

Community Engagement Advisory Network (CEAN) Forum **October 22nd, 2011**

Powerful Knowledge - What we know about our health and how we use it

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. Each year we 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, and supporting VCH's new 'People First' lens. Based on feedback from VCH staff and CEAN members, it was agreed that the October 2011 event should focus on health literacy.

Background: Why is health literacy a priority for VCH?

The need for today's patients to be "health literate" is greater than ever as patients are treated with an ever-increasing array of medications, and are undertaking more and more complicated self-care regimens. People in our communities are often unclear on how to protect their health, how to manage their chronic conditions, and how our healthcare system works.

Health literacy is a key factor in creating informed, activated patients. According to the Canadian Council on Learning (2008), individuals with good health literacy are more likely to:

- Avoid hospitals or emergency rooms;
- Comply with physician orders and use medication more appropriately;
- Navigate the health care system;
- Engage in more effective self-management of chronic disease.

During the Spring 2011 CEAN forum, participants identified health literacy, and its influence on health status, as a topic of concern. This concern was echoed by VCH's Integrated Primary and Community Care (IPCC) team, which was facing challenges engaging their patients in chronic disease self-management.

The IPCC team believes that, by improving health literacy, our health system will become more sustainable, and patients will experience greater satisfaction with services. In bringing together VCH staff and leadership, healthcare providers, community partners and members of the public, the forum provided an opportunity for IPCC staff to explore ideas and potential initiatives to increase the health literacy skills of VCH's chronic disease populations.

Forum Planning, Agenda and Attendance

CEAN members and staff from VCH met from August to October to plan the forum. Given the topic, the decided on venue was the Vancouver Public Library. In addition to CEAN and VCH staff, invitations were extended to:

- Patient Voices Network – A provincial network of patients, their families and other community stakeholders from across BC
- Physician members of the Divisions of Family Practice within VCH

The agenda for the day included:

- Opening remarks from Dr. Jeff Coleman, Vice President, Regional Programs and Service Integration;
- Presentations from Carole Gillam, Executive Director for Primary Care at VCH; and Dr Marina Niks, an expert in the field of health literacy;
- Small group discussions to brainstorm ideas about how the IPCC Initiative can improve health literacy.

A total of 75 people attended the workshop, with strong representation from members of CEAN (18), the Patient Voices Network (7), members of VCH Mental Health Services advisory committees (8), as well as staff and leadership from VCH (23), Impact BC (2), Providence Health (1), community partners (5) and physicians (11).

Presentations and Discussion

To provide context and background for forum participants, two presentations were provided:

- 1) Carole Gillam gave a brief description of the Integrated Primary and Community Care (IPCC) initiative and explained how VCH wants patients and families to be ‘partners’ in health care decision-making and to be actively involved in their care planning and self-management. In order to do so, IPCC must nurture “informed, activated patients” who are able to participate fully in health care planning and self-management – thus the fundamental importance of health literacy (Appendix A).
- 2) Dr Marina Niks then delivered a comprehensive overview of health literacy including examples of resources and strategies to improve health literacy (Appendix B).

Following the presentations, forum participants were organized into nine small groups; each comprising of health care professionals, VCH staff, community partners, and members of the public.

The groups participated in two rounds of discussion addressing the following questions:

- a. **How can IPCC support patients and providers to use health literacy tools, skills and resources?**
- b. **What opportunities for collaboration exist between IPCC team, health care professionals, community partners, and members of the public to support improved health literacy?**

Each small group recorded the content of their discussion, and facilitators identified key recommendations for action. The main themes of the discussion are summarized below followed by opportunities for collaboration.

1) *Both patients and health care professionals require improved access to health information.*

Patients require access to good quality, evidence-based information so they can make informed decisions about their health care. While the amount of information available to patients is increasing (especially through the Internet), the quality of this information varies. Health care professionals have a duty to inform their patients, and as a result, both patients and providers are constantly searching for reliable sources of health information.

