And those folk could slot in pretty much anywhere on this list. Whereas again to revert to the prototypical downtown eastside aboriginal sex trade worker, those folk are going to need help bringing them to the place where they are intelligible to the students. [CVHEdC06,p.6]
	11. …it takes a fair amount of confidence to be persistent and make sure that they hear what you want to say. When I look at these levels of involvement, obviously as you go higher up it requires of people that they be articulate, experienced, confident and so on in order to participate, right. [CVHEdC07,p.4-5]
Need a mechanism	12. I’m an older guy and when I want to see a doctor I want to push the button and I want to go to the, I want them to take care ...So I’ve never seen myself as an active participant in the training or … equal partner because I’m old fashioned. I have a hard time to see it. {I: Okay} See I’m a patient and the doctor knows everything. …you know with the training that they have, you know, I have great respect… [CVHEdC08,p.14-16]
	13. I think equal partners and student education, I think is really a great idea. We, because of that advocacy requirement for residents, we sometimes get medical students who are, or residents to volunteer with us on some of the activities we have and I think that they actually can then feel like an equal partner in, but at this point I mean we don’t have a way for this number five to happen but if we did I think that would be great. I think that, I love the number four one. I think that’s really important to have people who have been patients to be part of the education and people with dementia love to do that and over the years we’ve convened a number of venues and where we are sharing this information with physicians and health care providers… [CVHEdC11,p.13]
	14. …yes I can imagine seniors who are sufficiently at home or comfortable with their chronic disease. They’re very well spoken, seniors, as you can imagine, um, and I can think of, well I can think of people who would be very able to do that. Um, I think that the example that I just gave you with the wellness clinic could be replicated in other contexts so for the Western Institute of Deaf and Hard and Hearing, I think I mentioned to you on the phone, they hold a weekly, um, a group meeting, drop-in, and they come from all over the region and so these are seniors who are quite well and able but don’t have the hearing so, um, I’m not sure, so there would be learning in that context of just how well they’re managing and if they’re not managing well or what is falling down because of the lack of hearing. Involved in teaching or evaluating students, um, oh they’re very, um, as I say able to you know stand up and speak their voice. I think that in the community you get a, so as activists you get a particular slice of the seniors population so these are not the meek seniors who don’t speak up for themselves in a doctor’s office. On the contrary they’re able to speak to a whole room. {I: Right} So you would have, and you know they speak for their friends too who for one reason or another are unable to speak for themselves. So you would get I think very able spokes people. …they don’t, their vision of just sitting at the planning table is inaccurate. In fact the seniors recognize that the name that we give these entities that we fund isn’t appropriate. They would prefer to be called seniors action networks….they make presentations to city council. They often talk about the frailty that comes with age and often the mobility limitations and they advocate for improvements, yeah, in sidewalks and bus stops and ... [CVHEdC13,p.6-7]
	15. I can think of individuals who would be extremely interesting to have in a classroom. I’m thinking of [Name]. She’s the retired RN in [Location] who developed this, what’s now is a little network of wellness clinics. You know, she would, with her professional experience be able to recognize what would be of interest. She could speak the language in a classroom. There’s, and that is a network that you could tap potentially is retired nurses in the community. [CVHEdC13,p.11]

All levels Require building relationships first	So maybe there's something that could happen that looks more like a health fair or something that, or we have a series of people who come in who want to specialize in something and we could have, and then the women could come and they could have a meal and they could experience what it was that people had to offer or what people wanted to learn about them. **I think one of the problems that we have is people always wanting to do research and really, we're really limited, we really limit that kind of connection for the women,** but I think that you know some of this, I see the word sustained, that might be really difficult for, to sustain a relationship. ...Well just because of people's lives and the other demands that they have. I think, truthfully I think **being poor is a full-time job.** It's very difficult because you go from place to place to place to meet whatever needs you have. But if it became, for instance, if they went to Native health, let's just say, because people are used to going to [Name] Clinic, the downtown clinic, Native Health, so what about if there were clinics there that brought in the health care professionals and/or the students or both, and it was a day of, you know, actually maybe there wouldn't be anyone in the waiting room because there'd be so many people there able to provide services and respond to the needs of those individuals. It just seems to me that that way there are people who would get engaged, who might be able to then through relationship building be able to fit into some of this framework. And they might be able to go to UBC or they might be able to go to [Hospital] or you know whatever teaching hospital to assist. ...I think it's that whole relationship building and I think that then the folks who are the educators, not the patient educators but the university based educators, then they would, they would be able to start building some relationships and offer opportunities for those folks and pay them. … Well I think the first, okay so we should maybe just go back to the first part a little bit which is that build, **just building the relationship on service provision and the, and so for the health professionals or the student health professionals or whatever, to be able to engage with people and provide services. And then as time goes on when relationships are built, start having those conversations about, you know, would you be interested in taking this further and coming to where our practice hospital or whatever it is that you want through these things or the evaluations or whatever and see if people are interested and then introduce the possibility of it being like a paid job.** But if they come here and say okay we'll pay you to come and we'll give you health care, that's a big, obviously a huge problem because everybody needs money. So then it's gonna be okay why would I go to my regular physician at Native Health when I can go to wherever and get paid to go to the doctor. So we don't want to get that relationship ever set up. **But eventually there may be ways to build those relationships so that people will want to go outside of here and are very able. There are lots of people who are able, it's just that if you don't, there's also I see a lot of people here who have abilities to engage with a variety of people who always get the opportunities, but then there's all those people who will never get the opportunity because that's just not who they are and they're not gonna be able to leave here. But they have valuable input. … So I see what you're saying about equal partners and student education. And there's lots of people who can do this evaluation curriculum development, but I think it has to be kind of based here for awhile.** [CVHEdC02,p.11-12]

4.What needs to happen to involve community members in health professional education? (Interview Questions 6 & 7)

Table 4. Key ingredients for participation of vulnerable citizens in HPE.

Accommodate special needs / Create supportive environments Self-efficacy	1. I think part of it is getting people to realize that they might possibly be able to affect change. I guess **safety.** I think feeling that the part that they will play will not jeopardize any care that they're gonna get. No one wants backlash. I think people need to feel a bit more empowered. I think there is a disconnect from it's academic institutions. I think also for hospital care, I think there is a sort of a mystic them and I think when you're working in community it really does feel like you've got a really good connection with the other little people and that the institutions just happen and that people dip in and out of connecting with them but it's not a continuous connection. I think people graduate in their own areas and then I think unless you are in the medical professions or have been through medical education or health care education, it's just something that's happening out there. So I think if you asked the average person who's receiving services here, it wouldn't even dawn on them that they could be connected to that. It's out there, it's like government. It just happens. [CVHEdCPilot,p.9]
Safety	2.…often we are looking for people who are well to tell their story and I think if there was some way where we could support people who were less well to be in those circumstances, I think it would help round out people's appreciation of what, how the illness journey looks. I know it makes it really difficult to deal with. It's difficult to deal with people who are volatile or not necessarily as predictable, not quite sure how the story's gonna go but I think it's a bit more real world … So that goes back to the safety… and how do we make it so that it's successful even if they're not really able to be very articulate or give us something that's linear. [CVHEdCPilot,p.10-11]
Break down the power differential value their expertise	3. Do run into people who say well you know I have a mental illness and that makes me incapable of some part of, it's the empowerment piece I think is really important and also access, so how do you access folks who aren't being protected, well meaningly protected. So if I was to walk into a mental health team and say could I sit down with the five people you think are struggling the most right now and ask them a few questions about service, I don't think I'd get very far. I don't think anybody would be happy to do that. [CVHEdCPilot,p.11]
meet them where they're at accommodate their special needs safety in numbers (e.g. group setting)	4. **Validation** of course is always a huge piece. Feedback, **positive feedback**. I mean you think about the techniques that are used in therapy sessions, I mean this isn't a therapy session, that isn't what this is about, but it is about validation. It's about **recognizing and understanding the value of the people that bring to the table.** I think it's very easy for somebody to put their heart out there and to put their lived experience out there and have it trod on. This is gonna be a very very dispiriting and very disengaging thing for them and they'll step away from it and that will spread within the community and you'll lose your support and you'll lose your ability to attract within the community if that happens. So I think in terms of actual logistics, I'm not sure. I mean I guess maybe keeping the number of people involved. I think it becomes overwhelming if you stand in front of a room of 30 people as opposed to sitting down in a more of a, I don't know how this would look, but yeah a more intimate environment with five or six people would be far more attractive to a lot of people. And the, being encouraged to voice. I think many of us would sit there, I mean neither [Name] or I would have a problem speaking their mind but I know that there are others that would have to be encouraged to voice, so. … We're beginning to sound like we're developing a psych course here for people ... That's not what you're after, I get that but I think the psychological and emotional environment they should provide in a context that your provider is key to this, key to our success in being involved here. … One of the things that we tell all of our board members and guests at any of our meetings that if you need to step out, do so, make it, make yourself comfortable with what you need to do. I think that would be something that would have to be relayed to everything because there's times when my peripheral neuropathy is so bad that I have to stand up because I can't, I need pressure on my feet to reduce the pain. …And some people will find that uncomfortable if I'm standing up in the middle of the meeting. There's, gonna need the understanding that there's just gonna be times when I need to make myself comfortable in order to actually continue with the meeting instead of adjourning it for another day. [CVHEdC05,p.12-13]

