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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 2: Community Dialogue Report

December 2013

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a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

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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

Angela Towle (Lead Researcher UBC), Co-Director Division of Health Care Communication, College of Health Disciplines, UBC

Cheryl Hewitt (Lead Researcher Partnering Organization), past Executive Director, PeerNet BC

Wafa Asadian (Graduate Student), UBC Faculty of Education

William Godolphin (Team Member), Co-Director UBC Division of Health Care Communication

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Cathy Kline (Research Coordinator), UBC Division of Health Care Communication

Research Advisory Committee

Michael Clague, Community Developer

Jane Dyson, Executive Director, BC Coalition of People with Disabilities

Louise Nasmith, Principal, College of Health Disciplines, UBC

Eyob Naizghi, Executive Director, MOSAIC (Multilingual Orientation Service Association for Immigrant Communities)

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Executive Summary

CVHEd Community Dialogue

June 25, 2013, Roundhouse Community Centre

Purpose of the Dialogue

The Community Dialogue was the second major participatory activity in the Community and Patient Voices in Health Professional Education (CVHEd) project. It followed interviews with key informants representing 13 Lower Mainland community-based organizations. The interviews explored 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 the University of British Columbia (UBC). The purpose of the Community Dialogue was to check and confirm the 15 key findings from community interviews; get input on process to identify action items and next steps; and build connections and collective commitment to take the work forward.

1. **Key Points and Action Items from Dialogue Tables**

   1.1 **Participants validated the key findings** from the interviews to the degree it was possible.

   1.2 **Health professionals need to be better at working in partnership** (key finding from interviews) was identified as the ultimate long-term goal of involving people from the community in the education of health professionals.

   1.3 **People from the community have a variety of expertise to share with health professionals** (key finding from interviews) was identified as a good place to start. A mini-project that documents the expertise that the community has that could benefit health professional education could put power in the hands of the community and reduce dependency on the university.

   1.4 **Prepare students for a different kind of learning** (key finding from interviews) generated some disagreement about whose job this is. Most dialogue participants took this to be a university responsibility but also saw a need to engage the community. A working group of university and community members could conduct a mini-project to develop ideas for jointly preparing students.

1.5 **Recognize and honour patient and community expertise** (key finding from interviews) was identified as a priority. Participation will depend on a range of options, including emotional and monetary compensation. Communities should be involved in creating guiding principles – a possible task for a joint university / community working group.

1.6 **Reciprocal, long-term, respectful relationships between the university and community organizations** were identified as most important – building relationship with and alongside people, as well as the institutional co-creation of mutually beneficial agreements. The group suggested we seek opportunities to create a common vision between community and university.

2. **Project Team's Conclusions**

2.1 The concept of patient / community involvement in the education of health professionals founded on a partnership between community and university is a new idea.

2.2 The power imbalance between university and community organizations permeated many of the comments. The university is still seen as 'all knowing' and the community as reactive to university requests.

2.3 Language and terminology continue to be barriers. Community organizations are uncomfortable with words that are used commonly in health professional education, 'patient' being a major trigger for heated debate, without agreement on an alternative that facilitates shared understanding.

2.4 We need to change the language and attitude away from 'us' and 'them'. We need to develop a set of guiding principles for the university and community to work together. This could be a task for a university / community working group.

2.5 Although the project has a large vision, it is made up of small steps. We need to identify little things that can be done by a task force of university / community members that can move us forward.

2.6 We need a parallel process for the community organizations to develop the idea of community collaboration, coalition or networking.

3. **Next steps for the Project Team**

3.1 The absence of Aboriginal groups in the key informant interview phase of the research is a gap that we need to fill.

3.2 We need to modify the project process by replacing the focus groups envisaged in the project plan with facilitated community-university conversations on issues arising from the interviews.

3.3 Our application to the UBC Teaching and Learning Enhancement Fund should pilot ideas emerging from the research project, including a series of university / community working groups on specific issues and a demonstration project(s) that allows people to put guiding principles into practice.

