



CPHA  **ACSP**

CANADA'S PUBLIC HEALTH LEADER
LE LEADER CANADIEN EN SANTÉ PUBLIQUE

LOW HEALTH LITERACY AND CHRONIC DISEASE PREVENTION AND CONTROL – PERSPECTIVES FROM THE HEALTH AND PUBLIC HEALTH SECTORS

Canadian Public Health Association

2006

This report was adapted from *Increasing Understanding of the Impact of Low Health Literacy on Chronic Diseases Prevention and Control*, researched and written by Lynn Chiarelli, July 2006.

Table of Contents

INTRODUCTION.....1

CHALLENGES LOW HEALTH LITERACY PRESENTS TO CHRONIC DISEASE PREVENTION AND CONTROL EFFORTS.....1

 Challenges in Chronic Disease Management2

 Additional Challenges in Chronic Disease Prevention2

IDENTIFYING PEOPLE WITH LIMITED HEALTH LITERACY IN CLIENT POPULATIONS3

BARRIERS PEOPLE WITH LIMITED HEALTH LITERACY EXPERIENCE IN PREVENTING OR MANAGING THEIR CHRONIC DISEASE.....5

IMPACT OF HEALTH LITERACY CHALLENGES ON THE EFFECTIVENESS OF PREVENTION AND CONTROL EFFORTS7

PRACTICES OR TECHNIQUES USED IN WORKING WITH PEOPLE WITH HEALTH LITERACY CHALLENGES8

 Practices to Improve the Patient-Provider Interaction8

 Use new Models for Chronic Disease Management and Primary Care Delivery..... 11

RESOURCES, INFORMATION AND TRAINING FOR WORKING WITH PEOPLE WITH HEALTH LITERACY BARRIERS 12

ADDRESSING LIMITED HEALTH LITERACY IN THE HEALTH SYSTEM..... 15

INTRODUCTION

This report summarizes the findings from key informant interviews that were conducted by CPHA in 2006, as part of a project looking at the impact of low health literacy on chronic disease prevention and management. Health literacy refers to a person's capacity to find, understand and use basic health information and services needed to make appropriate health decisions.

A total of 24 key informants were interviewed to provide a broad range of perspectives from institutional and community settings involved in chronic disease prevention and management across Canada (British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia).

Key informants included:

- practitioners (primary care physicians, nurses, physiotherapist, respiratory therapist)
- program managers in chronic disease prevention or management
- experts in literacy and consumer health information
- researchers involved in related health research.

Practice settings included primary health care practices (affiliated with academic teaching centres), community health centres (urban, rural), community programs (literacy, public library), rehabilitation centres, hospitals, patient education department/centre.

Program managers worked in a range of programs that: (1) targeted specific chronic disease prevention areas or risk factors (e.g., cervical screening, healthy eating, diabetes, heart disease, respiratory diseases); or (2) specific populations (e.g., seniors, Aboriginal communities, ethnocultural groups, homeless people).

This summary reflects the broad range of experiences and perspectives of the key informants interviewed and provide an exploratory view of issues of interest but it is not a comprehensive or systematic survey of chronic disease prevention and management practice as it relates to low health literacy.

CHALLENGES LOW HEALTH LITERACY PRESENTS TO CHRONIC DISEASE PREVENTION AND CONTROL EFFORTS

Key informants were asked to explain the challenges that low health literacy in their client population presents to their work. All key informants noted significant challenges in areas of both chronic disease prevention and management.

In order to understand the challenges presented by low health literacy, key informants typically began by describing the demands placed on an individual to prevent or manage chronic disease. Understanding these demands helps to explain why people with low health literacy may face serious challenges that compromise their health.

Comments from key informants working in primary care practice settings providing chronic disease management are presented below in terms of challenges for managing chronic disease as well as challenges specific to prevention.

Challenges in Chronic Disease Management

Key informants identified the following demands on an individual to manage their chronic disease:

- high level of complexity
- high level of self-care required
- understanding of the condition and treatment is required
- navigating the system is required .

Within this context, key informants identified a number of challenges that low health literacy presents in their own work in chronic disease management. Some of these challenges are at the level of direct patient-provider communication. Other challenges are at the broader level of the health system and deal with how we structure and provide care.

