VCH Community Engagement



Community Engagement Advisory Network (CEAN) Forum:

What does 'quality' in health care mean to you?

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Introduction

The Community Engagement (CE) department of Vancouver Coastal Health (VCH) is supported by a group of members of the public, the Community Engagement Advisory Network (CEAN), to enhance patient and public involvement in health service planning and decision-making. Annual forums have been held since 2003 to provide opportunities for VCH staff and leadership to meet with members of CEAN to discuss health service issues of concern to both VCH and the public. Past forums have covered topics such as cross-cultural health needs, advance care planning, health literacy and how to support VCH's new 'People First' lens.

As part of Vancouver Coastal Health's commitment to the People First strategy, CE continues to hold annual forums inviting members of VCH staff and leadership, the public on advisory committees, community partners, patients and family members to join in guiding VCH strategies.

Update from the 2011 CEAN Fall Forum

In October 2011, the CEAN Fall Forum focused on health literacy – exploring ideas and potential projects to increase health literacy skills of VCH's chronic disease populations. Since that forum, the Integrated Primary and Community Care (IPCC) team at VCH has:

- 1. Used the information gathered at the forum to shape education given to family physicians, emphasizing patients' needs for health literacy support;
- 2. Adopted a health literacy lens to all IPCC materials;
- 3. Started discussions about a potential website for the IPCC initiative;
- 4. Conducted education sessions with Home and Community Care clients to help them build skills to communicate effectively with their providers;
- 5. Shared the forum report province-wide through the Ministry of Health *Patients as Partners* program and the BC Medical Association.

Background: Why is 'quality' in health care a priority for VCH?

In the fall of 2010, VCH refreshed their vision and values and made an important shift in its strategic renewal by creating the "People First" lens to guide and govern all we do. Part of the goal is to provide patients, clients and residents with more say in their care by adopting the "nothing about me without me" approach as we treat and care for them. In alignment with the People First lens, VCH aims to:

- Promote better health for our communities
- Develop the best workforce
- Innovate for sustainability
- Provide the best care.

Like all health care organizations, VCH uses rigorous standards to measure and report on the quality of our work. But does VCH's definition of quality match the public's understanding of quality? Are we measuring the things that are important to members of the public? Are we reporting out to the public on quality in ways that are meaningful and accessible?

To answer these questions, VCH leadership requested a forum to explore:

- 1. The similarities and differences between VCH's definition of quality and how members of the public define health care quality.
- 2. How VCH can improve reporting to the public on health care quality.

Workshop Planning, Agenda and Attendance

VCH staff worked in consultation with CEAN members to plan the forum. A total of 60 people attended the event on November 17th, 2012 at the Radisson Airport Hotel in Richmond, BC and attendees included:

- VCH Community Engagement Advisory Network
- Patient Voices Network A provincial network of patients, their families and other community stakeholders from across BC
- Members of VCH Mental Health Services Advisory Committees
- Members of VCH Transgendered Health Advisory Group
- Select representation from members of the VCH Board, senior executives and senior staff.

The agenda for the day included:

- Opening remarks from Dr. Jeff Coleman, *Vice President, Regional Programs and Service Integration*;
- A presentation from Linda Dempster, *Executive Director, Quality and Patient Safety* on how VCH defines, measures and communicates quality;
- Small group discussions to learn what quality means to members of the public across different health care settings;
- Small group discussions about how VCH should communicate information about quality to the public.

Presentations and Discussion

To explore public understanding and interpretation of quality, the first small group discussion topic was "What elements would contribute to a good quality health care experience for you?"

Each participant choose two of the following settings to discuss:

- Emergency department
- Home health care
- Family doctor visits
- Residential care
- Longer-term hospital stays

Each small group recorded the content of their discussion, and after two rounds of discussions, facilitators identified key themes from each health care setting.

These themes were used by CE staff and Dr. Coleman to construct a chart comparing the dimensions of quality used by VCH with the major themes emerging from forum discussion.

Subsequently, Linda Dempster gave a presentation (see Appendix A) to provide context and background on:

- 1. How VCH defines 'quality' using eight dimensions;
- 2. Ways that VCH ensures quality in health care such as patient satisfaction surveys, the surgical safety checklist and hand washing compliance;
- 3. Methods that VCH uses to communicate with the public about health care quality including the Accreditation process, the VCH website and the VCH public report card.

Defining Quality

CE staff and Dr. Coleman presented the chart comparing the similarities and differences between VCH's definitions of quality and the public's definitions of quality, followed by large group discussion. The themes from the chart and discussion are presented below.

Quality Themes: What is important to the public?