3.4 We need to plan how and when to involve students in the project.

3.5 We need to make strategic decisions as a project team about where to invest our time and energy with respect to engagement with community organizations.

Introduction

The Community Dialogue was the second major participatory activity in the Community and Patient Voices in Health Professional Education (CVHEd) project. It followed a set of interviews with 17 key informants (e.g. Executive Directors, CEOs) representing 13 Lower Mainland community-based organizations (see Research Report 1). The interviews explored 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 the University of British Columbia (UBC).

The purpose of the Community Dialogue was three-fold:

- Check and confirm findings from community key informant interviews.
- Get input on process to identify action items and next steps.
- Build connections and collective commitment to take the work forward.

We invited all those who participated in the key informant interviews to the Dialogue, as well as representatives of organizations contacted for interviews but who were either unable to take part or did not respond to the initial invitation. Key informants were invited to bring along a colleague from their organization. A copy of the report of the key informant interviews was pre-circulated to participants. The Dialogue was attended by 26 participants (from 13 community organizations) including members of the Research Advisory Committee and Core Project Team (Appendix A)

The Dialogue program consisted of presentations about the overall project, a summary of the findings from the key informant interviews, dialogue tables, and finally a report back of the key ideas from each table (see Appendix B for details). Participants self-selected into three dialogue tables, each of which focused on a cluster of the key findings from the key informant interviews as summarized in Research Report 1 (see Appendix C):

Table 1: Involvement in the education of students (what health professionals should know; what community members could teach; how they might be involved (levels); preparing students);

Table 2: Supporting community educators (training and support for educators; mentorship, recognition, mechanism to accommodate special needs);

Table 3: Engagement between community organizations and the university (reciprocal process; mechanism for communication; liaison positions; collaboration between community organizations).

Key findings that related to the current range of educational activities provided by community organizations and the episodic nature of their involvement in health professional education provided a base-line from which to discuss possible future involvement in health professional education.

Each dialogue table was given the following tasks:

1. Review the subset of key findings;
2. Rank order them in importance
3. Identify issues or disagreements and make a brief statement about them
4. Suggest action items for each key finding
5. Identify two or three specific next steps to act on the key findings in the subset
6. Propose ways to build these into the overall project process (see Appendix D; depicted on a large wall chart for ease of viewing by dialogue participants)

The Dialogue concluded with presentations of the key points from each group and a summary of next steps, including modifications of the project process based on ideas emerging from the dialogue tables.

Results

General response to findings

1. To the degree it was possible, participants at the Dialogue validated the key findings from the key informant interviews, i.e. although participants probably did not go back to the details of the analysis, we did not hear anything to suggest that the findings were inconsistent with their own views or experiences.
2. Participants pointed out the absence of Aboriginal groups in the key informant interview phase of the research and stressed the importance of filling this gap.
3. Some of the language (e.g. patient / client) is problematic.

Dialogue Table 1: Involvement in the education of students

[Key findings 3, 4, 11, 14]

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.

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.

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.

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.

Key points from the Dialogue Table

1. Key findings were ranked using a chronological approach / circular timeline to decide what should happen first, second, etc, rather than ranking in order of importance. The agreed order was thus:

    - **People from the community have a variety of expertise to share with health professionals**
    - **Patients and community members could be involved in many different educational activities**
    - **Prepare students for a different kind of learning**
    - **Health professionals need to be better at working in partnership**

2. The finding **Health professionals need to be better at working in partnership** was identified as the ultimate long-term goal: if involving people from the community in education works then health professionals will be better at working in partnership.

3. **People from the community have a variety of expertise to share with health professionals** was identified as a good place to start and participants provided examples of community expertise.

4. In relation to community expertise, participants debated whether we might use information from the community interviews as a 'teaching moment' for faculty in the university key informant interviews, or whether this information should be shared later so that faculty may give their views uncoloured by what the community said.

