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FINAL

EVALUATION OF THE SECOND PHASE OF THE CENTRE FOR LITERACY OF QUÉBEC'S HEALTH LITERACY PROJECT AT THE MONTREAL GENERAL HOSPITAL OF THE McGILL UNIVERSITY HEALTH CENTRE (MUHC) (SEPTEMBER, 2001 – JUNE, 2002)

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INTRODUCTION

The purpose of this document is to report on the evaluation of specific components of Phase 2 of the Health Literacy Project co-ordinated and administered by The Centre for Literacy of Québec at the Montreal General Hospital (MGH) of the McGill University Health Centre (MUHC).

Phase 1 of the Health Literacy Project was a needs assessment related to health information and education for hard-to-reach patients and their families. It ended during the summer of the year 2001 and was immediately followed by another phase that focused on finding ways to meet these needs. For all intents and purposes, this second phase is still under way and this report covers its activities from September, 2001, to the end of June, 2002, inclusively. The project's momentum increased significantly late in November of last year with the arrival of a full-time co-ordinator for it following confirmation in October of funding from Health Canada and dropped off with her departure in July, 2002.

My services as the outside evaluator of Phase 2 were retained in September, 2001. It should be noted that I was quite familiar with the project, having previously been asked to review Phase 1 for the Research Ethics Committee of the MUHC in March, 2001, and subsequently to attend meetings of the Needs Assessment Steering Committee as an advisor. In my current role as evaluator for Phase 2, I have also provided counsel to the project's Steering Committee and staff as well as to The Centre for Literacy's director and staff on issues related to this project. In particular, I assisted both the project's co-ordinator and The Centre for Literacy's director in framing the project's objectives and tasks.

METHODOLOGICAL CONSIDERATIONS

This evaluation focuses on an uncompleted project that is still in an initial development stage. Indeed, the dominant activity of Phase 2 has been the combined establishment of Health Education Committees in three units of the MGH and production of new materials by each one under the watchful eye of the project's Steering Committee. The Health Education Committees are still, nevertheless, in an implementation mode and the Steering Committee is still being shaped. The organisational processes at work in these committees hence became the primary evaluation targets, although some more tangible outcomes

were also investigated. However, these latter results were not related to one of the project's original objectives that foresaw the evaluation of "the effectiveness of the strategies used to improve patient education" (as indicated in the first draft of the job description posted for recruitment purposes of the project's co-ordinator). On this matter, the evaluation plan that I proposed and that The Centre for Literacy later approved noted the following:

> Although anecdotal evidence of the effects of the committees' work may be available (such as feedback from patients, family members and nurses about the materials created and adapted for the project), it is premature to attempt to formally evaluate these effects until the committees have had more experience. On the other hand, an evaluation of the direction that the committees are taking is essential to ensure that it corresponds to the project's objectives. This evaluation is thus primarily but not exclusively focussed on the processes underlying the choosing and the taking of these directions. The perceived quality of certain products and activities, as it pertains to the communication needs of patients and families, will also be noted in order to inform the next phase of the project.

Given these factors, a qualitative methodology seemed more appropriate for this evaluation. Methods included in-depth interviews with key informants, an examination of relevant documents and some participant-observation of the Steering Committee (see Appendix I).

Communications between the project's co-ordinator and me were frequent during the last two months of her tenure. Her help in scheduling interviews and in obtaining materials for examination was invaluable. She also provided me with a copy of her activity report in July (after having received permission from The Centre for Literacy). I am very grateful for her exceptional collaboration.

EVALUATION

The presentation of the findings on the next pages follows the order of the project's objectives in the workplan. Unless otherwise specified, the evaluation criteria and methods used herein were those identified in the evaluation plan approved by The Centre for Literacy and presented to the Steering Committee[1]. Results are provided for each task in the workplan and are identified by a diamond (◊). These are followed by a discussion of specific issues raised for

[1] This document is available upon request from the author.

each sub-objective. Recommendations contained therein are summarised at the end of this report.

All recommendations are based on the assumption that the Health Literacy Project will continue in some fashion, even if funding is not found to hire staff again.

OBJECTIVE 1: OFFER APPROPRIATE AND EFFECTIVE HEALTH INFORMATION AND EDUCATION TO HARD-TO-REACH PATIENTS AND THEIR FAMILIES

SUB-OBJECTIVE 1.1

Set up Health Education Committees in each unit. The committees will act in an advisory role during this stage of the project and will consist of health care professionals, patients, family members and/or volunteers.

1.1 Results for each task

1.1.1 Recruit members based on their sensitivity to the communication needs of patients and families.

◊ Each committee has at least three members (two have five), one being the project's co-ordinator (who is not a health care professional), another being a health care professional (a nurse who also sits on the Steering Committee) and the third, a patient or a patient's caregiver. There is little diversity of members based on professional status, however, since many of the patients and volunteers of the committees are, in fact, health care professionals who are no longer active because of illness or retirement.