Break down the power differential value their expertise meet them where they’re at accommodate their special needs safety in numbers (e.g. group setting)	5. Occasionally we need to take the other tactic and **disarm them** completely. An example that I can give is early on in this epidemic I was asked to give a speaking presentation to a group of doctors and nurses at St. Paul’s and this was a very early morning breakfast meeting and they wanted my lived experience of living with HIV. So I spoke to them, but I had to give them a reality shock. I asked them how their meal was for breakfast. They all said they had a good meal. Then I started unloading a huge bag full of pills and supplements and I’m going ‘this has been my breakfast this morning. I haven’t had a chance to eat yet because I have to wait another two hours before I can eat because of all the medications that I’ve just taken. I’m glad you’ve had a chance to eat.’ And it was at that point that it was a reality check for many people and many of the doctors in there that this isn’t as easy as it is actually perceived to just write a prescription and away you go. After that meeting I had a lot of people come up to me and ask me about this experience and I was able to relate more information at that point in time, but I had to disarm them first from these preconceived notions in order to get the message across. [CVHEdC05,p.14]
	6. …we can be a bit prickly at times and I think a lot of that comes from some of what [Name] talked about, just simply the difficulties of navigating through a day’s existence and so there needs to be a **sense of appreciation** and a sense of understanding. Again, this plays into the episodic nature of the disease as well. The episodic piece I’m referring to earlier is more to do with, you know, days or weeks at a time, but I mean there are also bad points throughout the day as well, right. And so as [Name], you have to get up and relieve your neuropathy or you just simply are, had a bad night, you didn’t sleep well because you’re upset or whatever and you’re just not fully present. [CVHEdC05,p.15]
	7.…for people to know, okay so if I contribute to this education to try to educate people on how to better serve me or us, what’s gonna be done with it because you know people really have to know why they would, that there’s a real value in their participating. [CVHEdC03,p.4]
	8. …people **feeling safe** to talk about, disclose the experiences they’ve had and **not to feel judged** about that. I think that’s been often the challenge with the health system. So again, creating a safe environment for people and acknowledging that they’ve had a history in experience and I think that would be really important. Other barriers are just around practicality. A lot of people on medication have trouble functioning early in the morning, so we do a lot of programs in the afternoons. Travel, you know, people, bus passes, transportation, ability to get around, those sorts of things. [CVHEdC03,p.6]
	9. I think there is a perception by those that are marginalized of the medical profession of being superman, of being rescuers, and that is probably something that you’re going to have to overcome and so it’s going to take a concerted effort to come down off of that perceived pedestal. It may not be real but if it’s perceived then it’s real for the individual, so in meeting the people where they are is absolutely key and absolutely, we have found that in our work here. **One time there was a thinking around here, build and they will come, and we’ve come to recognize that we have to take, we’ll build to our people.** And that includes not just physically but it includes emotionally as well. Again, knowing people, people are at different places in their lives and at different places in this disease and at different comfort levels with this disease and not everybody is going to be at the same place, so understanding that and **recognizing an individual and their uniqueness I think is key to this**. And if you do that, it’s a form of evaluation and if you do that you will get a lot more out of the individual. And it maybe sounds a little soft and maybe it sounds very unacademic, but it’s the reality of our world. [CVEdC05,p.14]
	10. ...the communities that we’re working with are **more comfortable in a group setting**. [CVHEdC04,p.7]
	11. So a sense of people coming from the university and, you know, taking my story, my experiences, my whatever and going off and doing their thing… [CVHEdC07,p.11]
	12. …you need all kinds of expertise at the table when you’re talking about improving the service to the community and so on and so forth. But just calling it patient already sets up that inequality… [CVHEdC08,p.15]
	13. A lot of people get their injury or their home situation has oppressed them to the point where their confidence levels to go and speak or get in front of people or say yes to a question and think, ‘okay I’ve got to get up today, I’ve got to get on the bus, I’ve got to figure out a way to get there, be on time, I’ve got to figure out what to wear,’ a whole bunch of things got to evolve in someone’s mind and to make sure that they, and you have to start small and start building up because there’s a whole bunch of people out there with a ton of valuable information and awareness, and everything you need to provide for people that are held, that are sitting at home because they got caught up in a system that’s helping them. They live off barely enough money to do anything extracurricular at the end of the month. They don’t have the where-with-all to talk to their social worker about getting bus passes, free bus passes. They don’t know that these resources exist and that takes a certain level of confidence and taking some risks. Like not just knowing that it’s there but expecting that it’s there for them. [CVHEdC10,p.14]

Break down the power differential value their expertise meet them where they're at accommodate their special needs safety in numbers (e.g. group setting)	14. I think that with this disease [Alzheimer's / dementia] because episodic is not so bad because they could have periods of time where they can get really involved and then as a disease progresses maybe they have a bit of less and then maybe as the person goes into care then all of a sudden they're freer again to participate. So for caregivers to be involved, episodic might work but with vis a vis the society, then yeah, sustained thing so that we, that we have a built a process that works for us … [CVHEdC11,p.14]
	15. …they need to make an effort to, rather than saying come on patients, come here to us, but actually go out and to talk to people who are affected by it cause we're not the only disease like that. … So I think that they can sort of find other ways to get the voice out, is there ways that, like us, we use, I'd never go anywhere without a person with dementia and a caregiver. So when I have meetings I, and speak, I always bring the voice of the people who know what they're doing and who know what their experience is and who share it and I think it has a great impact, so I think that this is a very important piece but it has to be recognized that only people with capability are going to step up so you have to work hard to get people who are the hidden and they're the ones whose voices who are the truly missing ones. [CVHEdC11,p.13]
	16. A lot of these [levels] are at the space that belongs to the educator or the educated, or the educatees I guess but if it came to the place, the ground, the home, the place where people with dementia and their families live you learn a lot more and that would be the same with any disease… [CVHEdC11,p.15]
	17. …funding for a taxi. Cause a lot of people, not everybody with a disability but many people with disabilities are living on a limited income and so they either try to drive themselves and that's tiring, and then we have very high parking fees at UBC or have to rely on public transit or even Handy Dart and then, and that again, unless you live sort of on the west side sort of close to UBC it's a long haul, it's a very long haul. …We have clients that don't even want to go to the clinic out there, right, like that's to see their doctors. It's really challenging, so to them be involved in something where they're volunteering their time. So I think paying for taxis to get them there or set up a program that the bus gets rented and various people get picked up for meeting of where the program is, something like to help really with, in a meaningful way with transportation….if they're actually physically going all the way out to UBC and then participating in that for people with MS that would be really, potentially could be very exhausting for them. [CVHEdC12,p.10]
	18. Time of day when you choose to do something would also be huge and I mean that can be done also just through polling the people, finding out what is a good time. I mean you're gonna have people that are good in the morning and then people who are good in the afternoon, you're gonna have people that need to nap mid day. So I think being really conscious of that. …Length of sessions… So I'm also thinking about people with other types of disabilities and there's quite a few situations or conditions where people just, an hour or two hour is kind of the maximum. So a whole education day would be too much. Whereas having an hour, participating in an hour long presentation might be doable. I think offering different types of interaction. [CVHEdC12,p.12]
	19. …not everybody also feels comfortable presenting and talking to a large group of people. So some people with disabilities might be much more comfortable to meet with a small group of 10 people or even be available for one on one. I'm thinking about the peer support program. One on one being matched with some people for one on one telephone contact. So doing a specific course and talking to people on the phone might also be a way to go. [CVHEdC12,p.12]
Language	20. …there could be language barriers. …So maybe people that have really valuable things to say but their English is quite broken and so they may not feel comfortable talking about it but if there's an interpreter available they might be able to really tell a really valuable story of, not only about the disability but the double whammy of being ESL, being an immigrant, being new to the system, and how do we deal with that. [CVHEdC12,p.14]
	21. Transportation is key for many seniors. They don't drive, they never got a drivers license or they can't drive any longer. They've been pushed off the road, you know, forced off by family or doctors and they don't typically don't have an income that enables them to take a taxi. We fought and saved the Taxi Saver Program which was huge for seniors and people with disabilities having the spontaneous ability to do out and do things. So the Taxi Savers could, so that would, the transportation as part of an honorarium would be a typical package that, for example, um, any event that has that senior featured as a speaker would almost now automatically offer to a senior. We would like to come, you to come and speak for 10 minutes, we'll provide your transportation and a small honorarium. That honorarium, it could be $50, $100, it depends, but that would be typical now, or at least increasingly typical. [CVHEdC13,p.10]