Table 1: Challenges Low Health Literacy Presents to Chronic Disease Management

- clarifying who we mean by "people with low health literacy", recognizing sub-groups
- identifying patients with low health literacy
- overcoming stigma, shame and low self-esteem
- overcoming limited understanding of health, chronic disease and treatment
- overcoming language barriers
- understanding different cultural concepts about health and illness
- finding/developing plain language written information
- developing/using alternatives to print to support different learning styles
- working within current models of chronic disease management
- overcoming provider frustration/apathy

Additional Challenges in Chronic Disease Prevention

Key informants talked about the demands on individuals to prevent chronic disease for themselves or family members:

- requires awareness of risk factors and what can be done to modify risk factors
- requires belief that change is possible
- requires motivation to change
- requires support to make the change (support at the individual level in the form of practical resources and skill building and from the environment (family, community, healthy public policy)).

All of these demands on the individual are compromised by health literacy barriers. As noted, all of the challenges raised by key informants for managing chronic disease from Section A also apply to prevention. Key informants noted additional challenges specific to prevention efforts:

- improving reach of screening programs
- changing how we approach delivering health messages
- adapting prevention tools/building capacity for using tools
- overcoming media influence and misconceptions
- reducing systemic access barriers.

Key informants emphasized that every community or population group is different. The majority of health messages are aimed at reducing risk factors and encouraging preventive health behaviours in the mainstream population. Key informants noted the limited resources available to public health units and health charities, limiting their ability to develop and

deliver health messages. Examples of effective practices through public health and community -based health organizations were mentioned. However, the common characteristics are not typical of what is seen in practice.

Table 2: Common Characteristics of Effective Chronic Disease Practices Addressing Health Literacy Barriers

- extensive needs assessment of the particular population
- involvement of population group members in developing messages/prevention program
- involvement of group members in delivery of message or program
- use of multiple approaches to learning (individual, group, informal)
- extensive, tailored behavioural interventions
- intense time with providers/support people
- frequent contact over long period of time
- commitment to building individual and community capacity

Key informants talked about the link between low health literacy and other social determinants of health. People with low health literacy may experience systemic barriers to preventing and managing their chronic disease. Overall, key informants suggested the challenge for service providers is to work with groups in the community to identify the barriers that exist and to find practical solutions that improve chronic disease prevention efforts.

IDENTIFYING PEOPLE WITH LIMITED HEALTH LITERACY IN CLIENT POPULATIONS

Key informants working in primary care practice settings indicated they do not formally test for literacy or health literacy. They noted that few patients will self-identify as having literacy barriers, and listed a number of "clues" that may indicate that barriers exist. See Table 3.

Some key informants indicated that health literacy barriers are identified through individual assessment, as part of their model of chronic disease management. By taking the time to talk with patients to develop tailored self-care plans, health literacy barriers are identified and problem-solving takes place to overcome specific barriers. Others based identification on the demographics of their practice, paying attention to patients in groups that may be expected to have health literacy barriers (e.g., seniors, immigrants/refugees, and people with low socioeconomic status).

Table 3: Possible Indicators of Health Literacy Barriers

- The patient is frustrated and angry about a treatment that hasn't worked.
- The patient has not followed instructions or recommendations for self-care; e.g., "non-compliant."
- High frequency of visits or not showing up at all for scheduled visits.
- With repeating the same instructions over several visits, the condition is still not being managed. E.g., high blood pressure or high blood sugar persists, despite prescribed medication and instructions for self-management.
- The patient won't look at pamphlets or information provided or will say no when they are offered.
- When given forms to fill out or written information, the patient may say that they have forgotten their glasses or that the print is too small to read.
- The patient may bring someone along to the appointment and defer to them to answer questions.
- When taking the social history, the patient may say they have a low level of education, or an off-side comment may be made, such as "I never was much good in school."
- Noting obvious language barriers.
- Noting non-verbal signs of lack of understanding. For example, people may just want to please you and just nod, so it goes undetected.

Key informants working in chronic disease prevention talked about using interactive health education methods to assess levels of health literacy and adapt to learning styles. In group settings, informal question/answer exercises reveal important health literacy information regarding knowledge, attitudes and behaviours in relation to a particular area of chronic disease prevention.

Many key informants talked about the value of developing a simple, easy to apply identification tool for use in practice settings. Key informants talked about feeling like they were missing people who had health literacy barriers in their practice, and needed more support to address barriers. One key informant summarized this feeling as follows: "I am worried about the large number of people who I think understand, but really do not...this may be a significant group."