5. In relation to **Patients and community members could be involved in many different educational activities** the group offered a range of examples of the ways community could be involved in educational activities/ They also raised issues such as differences in language (between university and community), the need for the university to recognize different educational activities as valid (such as experiential learning), and the university not asking the community after the fact.

6. There was some disagreement about whose job it is to **Prepare students for a different kind of learning**. Most dialogue participants took this to be a university responsibility but also saw a need to engage the community. A working group of university and community members could conduct a mini-project to come up with ideas for jointly preparing students.

Note: the Core Project Team will review the wording of this finding to make sure it reflects accurately what was said in the interviews, especially with respect to who should do the preparing.

Dialogue Table 2: Supporting community educators

[Key findings 5, 9, 10, 12, 13]

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.

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.

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.

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.

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.

Key points from the Dialogue Table

1. Participants ranked the key findings in order of importance.

2. Recognize and honour patient and community expertise was identified as the most important. Participation will depend on a range of options including certification and payment, and recognition of the specifics of vulnerable populations. Emotional and monetary compensation are distinct forms of recognition but both are important. Communities should be involved in creating guiding principles – a possible task for a joint university / community working group. The university could provide benefits to represent goodwill and reciprocity (such as free passes to the botanic gardens); reciprocity should be probed in the university interviews.

3. In relation to **Learning activities that involve vulnerable citizens need to be based in the community** participants identified a number of factors that need to be addressed in order to include vulnerable populations from the community, including appropriate meeting spaces, meeting times, and important etiquettes. The group noted that there are also vulnerable populations on campus.

4. In relation to **Develop mechanisms to accommodate special needs and vulnerabilities of community educators**, we need guiding principles, including awareness and understanding of the intersection of vulnerabilities and identities and the importance of a strengths-based approach.

5. We should encourage curriculum opportunities for students to explore their own vulnerabilities rather than seeing themselves as 'fix it' persons – students should be more mindful and aware of their own vulnerabilities and the behaviours that spring from that. Starting with the most vulnerable will allow connection with others.

6. **Training and mentorship are needed for some levels of involvement in education** and Provide appropriate training and support for community educators seemed to be very similar. We need to make sure the wording of the findings distinguishes the two more clearly.

Dialogue Table 3: Engagement between community organizations and the university

[Key findings 6, 7, 8, 15]

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.

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.

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.

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 points from the Dialogue Table

1. The group did not seek consensus about the priority of the findings given that all are interlinked.

2. Most important was the idea of reciprocal long-term, respectful relationships – building relationship with and alongside people, as well as the institutional co-creation of mutually beneficial agreements.

3. People in the group knew how community organizations work and how to get things done, e.g. what information would be needed by Boards and formal memoranda of understanding (MOUs).

4. The group suggested we seek opportunities to create a common vision between community and university, such as linking involvement in health professional education to wider movements, like patients as partners in care.

5. The group saw a need for a set of facilitated conversations through which we address some of these bigger issues such as language, power differences, reciprocal relationships that will form part of an eventual MOU.

6. The group confirmed the need for a single agency in the community (a vessel or container that keeps all the groups together). Each organization will have different assets and needs – how do we create unity of purpose? How do we build and maintain the interest? The group gave a warning not to underestimate the amount of time this will take – it's a complex topic.

7. Although community organizations see the benefit of collaborating with the university, practical considerations such as funding and time need to be addressed. Participants referred to how under-funded and under-resourced community organizations are when it comes to planning a large-scale educational activity.

Conclusions

Project Team commentary on the Dialogue

1. From comments made at the Dialogue, some people understood the purpose of the project more clearly than others. The concept of patient / community involvement in the education of health professionals founded on a partnership between community and university is a new idea, an observation consistent with our experience. Where involvement does exist, the community has largely reacted to requests from the university. We also perceive a need to engage community representatives in more dialogue about what it means to be a teacher and educator, underlining the need to further engage with community representatives about the intent of the project. The strategic questions raised for the project regarding where to put our efforts include: How do we keep those currently involved engaged? What is the trade off between being inclusive or limited? Should we put our energy into investing in robust relationships with a few organizations?