Preparation & Training	1. ...we would have developed a core group of people who would be the people who would participate in this education at those different levels that you're talking about. Um, do some training with people about what the program is, what their role will be. Um, training would probably involve some very practical kinds of training and role playing, how you actually would do this. Putting together their own little curriculum I guess of the things they want to say, important things that they want to get across... [CVHEdC04,p.10]
	2. ...training mostly in presentation and that sort of thing and counselling to diminish the natural mistrust such people feel for well to do professionals to address questions of internalized inferiority. Basically to attempt to overcome the internal barriers such a person would confront in attempting to relate information to such students in a way that those students could accept and incorporate. [CVHEdC06,p.6]
	3. I wonder too about training, you know, if you're going to be utilizing the clients. Like some clients might want some type of training. [CVHEdC12,p.12]
	4. I think something else that might be really helpful is, um, to have really clear descriptions of what's expected and, um, so not just like a little blurb but example, with examples with clearly, clear questions with the presentation, clear questions, we would like you to address these kinds of points so that people have a guidance....that's really important cause then you can manage the expectations on both ends. [CVHEdC12,p.12]
Incentives	1. …the term in the trade these days is incentivization which is, you know, just a ghastly neologism but there you are. Frankly, I don't see what was wrong with bribery. But yes I mean you're going to get more concerted participation if you pay for it which should come as no surprise to institutions of higher learning because that's what they demand of their students. So yes, it never hurts to offer the people from whom you are seeking otherwise free enrichment to acknowledge that in the form of cash. [CVHEdC06,p.6]
	2. ...if you could offer an honorarium to people, that's really really helpful because you know probably the majority of these people aren't working so if an honorarium can be offered or, you know, a lunch or something is a nice gesture for people when they're taking, you know, time out to educate and help, I think it's important. [CVHEdC12,p.12]
	3. I'm gonna talk about money because it could form a real draw and the seniors are increasingly on a fixed income and living longer and I think could see their way to volunteering as individuals on their state of their health and wellbeing and report out. [CVHEdC13,p.11]
Mutually beneficial relationships	1. …the patient is getting something out of it. The students are getting just as much. The educator, the professor is getting just as much, that the whole process is a win-win situation. [CVHEdC10,p.16] 2. …initially you would want to have some type of forum where whichever designated organizations that you want to work and that UBC wants to work in partnership with, I think you'd have to have a community discussion about that. …I think that that would be the starting place. For me that would be. Although it's more time consuming, I think in the beginning of these types of projects if you put that time in it pays off and stays in the end. So I think probably having some type of community discussion. Cause whatever we do has to work for everybody. [CVHEdC12,p.16]
Resources	The refrain in much of the non-profit community these days is resources to do it so that if there were grants that allowed you know that, the support for people to put something together, the more support they have to do it the more professional it becomes… [CVHEdC09,p.14]

5.Community process / structural requirements (Interview Question 8)

The key community processes and structures needed to facilitate patient involvement in education concerned coordination and recruitment processes based in the community. Dedicated staff within community organizations could provide consistency and continuity necessary to cultivate relationships for on-going recruitment and support of patient educators. People "on the ground" in the community would also have contextual knowledge that would be important for screening, preparing and engaging vulnerable people for appropriate educational roles. The UBC School of Social Work's Centre for Inclusion and Citizenship and Patient Voices Network were offered as potential models that could facilitate patient involvement in health professional education. Another model of how the relationship between the community and university could work came from how collaborations work between community organizations – responsibilities are determined by the expertise and resources each brings to the partnership. For example,

> *…we work successfully with multitudes of organizations. The Positive Gathering is an example, we work with seven other AIDS service organizations in the Lower Mainland in order to present this gathering that we have ...They provide the logistics, we provide the infrastructure but the development of the program and the delivery of the program is not, we do the logistics at the hotel but the actual delivery of the seminars and the workshops that go on are, we don't do a lot of that. That's done by the participants themselves. It's about taking that peer model. [CVHEdC05,p.16]*

Table 5. Community processes/structures for engaging vulnerable citizens in education at UBC

Coordination in the community Continuity	1. …**one of the pieces that would be absolutely essential to our involvement here is at least some staff support** within either provided by UBC located here or the ability for say a half-time FT. I'm not sure what the time involvement would be, but a full time staff person or a staff person, so a staff support person of some sort. They almost provide, and this is something that came to light last night when we were hosted a west end citizens action network thing and I was talking to some of the kids from [Organization] and they talk about how they keep re-inventing the wheel there and the piece for me is the **institutional memory in with any agency like this that's dealing with a disease with this nature lie within the staff, not within the volunteers necessarily.** [Name] is a bit of an exception. [Name]'s the only one I know that's been with this agency as long as he has. Other people of our caliber tend to get involved for around 8 to 10 years, but most of the people that come in and out of this agency are probably in the 3 to 4 year level. **So in terms of consistency and continuity, a staff person is critical to that. It is also a go-to person for whomever, you know, somebody like this would be involved with it, so there needs to be a sort of a mentoring capacity in terms of a staff function, that absolutely would be key, absolutely be essential.** It would become very difficult to get things done if you didn't have that commitment. [CVHEdC05,p.15]
Recruitment / screening / preparation / gradual entry	2. …**having a coordinator and making it like a program**. Like we would probably have to operate it the way we operate a program, so we have a program coordinator and we have, um, you know this is how, we sort of **have guidelines** with **what we want to do** and **what we want to achieve and set the goals and then interview women** to come into the program and you know work with women who would hopefully be the most likely to be able to be sustained with this program and say it's six months and at that point we usually, usually everyone has a {s/l stippened} when they come, so if we were gonna do it that way instead of the big group process, like a free for all, that way everybody say has $10.00 every meeting they come to or whatever, and then that it starts to be built and it builds and builds and builds and then there's the field trip and then there's another field trip and then everyone becomes familiar with the field trip. And then the sort of what the next steps could be outlined at each step of the way. Like these are our goals, could come at the beginning but it could scare somebody, but it could be step by step goals. And then, you know, I think it's very plausible but I do think the sustainability of it would be difficult, no matter, no matter what. **To have women continue to go to UBC I think would be difficult.** [CVHEdC02,p.14]

