



Patient & Public Advisors Handbook



Developed in collaboration with VCH Community Engagement, Patients as Partners, and Impact BC Patient Voices Network

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1. What is an ‘Advisory Committee’?

An advisory committee is a group of people who meet to provide advice, and sometimes to accomplish a specific set of tasks. An advisory committee is not like a board (which has authority over a company or institution), and so it does not oversee the organization, its staff, director or policies.

The Community Engagement department supports members of the public on various advisory committees at VCH. We want Community Engagement Advisory Network (CEAN) members to feel confident and welcomed when they take on these opportunities. We have developed this handbook to answer some common questions and offer some guidance on the preparation for and participation on these committees. If you have already sat on an advisory committee you may find some of this information quite basic – but we do hope everyone will find something useful in this handbook.

Advisory committees can differ in several ways:

- *the length of time for which they will meet*: sometimes for just one or two meetings, sometimes for several years.
- *the complexity of their task*: sometimes to accomplish a specific task, sometimes to support strategic direction for a complex set of services.
- *the types of members on the committee* (e.g. staff, public and community organizations), and the proportion of each group on the committee: there may be two staff on an advisory committee with ten members of the public, or two public members on a committee with many staff.

‘Advisory committees’ may also be identified by several different names, such as:

- Program advisory council
- Health service working group
- Community reference committee
- Working group
- Steering committee

There are many variations on these examples! All these examples usually mean the same thing: a group meets to provide supportive advice, and sometimes to accomplish tasks.

What are some examples of the kind of work an advisory committee might do?

- Consider the concerns of various stakeholders with regard to a new service
- Provide a two-way communication link with the community
- Look at ways to build capacity in the public or in the organization to respond to challenges in the healthcare system
- Give feedback on policies, programs, documents or projects
- Provide ongoing feedback on the implementation of a plan or program
- Explore ways to better respond to patient and family needs

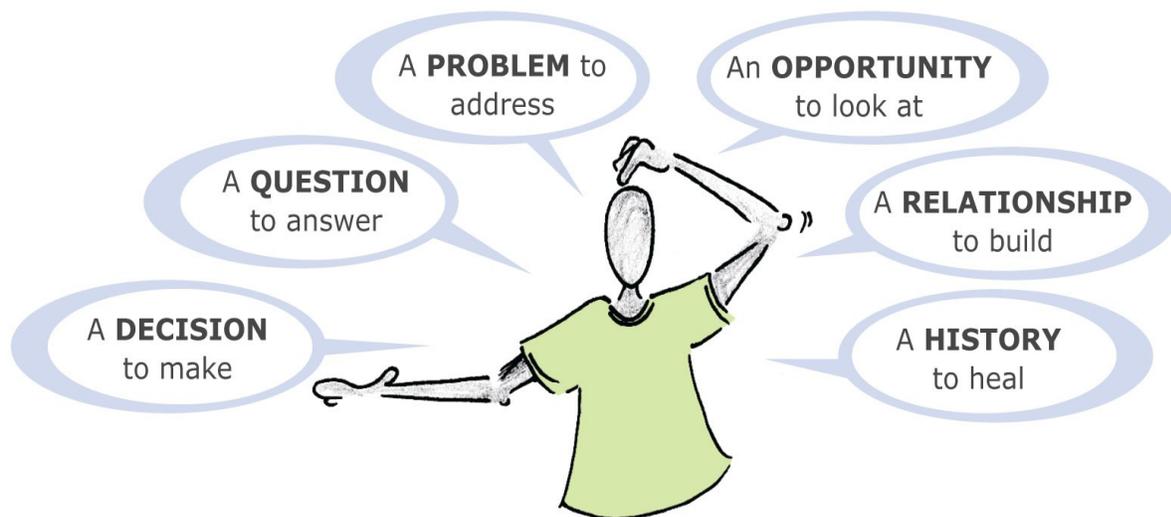
2. Why involve the public?

Community Engagement (CE) enables a two-way interaction between VCH and its communities, so that people have a role in the planning and decision-making for health services and policies that affect their lives. It encompasses a wide variety of activities, from consultations with the public, to community development and community-capacity building. A public advisory committee is one of the tools for engaging the public in an ongoing conversation.