There was some difference of opinion regarding the best approach. The following points were raised by key informants:

- recognition of the various sub-groups that have low health literacy is important
- current tools available for health literacy assessment in research are limited and are not suited for use in the practice setting
- formal health literacy assessment (e.g., administering a test) is not a helpful approach, and may increase stigma for people with health literacy barriers
- a simple tool for use in the normal course of the patient-provider encounter is desirable
- for patients living with a chronic disease and requiring significant patient education, it may be useful to selectively assess health literacy and learning styles to provide the best supports for self-management
- a "universal precaution" approach to low health literacy is one approach, and would be based on the assumption that everyone/anyone in the system can have health literacy barriers; communication in the health setting would need to be adapted according to this principle
- cultural competency of health care providers will help to identify health literacy barriers that have their roots in different cultural understandings of health, using the health system, preventing and treating chronic disease.

BARRIERS PEOPLE WITH LIMITED HEALTH LITERACY EXPERIENCE IN PREVENTING OR MANAGING THEIR CHRONIC DISEASE

All key informants identified barriers that people with limited health literacy experience in preventing or managing chronic disease. One key informant summarized the barriers very simply: "Everything is that much harder without the skills and resources."

Table 4: Barriers to Prevention and Self-Care for People with Limited Health Literacy

- health information is not presented in a way they can understand
- providers are not trained in clear verbal communication and how to work with people with health literacy barriers
- "locus of control" is with the provider
- difficulty navigating the system and knowing what options are available
- limited basic knowledge and skills for prevention and self-care
- understanding how the body works, the condition and the treatment
- difficulty advocating for themselves in the health system
- practical supports for healthy lifestyle or self-care may be unavailable or inaccessible
- language and cultural barriers to prevention and self-care are present

People with low health literacy may have had difficult life experiences, linked to stigma, poverty and social isolation. They may not feel that they have control over their health or health decisions. This is a major barrier to self-care, as patients with low health literacy may not feel they can make a difference in their own health, and depend more heavily on the provider for support. They may not feel confident to question their provider or advocate on their own behalf. In the face of this barrier, it is a major challenge to build capacity for self-care, with these individuals relying heavily on the provider to manage their chronic disease.

Knowing who to call, where to go and what's out there is a major barrier for many people with low health literacy. A number of key informants emphasized that many people with health literacy barriers want to be able to take care of themselves and their families, but often don't know where to begin or where to go for support.

Health and other service information is primarily provided in print format, and increasingly through the Internet. Some of the groups with higher rates of low health literacy may not have access to computers, be familiar with searching for information or critically analyzing information to support their health decisions. Often, members of these groups rely on informal learning and face-to-face contact to find information for health decisions. At this time, the standard practices for disseminating health information for chronic disease prevention and self-care only support this type of learning to a limited extent.

Key informants provided a number of examples of the barriers presented by limited knowledge and skills for prevention and self-care. In general, low health literacy impacts the individual's ability to self-assess and take action to prevent more serious health problems from developing.

These types of barriers are linked to other barriers noted in this section which relate to accessing information and resources for self-care: difficulty navigating the system, heavy reliance on print information for prevention and treatment, the high level of readability of written material, and the cultural appropriateness of the information provided.

Key informants also drew a direct connection between these types of barriers and systemic limitations on provider time for patient education, for answering questions and for problem-solving to overcome individual barriers to self-care. Limited provider knowledge and skills in working with patients with low health literacy was also noted as a barrier to self-care. New models of chronic disease management and primary health care delivery are working to address these types of barriers; however, they are not what is seen in typical primary care practice.

Understanding how the body and how treatment works was barrier mentioned by several key informants working in primary care settings. This barrier is distinct from challenges with reading, writing and numeracy.

Key informants talked about the current expectation in the health system for patients to take an active role in making health decisions. People with low health literacy may not know about the options that are available to them because of access barriers to information and services. They also may lack the ability to critically analyze these options to make informed health decisions. This is compounded by being intimidated by the health system and lacking the confidence to ask questions or raise concerns with health professionals. With some exceptions, the system is generally not set up to welcome questions or provide additional support where needed.

Key informants talked about the practical supports required for healthy lifestyle changes to reduce risk factors such as diet, exercise, stress and smoking. People with low health literacy may not have the same range of options for modifying lifestyle because of limited income, type of employment and living arrangements. There may also be cultural barriers that limit options for healthy lifestyle or self-care.