Database / registry	3. Well I would like to have an ongoing **database of people,** chosen people at first that could go into the education situation at UBC where **they believe in us** first of all they're not, 'oh they sent us a couple more flakes that are just gonna talk about oh woe is me.' Instead of giving, taking advantage of that time and really giving good information and being a good educator and facilitator. So finding that group of people, continually giving them education, other things, facilitation skills, …just to so many things that we could provide for them aside from UBC that gets them ready for that so we create that database to go and then UBC calls us and goes okay we have nursing is looking for this. Yeah, we've got a great speaker, Marcy, she was a nurse before her injury, she now has had a spinal cord injury, she can bridge that. I've got this person who was a dentist or a doctor but gone through the schooling, can go in and speak to students because he's been in that role before. We could pull from that group cause they're people that have had these situations. … but there needs to be s**omeone like us that creates a database of those people, like a nucleus that starts to utilize them**. [CVHEdC10,p.22-23]
Support staff	4. …what we would do is really put it out through our network so all of our 19 resource centers would say, we'd say to all the caregivers they each have their own database of people who are connected. Sometimes people come to support groups every time they have one, and sometimes they only come once a year and sometimes they don't go at all but they're still connected to the network and get our materials… So anyway, through those networks to let people know about the opportunity…[CVHEdC11,p.14]
Trust & contextual knowledge	5. We do have some individuals when I've looked down the levels of involvement that would be willing to come out and talk to groups or talk to classes. That would take some organizing and I think for the Kettle, because we have very sparse resources too that we would want to have some resource maybe to pay some staff support for that. So if it's more, if it takes a lot more of our time then we would need some support for that, maybe some outreach hours to work with the individuals to come and do that. [CVHEdC03,p.4]
	6.…having some support from the organization here to support people to get involved would be really important because there's a level of trust. Everything is very much, our model is very much based on relationships so people develop a trust and with the workers here and with their, and with their peers. So I think engaging us in being part of that would probably really help. And again, honorarium bus fares. And acknowledgement, asking people what they need. You know, it's like today if you were having people at a coming out to UBC, if they didn't have a meal before they came they probably don't have any money to eat. It's two days before cheque day. So just being really aware of people's circumstance. [CVHEdC03,p.6]
	7.I think we probably could designate a person to become part of a project like that and I think it would be a fascinating project. But it would be really important then to have, and again the same would probably be similar to other organizations to really think how can we, can the work be done with as little time involvement as possible? [CVHEdC12,p.16]
	8.…something like Patient Voices Network that would tap representatives from these different locations in the community that I've identified and they could be scheduling visits to venues, knowing schedules, things like that. Or they could be sending the well spoken person dealing with dementia. [CVHEdC13,p.9]
Matching	9. We have volunteer matching programs where you know an agency has a need, seniors in the community have interests and the match is made between the two and off they go… So that basic match-up could be done by a coordinator. A lot of our funds go just to that part-time coordinator even that, and they, a coordinator often does the scheduling or they you know make it even, um, less contact and just introduce through email the two entities and then off they go. [CVHEdC13,p.11-12]
Representation	1. One of the things we struggle with is whether people are well enough. So are they well enough to be able to give us an informed opinion? Are they well enough to handle the stress of being involved in engagement? Do we believe what they're saying? So I think there's always a questioning. I think in my particular area, one of my programs provides service led by people with lived experience to other people and we're finding right now it's kind of gated so what we thought would be quite a fluid system isn't. People are not able to access that service until someone else is deemed them ready. So it's particularly frustrating. I mean who gets to determine ready and who gets to determine well enough and I think maybe we are losing things by only wanting to hear from people who are well enough. [CVHEdCPilot,p.10]
	2. Organizations like Positive Living BC can help in marshalling patients as the phrase is used here, in particular venues, and in fact I mean we do that with UBC now. But I'm not certain you would find organizations similarly capable in other disease groups, and of course at some point you confront the question, well how many disease groups do we have to accommodate in this exercise? Are there not at least some common denominators that will for these purposes enable an HIV positive young gay man to stand in for young gay men suffering other conditions. And the answer of course is in all likelihood yes. [CVHEdC06,p.5]

Logistical supports	1. ...we promote all of the stuff that's happening now to all of our groups and individuals. **We would be happy to offer meeting space to provide a common ground for people to come and meet.** We would be happy to offer speakers, people to go and talk about various issues. We would be happy to support it in whatever way we could. So we have people, we have access to people, we have, um, you know, we have people living with chronic illness disabilities who are health care professionals so you know we can access all kinds of different perspectives… [CVHEdC07,p.12]
	2. We have something that might be helpful, or at least it was developed in New Westminster and the acronym is SET, Seniors Engagement Toolkit, and it has a whole range of suggestions for how to effectively engage seniors in the community in the course of doing its community focused work but it could be useful for university. So it has things, it has to do with font size on any communications, best times of day, you know, not too early, not too late basically, not too long is another, things like that. [CVHEdC13,p.10]
Preparation, training & support	1. ...preparing people for involvement, not just expecting that people will know how to be involved in a development process or even involved in being a representative. …we do have a little piece that we worked on and it's called Consumers In Action and what it did, it was supposed to be entry level leadership training and maybe that's how we have to look at it is if we were going to get people involved we have to think of them as leaders. Even if it's not leaders in a big sense and I think that might help people, encourage people to take risks, take risks that are calculated. So giving people some, like this is what it's like to be part of a committee, this is what it's like to be an advocate, this is what it's like to be an instructor. So giving people a little taste of all the things that they might possibly be involved with and then letting people maybe self-select which things they're more passionate about and then having a mechanism to encourage that involvement. So we piloted this wonderful program that people wanted to be part of, but the back end wasn't prepared so we didn't have opportunities then for people to practice those skills. So I'd see that as a, so I think before you can get people involved in the helping people in an academic setting, you really have to give them an opportunity to practice. Because the students are only gonna have one shot at their education, hopefully they're gonna get it right the first time. But, you know, I think a place in community where people can practice these skills and test them out and make mistakes and then get to a point where they say yes I am definitely ready, willing and able. Or we learn as a community to help support people who may never get there with a certain piece but still get it to a point where they could have meaningful input in a certain area. [CVHEdCPilot,p.12
	2. ...the more we can do in the consumer area to help other people feel that there's an expectation that people who are providing service are collaborating and listening to them and that people are not waiting for it to happen but are being more proactive so I think what we could be doing at our level is priming people, priming people and bringing the subject up, getting people to think about, yeah, if I was involved in education, you know, what would that look like? So helping people see potential. But again I think the training piece will be more effective if it's happening at the institution that we're trying to influence. But that the preparatory work could be done at the community level, so the peaking people's interest and encouragement and stirring the pot. And right now if we were to stir the pot and there was nothing for people to attach to, that could just make people frustrated. [CVHEdCPilot,p.14]
	3. …having organizations like ours, like the Arthritis Society and the Community Mental Health Association and all those groups, um, Schizophrenia Society and then it's like oh to with their support maybe then they can find ways to also support the person to take that role, to take that role. And I think the Patient Voices Network is a really strong, it's got a great mechanism and it's got, um, and it's well supported I think from government and at Impact BC and if they were engaged in this they would be a great, I think, a great partner because they know how, they've learned now how to engage individuals who have been patients and to train them to take positions of leadership within boards, committees and also education events. And so except for my caveat that they don't bring all the most vulnerable people there and so that you know that voice is missing and to make sure that you don't ignore it and find another way of getting to it then I think that, I think that's the perfect connection for this piece. [CVHEdC11,p.16]

6.University process / structure (Interview Question 8)

Informants consistently identified the need for the university to create conditions that are conducive to involving marginalized people in the education of health professionals. The university needs build long-term, mutually beneficial relationships and recognize that each individual's ability to participate will be highly variable. Due to the inherent power imbalance between the university and vulnerable citizens, relationships need to be invited and nurtured by the university. There was an awareness that the university has a different culture, with protocols and politics that are unfamiliar to people from the community. To "bridge" these cultural differences, the university will need to create environments that invite and support meaningful public participation.

Table 6. University processes / structures for engaging vulnerable citizens in HPE at UBC.