2. The power imbalance between university and community organizations permeated many of the comments. The university is still seen as 'all knowing' and the community as reactive to university requests. We identified a need to explore through this project how the university and community could work together more as peers.

3. Given the identification of the finding **People from the community have a variety of expertise to share with health professionals** as an initial step, we propose an appropriate action item for the project is to document the expertise that the community has that could benefit health professional education. This mini-project may be a way to put power in the hands of the community and reduce dependency on the university.

4. Language and terminology continue to be barriers. Community organizations are uncomfortable with words that are used commonly in health professional education, 'patient' being a major trigger for heated debate, without agreement on an alternative that facilitates shared understanding.

5. We need to change the language and attitude away from 'us' and 'them'. We need to develop a set of guiding principles for the university and community to work together. This could be a task for a university / community working group.

6. Although the project has a large vision, it is made up of small steps. We need to identify little things that can be done (in 3 weeks, or 3 months) by a task force of university / community members that can move us forward towards developing a coalition or MOU. Working on the details will give small examples of what we expect the bigger outcomes could be while we are learning how to talk to each other.

7. We need a parallel process for the community organizations to develop the idea of community collaboration, coalition or networking. We could bring together the groups who are currently involved in the Division of Health Care Communication patient and community involvement initiatives (Patient and Community Voices workshops; health mentors program) to share experiences in teaching health professional students. We may also be able to collaborate with the Doctor, Patient and Society (DPAS) course's Community Advisory Board in the Faculty of Medicine and to hold a second Community Dialogue at the Patient and Community Fair in October.

8. Different kinds of meeting space **(Learning activities that involve vulnerable citizens need to be based in the community)** are important not just as suitable spaces for meeting people from the community but as learning environments that are different to the university classroom. We need to continue to make an inventory of meeting spaces / network of contacts to identify places where students could meet in the community / good places for events.

9. We should consider an advisory group of people who know how to get things done in the community as we move from the research to implementation phase.

Action items / next steps

1. A modification to the project process emerged from the dialogue, namely to replace the focus groups envisaged in the project plan (separate focus groups with university and community participants) with facilitated community-university conversations on issues arising from the interviews.

2. The application to the UBC Teaching and Learning Enhancement Fund (TLEF) that would pilot ideas emerging from the research project should include a series of university / community working groups on specific issues, e.g. recognition, preparation of students. It should also include a demonstration project(s) that allows people to put guiding principles into practice.

3. We need to plan how and when to involve students in the project.

4. We need to make strategic decisions as a project team about where to invest our time and energy with respect to engagement with community organizations.

Appendix A: Dialogue Agenda and Participants

Community Dialogue

3.30 to 6.30 on Tuesday June 25 2013

Room B, Roundhouse Community Arts and Recreation Centre, 181 Roundhouse Mews (Corner of Davie and Pacific), Vancouver

Agenda

3.15 to 3.30: Registration (Light snacks will be served and people can help themselves throughout the meeting)

3.30: Welcome and introductions

3.45: Overview of the project and process

- Project rationale and purpose
- Origins of the project
- Description of the proposed process and timeline of the project
- Goal for today and overview of the agenda

4.00: Key informant interviews and summary of the main findings

- Brief description of key informants
- Summary and explanation of key findings

4.15: Question and Answer period

4.30: Introduction to the dialogue process

Participants will self select into three tables. Each table will take a cluster of findings

Cluster 1: Involvement in the education of students (Key findings 3, 4, 11, 14: what health professionals should know; what community members could teach; how they might be involved (levels); preparing students)

Cluster 2: Supporting community educators (Key findings 5, 9, 10, 12, 13: training and support for educators; mentorship, recognition, mechanism to accommodate special needs)

Cluster 3: Engagement between community organizations and the university (Key findings: 6, 7, 8, 15: reciprocal process; mechanism for communication; liaison positions; collaboration between community organizations)

(Note: key findings 1 and 2 provide the context for the discussion of the other findings)