Forum participants explained that health information needs to be patient-centered, culturally appropriate, and easily understood by individuals with varying literacy. Participants described the benefit of sharing information through multiple formats and suggested some alternative ways to share information with patients which include:

- Community-based information sessions (at schools, community rec centers, libraries, faith groups or cultural functions, craft fairs, local kiosks) discussing specific topics including “Ask the Expert” Q&A opportunities.
- Group medical visits
 - A group medical visit typically includes several patients with the same or similar chronic conditions who meet with a health care team.
- Peer support or peer coaching
 - The reciprocal relationship created through sharing experiences and knowledge with others who have faced or who are facing similar challenges can help patients do the things they need to do to stay healthy through:
 - Increased understanding of health condition and self-care
 - Shared problem-solving
 - Modeling of effective skills
 - Decreasing sense of isolation
 - Providing encouragement and reinforcement.
- Various forms of self-paced education, including audiotapes/CDs, written material, DVDs or other multimedia sources, TV programming on various health conditions
- Website - information-based, with multiple languages, providing a contact person for questions and support.

Some participants stressed that health care providers need to recognize that **not all patients are using the Internet** as a source of medical and health information, and therefore providers should be prepared to direct patients to high-quality paper-based health resources. Furthermore, low literacy and limited proficiency of English present additional barriers to understanding and interpreting written health care information.

Participants emphasized that fragmented organization of health information is a barrier for patients and they suggested that a **centralized information system**, housing recommended resources, would make it easier for patients to access quality information.

Opportunities for Collaboration

- IPCC could create a clearinghouse/website of health information that can support patients and also provide health care professionals with quality, culturally-appropriate, plain-language materials to distribute to their patients.
- IPCC further collaborate with the public libraries and literacy organizations to make health information more readily available.
- Use of TV or media campaigns to share health messages and educate the public.
 - NOTE: During discussion, some group members raised concerns about the role of media and news, indicating that their involvement in health messaging would need to be carefully managed.

2) Navigating the health care system, preparing for and managing appointments: patient education is essential to improving health literacy.

Participants suggested that patients and supporting community partners need a **better understanding of the health care system**. Specific areas mentioned include:

- Clear expectations for appointments and adequate preparation for appointments
- Understanding roles and responsibilities of each health care provider
- Description of provider qualifications , including any restrictions and suggestions of how patients can best interact with them in that context

Many participants also acknowledged that **patient education workshops** on how to prepare for medical appointments will help patients maximize their visit, with tips such as:

- Make a list of symptoms and prepare questions in advance
- Make an agenda and set the priorities for your appointment
- Questions to ask the health care provider
- Engage Medical Office Assistants (MOAs) or other physician support staff such as nurses, medical residents, and nurse practitioners as a mechanism to help prepare patients before visit.

Opportunities for Collaboration

- IPCC can lead or train community agencies to deliver workshops for patients and the public to establish a clear understanding of the structure, expectations and limitations of health care system.
 - NOTE: These workshops should be community-based and delivered in multi-lingual formats, enabling patient education to be integrated into community programs, faith groups and cultural events. The “How to talk to you doctor” workshop offered by Impact BC’s Patient’s Voice Network was noted by participants as a particularly effective model. The following is a list of some additional workshop activities and tools suggested by forum participants:
 - Role playing exercises where the patient could practice interacting with a health care professional
 - Vocabulary
 - Worksheets to take to appointment or to prepare for appointments
 - Exercises to build patient abilities to assess the quality of health information

- IPCC could partner with community agencies to develop and coordinate skill-building workshops so patient can communicate confidently and effectively with their health care providers.
- Participants also suggested that peer support groups and patient navigators are significant and important resources to assist patients, and felt these programs should be supported by IPCC.
- Participants proposed that IPCC can collaborate with others to address the gaps in services or resources. For example:
 - Community based organizations, English Language educators or literacy specialists, and immigrant services can play an important role in educating patients about the health care system because they have ongoing, trusting relationships.
 - Business partnerships have the potential to deliver health information (i.e. with businesses that promote health and wellness or those that employ new immigrants etc.).
 - Engage health care professionals in the design and implementation of patient education workshops to raise awareness of these programs.

3) Patient and health care providers require increased awareness of existing services and resources.

Participants shared many new and exciting resources that are available to patients (i.e. 811 non-emergency health hotline, BC Nurse Line, “How to talk to you doctor” workshops). However, some group members pointed out that patients feel that health care professionals are often “gate-keepers” to other services and resources and yet many primary care physicians feel inadequately informed about services and resources offered in their community or through VCH.

Where services and strategies do exist, participants believed that a culture shift is required so that health care providers are prepared to work collaboratively with activated patients. For example, many participants recognized the value of bringing family members or “medical companions” to appointments but they felt many health care professionals still need to endorse this model.