◊ Every person interviewed displayed a strong sensitivity to the communication needs of patients in their respective units but it is difficult to determine if this sensitivity was a reason for their recruitment or if it had developed during their participation in their committee. Indeed, one non health care professional committee member said that, as time went on, she became more and more aware of the importance of reading messages, signs and posters that abound in the MGH and in other hospitals, and more critical of the small typeface or the complex language used in published documents and posters.

1.1.2 Hold meetings of the Education Committees. Record their activities and decisions.

- ◊ Meetings were held for each committee, but the frequency varied according to the tasks to be performed. While all members attended meetings at least once, the committees with the largest number of members were rarely able to hold a meeting where everyone was present. The absentee members were generally current or former patients and the main reasons motivating their missing meetings were related to their health and their jobs.

- ◊ Meetings were chaired by the project's co-ordinator. She generally developed the agenda, often in collaboration with the health care professional committee member.

- ◊ Generally, although reports of the meetings of the Health Education Committees were drafted, these were not formal minutes. Moreover, no formal reports of the discussions during the meetings of the Health Education Committees were conveyed to the Steering Committee. However, the project's co-ordinator regularly informed the Steering Committee during its meetings of progress made on the production of documents, with the health care professional committee members adding information as required.

- ◊ Decision-making processes appear to have been very inclusive, with non health care professional committee members actively participating at each stage. Every person interviewed stated that he or she participated freely in all decisions taken when he or she was present and that the tools produced by each committee prove that the advice that they had given was taken into consideration. None felt that their participation was token.

- ◊ Among the non health care professional committee members, the role of their committee is not clear for those who do not have a professional background (in the medical field or elsewhere) even though a document listing the committee's objectives seems to have been distributed at the first meeting. For all, the primary focus of their Health Education Committee is task-oriented, linked to either specific medical concerns in each unit (hygiene, pain management) or to particular patient needs (such as what to expect when spending a day for treatments in a specific unit).

- ◊ None of the persons interviewed knew if their Health Education Committee would be meeting in the future and, among the non health care

professional committee members, none knew if they were to be invited to participate again but each hoped that he or she would.

1.1 Issues

a) Recruitment:

Ideally, committee members should be recruited based on their sensitivity to the communication needs of patients and families, even though it would seem that it s possible to develop this sensitivity with time. Appropriate training and support should be foreseen when sensitivity to the communication needs of patients and families is not a selection criterion.

Another more seemingly problematic issue relating to committee members is the irregular attendance of meetings and the resulting lack of continuity. This is especially true for the non health care professional committee members. Because of the unstable nature of certain medical conditions and of working hours, it is not clear that regular attendance of meetings by patients can be expected. This situation might call for an increased number of non health care professional committee members to ensure continuity.

Moreover, it seems doubtful that meetings will ever be scheduled outside of the working hours of health care professional committee members since the activities of the Health Literacy Project are not a recognised part of their job — outside of Steering Committee meetings for some of them. Meetings of the Health Education Committees must therefore be integrated into their breaks or other free time. Availability for meetings often held on lunch hours thus becomes an important selection criterion. If this is a problem, defraying the cost of meals might warrant investigation in order to encourage attendance.

The committee members who are inactive health care professionals bring with them both a health care professional and a patient or a volunteer perspective, depending on the case. This is clearly a strength, but such members are not really typical of patients or volunteers unfamiliar with medical systems and processes. Their input cannot truly, therefore, be considered representative of patients and their families. Notably, the two "true" non health care professional committee members interviewed believed that they were recruited to represent patients and their families. Moreover, the health care professionals involved are extremely articulate when it comes to health concerns, and so it takes very

articulate individuals to put forward other points of view. An effort should thus be made to recruit at least one member per Health Education Committee who is a patient without a background in a health care profession. These individuals should also receive particular support from the Project's leaders to assist them in voicing their opinions during meetings.

Since the Health Literacy Project is grounded in the Montreal General Hospital, it comes as no surprise that health care professionals, active and inactive, dominate as members of the Health Education Committees. This situation has an adverse side effect in that the literacy perspective is sometimes lacking in discussions and decisions even though the health care professionals are becoming increasingly sensitive to this issue. Some thought might be given to recruiting "external" members whose principal concern would be literacy, especially for hard-to-reach patients and their families, for each Health Education Committee.