4.40: Dialogue tables:

Each dialogue table will have a dialogue host and note taker and will respond to the following tasks:

1. Review your subset of key findings (these will be provided on a separate sheet for each group)
2. Rank order them in importance
3. Identify issues or disagreements and make a brief statement about them
4. Suggest action items for each key finding
5. Identify two or three specific next steps to act on the key findings in your subset
6. Propose ways to build these into the overall project process

5.40: Report back from dialogue tables

Five minute presentations of key ideas from the three groups

6.00: Next steps

- Next steps and the project process / timeline
- Who else should be involved in the project?
- Communications strategy

6.30: Close

Dialogue Participant List

Wafa Asadian UBC Faculty of Education & Core Project Team
John Bishop, Positive Living BC
Adrianne Boothroyd, MS Society
Lynn Bruce, Community Living BC
Michael Clague, Research Advisory Committee
Brian Conway, ResoSante
Jane Dyson, BC Coalition of People with Disabilities & Research Advisory Committee
Nusha Elliot, Community interviewer
Louis Gigere, ResoSante
Bill Godolphin, UBC Division of Health Care Communication & Core Project Team
Scott Graham, Social Planning and research Council of BC & Core Project Team
Cheryl Hewitt, PeerNetBC & Core Project Team
Shelley Hourston, BC Coalition of People with Disabilities
Paul Kerston, Positive Living BC & Community interviewer
Cathy Kline, UBC Division of Health Care Communication & Core Project Team
Darren Lauscher, Pacific AIDS Network
Sue Macdonald, Vancouver Community Mental Health Services
Jim Mann, Alzheimer's Society
Eyob Naizghi, MOSAIC & Research Advisory Committee
Sharon Paulse, Leukemia and Lymphoma Society
Beverly Pitman, United Way
Jack Styan, Community Living BC
Jenny Soukphamuong, Leukemia & Lymphoma Society
Angela Towle, UBC Division of Health Care Communication & Core Project Team
iris young pearson, PeerNetBC
Jennifer Vadeboncoeur, UBC Faculty of Education & Research Advisory Committee

Appendix B: Description of the Dialogue Process

Dialogue preparation

The format of the Dialogue was developed by the Core Project Team and Research Advisory Committee based on previous experience with designing community-based participatory events. An important preparatory step was to reorganize the key findings from the key informant interviews which, in Research Report 1, had been summarized in the same sequence as the interview questions. For the purpose of the Dialogue the findings were clustered into three themes to facilitate more coordinated discussion. Dialogue participants were provided with the agenda and report of the key findings from the community interviews in advance.

Dialogue program and format

The program consisted of presentations about the overall project and findings from the key informant interviews, followed by dialogue tables and report back of the key ideas (see Appendix A).

Overview of the project and process (presented by the co-project leads) included the following:

- Project rationale and purpose (including reference to problems with terminology such as patient community and the Core Team definitions).
- Brief description of the origins of the project including existing DHCC initiatives to involve patients and community organizations in health professional education at UBC which some of the Dialogue participants have been involved in, and how this project will take the work forward. These were mapped out on a wall poster.
- Description of the proposed process and timeline of the project (depicted on a large wall poster)
- Purpose of today's dialogue in relation to the process (emphasis on the project as a research study to identify best ways to build a partnership between community organizations and the university to enhance the education of students).
- Overview of the agenda

Key informant interviews and summary of main findings included:

- Brief description of key informants and their selection;
- Summary and explanation of findings
- Question and answer period.