Theme	Key idea	Full quote
Invite	*They need to be invited in.*	They need to be invited in. They need to feel that they, that the health profession, that the educational institution values their involvement. I think that many people as consumers of health care feel that they're almost an afterthought and certainly in the education. So to be invited in, to feel that they're valued, feel that there's something that they have relevant to contribute to the education of the professionals. [CVHEdC01,p.5]
Support	*An open door…*	an open door…that any time I had any issues or I had any questions that I could call and be acknowledged and responded to within reasonable time. That I felt that that sort of engagement was encouraged and validated. [CVHEdC05,p.17]
Share responsibility	*Co-leadership with community*	1. …it's so interrelated I'm not sure where you would start. I guess somebody has to be accountable so if there was a network in the community that was connected with the university or universities and other post-secondary schools to I guess push from both sides, so, I think if the community is putting pressure on the teaching environment and the teaching environment is saying yes but this is the barrier, there needs to be some sort of collaboration about that middle piece and I think that middle piece is just the part I'm having a hard time defining. [CVHEdCPilot,p.13]
		2. We definitely need a person in each organization to lead it, co-lead it. [CVHEdC04,p.10]
		3. If you can kind of have some level of collaboration in that organizing, I think you'll get more community involvement. [CVHEdC12,p.17]
Build on-going relationships	*Avoid "academic projectitis"*	1. …one of the experiences common in community in dealing with academia is the projectitis, you know, and that's just because of the way things operate, right. But you know we get students who come and work on a project and that's fantastic and I'll rarely turn that down, you know, it's just, it's great. But if you're trying to get long-term buy in from the people in the community and you're trying to affect long-term change, I think somehow we need to, we need to establish a relationship that's just, that's not just around a project but you know, UBC wants to be part of what we do and we support what they're doing and you know we're partners now, you know. And so that would be a very different relationship than having a relationship with an organization that is supporting a peer mentor for example or it's making a commitment to being available and to providing people or having somebody come and talk to a group or being kind of available to offer what you can when you can on both sides, right. [CVHEdC07,p.10]

Theme	Key idea	Full quote
Build on-going relationships	*Avoid "academic projectitis"*	2. …having a realistic time frame, right, so you don't want to be trying to push things through too quickly so I think it's having a time frame that's set up collaboratively with whichever organizations and UBC because perhaps you have a time frame cause you're funded by the Vancouver Foundation so maybe you have submitted some type of time frame, I don't know, but making sure that that's realistic, right. Keeping in mind that I think the majority of not for profits are super under-resourced. I don't know how it is at UBC but making sure that whatever is in place it's gonna be realistic because you want to set it up for success so I think that would be key. [CVHEdC12,p.17]
		3. …my preference would be that it would be reciprocal or more reciprocal. Patient Voices Network takes people, as I understand it, from the community and feeds them in. It would be great to have the university, in this case, not the public health, coming out into the community and in various venues right in the community. It makes such a difference to how people perform just even in the, and the information you pick up to see them, you know, where they live and in the company of who they keep company and so on and so on makes a difference to how they function and what you learn. [CVHEdC13,p.13]
On their turf and terms	*Meet them where they're at…It's not build it they will come…* *They'd have to come here.*	1. …it's about understanding the individual and where they are and meeting them where they are. It's not build it they will come, it's about building it and taking it to them. [CVHEdC05,p.23]
		2. …this [levels of involvement] presumes that these people all have the capacity to go someplace else …to the university or to the hospital or the teaching hospital or whatever. It has that assumption and that they are able to do that. Like to me this seems quite you know something they have to do on a regular basis, they have to be able to write, they have to be able to engage. But it doesn't really leave a lot of room for folks who aren't really confident to do that. **They'd have to come here.** The clinical providers would have to come here, I think, and then that way they could hold clinics and see people in a different way because they would see people that could never go to the university. I mean the university is very inaccessible anyway to most people, unless they're students. Like there's not one woman I know who would hop on the bus and go to UBC for the afternoon. I mean it's just not plausible, partly because of exactly how they behave, how they look, how people perceive them and so on. It's not really a safe setting for them and their comfort zone isn't outside of here. So their comfort zone is gonna be here so why not bring people into here. [CVHEdC02,p.10]
		3. I would like to see the students come to real settings. But I think it could also be valuable for people to be able to go out there, the patients or people from immigrant communities to be able to go out there and be part of that learning setting as well. [CVHEdC04,p.7]
		4. …a lot of it takes place at UBC and so with clients that have like so many challenges with mobility or energy or cognition to get themselves to UBC… [CVHEdC12,p.9]
		5. …always being aware of that that if you want the client to participate it needs to be in an area that works for the client probably before the students… [CVHEdC12,p.10]

Theme	Key idea	Full quote
Accommodate vulnerability	*…there's that ebb and flow*	We have a supported employment program where women are on the payroll, they make money, and it's fully supported by a coordinator and staff at the drop-in center. **But they can't always come.** You know, **people's lives go through cycles and women particularly who live here and might be involved in drug use, still involved in sex work and so on, their lives go you know pretty up and down.** So you know and you'll have somebody that can work for you know three months and then they need three months off. You know, it's just how it works and they just might hit a slippery slope, they might of, it might not be, what's that word, sort of the bloom is off the rose, you know, those sorts, you know it's just not as exciting and then they'll come back. But **there's that ebb and flow that we experience very much with people who come in and out of our programs**… [CVHEdC02,p.14-15]
Create safe, non-judgemental environments	*it's set up to succeed …it's organized, it's supported, there's food, there's transportation… comfortable space and you need some privacy*	1. …feeling that they had the right to say things that were maybe not complementary to the existing medical system. And for some cultures that's more than others that they don't feel that they can say that they wanted you to do this better. …sometimes it's a really big burden for us when we're doing evaluations for instance, they never tell you anything that needs to be better, it's all perfect. So, um, maybe just by wording things differently so that what they're saying is not perceived as an insult, it's perceived, you know, how you word the questions I think. …we talk about change in evaluations as opposed to did you like something. We try and determine did something change for you, and not like did it improve but did it just change. So making more neutral language I think. But again it's not, we always know that there's some evaluation forms that are gonna come back differently, with everything wonderful, 98% of strongly agree, strongly agree. [CVHEdC04,p.9]
		2. …it's organized, it's supported, there's food, there's transportation, like **it's set up to succeed** and I think that that's one of the things that has to be set up to succeed. … you need some space, comfortable space and you need some privacy which is so, as I'm sure you know not very common for people who live in poverty and who, you know, and it can't in the middle of WISH dinner, you know, because it would get crazy. [CVHEdC02,p.13]
		3. …the environment can have a big impact on whether or not people will participate. So for example if UBC were to schedule a meeting to meet with people here, they would probably get different people than they would out at UBC because people know us and they know what to expect, they know there are people here who will understand and will ensure that it's a safe place, right. So and that's something that could be arranged by the way. But there are all kinds of community organizations around that would be probably very happy to do that kind of thing. So I think that you might be able to get higher levels of involvement if you were to negotiate different environments. [CVHEdC07,p.7]
		4. So and they're gonna be intimidated too because all of us in the community don't feel we know as much as a health care professional or a provider, even if they're in training they know a lot more than we do. They had to get, worked like hell to get to that point and when we haven't done that. So we're already feeling a bit intimidated so I think it's making its space that's comfortable for them to come in and to really recognize that they have a piece to bring. [CVHEdC11,p.15-16]