These are some of the reasons why VCH might need to consult the public:

- To build partnerships with the community
- To inform decision makers within VCH of community perspectives
- To promote an understanding of different perspectives
- To provide a forum for resolving issues
- To facilitate effective communication between VCH and community members

A community representative can lend a unique perspective when a committee is dealing with any of the following challenges:



3. Advisory Committee Recruitment

VCH periodically creates opportunities for public members to join an advisory committee. When these opportunities arise, Community Engagement staff will send a message out to its CEAN members. We will provide as much detail as possible about the advisory committee and the kind of skills and experience needed. The sponsoring department and CE staff will review applications to find the best possible match between the sponsoring department’s needs and the CEAN member’s skills and interest.

There are many qualities to be considered in forming a well-rounded group of advisors, such as:

- *Specialized experience* as a patient or family member who has used VCH healthcare services, directly related to the purpose of the committee
- *Geographic representation*: if the public perspectives on the issues may depend on regional differences, it is important to choose members who represent the various geographic areas in our region
- *Diversity*: we live in one of the most broadly diverse regions in Canada and committee membership should strive to reflect our communities, looking for variety in:

Education	Ability	Economics
Age	Gender	Ethno-cultural background

As well, advisory committees seek members who have the following skills:

- Articulate their interests, concerns and perspectives on the issue being addressed
- Read, learn and absorb relevant information
- Maintain an open mind regarding other people’s views
- See the ‘big picture’ of how services work together, or how they may affect different groups (not just one’s own experience)
- Work in a collaborative manner with other committee members
- Understand that the committee’s purpose is to give input, but that recommendations may not necessarily be adopted.
- Attend the meetings regularly

VCH PATIENTS & CLIENTS

Add your voice to public health planning and decision-making.

Join our team of trained **Community Engagement volunteers** and work with staff to:

- Explore how to improve patient and client experiences
- Discuss new opportunities for client- and patient-centred care
- Consider the impact of new strategies from a public perspective



Who can join? Anyone! Your voice and experience can make a difference.

Find out more:

- Email: ce@vch.ca
- Phone: VCH Community Engagement at 604-714-3779
- Website: www.vch.ca/ce

Community Engagement



Promoting wellness. Ensuring care.

4. Is the advisory committee a good fit for you?

Some questions you may also want to ask:

- Where did this committee originate, and why?
- If the committee has already existed for some time, why is it asking for members of the public to join at this time?
- What does the committee hope that public members will contribute to the committee and its discussions?
- What do you think you could contribute?
- What kinds of work or discussion would make this a meaningful and respectful use of your time?
- What about the commitment required to fulfill this responsibility?
 - o Are the meeting times convenient to your schedule?
 - o What level of participation is required – including preparation and ‘take-home’ tasks?
 - o Is the length of committee term (e.g. two years) realistic, given other commitments in your life?

Feel free to ask CE staff any questions, so that you feel comfortable and informed in your decision to work on this committee.



5. You've joined a committee! What's next?

Once you have accepted an invitation to join an advisory committee, CE staff will provide for you:

- Contact information for the VCH staff
- A copy of the Terms of Reference (also known as ToR: a statement of the purpose of the committee)
- An organizational chart mapping out where the committee fits into the VCH structure
- Any background documents that can help you catch up on the committee's work, such as strategic plans, annual reports, research/articles, glossary of terms/acronyms, etc.

Also, be sure to request some time with your advisory committee support staff for an orientation session.

CE staff will be responsible for providing both you and the advisory committee leadership with support so that your role on the committee can be fully realized. It is also important for you to prepare for meetings so that you can take full advantage of the opportunity to bring a public perspective to healthcare planning and decision-making.

Advisory Committee Agreement

You may also be asked to sign an Advisory Committee Agreement (please see page 15). This document is intended to act as an informal 'contract' between the public representative, the CE representative and the sponsoring department's representative. This Agreement provides a skeletal description of the functions of the committee (much like a ToR), and additionally gives a brief description of each representative's responsibilities to each other.