Dialogue process

Participants self selected into three dialogue tables. Each table took a cluster of the key findings from the key informant interviews as summarized in Research Report 1 (see Appendix D):

Table 1: Involvement in the education of students (Key findings 3, 4, 11, 14: what health professionals should know; what community members could teach; how they might be involved (levels); preparing students)

Table 2: Supporting community educators (Key findings 5, 9, 10, 12, 13: training and support for educators; mentorship, recognition, mechanism to accommodate special needs)

Table 3: Engagement between community organizations and the university (Key findings: 6, 7, 8, 15: reciprocal process; mechanism for communication; liaison positions; collaboration between community organizations)

(Note: key findings 1 and 2 provide the context for the discussion of the other findings)

Each dialogue table had a dialogue host and note taker from the core project team and were given the following tasks:

1. Review your subset of key findings (these will be provided on a separate sheet for each group)
2. Rank order them in importance
3. Identify issues or disagreements and make a brief statement about them
4. Suggest action items for each key finding
5. Identify two or three specific next steps to act on the key findings in your subset
6. Propose ways to build these into the overall project process (depicted in large wall chart)

Report back and wrap up

Each Dialogue facilitator made a five minute presentation of the key points from the group, with invitation to all other group members to contribute. The final discussion summarized next steps with reference to the wall diagram of the project process and identified modifications to the process based on ideas emerging from the dialogue tables.

Appendix C: Key findings from the key informant interviews

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.

Appendix D: Project Activities and Timeline

Previous educational initiatives of the UBC Division of Health Care Communication with community partners		
2005	"Where's the Patient's Voice in Health Professional Education?"	International conference in Vancouver
2006-present	Aboriginal Community as Teacher	Partnership with Fraser Valley Aboriginal Children & Family Services Society (Xyolhemeylh). JW McConnell Family Foundation national award for community-service learning 2012
2008 – present	Patient & Community Voices workshops	Patients and clients teach UBC students about living with HIV, arthritis, mental health, epilepsy, aphasia and other chronic health problems.
2009 – present	Community & Patient Fair for Health Professional Education	Yearly 'in-reach' from 40+ community organizations and patient support groups to UBC students and faculty.
2011 – present	Interprofessional Health Mentors program	The first 'patient' they meet is their 'teacher'. UBC students in groups of 4 over 1 ½ years learn from a mentor with a chronic condition.

Community Voices in Health Professional Education (CVHEd) – a Participatory Action Research Project		
2012 Jan	Request to Vancouver Foundation: Community Based Health Research	Improving care for vulnerable populations through their participation in the education of health professionals"
"2012 Jun	Funding awarded	45% of total budget over 3 years for research component of project
2012 Aug	Core project team	Towle (UBC lead), Hewitt (PeerNetBC lead), Graham (Sparc BC), Godolphin (UBC), Kline (UBC coordination), Asadian (graduate student)
2012 Sep–Dec	Foundational work	Ethics approval, Literature review, Guiding principles, Definitions, Stakeholder identification
2013 Jan	Research Advisory Committee	Clague, Dyson, Naizghi, Vadeboncoeur and Core Project Team
2013 Jan–Jun	Community Key Informant interviews	Identified and invited key informants, developed interview questions, trained community interviewers, 15 interviews, analysis and draft report
2013 Jun	Community Dialogue	12+ organizations, Engage in participatory action research, Validate findings, Provide input to project process
2013 Jul–Aug	University Key Informant interviews	Identify and invite key informants, 15 interviews, develop interview questions from community ideas, analyze and draft report
2013 Sep–Oct	Draft research synthesis	Curriculum and pedagogical models for community involvement in health professional education, operational plan, sustainability plan
2013 Nov–Dec	Test and refine model	Focus groups with key informants and stakeholders
2013 Oct–Nov	Apply for funding to pilot implementation	UBC Teaching and Learning Enhancement Fund for pilot project(s)-project team, students
2014 Jan	University-Community Forum	Key informants from Community and University plus other stakeholders to discuss draft recommendations, model and implementation plan
2014 Feb	Final report	Recommendations
2014 Feb–Jun	Dissemination	Disseminate report and recommendations; Prepare and submit abstracts for meetings, conferences, other forms of communications
2014 Jan–2015 Apr	Implementation	Committee, planning, recruitment, pilot(s), evaluation
2015 Mar–Jul	Operational & sustainability plans	For example: Memorandum of Understanding UBC & Community entity

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