Theme	Key idea	Full quote
Create safe, non-judgemental environments	*it's set up to succeed …it's organized, it's supported, there's food, there's transportation… comfortable space and you need some privacy*	5. …being very careful to respect the different perspectives of the different cultures as being legitimate health care practices and not, I've heard them, people calling other people's practices, other culture's beliefs as superstitions and I think that's pretty judgmental…[CVHEdC04,p.12-13
		6. …make sure that people are speaking in plain language and not in academic jargon or you know like so it's just really important to be really clear and to sometimes we tend to speak really quickly and that and to just get people, to really be clear that people are understanding, that it's nothing to do with intelligence, it has to do with the experience and to be sure that people are using plain and accessible language. [CVHEdC03,p.6]
Honour their expertise	*you have a gift to give us… and we appreciate you for it.*	1.…they have to be welcomed as a partner, right. To be, like that you have a gift to give us, you have a piece that we want and we appreciate you for it. [CVHEdC11,p.15]
		2.…value individuals' times we do it with individuals and the families often where they work in a committee setting and you know volunteer their time is to pay an honorarium. [CVHEdC09,p.23]
Provide training, mentorship & support	*But many people are not from that place.*	1. It would be very interesting if that [leadership/instructor] type of training could be done at the university. So helping, if the community is starting to support people to access opportunities to learn those skills but have the skills embedded at the university so that people are getting the rhythm of the environment as well as the demystifying piece. I think there was a part that was being done in downtown where people were able to take courses, people who had never gone to university, so ...getting them, getting and feeling part of the process. … And you know that's not discounted. There are a lot of people in the system who've gone to university, have done their own training, but if they end up with a community mental health team, which is where I'm working now, something's gone really wrong, they're not able to do what they thought they were gonna do so there's some loss. I think in mental health there's a great deal of loss and so if something like this could be seen as a plus, I think that would be very empowering at the end of the {unclear} but I think it would be enriching at the broader level. So maybe having these skills taught in the community is not enough to make people feel like they want to take the next step. So maybe if those skills were accessible in an academic setting might, it might be the catalyst. And maybe it doesn't have to be university, maybe it's something that's available at one of the community colleges or, you know, at some part of that education continuum. [CVHEdCPilot,p.13]
		2. I think just with some practice I think cause the skills are there, I think it's just building the confidence with and some support. Getting a mentor maybe at UBC who might work with them individually so that they get to know them a bit. [CVHEdC04,p.9]
		3. …we have some amazing people in this organization but they need to be mentored to become effective within our organization, never mind within a cross organizational activity, right. So what could UBC do? Um, yeah I guess, you know, I mean obviously reach out and to engage us and make it attractive to us in terms of supports. Um, and recognition of the frailty, I don't like to use that word but I think it's the realities of living with an illness. [CVHEdC05,p.17]

Theme	Key idea	Full quote
Provide training, mentorship & support	*But many people are not from that place.*	4 …offer some **training workshops to people to learn how to present their story.** Now I know there's some of that that goes on, especially when they're doing the, you know, presenting their cases to students, but I'm thinking of something a bit broader and a little less specific. So part of it is communication, part of it is **knowing how to temper or channel your anger so that it doesn't come out and break communication down because that's what happens, right, people just want to blast anybody who's there to listen. And to present your story in a way that communicates how, what's happened to you as a result of these things,** what the effect it's had on your life and who you are. … I've been in the education system for so long that it's hard for me to remember what it's like to not be from that place. **But many people are not from that place. It's very foreign,** um, what's the word I'm looking for, elitist, all of those negative things, right, it's part of the system. So in order to be perceived as a positive thing it needs to be promoted in a, and a bit of time and, …I would do whatever I could to support this kind of thing, a workshop where people could learn how to talk about, learn **how to communicate with health care workers and how to talk about their story to anybody in a way that is helpful for people to understand and not alienating or scary.** [CVHEdC07,p.7-8]
		5. when you recruit people to be things you say support is provided to ensure that you do not feel alone through this process, right, so that, and if you feel like you've been mistreated in the meeting that there's, that you can come to me… [CVHEdC11,p.19]
Prepare students for a different kind of learning	*Students prepared to "get their hands dirty"*	And I think that if you want to send us a student that's as useless as she, she was completely useless. She just didn't feel like doing anything. …I think that she thought that she was somebody who was above all this, really. I mean that's essentially what she told us. And I thought boy, you know, you're gonna have to learn to **get your hands dirty** somewhere. And if it's not with us it'll be somewhere. [CVHEdC02,p.5]
Institutional commitment	*…they're prepared to keep picking it up off the floor and keeping it going.*	1. if it's essential that people with compromised health are involved in the teaching experience or the learning experience, then you need to be cultivating those people so it's a good experience for them as well. So maybe there's a staging so maybe you can't just have somebody walk in off the street and be involved in there, but maybe there is a way of raising the right, raising community involvement. So, sort of giving people a head start and then maybe people are self-selecting or maybe people are electing to be involved, but I don't think it's gonna happen spontaneously and I don't think it's just gonna happen overnight. I think you have to do information sharing at both levels and I think often we think that if one part gets it right then the other part is just gonna automatically follow and I think we have to see the constellations as both needing information and support. And then I would say if we're trying to influence the education piece, then the ownership needs to lie at the institutional level so that we can't back pedal. I think it has to get in there and be intrinsic and I think maybe the position of the community organization should be the watchdog or making sure it's occurring. [CVHEdCPilot,p.14]

Theme	Key idea	Full quote
Institutional commitment	*…they're prepared to keep picking it up off the floor and keeping it going.*	2. …ensuring that you have champions, people who feel so strongly about it that they're prepared to keep picking it up off the floor and keeping it going. ensuring that you feed your champions and that works both ways too. …people will come on board and be willing to do all kinds of work as long as it's for something, but and that's the danger of having a long-term gains. So never losing sight of the fact that you're working towards something so and that's a matter of communication and fanning that flame so that people don't lose sight of the fact that it's actually meaningful. [CVHEdC07,p.10-11]
		3. But if it becomes a bureaucratic piece then it will fall apart I think eventually, and if there's some, and if it's like a pro forma, like oh yeah we got that person in so good, yeah, that person said a few words and now we can say tick, we got that piece done. If it's like a tick box exercise people will know it and then that won't be meaningful and it's just not worth it. So I think it has to be a valued in the organization, it has to be commitment by everybody and there has to be infrastructure around it and I just, I personally think that people are gonna go great idea, yes, that's a lovely idea, and nice to have but in our time of financial stress and structure we'll just have to focus on the basics of the work that we do. [CVHEdC11,p.21]
Organizational supports		1. …there's always a trade-off that it's good for us to be involved in the process, however it often ends up tying up some of our staff time and if there's any way to compensate for staff time that would be helpful. [CVHEdC01,p.7]
		2. …you know you get paid to do this, to offer this course and then you farm somebody out on us who takes our time and drains our resources and you're still getting paid for it. And I said there's absolutely not a hope in hell that you'll have another student with us, no. And it's because of the way they handled it. They could have phoned and said 'gee, we're really sorry, didn't know this was gonna work out this way, I appreciate your help, whatever.' No, nothing. And you know we don't have time. We have, like we have, busy busy busy like hell. So we don't have time for that. [CVHEdC02,p.5]
		3. If it is principally a recruiting and working up endeavour then I think most of the participants would want to be in the position of suggesting possible candidates who could then be recruited and dealt with by particular people wherever they may be situated who would be paid for by the project. Not many organizations enjoy the financial ability that Positive Living BC enjoys actually to devote staff resources to this kind of work. And I mean our resources in that regard are hardly infinite so if we were to undertake that kind of partnership work with other community organizations, we would need extra money to support the consequent call on our human resources, on our paid staff. [CVHEdC06,p.7]
		4. In an ideal world, like I said, if you would pay us for our time because we tend to donate all our time for a lot of things we do and we don't have a lot of resources, so if someone here could be dedicated to if it was, you know, two days a month or a day a month, or whatever the, so that we would be able to provide you some staff support to engage folks, that that would be one piece and then again honorariums for people participating. For the long term then I would say that we would need to have some sort of position here that would connect and work with you at UBC. …Well for instance we have a half time volunteer coordinator. If we had a day a week or so many hours a month for an educator of some sort or an educator facilitator that worked in partnership then that would probably be effective, yeah. [CVHEdC03,p.7]

Theme	Key idea	Full quote
Organizational supports		5. …we would need financial support just because we're always stretched you know for staff time and that so for compensation with people that would be trained, I think there would have to be some training staff wise and with the community members as well. I don't know how much that would be or what that would involve but you know it would, sometimes community organizations do everything off the side of their desk and it's not the best way to do it. [CVHEdC04,p.9]
		6. Um, recognition of the organization in whatever form might be possible, whether it's on a website or the date the information is published. That would be good. [CVHEdC01,p.7]
		7. …having someone from UBC to be able to either be at, our clinics have certain hours that they're open so you know having a grad student or someone that could do the actual intake might be helpful. Or if it's a matter of doing an info session where our volunteers or nurses have identified a number of clients who might be interested and then have a UBC person come to that session where you gather them together and talk to them. [CVHEdC01,p.6]
		8. …really good materials that we can share with our clients. Actually one thing that's also really important is to have enough time to have enough warning. So if you get a week's warning there's a, we need some clients who participate in this, or even two weeks, it's very tight, because of, because of our own workload. And so as an organization, that's probably the same with all not-for-profits these days, is having enough warning, this is coming up, and a clear description this is the type of client we need, these are the, so that we can then go out and spread the word amongst the people we know, we're in contact with, and help them and get them in contact with you. [CVHEdC12,p.15]
		9. So if meetings amongst service providers to develop something like that are always gathered at UBC, it means for us a huge amount of travel time and that means time away from our work. …So then tele-conferencing or helping organizations to set up some kind of video conferencing if that's possible as one means. I mean there may be meetings, in-person meetings maybe necessary but then also maybe there's a more central location that can be identified where the UBC involved people would travel to and from different organizations, people would travel to for a meeting rather than the assumption it's all happening at UBC. Because if you have to take an hour and a half out of our day, that's a big chunk out of our work time. We can do that once but to do it on a regular basis it would just add to the burden. [CVHEdC12,p.16]
		10. …you have funding for the project and usually with funding there's staff time as part of the funding. But we don't get that funding so we don't get extra funding for extra staff time so it's a new project for us to add to our normal duties which are already spread pretty thin and, again I think the same is the case for most organizations like ours. [CVHEdC12,p.17]