Confidentiality Policy and Agreement

All members of advisory committees must review the confidentiality policy and sign a confidentiality policy before attending the committee meetings. Please ask a CE staff person for more information.

Ongoing support

CE staff will support your involvement on an advisory committee. This may include attending one or two meetings with you so we can learn more about the committee and how it functions. We will also touch base with you regularly after meetings to answer any questions, provide additional information or discuss issues with you.

Example of committee work

Please see pages 12 - 14 for examples of some VCH committees with public involvement.

6. Preparing for Meetings

Common Terms

Agenda: a document that states where and when the meeting will take place and what will be discussed.

Meeting minutes: the notes describing what took place during a meeting. Committee members are expected to have reviewed the minutes from the previous meeting before the next meeting, and let the note-taker know if any corrections are needed.

Chairperson: the person who is in charge of running the meeting. This may be the same for each meeting or the group may have a different chair for each meeting (often rotating between members).

These general terms, above, are common to most meetings but you will observe that each group has its own 'culture' and set of norms. Do check in with CE staff if you have any questions.

Preparing for the initial meeting:

Prepare a brief verbal introduction of yourself, in advance, telling people:

- your full name
- you are a member of CEAN
- any relevant experience (professional, voluntary, personal) that illustrates what you can bring to this committee's discussions
- what motivated you to join this committee

Bring paper, pens and any documents that you were sent before the meeting, such as the agenda or items for discussion. You may want to create a binder to keep all documents and papers together.

Preparing for subsequent meetings:

To be an active and effective member of a meeting, you can:

- Be well prepared – if possible, go through the agenda in advance and review items.
- For each agenda item, ask yourself: "How can I contribute to the discussion? What could be some possible public concerns?" "What is relevant information to bring to this discussion?"
- Be involved
- Be a good listener



7. What is the role of the public on advisory committees?

Q: What is the role of a public representative on a VCH advisory committee?

A: To bring forward patient, public and community priorities in committee discussions.

The responsibilities and tasks for the public member will sometimes differ from committee to committee but generally, the public member's role is to act as both:

- *A Community Link*: bringing patient and public experiences from their social network to the attention of the advisory committee
- *A Critical Friend*: helping the committee to see how their discussions might be understood from a non-institutional perspective

Picture your role as a continuous loop: you are a 'channel' of information between the advisory committee and the community. Listen for relevant experiences and examples among your community contacts, bring that perspective to committee discussions, and repeat this cycle over the length of your term.

We note here that your role is **not** to advocate for specific individual needs, a specific community's needs, or to speak from a healthcare provider perspective if this is your professional background, but instead to:

- help VCH consider patient and family needs in their planning, looking together at the variety of needs expressed by a variety of communities
- share your knowledge, skills and experience with VCH staff and leadership, and with each other, as well as learn from and support each other's perspectives in the committee's discussions

For additional reading on this topic, please see the articles by David Gilbert in the CEAN orientation manual.

8. Being effective in the role: Using your voice to effect change

Sitting on advisory committees requires a wide range of skills. Many of these skills can be developed over time, and can be immensely helpful in strategic work.

1. **Communication and presentation skills** – learning to listen and communicate in a range of styles.

- An effective listener is solution-focused and looks for possibilities instead of what is wrong.
- An effective speaker speaks to the topic from his/her own experience and role as a member of the public.

2. **Knowledge and understanding of healthcare** – learning about how the healthcare system works; understanding the impact of budgets, legislation, workplace regulations, and other constraints on healthcare; knowing who to go to for different types of support and information.

3. **Analytical skills** – learning to understand healthcare data, and information from the community, and then use these two areas to complement each other.

4. **‘Critical friend’ skills** – asking challenging questions in a non-threatening way; working with healthcare professionals face to face, respecting their feelings of vulnerability and knowing how to frame questions.

5. **Influencing skills** – learning how to use persuasion and ‘behind-the-scenes’ influencing; using different influencing styles at different times, as well as negotiation skills and understanding where power lies.

From the article “Tap into the Patient Perspective” by David Gilbert



VCH staff members and members of the public discuss their experience of advisory committees
-CEAN Workshop – March 2011

9. Debate versus Dialogue

Another aspect of being effective in the advisory role is to look at your goal when meeting with others.