Key informants talked about language and culture as two distinct barriers that contribute to health literacy barriers. They noted consultations with members of different ethnocultural groups, indicating that communicating in English rather than their first language is a barrier to understanding health information for prevention and treatment. Translators are available in some settings to assist; however, their preference is to be served by someone from their language and cultural background.

Table 5: Practical Supports for Prevention and Self-Care

- getting help to address other barriers to health (e.g., income, food security, finding employment, counselling for trauma or loss)
- having adequate income to eat well and access recreational activities for exercise and stress reduction
- having time for self-care and/or child care to create windows for exercise and stress reduction
- finding ways to overcome social isolation and to build social networks for support
- finding transportation to screening or medical appointments
- having a family member or advocate that can assist in health care encounters in the hospital or community
- having one-on-one time with a provider to develop a personal care plan, identify barriers to self-care, problem-solve and follow-up

Cultural barriers are distinct from language barriers. Key informants provided specific examples of cultural barriers identified that impact on help-seeking behaviour, risk factor reduction, screening, diagnosis and treatment of chronic disease. Much of the available health information and practice guidelines for chronic disease management do not take into

account the real-life context of people from different cultural or religious backgrounds, including marginalized populations. This has major consequences for promoting changes in health behaviour and strategies for self-management.

IMPACT OF HEALTH LITERACY CHALLENGES ON THE EFFECTIVENESS OF PREVENTION AND CONTROL EFFORTS

Key informants talked about the impact of health literacy barriers on the effectiveness of their work in terms of patient-provider communication and in terms of the types of interventions used for chronic disease prevention and control.

One key informant outlined the importance of supporting good communication. She stated that:

Human interaction is at the core of health literacy barriers and the solutions that can be found. How providers communicate and what they communicate makes a big difference to understanding. How the health system supports the patient-provider interaction is also an important factor.

Many key informants noted that effectiveness in patient-provider communication is limited by health literacy barriers. As a result, patients do not achieve the same level of control of their chronic disease.

Some key informants were familiar with research demonstrating clear links between low health literacy and poor health outcomes in chronic disease management. Although they do not systematically track outcomes in their patient populations, they have all observed poor health outcomes that they, at least in part, attribute to low health literacy. The impacts of low health literacy on health outcomes observed by key informants are listed in Table 6.

Table 6: Impact of Low Health Literacy on Health Outcomes

- limited knowledge of condition and treatment
- blood pressure that is not controlled
- blood sugar levels that are not controlled
- limited improvement in functional status during rehabilitation
- correlates with "disaster" situations such as diabetic coma or amputations
- more visits to the emergency or doctor for respiratory complications of asthma/chronic obstructive lung disease
- lower rates of screening for cervical and breast cancer
- higher rates of smoking and substance use
- less success with healthy lifestyle changes (e.g., modification of diet, physical activity)

Key informants cited studies which show higher rates of hospitalization for ethnocultural groups, regardless of education, higher diagnosis of heart disease, diabetes and some cancers, and lower rates of screening practices among some ethnocultural groups. There is some evidence that attributes these outcomes in part to language and cultural barriers, both contributors to low health literacy.

Key informants also cited the body of evidence that has examined health disparities in the population. There are higher incidences of major chronic diseases in underserved populations, especially those with low socioeconomic status. These populations groups tend to have lower health literacy. This suggests that the presence of low health literacy in these

populations may impact the effectiveness of current practices for chronic disease prevention and control; however, more research is required to fully understand this relationship.

Key informants emphasized that it is difficult to pinpoint low health literacy alone as the cause of poor health outcomes in chronic disease prevention and management. This is because the sub-groups which tend to have higher rates of low health literacy typically experience other barriers or complicating factors. Knowing more about the extent to which low health literacy is responsible for poor health outcomes in these population groups will guide the development of effective interventions.

With respect to reducing risk factors to prevent chronic disease, key informants stressed that the impact of low health literacy on effectiveness depends on the type of intervention. For example, the impact of low health literacy would be minimal on the effectiveness of an intervention such as a community kitchen. This type of intervention, designed to promote healthy eating, takes place in a practical setting and familiar context for individuals. Learning is primarily through verbal exchanges and use of hands-on demonstrations. On the other hand, interventions that rely heavily on print material would be seriously limited by low health literacy in the target population.

Key informants working in chronic disease prevention thought that low health literacy impacted the effectiveness of their work. People with low health literacy may have difficulty making the connections between risk factors and chronic disease; e.g., obesity and diabetes, smoking and heart disease.