Opportunities for Collaboration

- IPCC can identify and increase awareness of existing services such as the Health Link 811 non-emergency health hotline, BC Nurse Line, “How to talk to you doctor” workshops.
- IPCC can create a mechanism that connects health care professionals to community agencies to improve their knowledge of services and resources available to their patients. For example, one group suggested contacting university communications programs to develop a public relations campaign to inform patients/providers about all programs.
- IPCC can collaborate with professional organizations to encourage health care providers to shift their culture around working with activated patients.

4) *Multidisciplinary teams provide benefits to both clients and health care professionals.*

Participants discussed the perceived value of a team-based approach to primary care, believing that this model would improve quality of care and reduce the burdens experienced by primary care physicians. The merits of the “One-stop shop” for model of care were described as particularly valuable for seniors and other groups with restricted mobility, but the benefits of this model may extend more broadly.

Participants detailed the many ways the IPCC initiative could endorse collaboration. For example, participants suggested that:

- Team medical visits would be a useful mechanism for connecting patients, health care professionals and community agencies.
- Group visits for patients with the same conditions can encourage peer support, empowering patients to be more involved in their health care, in addition to connecting them to health resources.
- Sharing patient information between providers more readily.

While the benefits of collaboration were easily identified, participants mentioned that many underlying communication issues exist between health care providers – stating the need for better communication protocols between emergency department physicians, family physicians, allied health professionals, patients and caregivers.

Opportunities for Collaboration

- IPCC team to explore potential opportunities for Medical Office Assistants, community care staff, community agencies, pharmacists, and patient navigators to support primary care physicians with patient follow up.
- Until e-health technology is standardized (likely several years off) participants suggested sharing ‘care plans’ between providers as well as providing a copy to patients.

5) *Effective communication is essential.*

Communication is essential for the effective delivery of health care; unfortunately, there is often a mismatch between a clinician’s level of communication and a patient’s level of comprehension. Effective and compassionate communication is essential in building the relationship between patients and providers. One participant stated that IPCC should encourage the “barbershop model” (which emphasizes open, trusting relationships and easy communication) instead of the “banker model” (regulated by rules, and restrictions) sometimes used in health care. Another participant shared that a patient experiences his symptoms as a story within the context of his life, whereas health care professionals want a list of symptoms.

Participants felt doctors could further support patients by **providing written or recorded information for patients to take home** after appointments to help them remember information and instructions. In addition, this information would enable community partners to better assist patients. One community partner explained that a written diagnosis is critical to her ability to

accurately assist the patient since many patients do not remember or fully understand the medical terms used during appointments.

Participants expressed that the **multilingual and multicultural diversity** of the Vancouver Coastal Health region needs to be acknowledged when developing resources for communication between patients and their health care providers.

Opportunities for Collaboration

- IPCC initiative to collaborate with professional training programs such as the BC Medical Association's General Practice Services Committee Practice Support Program to improve communication skills of health care providers with a focus on:
 - Having open-ended conversations
 - Avoiding professional jargon
 - Allowing patient a chance to talk
 - Using "talk-back" techniques to confirm understandings
- IPCC to support the development of multi-lingual and multi-cultural supports/resources as well as mechanism to connect patients and providers to interpreter services.

Next Steps

Feedback generated from this forum will be used by VCH's Integrated Primary and Community Care initiative to develop new health literacy initiatives. Within a week of this event, VCH's IPCC staff received copies of all small group discussion notes and started integrating these contributions into program planning. The Community Engagement department will update forum participants with the progress of the VCH IPCC Initiative.

Evaluation

Workshop evaluation forms were completed by 55 of the 75 participants and indicated a high level of satisfaction for the event.

The knowledgeable guest speakers 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 participants who share a common interest in health care reform.

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

"Small group discussion was excellent, amazing that each table came up with a different primary idea/goal"

"Sharing ideas with different stakeholders, not just health care"

"The participation of people at the tables went well – everyone participated"


Participants expressed the need to know how their input was used by VCH, what actions were informed by their comments and how it would impact system change.