Many think dialogue is just talking back and forth but it's more than that!

Dialogue is the art of a good conversation. Not to be confused with debate, dialogue is the peaceful way of working out a problem. Debate means stating your point of view without taking time to consider other options, or getting your point across while trying to make others back down.

Dialogue is the process of putting two or more different opinions together to create a unified idea.

Debate	Dialogue
<i>Assumes that there is a right answer and someone has it.</i>	Assumes that many people have pieces of the answer and that together they can craft a solution.
<i>Defending assumptions as truth.</i>	Revealing assumptions for re-evaluation.
<i>Combative: participants attempt to prove the other side wrong.</i>	Collaborative: participants work together toward common understanding.
<i>Defending one's own views against those of others.</i>	Reflecting on and re-evaluating one's own views.
<i>Listens to find flaws and make counterarguments.</i>	Listens to understand, find meaning and agreement.
<i>Searches for problems and weaknesses.</i>	Searches for strengths and value in others' ideas.
<i>Countering of the other position without consideration of feelings or relationship -- often belittles or deprecates the other person.</i>	Genuine concern for the other person and seeks to not alienate or offend.
<i>About winning.</i>	About discovering new options.

Excerpted from:

- Yankelovich, Daniel. *The Magic of Dialogue: Transforming Conflict into Cooperation*. New York: Simon & Schuster, 1999.
- Paper prepared by Shelley Berman, which was based on discussions of the Dialogue Group of the Boston Chapter of Educators for Social Responsibility (ESR).
- <http://www.youblisher.com/p/66699-Dialogue-Vs-Debate/>

10. Dimensions of Patient Experience

What matters to patients, family and the public

Sitting on an advisory committee, it can take some time to understand the complexity of the health system, and how a specific program or department works. There are many aspects of our health system that can impact decision-making (funding, professional bodies, legislation, etc.) and it is not possible to ‘know everything’ when involved in an advisory committee. But a helpful framework can guide your contributions, knowing broadly the ‘*dimensions of patient experience*’ that research evidence says matters most to people. You can also become more conscious of your own experience, and how these two aspects – your experience and the dimensions – relate to each other. It can also help to know some of the language that the healthcare system uses to describe these dimensions.

Dimensions of Patient Experience

What matters to members of the public	What the healthcare system calls this:
Getting better, feeling better	Outcomes of Care
Getting the right care from the right people	Clinical Quality
Being treated with respect and dignity	Humanity of Care
Information, communication, having a say: receiving clear information and explanations; being able to actively participate in decisions about treatment options	Involvement
Assistance and support to access healthcare services; guidance through the health care system	Navigation
Practical and emotional support. This includes support for family, loved ones, caregivers	Psychosocial support
A safe, clean, comfortable place to be, including privacy, food and hygiene	Environment of care
Right treatment at the right <i>time</i> ; prompt response to an emergency, wait times, etc.	Access: Timeliness
Right treatment in the right <i>place</i> – convenient locations, transport, parking, etc.	Access: Convenience
A smooth journey between different sections of the health service, e.g. staff are prepared for the patient when s/he makes a transition from one department or facility to the next; e.g. support and services in the community are prepared and in place for the patient’s arrival home.	Continuity of Care

This chart is partially based on material from David Gilbert’s chapter, ‘A Change of Heart’, in the book Involving People in Healthcare Policy and Practice, by Susie Green (Radcliffe Press, 2007).

11. Common challenges for members of the public on advisory committees

Staff members see you as ‘representing the public’.

It is not possible, of course, for you to represent all public opinion on the committee, as you are one person with one set of life experiences. Even if you have worked or volunteered with many people whose health is affected by the committee’s scope (e.g. diabetes or mental illness), you cannot ‘represent’ their opinions or experiences.

But you can speak to themes that are common across health services. When going to meetings, it can be helpful to refer to the section, ***Dimensions of Patient Experience (page 10)***. During the discussion, see what priorities seem relevant to the discussion and refer to that priority.

“So, David, what do patients think?”