Key informants noted good examples of targeted health education interventions developed through public health units, community health centres and patient education centres. One key informant noted that health education is "very doable and we can develop health education systems for people at all levels of literacy and health literacy." However, she went on to say that "the challenge is translating this into changes in behaviour, to find out the barriers to change and break them down; it takes a long time to move people through the stages of change."

Major limitations on effectiveness were restated, and related to time restrictions, resource restrictions for the intensity of intervention required, limited training and communication tools for use in practice settings, traditional models of chronic disease management that don't accommodate people with a wide range of health literacy barriers .

PRACTICES OR TECHNIQUES USED IN WORKING WITH PEOPLE WITH HEALTH LITERACY CHALLENGES

Key informants talked about practices or techniques used in direct patient-provider interaction in managing chronic disease with people with low health literacy. They also talked about approaches to program interventions for both chronic disease management and chronic disease prevention.

Practices to Improve the Patient-Provider Interaction

Key informants talked about a number of good communication techniques they use in their own practice.

Table 7: Practices to Improve Patient-Provider Interaction

- asking patients to explain what they know/understand about their chronic disease as a starting point for identifying level of health literacy and/or misconceptions that may present barriers to self-care
- "slowing things down completely" to allow adequate time for explanation and questions
- using simple terms in common use rather than complex medical terminology or jargon e.g., high blood pressure rather than hypertension or blood sugar rather than glucose
- asking patients how they learn best
- asking patients to teach-back what has been recommended to check for understanding of instructions and to identify areas for reinforcement or where barriers to learning exist
- reinforcing messages several times and explaining in several different ways during and at future appointments

Key informants who were physicians working in primary care teams rely heavily on other team members in cases where more time or intensive support is required to support self-care. Other team members included nurses, dietitians, pharmacists and social workers. In hospital settings, patient education specialists, rehabilitation and respiratory therapists and discharge planners were also noted as points of referral for extra support to patients with health literacy barriers.

Other external supports noted were:

- Involving family members or other support people in appointments to assist in communication and in carrying out the care plan.
- Using interpreters to address language and cultural barriers

Key informants who played a significant role in providing one-to-one patient education noted some additional practices they use in working with people with low health literacy:

- using visual aids like hands-on models, simple line drawings, pictograms, photos, and video, "images are everything"
- restricting use of written information: only as back-up to what has been explained verbally and only easy-to-read materials, when available (Grade 6 level)
- creating their own resources, in partnership with the client group, to ensure that content is clear and culturally relevant and that the format is easy-to-use.

However, for each of these practices, they noted serious limitations in accessing relevant, plain language resources. In other words, they do their best to follow these practices and often "make do" with what is available. Information from disease-specific health charities is typically at a high reading level and rarely fits with the groups that tend to have low health literacy. This was especially the case with respect to finding health information and tools that are culturally relevant and in languages other than English or French that fit the realities of people from low socioeconomic groups or Aboriginal communities.

Key informant comments about currently available information/tools to support their chronic disease work with people with low health literacy included:

- 90% of what is available is useless and has no meaning in their life.
- We are posterized and brochured to death, and this intimidates people.
- Leaflets alone suck.

Some key informants provided patient education or health information for chronic disease prevention in a group format. They also noted that groups may not be the preferred

learning style for some people with low health literacy. Some examples of group practices used include:

- organizing informal group sessions with peers and in the first language of participants
- using a familiar setting for the session (e.g., church, community centre, meeting place of an established community group)
- encouraging personal stories about living with and managing their chronic disease
- training peers to lead discussion and share about their challenges and successes with risk reduction or self-care
- using role play to open up discussion and to practice skills that might be used in navigating the health system
- using humour and interactive games to share health information.

Key informants were unanimous that low health literacy presents serious challenges to effective chronic disease prevention and management. However, there were a number of approaches or interventions that were used as examples of practices that show promise, although formal evaluation has not been done.

Table 8: Promising Chronic Disease Practices to Address Health Literacy Barriers

- provide information in plain language and use multiple media
- provide more than information alone
- base interventions on targeted community needs assessment
- involve target groups in developing and delivering health information/ programs
- offer face-to-face and informal learning opportunities
- build capacity of health professionals to work with low health literacy groups
- build the capacity of patients/health consumers with low health literacy
- use new models for chronic disease management and primary care delivery
- partner to provide prevention education

In delivering interventions, involving community members was identified as a helpful way to reduce stigma, decrease fear and to overcome language and cultural barriers. This approach also improves both individual and community capacity to address health literacy barriers. Key informants noted a number of strategies for involving members of groups that have high rates of low health literacy.