7.What could they teach? (Interview Question 9)

Key informants thought that people from their communities would be able to teach students about their lived experience, stigma, advocacy, communication skills as well as cultural knowledge.

Lived Experience	1. I think people could talk about what's worked for them, what's helped, what's been most helpful in services to have better health. I think the people have a lot of information about that that could be shared and would be really useful. Smoking cessation is a big one and talking about the challenges with their medications and the interplay, the interaction of those things. I think the biggest value would be hearing from people what actually has worked for them. And what hasn't worked for them. [CVHEdC03,p.5]
	2. We certainly have a lot of experienced employees here who could probably help. For instance, we just had the housing director talk about the different challenges, barriers to people to accessing housing or supported housing. We provide housing, we can give you some insights into that. I think the experience of our transition house staff would be very valuable for people in the system to hear. [CVHEdC03,p.7-8]
	3. We can tell and in some instances actually show would-be health care professionals real folk with real problems of the sort that they can reasonably, they being the students, anticipate encountering. And even if HIV is cured next year, which by the way ain't going to happen, but even if it did, the thing about HIV is it is more than just about any other a disease of the wretched and rejected and the wretched and rejected are gonna be around for the foreseeable future and even if it's not HIV that's bringing them into contact with the health system, it'll be something else. [CVHEdC06,p.7]
	4. What we can do is speak with authority and I think with conviction and accuracy and authenticity is the issues of what this disease means for families, what this disease means for individuals, the impact of this disease on families and on individuals. We also know a lot about ways for coping and we know how the systems currently work and we know how to help guide people through them… [CVHEdC11,p.15]
	5. What it's like to navigate the health care system. We have a part-time advocate at our Peggy's Place site, when they've taken, women are really engaged in the health, like emergencies, a lot of emergencies, using ER's, using doctors, using teams, and they've had people successfully have their hepatitis cured, but that's taking a lot of support and I think those experiences are really valuable for to as part of people education. [CVHEdC03,p.8]
Stigma	1. There is also a lot of preconceived notions out there. The fact that someone may have had an addiction problem 25 years ago that comes into Emerg and says that they, yes, had an addiction problem 25 years ago, automatically the thinking goes to that this is attention seeking behavior and you are here to get drugs, even though you've been clean for so many years. There's a lot of these preconceived notions that need to be unlearned and hopefully that there is some way that we can help assist in that especially when it's unlearning stigma, unlearning AIDS phobia, unlearning some of the other discriminations that are out there because there are quite a few.[CVHEdC05,p.18]

Stigma	2. …being able to reach into the starting point of the training of those who give care to others and having the ability to affect a mind set early on I think is key. But I also think that this is something that needs to be reinforced through, the doctors spend seven years trying to learning these skills and the rest of it and it's a huge piece of work and many of them come out the other end, come out just probably overwhelmed and overloaded with what they've learned and so that many of them are looking at actually starting an active practice and getting out from under their debt load and the rest of it. So they have their own agenda, I get that. But nobody can be effective in healing another person unless they recognize that individual's humanity, and that individuals need to be empowered with their own health care. That's a very broad brush statement but I think it's, from what I understand and what I see today I think those that train our medical practitioners are beginning to understand that and bring that into the training, so I recognize this is a key piece and a good piece to be happening right now. [CVHEdC05,p.21-22]
	3. But there are others out there who simply want to be told what to do and when to do it. And so I think there is absolutely essential to recognize the individual where they're at, you want to move them to an empowered state, how you guide them to there, to that place is tricky because if people are coming at you disempowered, disenfrachised and marginalized, they don't understand that they can have that power. So it's educating the person. So I think flexing style was where I was trying to get to, so an understanding of the individual, where they are in the spectrum of their life and in the spectrum of the number of years they've lived with this disease and how comfortable they are with this disease. HIV, and it's been said many times again before and it, I'm beginning to sound like a broken record but this disease changes people. It brings your mortality right smack into your face. But it also means, it changes your life in terms of you now are tied to a medical system for your health and you've lost a certain amount of your independence if you will because you're now absolutely dependent upon the medication, you're dependent upon your health care providers for your quality of life and most of us want a say in that, most of us, but not everybody has the capacity to do that yet. And so that to me is a huge piece of what our challenge is here is to take those who don't feel empowered, who don't feel enfranchised and to teach them that they do have that and to teach them, give them the skill set so they can make good decisions for themselves and that's a huge piece of it. That to me is a huge piece of a caregiver's work. [CVHEDC05,p.22]
Advocacy	1. …we've got a long history of running campaigns and developing an approach to make systemic change. So that's not something you can just take a course at university and know how to do. It's the kind of thing that you really need to be involved in it and roll your sleeves up and do it. So we, you know, we get people involved with that kind of thing when we can. [CVHEdC07,p.3]
	2. …the idea of actually putting the seed in the minds of medical professionals that people with developmental disabilities could be employees is quite interesting… we're not necessarily trying to find people full-time work because it's not necessarily income they're after, it's really that participation, that collegiality, the social, the self worth, the identity and all of those kinds of things. [CVHEdC09,p.19-20]
Communication skills	I think meeting with the actual people, not even the workers, but the actual participants in our programs. Having them talk about it, talk about what their vision of health care is I think. And it wouldn't be the same for every culture obviously but I think if you looked at it there are probably commonalities in more traditional practices, right. Attention, listening, asking questions. Getting more information and not just focusing on the need that's, they went in for their need but how that need fits in to their life. [CVHEdC04,p.5]

Cultural knowledge	…there's a whole, an amazing amount of expertise in the people that walk in the doors in here, really have so much to offer. I don't know that they have a lot of them yet. I mean I think of some of the health care professionals have a wealth of knowledge that they can't use here and I think one of, what would be a benefit to them, we have a group of Latin American professional men who meet every week as a way of kind of, they're trying to re-invent themselves because they don't have, they aren't able to practice their professions and they're not all health professionals but many of them are. So there's, there's a whole wealth of knowledge in that group for instance, and there's other organizations that we work with, you know. There's a woman who was a physician, she's from Afghanistan, she was trained as a physician in Russia, she speaks about six languages and she's not able to practice here either because she just can't get, you know, there's so few positions, residencies and things so she, but she is amazing. She would be able to provide a lot of information on working with Middle Eastern community for instance. [CVHEdC04,p.11]

8.Benefits to community (Interview Question 9)

