

Chronic Disease Management Synthesis Report

Community Engagement Consultation Summary

Executive Summary

Introduction

Vancouver Coastal Health is developing a regional strategy and service framework for chronic disease management. Consultations with the public have previously been conducted by Community Engagement (CE) staff for a number of chronic conditions. At the request of the VCH Chronic Disease Management Strategy Team, a report has been written synthesizing themes from consultations on the following health conditions:

- Congestive Heart Failure
- Diabetes
- Mental Health
- Arthritis and Osteoporosis
- Pain Management

In a health care environment of increased chronic disease and dwindling resources, how can Vancouver Coastal Health best use its resources to support people's management of chronic disease? Following guidelines suggested by the Chronic Disease Management Strategy Team, the following themes were used to structure public feedback on models of service that can encourage and motivate people to take care of their health:

1. Roles and Preferences for Healthcare Providers
2. Role of Community Partnership
3. Self-Management: Education and Support
4. Cultural Competence and Cultural Needs
5. Financial Barriers
6. Communications: Sources of information about our services

1. Roles & Preferences for Healthcare Providers: From 'Provider' to 'Partner'

Partnership between patient and doctor

The role of family doctor, specialist and other health care providers is crucial, as this is usually the patient's primary source of information about their disease. People want a sense of working in partnership with their health care providers, and as part of a larger team to support the

patient's health. Those patients who reported greatest success with their disease management were those who felt their healthcare providers treated them as a partner, for example, giving detailed explanation, demonstration and encouragement of self-management techniques, having information about resources for ongoing support, sharing knowledge about new techniques and medications, showing openness to supporting the patient's choice amongst options.

Partnership between doctor and family/caregivers

In consultation with the patient, it is important for healthcare providers to honour the essential inter-connectedness with family that is perceived by some patients, and find methods to include them in discussions of treatment and care planning.

Partnership between doctors

Members of the public would like to see improved communication between healthcare providers. Examples of tools to lessen miscommunication include shared electronic medical records, and paper-based client health records (recorded with and carried by the client).

Partnership between mainstream and alternative/complementary healthcare providers

Many people use a variety of holistic and complementary therapies, and look forward to working with mainstream healthcare providers as part of a team that includes their holistic healthcare services. By sharing information, patients can explore the efficacy of such methods, as part of a larger healthcare plan, with their doctor as a source of guidance.

Partnership with community-based agencies

There are many opportunities for healthcare providers to partner with community-based services. The more contact that healthcare providers have with community-based agencies, the more likely that mutual benefits (e.g. shared resource information, patient referrals) will prove of subsequent benefit to members of the public at risk or living with chronic disease.

2. Role of Community Partnership

It is strongly recommended that VCH continue its commitment and initiative to provide services in partnership with community organisations, as these are trusted and already-familiar locations for members of the public.

Some examples include:

- Bringing services to community locations, such as recreation centres, churches or temples, to increase accessibility, comfort and convenience for their community members
- Examples of services in the community can include provision of testing, educational workshops and support groups at local community facilities
- Sharing service plans to reduce the risk of duplication of services
- Particularly when working with specific communities (by language, ethnicity, geography, etc.), it is very important that VCH staff work in cooperation with local community members to learn about community norms and values

- Involvement of staff from non-healthcare services can raise their awareness of health topics and resources for at-risk clients, hastening early intervention for those who might otherwise not seek treatment
- Advisory committee to look at strategic implementation of services

3. Self-Management: Education and Support

- The ideal VCH service framework would:
 - provide options for members of the public to learn *as much as they can*, providing a range of educational and support opportunities to encourage self-management
 - encourage staff to facilitate patient learning and use client-directed goal-setting, pace and topics
- Most people express strong need for initial intensive education, followed by ongoing support to maintain lifestyle changes and continue learning new information. This combination of education and support has a strong and significant impact on patient ability, confidence and motivation to manage their disease over the course of their lives

In the acute care setting:

- Start education about resources and self-management in the pre-discharge setting
- Empowering messages in the early stages of diagnosis are reported to have a dramatic and successful impact on patient perception of self-efficacy and agency
- Provide paper-based information about the disease, treatments and resources in the emergency room and on units, for patients, family, volunteers and staff to review

In the primary healthcare setting:

- Patients often want detailed explanation of their condition, the treatments, and to learn how to use self-management tools from their family doctor and specialists
- Diabetes patients have expressed strong dislike for the Group Medical Visit used in some facilities (required attendance in addition to their Diabetes Education classes), wherein many patients are scheduled over a full day to see a variety of medical specialists for routine medical check-ups, rotating from one specialist to the next with a few minutes for each session

In the community:

- When group support is not possible or preferable, it is recommended that a healthcare professional with disease-specific knowledge follow up as soon as possible after diagnosis, via phone or home visit -- perhaps in partnership with a community health nurse or other agency staff, who can then provide ongoing support during their visits
- Benefits in the group model:
 - meets a variety of needs for both physical and emotional health
 - for newly diagnosed patients, groups can provide the option to immediately begin learning about their condition and how to improve their health
 - emotional support provided in the group setting is an essential component to many patients' motivation and confidence to develop and maintain self-management practice

Group Structure:

- Many people express strong preference for two-hour classes that are held weekly or bi-weekly, instead of full-day sessions held in one week
- Preferences for structure, scheduling, location, format and content will vary widely between communities, and successful educational efforts will depend on consultation and partnership with local agencies
- The favoured model across all consultations is the interactive workshop that includes facilitated group discussion
- Classes to be divided by disease type so that training sessions sufficiently address specific health needs
- After the initial education classes are completed, some sort of open group session (where anyone can attend) once per month (one during the day, and one in the evening) would be very beneficial
- People want simplified information, especially for the initial education classes, presented at a slow pace that allows for discussion and questions

Location:

- Generally, in Vancouver participants reported preference for sessions to be held in community-based facilities (community health centres, recreation centers, etc.), and do not like the hospital-based sessions -- people want to meet at locations that are in or near their local neighbourhood, and want to meet in places that are warm and welcoming – hospitals are perceived as sterile and cold
- Participants in Richmond and the North Shore did not express concern about sessions being held in their local hospitals
- For rural and remote areas, the primary concern was that of distance: locations should be chosen that are most central, and are recognized community gathering-places
- As well, rural and remote communities suggest it would be helpful if education classes are brought to their communities on a regular basis, for example, a ‘travelling road-show’ every 6 months, presented in partnership with local community groups

Facilitation:

- Selection of facilitation model is highly specific by community, and must be considered carefully before program implementation, e.g. whether by a medical professional, community worker and / or peer support worker
- Many participants feel that it is very helpful, at some time in the patient’s education, to encounter a ‘peer’ (someone living with the same condition) as educator and leader, demonstrating a model of partnership with health professionals

Family Involvement

- Participants feel that involvement of the family in education and support groups is integral to their improved health, particularly for family of elderly patients
- If newly diagnosed patients are to make required changes, family and community members may need education in order to support changes to cultural norms

4. Cultural Competence and Cultural Needs

- Workshops are best facilitated by professionals and/or lay-professionals from within a cultural community, not only for the benefit of common language, but also common norms of behaviour and tradition
- Disease names and categories, perceptions of disease and healing, even modes of communication are often culturally specific, and health education should be carefully reviewed in partnership with community members
- Language was identified as the most significant barrier to participants' understanding of their disease condition and its treatment
- Language-specific education classes, printed materials and self-management groups are crucial
- If services are not available in one's own language, provision of professionally trained interpreters and translated materials is crucial
- Educational materials also need to be adapted to culturally appropriate images and norms
- Many ethno-specific communities revolve around the family as a unit, and information aimed only at the individual is not relevant or helpful. Services for some cultural groups should make central a focus on the family and community, and be available to the family as a key factor in the patient's health

5. Financial Barriers

- It has been strongly suggested by many participants that special focus be placed on providing resources to support low-income communities, particularly immigrant and Aboriginal communities who are perceived to be most affected by chronic disease conditions
- Education and support models should be tailored to the predominant socioeconomic level of the host community
- Holistic / complementary therapies should be considered for inclusion under BC Medical Services Plan (MSP), in a parallel system (using quality control) allowing people to choose from a range of options for their care. It is recognized that Vancouver Coastal Health has no direct jurisdiction over provincially-insured medical benefits, but there may be a role for advocacy and partnership with others

6. Information Sources: How to communicate about services

- Development of a website, with links to specific conditions and other agencies would be of great help to patients, family and healthcare providers
- Many members of the public are not able to use computers, due to age, language and/or lack of access, so other suggestions include development of a province-wide free phone line (for example, as part of the BC Nurses Line), as well as paper-based information and educational videos
- Wherever possible, translation of materials into other languages is strongly suggested