Table 9: Strategies for Involving Population Groups to Improve Chronic Disease Interventions

- In education sessions, group members are encouraged to share their own stories about preventing or managing their chronic disease.
- Community volunteers assist with writing articles for community-focused publications or public service announcements for radio/television.
- Community leaders are involved in delivering health messages (e.g., encouraging community members to be screened, to participate in health promotion activities).
- Community health representatives are trained to assist with health education, health promotion and primary health care in Aboriginal, on-reserve communities.
- Health professionals of the same language/cultural group provide service in the first language of the target population.
- Foreign-trained health professionals not yet been licensed in Canada assist with targeted health education and/or chronic disease management to their own language/cultural community.

A number of key informants working with disadvantaged communities talked about the importance of maintaining respect for cultural norms, and cautioned using the "expert" approach. They recommended a balance between offering and sharing expertise with listening and supporting community members to identify their own issues and solutions.

Key informants talked about providing more intense and frequent contact to support people with health literacy barriers to manage their chronic disease. Traditional chronic care or primary care models do not generally support the required time or resources to do this. However, key informants provided examples of models which build capacity for self-care when health literacy barriers are present (see Use new models below).

There were few examples of initiatives noted by key informants to specifically build the capacity of health professionals to work with patients with low health literacy. These initiatives were not specifically targeting chronic disease prevention and control, but would most definitely encompass professionals providing this type of care.

The Health Literacy in Rural Nova Scotia Research Project resulted in the production of a DVD, "Health Literacy: Making the Connection". Through interviews with health service providers, literacy practitioners and adults with literacy barriers, the DVD presents the links between literacy and health, including consequences for finding, understanding and using health information and services.

This information tool has been distributed to all health authorities in Nova Scotia to assist in raising awareness about the impact of low health literacy on health and health services. In one health authority, workshops were held with service providers using a theatre presentation to highlight key issues. A checklist was handed out to workshop participants to help them identify people with health literacy barriers. The presentation and discussion included some basic strategies that they could use immediately to improve patient-provider communication.

The workshop evaluation indicated that health service providers could relate well to the barriers presented. A majority of participants had gained new knowledge through the presentation and, at 6-month follow-up, a significant proportion were actively engaged in adapting their practice in some way. A health literacy audit tool has been included as part of quality assurance policy in this health district.

Use new Models for Chronic Disease Management and Primary Care Delivery

Key informants talked about the limitations of the traditional model of chronic disease management and provided examples of different models of care that may improve chronic disease management for patients with low health literacy. Most of these models involved integrated teams in primary care or hospital-based settings.

Another model mentioned by key informants uses a community development approach to chronic disease prevention and management, delivered as a program of a community health centre in Ontario. The model engaged volunteers from the Latin American community to help develop a diabetes management program. Some volunteers were trained health professionals not yet accredited in Canada who worked under the mentorship of a Canadian licensed professional. The program was delivered through Saturday morning community events that included diabetes screening, individual evaluation and group education sessions. This model has received several national best practice awards and has been adapted in several communities across Canada, with different ethnocultural groups. The program expanded into a diabetes prevention program which targets children and families for

screening and risk reduction through participatory activities and discussions. This model was designed to address health literacy barriers in the target population and includes all techniques and practices mentioned in this section of the report by multiple key informants.

Two key informants provided examples of hospital-based interventions which showed promise, but faced serious implementation barriers. Based on extensive needs assessment, the Montreal General Hospital set out to improve health information and processes on three chronic care units in order to address health literacy barriers. Patient education centres on the unit were recommended; however, the space for these centres was unavailable once funding for the project was secured.

The other project involved the development of extensive tools for practitioners and patients with chronic heart failure in an inpatient setting. Tools included recording notebooks, checklists to help with self-management, and a guide to support the patient-provider collaboration. However, there was limited buy-in from cardiologists on the unit and reduced hospital resources (shorter length of stay) resulted in the inability to carry out the intervention. The approach to developing tools was well-grounded in needs assessment, evidence-based practice guidelines and health literacy research; however, the health system did not support this new approach.

A number of key informants discussed projects at the national, provincial and local levels which involved a range of partners from public health units, community health centres, immigrant-serving organizations, literacy programs, hospitals, federal and provincial governments, disease-specific health associations and the private sector.

