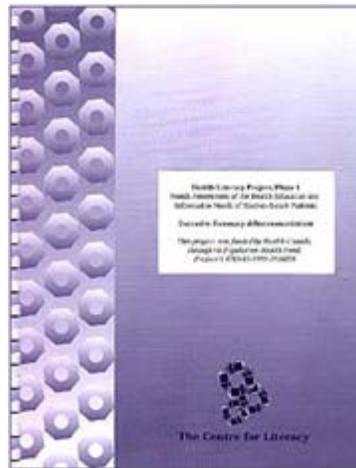


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# Health Literacy Project, Phase 1:

## Needs Assessment of the Health Education & Information Needs of Hard-to-Reach Patients

### Executive Summary & Recommendations



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## Acknowledgements

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This Needs Assessment was an initiative of The Centre for Literacy of Québec in collaboration with the Montreal General Hospital, McGill University Health Centre (MUHC). It was funded by Health Canada, through the Population Health Fund. The project was co-ordinated by the Steering Committee on Health Literacy of the Montreal General Hospital made up of six members from various departments of the Hospital, the director of The Centre for Literacy, and the project Officer from Health Canada. While the research and report writing were in progress, the principal researcher and her co-researcher were part of the Committee. In March 2001, an external evaluator commented on the project and the protocols developed for patient interviews. From May 2001 until the end of June, this evaluator attended Committee meetings and served as a resource person during the drafting of the final report. [See Appendix 1 for a list of committee members.]

Odette Langlais, an educational consultant, carried out the research under the guidance of the Steering Committee, with unmatched thoroughness and dedication. She forged strong relationships with all the patients she met, and showed great patience of her own during the entire revision process. She was assisted by co-researcher Claire Elliott, librarian at The Centre for Literacy in drafting the Background Document on Literacy and Health (please see Preface), and by consultant Charles Draper in conducting the interviews and focus groups. Ms. Langlais drafted both the Background Paper and the Needs Assessment with feedback from the Steering Committee, and later, from the external evaluator.

As requested by the Research and Ethics Committee of the Montreal General Hospital, a report by an external reviewer was prepared. Dr. William Ninacs, chairperson, Coopérative de consultation en développement La Clé, served as the evaluator. The Research and Ethics Committee approved the Needs Assessment Research Plan in March 2001. Dr. Ninacs accepted to serve as a resource person/external evaluator beginning in May 2001, after the data collection had been completed.

Dr. Linda Shohet edited both final documents, the Background Document on Literacy and Health and Report on the Needs Assessment.

Nursing staff on Dialysis, Oncology Hematology and the Pre-Operative Centre, the three hospital units that participated in this study gave unstintingly of their time and support, despite the perpetually stressful conditions in the medical system. The 114 informants who participated in interviews, focus groups and physician response also showed great generosity, the patients often in the face of extreme medical circumstances. The study could not have taken place without their cooperation and input. Health Canada also worked closely with the Steering Committee throughout the process. Their framework for continuous evaluation is a model of excellent funding practice.

The Steering Committee has approved the content and recommendations of the Report on the Needs Assessment. This report is dedicated to the patients, caregivers, support staff and health care workers who collaborated with us on this study, and to those whose needs we hope to meet through the recommendations we propose.

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## Executive Summary

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### Background

The Montreal General Hospital, McGill University Health Centre (MUHC)<sup>1</sup> is a large downtown teaching hospital located in Montreal. A large proportion of its patient population is multicultural. Many patients do not speak English or French as a first language, and many of them are low-literate. As a bilingual teaching hospital affiliated with a major medical school, it situates itself on the cutting edge of research and as a leader in the field of university medical teaching. The Montreal General Hospital is committed to providing the highest possible quality of healthcare.

These characteristics set the stage for the hospital's initial involvement in health literacy in 1995. It began when the Director of Nursing Staff Development attended a conference on health literacy and recognized that this issue affected many patients at the hospital. First steps included a series of professional development workshops on health literacy for health care professionals between 1997 and 1999, the product of a partnership between The Centre for Literacy of Québec and the Montreal General Hospital. Since then, the Department of Nursing Staff Development has sustained a continuing interest in health literacy. Hospital staff are aware that the changing nature of healthcare has led to a growing number of patients having to take care of themselves at home; many of these patients are potentially incapable of doing so because they have difficulties reading, understanding and applying health information received at the hospital.