Forum participants generally agreed that the following were essential to good quality of care:



The following descriptions are in order of largest to smallest numbers of comments (though not necessarily indicative of degree of importance to participants).

1. Communication and information

Every organization in a health care system must communicate complex information to a wide range of people. Communicating information clearly and effectively can be a challenge, but it is critical for ethical, high-quality health care.

The health care system is overwhelming for many people and individuals need a simple explanation of how the health care system works, services available across the care continuum, and specifics about the resources available in their community. For example, one participant suggested 'a play book' on how to access Home and Community Care services since "it's a secret to many people in the community."

Participants also want health care professionals to engage patients and their families in dialogue around care options but emphasized that health care teams need to use simple, easy-to-understand explanations that are free of technical language or medical jargon.

Participants also emphasized that information should be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

Another important topic was the frequency of communication. Many participants shared that they would like to be communicated with more frequently. Participants felt that increased frequency of communication explaining the steps along the way (i.e. reasons for long wait, which tests are being conducted) would help minimize patients' and their families' sense of uncertainty.

"Check in from staff with information on 'what's next'"

Despite the resounding predominance of the communication theme, participants recognized one of the chief barriers to clear communication is lack of sufficient time. Participants often felt appointments/interactions were rushed but recognized that this is a symptom of an overburdened health care system.

CEAN forum participants also described the role communication plays in establishing healthy relationships. Participants value health care professionals who are excellent listeners and who take patients' concerns seriously. These qualities convey caring about the patient. Giving thoughtful attention to the patient's concerns helps establish rapport and lays the foundation for partnership between the health care staff and the patient.

2. Respect, compassion and trust: Creating a welcoming environment

A healthcare system is, at its very core, a set of relationships between patients and practitioners; among clinical and administrative staff; between the health care system and the community it serves. The establishment of trusting, empathetic and respectful relationships with competent and reliable health care providers, and their administrative staff, is key to patients receiving quality care.

Forum participants emphasized that patients and their families need to be treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty. These relationships are founded on open, two-way communication; easy access to information; and emotional support.

"Treat me and my problem with respect and confidentiality."

"Main component of quality is amount of accessibility to staff (doctors and nurses) and their caring nature, advocacy, communication"

Participants also shared issues that negatively impact the quality of peoples' health care experience. For example, participants commented on the lack of privacy in a variety of health care settings. Additionally, some participants reported that they had felt judged by their health care team or been discriminated against for their health choices, which had negatively impacted their relationship with healthcare providers and the quality of care they received.

Since the VCH region is very diverse, participants suggested that health care providers attend cultural competency and anti-stigma trainings.

The importance of relationships in not limited to relationships between patients and their providers. Participants recognized that issues such as high levels of burnout and staff turnover, and low staff satisfaction would influence the care patients receive. Participants also said that they valued well-supported staff who have collaborative working relationships because they felt this would ultimately improve the care provided.

In addition to relationships with staff, participants described how physical space can help create a welcoming environment.

"Open, accessible reception – not hidden behind glass – to show respect/openness"

"Clear signage so people know where to go so we don't get frustrated"

3. Personal preferences and informed choice: Enabling individuals to actively participate in their care

Patients wish to be seen as an individual within the healthcare system. This requires health services to tailor services to the needs, preferences, and cultural values of the patient.

"Doctors should not be using a "cookie cutter" approach for all patients with similar diseases or health conditions. In other words, try to use 'holistic' approach keeping in mind an individual patient's medical history, cultural background etc."

"I want a choice of therapeutic interventions, a list of alternatives"

People wish to be considered active partners in their care own health care, and involved in the creation and management of their health strategy and use of services. However, for patients to be a partner in care, they must be prepared and have information needed to participate in a meaningful way. Many participants stated that patients and their families need more information about the processes, care options, risks and benefits of treatments, and want this information shared using "understandable language."

"Patient should know the possible pitfalls of the proposed treatment and providers need to clearly explain the risks"

"Facilitate educated decisions by patients/family"

People want to have more opportunities to discuss their health beliefs, concerns and preferences so that this information will inform their care plan. Several participants shared how difficult it was to access health care decision makers if they had questions or concerns. Moreover, people want to feel supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences so they can be actively involved in decision making and prepared to make fully informed choices about their care.

Participants stated that access to personal health information, such as copies of medical records and lab/test results, is critical to meaningful patient and family involvement. Participants also want their preferences for sharing information with family members or loved ones to be established early on and reviewed throughout their care.