Appendix A

Integrated Primary and Community Care, and Health Literacy


Health Literacy is a Key to Confidence in Managing Ones Health

Carole Gillam
Executive Director Primary Care
October 22nd 2011



Overview of Presentation

- Brief description of Integrated Primary and Community Care work
- Introduce why are we doing this and how the project will impact patients,
- Talk about the connection between our work and health literacy
- Discuss VCH primary care teams responsibilities in addressing literacy issues
- Ask for help from CEAN



Integrated Primary and Community Care (IPPC): A Ministry of Health Services Directive


- **Goal:** British Columbians will have the majority of their health needs met by high quality community based healthcare and support services
- **Outcome:** Deliver integrated primary care, home and community care, and community mental health and substance abuse services equitably across all local health areas



Population Focus Over Next Three Years

- Patients with 2+ chronic diseases
- Frail seniors
- Individuals with moderate to severe mental health issues

...really the most fragile of our neighbours



We Need to Change the Way We Deliver our Primary and Community Health Services...

- Community discussions, including patient representatives, will inform design of services, and influence the way that healthcare providers organize their work
- Key elements include:
 - a more overall approach, not just symptom treatment
 - Improving the continuity of care providers
 - coordination between members of the team
 - specialists and family physicians planning together
- Culture shift – improved health outcomes more than just a health care system responsibility



In the Patient's World...



This initiative is about making sure that the patient is the center of their healthcare universe.

Supported by, and partnering with, the family physician patients should be encouraged to participate in decision making about their health and manage their ongoing health status.



“Informed, activated patient”



Safe application of the patient-as-partner in self management principle requires that the patient...

- Is confident in talking to their doctor
- Is able to make informed choices
- Is able to manage on a daily basis
- knows signs/symptoms of complications
- knows how to manage exacerbations
- Knows when and who to call for support
- active in partnering with the care team

“This is an intention, but keep in mind that not all patients are capable to act on this way!”



The Importance of Health Literacy

- Between now and 2031 the increasing prevalence of chronic disease will threaten the sustainability of the health system in Canada
- How healthcare systems are organized and care is delivered for the chronic disease population will have a significant impact on efficiency and cost effectiveness of care (Hollander, Chappell, Prince, & Shapiro, 2007).
- Self-management has been identified as a lead strategy.



The Importance of Health Literacy (con't)

- Self-management can be complex, as patients are required to monitor fluctuations in health status and act accordingly.
- Bodenheimer, Lorig et al. (2002) and Farrell et al. (2004) indicated that self-management has the potential to occur when patients have the ability, understanding, and skills to partner with professionals in the management of one's own disease experience.
- By 2031, more than 15 million Canadian adults — **three million more than today** — will have low literacy levels, (Canadian Council on Learning 2010)



Some Examples of Events Resulting from Low Health Literacy

- An elderly woman with heart failure sent home from emergency (the hospital), develops a life-threatening event because she doesn't understand the warning signs listed in the discharge instructions, and her family physician wasn't made aware of her visit to the hospital.
- An 84-year-old diabetic patient is losing so much weight he has been admitted to hospital with “failure to thrive and falls”. His doctor told him eating a healthy diet is the secret to good health at his age. The patient only heard “diet” and was living on about 500 calories a day. Previously reasonably independent, he is now in residential care.



It's a Two Way Street!

Yes...many patients experience some degree of health illiteracy...not a surprise really!

But...within the healthcare system there are providers who experience a degree of health illiteracy themselves!



Care Providers Responsibility

- Cultural, language and communication barriers – together or alone – have great potential to lead to mutual misunderstandings between patients and their health care providers.
- Health care organization leaders are responsible for creating and maintaining cultures of quality and safety. Yet, awareness of the prevalence of health literacy issues is low among health care executives and other managers



Within Our IPCC Work at Vancouver Coastal We Commit to:

1. Ensuring that the challenges associated with Health Literacy are considered in all the planning work we do
2. Partnering with CEAN and others to work with staff and physicians to:
 - Explore care provider degree of understanding of health literacy
 - Raise awareness and educate where needed

Once this work is done we commit our staff to collaborate with CEAN partners to:

- Support patients
- Educate patients
- Listen effectively
- Then respect patients wishes for involvement



Summary

- Purpose of presentation today was to provide background to the IPCC work so we can start to work with members of the public to develop a strategy to include improve or support health literacy in our chronic disease populations
- Results of today will inform our IPCC team's planning



Appendix B

WHAT DO WE KNOW ABOUT HEALTH AND HOW WE USE IT?: A HEALTH LITERACY PERSPECTIVE

Marina Niks
October 22, 2011
CEAN Forum
VPL



- Literacy and Health
- What is Health Literacy?
- Strategies for Change
- Partnerships to support health literacy
- Ideas for potential work

Literacy is one of the most important factors influencing health status.