Sometimes a committee may unintentionally put you ‘on the spot’ in a meeting, asking “what do patients think?” with no preparation or warning. It is important for you as a member of the advisory committee to be given sufficient preparatory information to answer these questions with confidence and comfort, but sometimes that preparatory information has not been available. How to answer?

You could:

- Refer to the section, ***Dimensions of Patient Experience*** (pg. 10)
- Say, “I can’t speak to everyone’s experience, but here is my experience...”
- Say “This is a new topic for consideration. I’d like to take this back to our CE Advisory Network for more discussion and bring that feedback to our next meeting.”
- Suggest that the committee work with CEAN to hold a focus group or survey

Perhaps there’s an opportunity here for an online or in-person meeting with other CEAN members!

“This work is so slow! We’re not DOING anything!”

Advisory committees often work quite slowly – this can be frustrating for members of the public who may be accustomed to more tangible results and quick turn-around. But the health authority is a large and complex structure: change takes time, and it can take a considerable length of time (two-three years) before committee members start to see the impact of their efforts. These committees are usually working at a strategic level, trying to influence the philosophy of services (versus front-line delivery of services). The role of public members is vitally important to this work, but it must be understood as a ‘long-term investment’. Please do ‘hang in there’, and do speak to the CE staff person if these concerns arise for you. You may be raising a timely and important theme for the committee to consider!

12. Examples of Committee Work

What are some examples of advisory committee work at Vancouver Coastal Health?

Here are three advisory committees that have met over the last few years.

1. VCH Regional Palliative Community Reference Committee: 2006 to present

How and when did it start?

Started meeting in September 2006, as a result of recommendations from a community consultation on a new palliative care strategy for our region conducted in summer 2005.

Who meets? Ten members of the public meet with the two regional strategy leaders.

Purpose (from the Terms of Reference):

- To facilitate bringing the ‘community voice’ to the priorities and implementation of the Palliative Care Strategy
- To influence the decisions and recommendations of the VCH Regional Palliative Care Steering Committee through community consultation and engagement, ensuring the Palliative Care Strategy and any other future regional palliative initiatives meets the current and emerging needs of clients, caregivers and diverse communities

How were people recruited?

A notice was emailed out to members of the public and to community agencies who had participated in the community consultation. Interested people filled out an application form and were interviewed. Recruitment specifically focused on those who had used palliative care services for a loved one, and/or had been a palliative care volunteer.

How often does the committee meet?

Every month for the first year; then every two months; and now every 3-4 months.

What do they do at meetings?

This committee is an example of a long-term ‘conversation’ between VCH Leadership and members of the public. It is not a committee that accomplishes specific tasks, but instead “shares stewardship of the Regional Palliative Care Strategy in a partnership that includes the Regional Palliative Care Steering Committee, the Regional Palliative Care Leadership Team and Community Engagement, with expectation of mutual reporting and exchange of information.” (Terms of Reference). Items are brought to each meeting by VCH Leadership for discussion and reflection with informed members of the public.

What have they achieved with these meetings?

Shared reflection at this committee has contributed to VCH’s new strategy on Advance Care Planning, new education modules in palliative care for GPs in BC, and new potential models of palliative care services in our residential facilities.

2. VCH Vancouver Community Mental Health Services (VCMHS) Special Advisory Committee: 1999 – Present

The Special Advisory Committee for Mental Health is made up of approximately 14 mental health clients from around Vancouver.

Who meets: These 14 mental health clients meet with a staff liaison from VCH MHS.

Purpose (from the Terms of Reference):

To strengthen the voice of people who receive services in VCMHS to shape and evaluate service delivery, to play an enhanced role in public education and to continue information sharing.

Objectives:

- Provide feedback to Vancouver Community Mental Health Services regarding policy and practices
- Provide input to mental health teams through their Client Advisory Committees who send their representatives to this body
- Provide an opportunity for information-sharing between clients of the mental health teams
- Identify mental health service needs and forward to appropriate program managers for consideration as required
- Participate in evaluation of services as required
- Support public education and promote community understanding and acceptance of people with mental illness and mental health issues
- Bring information back from the Central Office level to the team level

How are people recruited?

Neighborhood-based mental health teams have Client Advisory Committees. Each Client Advisory Committee chooses two representatives to send to the Special Advisory Committee.