4. Inclusiveness and support for family members

Just as patients want to be more informed and involved with their own care, family members and loved ones may have a significant role in care as well. Participants at the CEAN forum stated that

health care should aspire to instill a sense of partnership with the patient's family and friends on whom patients may rely.

"Allow a patient's advocate (partner, spouse, child) to accompany them into examining room"

"Family need information regarding the treatment and care plan"

Depending on patient preferences, the partnership with family and loved ones can include making them feel welcome and comfortable in the care delivery setting; involving them in decision-making; recognizing their needs and contributions; and supporting them as caregivers.

5. Holistic approach to care

Participants indicated that it was important to adopt a holistic approach to patient care that incorporates mental, emotional, physical and spiritual health.

"Health is a whole body, holistic approach – use full scope of practice"

"Weekend activities in residential care, allowing pets... stuff to improve quality of life"

Participants also believe that the opportunity for the patient and their family to "tell their story" is an essential component of understanding of the patient as an individual, including how the condition affects him or her, and how the person's circumstances and experiences affect their condition and treatment.

"Respect for patients - Health care providers need to learn to listen"

Some patients stated they want to spend as little time as possible in the health care system and want to be cared for at home, or in the community, as much as possible.

"Better chronic disease management in the community and at home that is publically funded"

"Quality is when your visits are minimized, preferably one visit and your health problem is taken care of. Poor quality is when you have to keep coming back, getting more tests, trying another medication or referred to another doctor."

"In health care, we need to ensure independence as long as possible. I want to live in my home and want affordable home care options to support me."

Furthermore, participants expressed the importance for preventative strategies that focus on wellness, health promotion and rehabilitation.

6. Creating 'a seamless system' – Multidisciplinary teams, continuity and coordination of care

Since, complex health and psychosocial needs frequently require skills that go beyond one health care provider or even one health care discipline, a multidisciplinary team is often needed to treat a patient's needs. Because a single professional cannot always meet all of the patients' health care needs, efforts must be made to reduce care fragmentation. Participants at the CEAN forum emphasized that health care delivery would be improved by creating a 'seamless system' through integration and coordination of services, complemented by sharing of information between different health care providers.

Participants value health care services that are connected with appropriate communication between care providers. For example, individuals who use a number of different services (for example, attending different clinics in a hospital) want to feel that their care is well organized; and that health care professionals are informed and up-to-date about test results and care received

from other health professionals (including specialists, home health care teams, allied health professionals, etc.). Some participants reported that once treatment had been completed, their support stopped abruptly (i.e. particularly when discharged from hospital), despite their continued needs at home. The communication and transfer of information between clinicians, and with the patient themselves, is imperative to ensuring continuity of care in our complex health care system.

7. Fair distribution of services across populations

Participants want health care services distributed fairly according to population need. However, stigma and discrimination had personally affected some participants' ability to access high quality health care and many participants were concerned that some marginalized groups are still trying to meet their basic health care needs.

8. Timely and convenient access to healthcare

Participants want to be able to easily access health care in their community as follows:

- A range of services available in their community
- Minimal wait times
- Appointments running on schedule
- Enough staff, with enough staff time.

Participants also expect care to be prioritized based on need but when patients and families are required to wait, they want to be provided with regular updates to minimize uncertainty and manage their expectations.

"I would we willing to wait if needed, but would like someone to look in for reassurance and provide accurate estimate of how much longer."

Many participants were concerned about the limited availability of services in their communities because of limited spaces or staff which can create long wait times for services. For example, many participants were concerned about the current challenges of finding a family doctor, space in residential care or arranging home care.

While most participants wanted to preserve Canada's publicly funded health care system, there was also strong concern regarding the perceived sacrifice of compassionate care in order to meet efficiency needs:

"Felt like it was an assembly line – no thought to patient/family needs"

Some participants also felt that there was a need to educate patients on how to prepare so they use their time with health care providers to the fullest.

"Patient does his/her homework beforehand so asks right questions and makes the most efficient use of doctors/GP time"

9. Matching the right level of services to the health need

Participants shared that a high quality health care system should provide different levels of care that are suited to different levels of need. For example, participants acknowledged that often people seek treatment in the emergency department because they do not have an alternative. It was suggested that the health care system needs to consider re-distributing services so that there are enough staff and facilities to provide care at an appropriate level and location.

"Provide higher level of care in the community to prevent having to come to emergency department"

"Have a walk-in clinic adjoining or even in the hospital so people who really only need a doctor consult do not have to use the emergency system"

10. Staff education and training

Patients place high value on receiving careful attention from their health care team and want staff who are well educated in their health care fields, thorough when making a medical plan and well respected and well supported by their employers.