Perrin, Burt et al (1998) How Does Literacy Affect the Health of Canadians? Ottawa: Health Canada

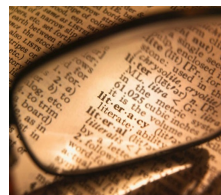
What is literacy?

Literacy is a complex set of abilities needed to understand and use the dominant symbol systems of a culture – alphabets, numbers, visual icons – for personal and community development. The nature of these abilities, and the demand for them, vary from one context to another.

The Centre for Literacy. <http://www.centreforliteracy.qc.ca/about/literacy>

Literacy and Health

- **Direct effect**
 - ✓ Preventative health practices
 - ✓ Early detection
 - ✓ (Chronic) disease management
- **Indirect effects**
 - ✓ Employment
 - ✓ Income



HEALTH LITERACY

The ability to gain **access** to, **understand**, **communicate** and **evaluate** health information to engage with the demands of different health contexts to promote and maintain good health across the life-course.

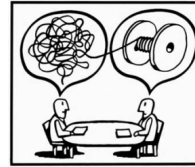
(BC Health Literacy Team, 2007)

ACCESS



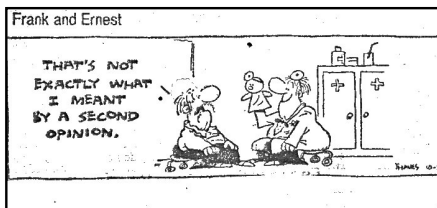
- Individuals have different strategies to access information
- Systems emphasize written communication
- There's a need to better understand how groups/individuals learn

UNDERSTAND



- Language plays a critical role but not the only one
- Contextual, cultural, and personal factors shape how and where individuals relate to health issues
- Systems present challenges

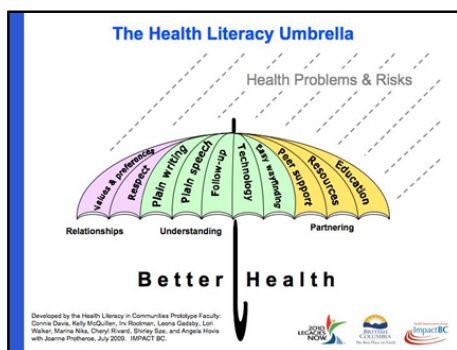
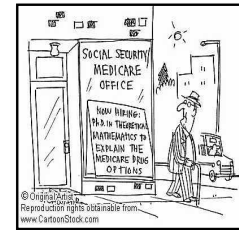
COMMUNICATE



Individuals need to feel comfortable, listened to, respected in their choices and values

EVALUATE

- Health information has become very complex
- Individual's lifestyle and values need to be considered as patients are supported to make choices

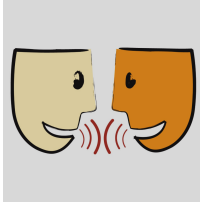


Relationships

1. Understand and consider values and preferences
2. Make health care a relaxed, friendly and respectful experience



Understanding



3. Use plain everyday words and pictures that are clear and culturally relevant in written materials

4. Use plain language when speaking and confirm understanding

Understanding (cont.)

5. Follow-up after a new diagnosis or medication

6. Use technology to access reliable information

7. Make it easy to find your way in health care settings



Partnering

8. Take advantage of peer support

9. Use accessible, supportive community resources

10. Participate in health literacy education



Implications...



- Health Outcomes are not the sole responsibility of one sector
- Working together is the best way to improve Health Outcomes: Build Strong Relationships!

What is happening in BC?

Networks:

- BC HL Steering Committee and Advisory Committee
- HL Health Authorities
- Mental Health Literacy
- HL and Public Libraries

HL and Public Libraries

Public Libraries are a key community resource:

- in the community and open long hours
- resources are free of charge
- a variety of resources are available
- friendly and knowledgeable staff to help you
- it is a safe place to access resources, no stigma, no suspicion



Richmond Public Library



Some ideas...

- Partner with Literacy practitioners
 - Literacy learners screen/test materials
 - Health professionals attend literacy classes to present information, answer questions and hear suggestions



- Office/healthcare unit “audits”
- Literacy practitioners and health professionals cross trained in plain language, communicating health information, etc.

Thank You!

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