In 2000, a Health Literacy Steering Committee was set up in collaboration with The Centre for Literacy to launch a major initiative on Health Literacy. They developed the concept for a proposed Patient Health Literacy Centre to address the communication needs of low-literate patients. A two-phase study was designed. Phase 1 included a literature review/background paper on literacy and health with descriptions of all related projects in Canada, and a needs assessment of the situation at the MGH. After the literature review was completed, the concept of "low-literate" was changed to "hard-to-reach" to reflect recognition that communication barriers could have diverse causes, of which low literacy was one. The Needs Assessment was to identify the precise nature of the local problem and to propose some solutions. The Committee foresaw that the results of the Assessment would guide the development of a pilot Health Literacy Centre<sup>2</sup> in a subsequent Phase.

This report presents the findings from the Needs Assessment. The research project is described in Section 1. Details of the Research Plan are in Appendix 2, and the concerns expressed by the external reviewer and the Research Ethics Committee can be found Appendix 4. Section 2 presents the results, and Section 3 gives the recommendations for the pilot Health Education Centres.

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<sup>1</sup> Since the first involvement of the Montreal General Hospital, the hospital has become integrated into the McGill University Health Centre (MUHC), an amalgamation of four large downtown teaching hospitals. They have been merged into one organization prior to relocating to a single site scheduled to open in 2005. The outcomes of the project are shared with the planning committee of this new facility.

<sup>2</sup> This is the term initially used by Committee members. As explained at the beginning of Section 3, the term evolved and was changed to "Health Education Centre."

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## Executive Summary

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### **Rationale**

The 1994 International Adult Literacy Survey (IALS) informs us that nearly half the population of adult Canadians has some degree of difficulty with everyday reading materials. This has serious consequences for the health of Canadian citizens since everyone needs to understand and use information on health and health care at some point in their lives. Low-literate patients face health information, materials and procedures that are difficult or impossible for them to understand and apply. But there are other groups of patients with whom it is also difficult for health care professionals to communicate effectively. These "hard-to-reach" patients include those who face language and cultural barriers, and those who have difficulties processing health information because of physical or cognitive disabilities. This study started by asking, "What can be done to improve health education and information for hard-to-reach patients at the Montreal General Hospital (MUHC)?"

### **Purpose of the study:**

- a. To determine the health information and health education needs of hard-to-reach patients at the Montreal General hospital (MUHC).
- b. To formulate recommendations for the creation of a Health Literacy Centre to improve the communication of health information and education for this group of patients.

### **Methodology:**

A qualitative methodology was chosen because of the nature of the research. Data was collected through 66 individual interviews and 7 focus groups with four groups of informants-hard-to-reach patients, members of their families, support staff and health care workers-from three units of the Montreal General Hospital (MUHC)-Dialysis, Oncology Hematology and the Pre-operative Centre (45 participants in total). The individual interviews included health care workers from two affiliated community health clinics (CLSCs). Physicians from the three hospital units were asked to comment on a synopsis of the results.

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## Executive Summary

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### **Some Key Findings**

#### *The health information needs of informants*

1. Patients identified their primary needs as medical information about the illness; information about daily living: diet, exercise, activity level; and teaching about tests and taking medication.
2. Family members/caregivers want to know about the patient's feelings, about coping with the illness, about impact on family life, and about health resources in the community.
3. Health care professionals believe these patients need disease-specific information, better-adapted teaching material, and an improved teaching process. They also believe that there is a core group who probably do not understand the health information currently given to them, and some who will be difficult to reach under any circumstances.

#### *Methods of communication currently used to inform and educate patients*

1. A majority of patients found that the written documents given in each unit are not directly useful to them, because they have a language barrier, or because they do not read and their caregiver does the reading for them. However, a significant number (40%) did find them useful.
2. A majority of patients were dissatisfied with the oral communication with medical staff.
3. Few patients receive health information from sources other than written documents and oral communication. The only other source cited by a significant number was videos.
4. Learning with computers was not a popular option among patient interviewees.