Validates their work, facilitates funding	1. …it's something that we could tell people you know when we're applying for funds for whatever, we could say wow we have this partnership with UBC, Health Sciences or whatever, and this is what we're doing. It's always, people love to hear those things… [CVHEdC02,p.15]
	2. …we take that information and we go to our funders and go we've got a group of people we're feeding into UBC that's helping UBC do this and the doctors and the nurses and … [CVHEdC10,p.23]
	3. …everybody working together can only create something that's gonna better benefit the clients and I think too if we can have a stronger link to UBC there may be ways that we can help each other in other capacities that we don't even know that exists… [CVHEdC12,p.18]
	4. I am finding my way around the transition from this old divide that we have had to respect between social and health services with the introduction of the social determinants of health approach. So, we have for example, so it would muddy the waters further {Chuckle} in a good way. …an example where these issues with the dementia friendly community initiative, assuming we get municipalities wanting to train their frontline workers so that they are privy to what dementia looks like when someone comes in to pay their utility bills and they can't figure out the right amount of money … We're going to be funding the training but we can't fund the health piece. So right now we're having trouble determining where the boundary is, wanting to go out and do this kind of training that we don't see being done and knowing that 70 percent of people with dementia live in the community. So I think I've just, the waters are gonna get more and more muddy. We need to find out way around in those muddy waters and find new protocols I guess new divisions of labor between health and social service sectors given this new very good approach I think, the social determinants of health. [CVHEdC13,p.14]
Short-term: Good for their members	1. …the crux of it is the women and their health and opportunities to grow. [CVHEdC02,p.15]
	2. …the benefits to [Organization Name] is supporting members to have their voices heard. I think that, I mean that is definitely part of our mandate is again getting people more involved in their own health and their own life and to be empowering and supportive of that. So I mean that would be a great benefit to our members. … I mean being able to be listened to, to actually be able to sit down and talk to someone for an hour. In the drop-in we have two staff with 150 people coming in and a cook providing a meal. So you know people don't get a lot of time to sit down and talk about what they're actually thinking about things so there's a great value in supporting people to be able to do that. [CVHEdC03,p.8]
	3. …they would have to have immediate and direct benefits to the people that participate, either that financial would be part of it but also building their skills so that they can use those skills to go on in some other employment and that they would then also be able to hopefully access the health care system better because they would have more knowledge of it that they've gained through this process. [CVHEdC04,p.10]

Long-term: Better health; Better health care	1. I think the work that we do will be more efficient and more effective as we move forward in encouraging patients and their families to be more activated. Any time you're trying to do more with less, something's got to give and I think, um, I think moving towards a quality in terms of who's responsible for what. So we have no problems letting the surgeon do the surgery but I think in general health care sort of the non-specialist stuff I think we need to be giving people more opportunities and encouraging and even pushing people towards being more accountable where possible. And I don't think that that's unique to our organization. I think that's a societal thing. I think it's a Western concept as well. I think we've created dependency. And I think what we're now doing is trying to back pedal a little bit on that and make something that's more sustainable. I think sort of wrap-around health care is not sustainable. And I think if we perpetuate that I don't think we're doing anybody a favor. And the health only gets more complicated as you get older, so if we're not helping people when they're well to understand that concept, when things start to break down I think it'll be harder for people to feel more hopeful and more in charge of what's happening. [CVHEdCPilot,p.15]
	2. …the benefits to our organization would be to build awareness of the issues for people with dementia and their families within people who are newly becoming health care providers and will be out there in the system for many years and have lots of influence on people's lives and therefore would be good for them to know, so yes that would be, bringing that awareness. …to affect some change in how people receive care and how the kind of care they do receive. So I think that we'd actually practice might be improved out there. [CVHEdC11,p.21]
	3. Well in the long run a more adept and culturally nimble health care system. And that is not a benefit to be underestimated. One of the things certainly in the early stages of the epidemic that I think caused half the suffering that was experienced was the intellectual incapacity of the health care system to deal with that which was confronting it. I mean there were technical incapacities too, the lack of an effective treatment being top most on the list, but even allowing for that, I mean the absurdities that positive people, the destructive absurdities that positive people were subjected to are you know 20 years later almost unimaginable. Well anyhow, there are still for the, I'm trying desperately not to use the word oppressed so I'll stick with wretched, for the wretched in our society the health care system is still at best an uninviting thing and at worst an active participant in their ongoing oppression. And to the degree that Positive Living can help alter that, um, that would be a very good thing for our members and many others besides. [CVHEdC06,p.8]
	4. I think having better educated health care professionals….And so ultimately it benefits our clients which means ultimately they have less problems which benefits us as well kind of thing. [CVHEdC12,p.18]

Appendix A

Key Informant (Community) Interview Protocol

Purpose: to discuss your ideas about how the involvement of community organizations, patients and citizens in the education of health professionals could be made a core part of health professional education at UBC.
The information will be used to inform the development of a mechanism for the community to work with the university for the purpose of influencing health professional education.

Materials to be sent in advance

Consent form
One page literature summary of patient / community involvement in health professional education including examples of the range of involvement to trigger responses (especially to question 5).

Introduction

- Introduce self
- Confirm purpose and structure of interview. Check received and read information summary
- Informed consent – review consent form (sent out in advance); confidentiality; anonymity; recording (remind them they can ask to have the recorder turned off at anytime, refuse to answer any questions they don't want to answer or withdraw their consent at anytime during the interview). Ask them to sign two forms; collect one and give them the other for their records
- Ask if they have any questions before you turn on the recorder and begin the interview
- Switch on tape recorder(s)

Questions

1. To begin with could you say a little about your organization and your role [to give us some context]?

2. Could you say a little bit about what educational activities your organization is currently involved in? Probes: Is education part of the organization's mission? For whom? Why (do you have a particular philosophy / guiding principles that underpins your activities)? What topics (content)? Who is doing the education (are actual patients / clients / community members involved)? Are you involved in any educational activities at UBC?

3. We are interested in improving the way that health professionals are educated. What ideas do you have about how health professionals should behave differently? Probe: What other ideas do you have?

4. Do you have any ideas about how your organization might influence those changes (what role could your organization play)? Probe: what would you like health professionals to learn that your organization could teach?

5. [Refer to information sheet – allow time to read through if needed]. Here is a range of ways in which patients and community members have been involved in the education of health professionals (examples include selection of students, curriculum development, teaching, assessment, program evaluation, strategic planning). Which of these are of most interest / relevance to you? Probe: how do you think that might work? What topics / skills would you teach? Can you think of other roles that aren't on the list?

6. What needs to happen to enable and support community members to participate in health professional education?

7. What are the barriers to authentic participation of [members of your organization / people with …] in health professional education? How might they be overcome or reduced? (Use backgrounder on barriers if they don't come up with anything) Probe: Do you have any experience of doing that [overcoming barriers mentioned]?

8. If your organization were to partner with UBC, what kind of process or structure in the community would facilitate the authentic involvement of patients / citizens in health professional education? What needs to happen at the university to facilitate involvement? Probe: If you were to join other organizations to partner with the university, what kind of infrastructure would we need to sustain and embed community / patient involvement in health professional education?

9. What could your organization offer to the education of health professionals at UBC? What would be the benefits to your organization?

10. Can you think of other organizations that would be interested and able to contribute to health professional education? (and name, contact) Probe: Why? Are there others?

11. I've finished my questions. Are there any other points you'd like to make?

Closure

- Turn off tape recorder
- Ask if they would be interested in participating in an educational forum to feed back results of study. If so, ask them to complete the consent to be contacted for follow up form).

Appendix B

Information for key informants to go with interview questions

*Patients have always been important in the education of health professionals, but their role has usually been as passive aids to learning. Active involvement of patients as educators has increased over the past 20 years as a consequence of government and professional policy directives relating to public and patient involvement in healthcare, moral imperatives related to social accountability, and the desire to broaden curricula to include the psychosocial aspects of health, promote patient-centred care and include the voices of those who are experts by experience. Patients are mainly involved in curriculum delivery and, to a much lesser extent, curriculum development and student assessment. In other professional programmes such as nursing and social work, a greater range of educational roles is found.

**Examples of patient roles in health professional education along a spectrum of involvement

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

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

Level 3 Involvement: Patient shares his/her experience with students within a faculty-directed curriculum. Examples: patients invited into the classroom to share experiences of chronic illness, disability etc.; community-based patient / family attachment programs; Senior mentor programs.

Level 4 Involvement: Patient-teacher(s) are involved in teaching or evaluating students. Examples:

Teaching associates trained to teach and assess specific clinical skills (e.g. pelvic or breast exam); parents give feedback to students on communication skills.

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

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

*Note: We use the term patient for the sake of brevity, to include people with health problems (clients, consumers, people living with [condition], community members, their care givers (including parents and family), and healthy people (community members, lay people, well women etc).

**Note: Patients may be individual educators or work in organized groups set up to deliver education and provide peer support. Some education may be delivered by organizations in the community.

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