RESOURCES, INFORMATION AND TRAINING FOR WORKING WITH PEOPLE WITH HEALTH LITERACY BARRIERS

The major disease-specific health charities were mentioned as general sources of education materials to support prevention activities or self-care in primary practice. However, all key informants who access these resources noted the materials are at high readability levels and generally not practical or culturally appropriate when health literacy barriers are present. The exception was the Dietitians of Canada, noted by several key informants as having produced useful materials for education purposes. Two key informants also noted that the Canadian Diabetes Association has been making efforts recently to address cultural barriers through partnerships. Organizations mentioned included:

- Canadian Diabetes Association
- Ontario Lung Association and Asthma Society of Canada for asthma information
- Canadian Lung Association for COPD information
- Heart and Stroke Foundation
- Canadian Cancer Society
- Dietitians of Canada

Table 10: Resources, information and training accessed by Key Informants to Support Their Work with People with Low Health Literacy

- "Health Literacy: Making the Connection" DVD produced in 2004 by the Nova Scotia Departments of Health and Education
- Checklist on identifying people with low health literacy and health literacy audit tool developed out of the Health Literacy in Rural Nova Scotia Research
- Easy-to-Read Health Series (Grade 6 Level) produced by the literacy publisher Grass Roots Press in Alberta. The reading series is culturally appropriate for low income women (topics include living with stress, aging and dying, living healthy, addictions). It has been promoted to a limited extent in literacy networks, but not yet through health networks. A facilitator's guide is in development.
- Canadian Public Health Association literacy and health resources
- Centre for Literacy of Quebec
- College of Family Physicians patient education centre
- American Medical Association material on health literacy
- Harvard University health literacy materials
- International Diabetes Centre (Minnesota)
- Community Health Association of British Columbia
- Helen Osborne Health Literacy Consulting (US)
- Pfizer US health literacy materials and conference proceedings
- Eli Lilly

Some key informants use this material as a starting point to adapt to their own work environment; however, time and resources were noted as limiting factors in doing this. This was especially the case for community-based or on-reserve health organizations with limited staff and financial resources to carry out chronic disease prevention and management in their communities.

Several key informants were familiar with plain language health information on a variety of health topics prepared through community health centres or through local health units. These resources target specific groups who experience health literacy and other access barriers. One key informant from the London Intercommunity Health Centre described extensive resources their organization developed for culturally-sensitive diabetes management. The material was disseminated nationally through a partnership with the Canadian Ethnocultural Council with funding from Health Canada and the Lawson Foundation.

Two key informants noted that disease-specific patient education centres for diabetes and respiratory problems prepare some of their own materials. Key informants working with Aboriginal on-reserve communities look to Health Canada national and regional offices for culturally-specific education materials.

Most key informants noted using the Internet as a source for current research to inform their practice or to find education materials. For research, accessing scholarly journals through Pub Med and academic databases were mentioned. A number of key informants indicated finding information about chronic disease prevention or management through professional conferences, some hosted by the major health charities.

Two list serves were noted as sources of information: Pat Net (for patient education), National Institute for Literacy, health discussion group.

A number of key informants who provide education for prevention and self-care talked about the need for a central place to go for easy-to-read materials that are visually-based and meet the needs of different cultural groups. Useful topics might include: nutrition (how fats, proteins and carbohydrates work), diabetes, high blood pressure, arthritis, how alcohol affects the liver. One key informant suggested that the patient education centre of the College of Family Physicians could be expanded to include resources for low health literacy.

All key informants working directly with patients talked about needing simple, concrete tools to use in their practice setting. These tools would help them identify and work with people who have health literacy barriers. The following specific training areas were mentioned:

- how to identify people with low health literacy
- how to improve patient-provider communication
- how to support patient self-management and teach skills
- how to identify and accommodate different learning styles
- how to deliver prevention education sessions to groups with low health literacy.

A number of different formats were suggested for training:

- lunch and learn sessions for practitioners in their practice settings
- distance education complemented with opportunities for face-to-face interaction and practicing skills
- workshops at disease-specific conferences on health communication as it relates to patient education in chronic disease prevention and management (e.g., as part of Lung Association conference)
- workshops and knowledge exchange at another national conference on literacy and health

Key informants working with Aboriginal or ethnocultural groups identified the following needs:

- cultural competency training for health professionals so they have an adequate understanding of the client groups they serve
- training of health professionals from within cultural communities to provide culturally-appropriate service in the first language of community members
- mentoring of volunteers from within these communities to develop and delivery chronic disease programs
- specific education materials that are adult-oriented and sensitive to culture on respiratory health issues, diabetes and heart disease
- human and financial resources to maintain or develop their chronic disease prevention and management activities.