"Quality is trust in doctor and system - that they know the evidence, have evaluated it in a way that seems reasonable and does not seem influenced by big pharma"

"Support care providers with education and enough staff so that providers are not overburdened"

Some patients acknowledged medical uncertainty to be a reality but think patients, families and loved ones need to be better informed about risks, effectiveness, and alternatives/options to treatment.

11. Cleanliness and hygiene

Aside from a few select comments regarding cleanliness of facilities and staff hygiene in the initial rounds of small group discussion, participants did not comment on safety. It was later revealed that people assume that treatments/care options will be safe, and that the physician will not recommend a treatment that will cause harm.

Ensuring Quality and Communicating Progress

"Quality for me is like having a pen that writes till the ink is gone – poorest quality is when the pen stops writing when there is still a lot of ink in it."

Participants at the CEAN fall forum were passionate about greater transparency and accountability and offered some suggestions to strengthen the accountability of health care systems to citizens:

- Greater patient and family involvement in hiring, quality improvement processes, service planning, staff and resident orientation
- An accessible process for monitoring care provided by family doctors and ethical conduct of physicians
- Standardized safety checklist for mental health like the surgical safety checklist
- Improved licensing or regulations for home care private companies for standards related to hygiene, care, safety, ethics
- Clear process for monitoring and reporting concerns (i.e. abuse of patients).

Public disclosure of VCH goals and progress regarding quality is seen as one mechanism for improving quality of care.

Methods to communicate with the public

At the forum, participants discussed how VCH could communicate more productively with the public about quality. There are two main groups that the health system needs to be aware of: a) people who want the information and are actively seeking it; b) people who will be affected by the information but do not know the information is available. Strategies must be created to connect with both these groups. The following are some suggestions from forum participants on how to improve communication about quality with members of the public:

- Share information where communities gather and how they gather. Make information available in the community locations where people congregate such as libraries, churches, community centers, seniors' centers, pharmacies, waiting rooms.
- Use multiple communication formats including newspaper articles, social media, print and online materials, public meetings, TV programming, radio, YouTube.
- Recognize the diversity of audiences and target messages for each audience
- Connect with hard to reach populations through outreach and partnerships with other organizations.
- Present information in user-friendly formats using simple, easy-to-understand language and graphics/pictures, with more detailed information available so that people can pursue more information as desired.
- There is a lot of information available online so websites need to be organized from the public's perspective so that it is easy to find.
- Communicate using multiple languages.
- Share success stories and human-interest stories to create a 'face' of the organization. Capitalize on in-person opportunities to put a face to the organization such as public board meetings and press conferences.
- Publicly reporting VCH's progress towards improved quality helps increase awareness of the current standard and raises the public's expectation of quality.
- Transparency about the current standard shows professional courage and commitment to improvement.
- Make it real. People want information on quality to be given context and want to know how a story/statistic/initiative will affect their lives.
- Engage in dialogue. Create more opportunities for the public to be involved in discussions about the future of the health care system. Promoting public engagement shows that VCH genuinely values feedback.

Topics that interest the public

When communicating quality to the public, it is important to recognize how "quality of care" translates to members of the public. The stories and information shared must resonate with the public's interpretation of quality. Below is a list of topics, related to how the public views 'quality', that participants at the CEAN Fall forum expressed interest in learning more about:

- Staffing and staff/patient ratio
- Infection rates in different facilities
- Wait times to see specialist
- Hand washing compliance of staff
- How many people are waiting in acute care when other care settings would be more suitable

- Patient satisfaction reports (i.e. 'how did we do last week?' posters in each facility/unit or comment boards)
- Comparative rankings of all facilities/hospitals in BC
- Interactive map that shows frequency of certain health conditions across geographic regions
- Financial accountability.

Next Steps

VCH leadership will use feedback generated from this forum to inform future strategies, communications and reporting on health care quality. Over the next year, the Community Engagement department will update forum participants on how this information is used.

Evaluation

Workshop evaluation forms were completed by 55 of the 60 participants and indicated a high level of satisfaction for the event.

The relevance of the topic and vibrant group discussions were specifically mentioned as positive aspects. Participants felt inspired by the opportunity to share ideas with such a diverse group of attendees who share a common interest in health care reform.

When asked what they liked about the workshop, respondents stated:

"Opportunity to be 'heard' - excellent and respectful"

"The broad range of ideas from participants"

"The topic itself is extremely interesting – good to have this opportunity to address quality with others passionately engaged in improving quality, with good ideas and practical suggestions from the public and VCH side."

Participants also expressed the need to know how their input will be used by VCH, what actions will be informed by the forum discussion and how it would impact system change.