How often does the committee meet?

Once per month, usually on the first Wednesday of every month.

What do they do at the meetings?

- Listen to presentations and then give feedback about policy and services in the mental health system
- Raise issues of concern to the system
- Exchange information on what is happening at different mental health teams

What have they achieved at these meetings?

Policy has been revised as a result of input from the Special Advisory Committee. Networking and a sense of community has been created. Information exchange happens regularly. An orientation manual for the Special Advisory Committee is near completion.

3. VCH Regional Integrated Primary Communities of Care (IPCC) – Steering Committee: June 2010 - present**How and when did it start?**

Integrated Primary Communities of Care (IPCCs) are a Ministry of Health mandated initiative in BC, and each Health Authority must work toward integration of primary health care services in our health region. Vancouver Coastal Health has established a steering committee, made up of staff, leadership, family physicians and the public to ensure collaboration and provide a common 'table' to bring up issues.

Who meets: Two members of the public meet with five physicians and fifteen staff.

Purpose:

The steering committee will have overall responsibility for guiding the Integrated Primary Communities of Care (IPCC) project team in the planning and implementation of the IPCC model and framework.

How were people recruited?

An invitation to join this steering committee was emailed to all members of the Community Engagement Advisory Network (CEAN) with an application form, and a background document about the steering committee. Interested applicants were interviewed and two were selected to sit on this committee.

How often does it meet: Every four months.

What do they do at meetings?

Members of staff give updates about IPCC work in their respective areas of the region and meeting participants give feedback. This committee is an example of a committee in its early stages. Participants are still learning about each other's work and roles, as well as the role and tasks of this committee. The role of public members is to keep patient and family needs prominent in these discussions.

What have they achieved with these meetings?

This committee is still in the process of learning together about this new model of care (IPCC), and is also developing its own model of work as it proceeds. Members of the public have been included from the very beginning of this committee's work, and it has been a significant achievement to have everyone moving forward in this committee's formation from the outset. Clarity about roles is also still in formation – requiring patience and good will from all!

Appendix 1: Advisory Committee Agreement - Sample

Name of Advisory Committee: VCH Regional _____ Advisory Committee

Purpose of this Advisory Committee:

Working within a spirit of collaboration, it is the mandate of the VCH _____ Advisory Committee to champion changes in patient care through innovation and inspiration.

General Purpose of Public Members on VCH Advisory Committees

- Community Link: To keep in touch with community networks, acting as a ‘bridge’ to bring the patient and public experience to the priorities of the Advisory Committee
- Critical Friend: To bring forward patient and public priorities in committee discussions, for example: safe and respectful care; timely and convenient services; sufficient information and education to navigate our systems and make decisions; support for patient and family/loved ones.

Public Member – Responsibilities Specific to this Committee

- To review documents as required, for development of recommendations, to ensure they respond to the needs of clients, families and communities
- When permitted by the Committee Lead(s), to share information with, and solicit feedback from community members for development of recommendations (e.g. educational materials, possible future initiatives)

Community Engagement Staff - Responsibilities

- To provide sufficient orientation for Public Members to participate fully in the work of the Advisory Committee
- To provide sufficient orientation for Staff Lead(s) and Committee Members so they can understand the role of the Public Members on the Committee
- To support the Public Members in preparation for meetings (for example, reviewing agenda and documents)
- To debrief with the Public Members after each meeting
- To perform an annual assessment of Public Member’s and Staff Lead’s experience of public participation on the Advisory Committee, seeking feedback on successes and further improvement

Advisory Committee Staff Lead(s) - Responsibilities

- To provide sufficient background information about the Advisory Committee and relevant health services in order to support the Public Member’s participation
- To provide agendas and other meeting materials in a timely manner (if possible, one week prior to the meeting), so that Public Members can be adequately prepared
- To participate in periodic reviews of the Public Member’s experience on the Advisory Committee, on an annual or as required basis

Length of Term

Public Members on this Advisory Committee are appointed for a 2-year term, with the opportunity to serve for an additional 2-year term.

Today’s Date: _____

Advisory Committee Staff Lead

Public Member

Community Engagement Staff Representative