#### *The needs of health care professionals as educators of hard-to-reach patients*

1. Health care professionals need more time to assess the literacy and comprehension level of patients, and to teach hard-to-reach patients; written material available in languages other than English or French; and more posters and health videos to show and to lend.
2. Health care professionals need more money allocated for translation, plain language writing, training health care workers and buying videos and visual materials.

#### *What health care professionals know about health literacy*

1. Informants had a general idea of what low literacy means, but few could describe low-literate patients or clearly define health literacy.
2. Many health care professionals worry about patient comprehension and how to validate their teaching.

### *Ideas on the Health Education Centres*

1. Patients said an Education Centre should be attached to each unit in a clearly marked, easily accessible room, and should house all the pertinent information/services.
2. Health care professionals would like the Health Education Centres to offer training on aspects of health literacy.

### **Analysis**

The patients interviewed had been identified as hard-to-reach by nursing staff. However, they did agree to the interview or to participation in a focus group, which indicates that they were reachable when approached individually and accorded time and attention. Most of the health care workers felt that there is a core group of patients that is harder to reach than those with whom we met. Care-givers often play a major role as listeners and readers for these patients, and health care providers rely on that. Patients and providers differed in their assessment of patient needs. Patients expressed a need for information and good teaching, but also wanted respect and sensitivity to their concerns. While health care workers spoke about empowering patients, most of them tended to focus on giving information and validating teaching. All groups saw the possibility of health education centres filling some of these diverse needs. Like any cross-section of the population, hard-to-reach patients are hard-to-reach for different reasons; they may be low-literate, speak another language, be traumatized by lives in war-torn countries, have a physical or cognitive disability, or belong to a cultural community other than the two mainstream ones. These sub-groups have different ways of learning. One of the most provocative findings was that most of these patients do not, and do not want to, use computers. As many Canadian hospitals and health care centres are increasingly relying on computer-mediated information systems for patients, this finding is critical. The recommendations for the health education centres have followed from these and other findings and analysis in the report.

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## Recommendations

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1. *One pilot Health Education Centre should be set up in each participating unit.*
2. *A health care professional should be responsible for coordination on a part-time basis.*
3. *Volunteers, including former patients, should be available to staff the Centres and be involved in programming, under the supervision of the coordinator.*
4. *Patients and families who use the information services of the Centre, and participate in the programs and activities, should be involved in evaluating them.*
5. *An Education Committee, composed of a patient representative from the unit, a family representative from the unit, the health care professional in the position of co-ordinator, a representative from the Health Literacy Steering Committee, and possibly a volunteer and a support staff member, should oversee each pilot Centre.*
6. *Groups, composed of patients, families and health care professionals in each unit, should develop their own guiding principles and hypotheses, using the present report as a starting point. The Education Committees could facilitate these group processes.*
7. *The Health Literacy Steering Committee, as the driving force behind the entire project, should assume a co-ordinating and research management role for all three pilot Centres.*
8. *The Centres should develop multi-faceted approaches to patient information and activities, and offer different kinds of health information to meet the different needs of patients and caregivers.*
9. *Computers and computer-based education should not be a preferred option in the short-term.*
10. *Financial resources should be allocated in order to research, borrow, adapt, reproduce or produce, if necessary, written material and videos offering basic health information in Italian, Greek, Spanish, Cree, and possibly other languages to be identified.*
11. *A professional development training program for health care workers should be designed.*
12. *Participatory group activities should be planned with patients and caregivers.*
13. *The Centres should offer a friendly, welcoming atmosphere free of stress and anxiety.*
14. *The first visit to the Centres should become part of the intake and orientation process for new patients.*
15. *Special steps should be taken to accommodate hard-to-reach patients who may be hesitant to use such Centres.*
16. *A system should be developed so those patients who go to the Centres do not lose their "place in line" (if there is one) for their treatment or appointment.*