They also emphasized the importance of having interpretive services in health settings and suggested training community members to act as advocates. Although health information in the first language of communities is needed, it was recognized that for broad-based self-care platforms like the BC Health Guide, it may be too costly to maintain updated, multi-lingual health information. Two key informants noted that the added value of simply translating material needs to be further explored within the context of multiple health literacy barriers.

The need for broader system support was flagged for community-based chronic disease interventions that engage community members from within ethnocultural groups.

Tools to build skills of adults with health literacy barriers were also mentioned by a number of key informants. Different tools would be required by different sub-groups. Adult education and English-as-a-Second Language programs were identified as useful routes to provide tools and training. New curriculum resources are needed for practitioners working in these settings to support their role in improving health literacy.

Opportunities for learning together, networking and sharing were noted as valuable by some key informants, involving primary care practitioners, health educators, representatives of disease-specific health organizations, adult educators and adults with literacy low health literacy.

ADDRESSING LIMITED HEALTH LITERACY IN THE HEALTH SYSTEM

Without exception, key informants identified low health literacy as a major health system, particularly with respect to chronic disease prevention and control. One key informant indicated that, although it was important, it was possibly not the most important issue, and that improved coordination was a higher priority. To explain why they believe it is important, key informants referred to the barriers that people with low health literacy face and the challenges to effective chronic disease prevention and management.

Recurring themes related to: (1) the major demands for system navigation and self-care required to prevent and management chronic diseases; (2) the current burden of chronic disease which rests on population groups that tend to have high rates of low health literacy (e.g., seniors, ethnocultural groups, Aboriginal communities, groups with low socioeconomic status); (3) implications for quality of care and costs in the health system as a result of low health literacy.

In terms of whose role it is to address limited health literacy in the health system, key informants ranged from identifying "everyone" as responsible, to focusing on specific areas of responsibility. In terms of "everyone" being responsible, the need for collaboration between health and education sectors was noted, and between different health professional groups, disease-specific health organizations, community-based organizations and patients/community members.

Most key informants pointed out that blame should not be laid on the shoulders of people with health literacy barriers. Many commented that it was the role of the health care provider to understand about health literacy barriers, to accommodate different styles of learning and to learn about the living environment of the people they are serving to facilitate/support self-management. This is especially true in the context of chronic disease prevention and management, where complex care and promoting healthy lifestyle "choices" may not take into account the multiple barriers people face in accessing resources for their health. One key informant summarized this belief as follows: "it is high time for the health system to recognize the barriers and respond by changing practice".

Specific areas of responsibility identified included:

- anyone who works directly with patients/clients in the health system, from reception/greeting through to chronic disease specialist
- health service providers who work in chronic disease prevention or management (physicians, nurses, dietitians, pharmacists, social workers, rehabilitation therapists, respiratory therapists, patient educators, health promoters)
- disease-specific health associations
- community health centres with experience in developing community-based chronic disease prevention and management programs

- national health associations and professional licensing bodies
- public health
- government health departments producing health information or supporting chronic disease program delivery
- adult educators, literacy advocates and adults with literacy barriers
- adult education and ESL programs
- policy-makers at all levels in government and non-governmental sector, including health authorities and hospital administrators.

Key informants indicated that working with low health literacy populations should be on the continuing education circuit. There is a role for health professional associations, professional licensing bodies, disease-specific health organizations and academic teaching centres to develop and deliver this type of training.

With respect to both Aboriginal and ethnocultural communities, a number of key informants indicated that solutions should be developed in partnership with community members and organizations: developing health messages and formats, designing and delivering health programs.

Key informants noted that there is no clear leadership at this time on the issue of addressing health literacy barriers. Some key informants mentioned the need for identifying champions within the medical profession and other health professional groups involved in chronic disease management in order for the issue to be taken seriously. One key informant noted that it is an "uphill battle."

Raising this issue within the context of primary health care transition was also seen as important. Key informants working in Nova Scotia and British Columbia indicate that some progress is being made in this regard provincially. Key informants emphasized the importance of promoting and supporting new models for primary health care delivery to improve chronic disease prevention and management. Integrated teams and community-based models that target specific groups with high rates of low health literacy were presented as promising models.