The large presence of health care professionals also ensures that most discussions retain a very pragmatic focus since these individuals are under a lot of pressure to provide concrete, usually curative services. It comes as no surprise to learn that they want to see the results of their actions — including their participation in the Health Education Committees as well as in the Steering Committee — measured against the health status of their patients. This can be a drawback during an organisational process such as the one that the Health Literacy Project is going through where time must often be spent on seemingly unproductive activities such as explaining goals or concepts to less familiar members. When such activities are reduced in scope or otherwise circumvented, confusion can arise and longer term efficiency reduced.

Gender imbalance is prevalent in all of the committees, with women dominating overall. This will likely continue but an effort could be made to try to recruit at least one man per committee, in order to have a male point of view on health literacy issues.

b) Autonomy and Procedural Issues

The complete dependency of the Health Education Committees on the project's co-ordinator is an indication that these structures lack organisational autonomy and will probably disappear if funding for a new co-ordinator is not found. Moreover, what appears to be a lack of formal meeting procedures when linked to few, if any, reporting requirements to and from the Steering Committee, may

convey the idea that the committees are merely ad hoc working groups or worse, that their work will not be taken seriously. Indeed, the focus on tasks has led some participants to believe that the mission of their Health Education Committee is limited to producing information documents. Roles and responsibilities of the Health Education Committees need to be clearly defined and communicated to their members, and more formal procedures need to be established and supported to ensure rigour in the participatory processes. The procedures should be simple, however, and not constraining given the limited amount of time that most of the committee members can devote to meetings.

SUB-OBJECTIVE 1.2

Design a teaching module in each unit on one health topic that meets the different communication needs of hard-to-reach patients using input from the Education Committees. Due to time and funding limits, only parts of the teaching module will actually be implemented during this phase of the project.

1.2 Results for each task

1.2.1 Review existing documents, programs and other teaching resources in each unit, taking note of materials that are useful for hard-to-reach patients.

- ◊ Two reviews of existing information and training tools were carried out, a first by the project's co-ordinator upon her arrival and then another one by the health care professionals in each unit, sometimes in collaboration with the other members of the Health Education Committees.

- ◊ In one unit, according to the person interviewed, this was easily accomplished given the dearth of teaching resources available for distribution to patients. In this unit, there was only a flyer available, one that had just recently been produced. Upon analysis, it was deemed inappropriate for hard-to-reach patients and redone (plainer language, easier to read, illustrations added) as part of the work by the unit's Health Education Committee. In the other units, the situation was quite different in the sense that materials were there but none were retained since none were considered appropriate for hard-to-reach patients. As one health care professional put it: "We actually went through the existing documents.

We looked at some of them, I don't know how many we did [...] but we are realising that it's maybe not tailored to the hard-to-reach."

1.2.2 a) In each unit, adapt one or two print documents to Plain Language in English and French. Education Committees to provide content and editorial input.

◊ The criteria used to choose the material to be adapted or developed was generally decided upon by the Health Education Committees. These criteria included having an impact on the greatest number of patients, something that was common to all patients in the unit, something that was a fundamental prevention issue. In one case, the Health Education Committee consulted the Needs Assessment from Phase 1.

◊ The work of the Health Education Committees went beyond simply providing content and editorial input. Decisions were taken and it was the results of these decisions that were reported to the Steering Committee

◊ Patients were surveyed by the project's co-ordinator for their reaction to draft documents as the process of production progressed and these results were communicated to the Health Education Committees (or to some of their members if convening a meeting was impossible). Action was generally taken as a result. In other cases, patients were observed. For example, "[…] so we only got [the posters] up on one side of the clinic. […] We are going to put them on both sides, because a lot of people were sitting underneath them and they didn't turn around and they didn't notice them."

◊ One unit decided upon a multimedia approach and began producing audiotapes for patients for whom reading is a problem.

1.2.2 b) In each unit, translate one print document that has been adapted to Plain Language into one of the following languages: Italian, Greek, Cantonese, and Cree.

◊ This work is still in process. A flyer and a poster are being translated into Spanish in the Dialysis Clinic, a flyer and an audiotape are being produced in Spanish and basic Chinese in the Pre-Operative Centre, and texts in these same languages are being developed to accompany the eleven-poster storyboard in the Haematology/Medical Oncology Clinic.

◊ At least one non health care professional committee member is opposed to this, indicating that documents in both official languages should be adequate.

1.2.2 c) Identify and, if possible within the timeframe of the project, purchase one non-print document.

◊ Some materials were purchased prior to the arrival of the project's co-ordinator. Work on this objective was informally suspended afterwards for a number of reasons. These included a growing ambiguity concerning the notion of "hard-to-reach" and the related difficulties in establishing selection criteria as well as what was perceived, by the project's co-ordinator, as a tedious approval process for items of relatively small value accompanied by what was considered a totally unrealistic budget.

1.2.3 Identify programs and interactive activities suitable for hard-to-reach patients to be implemented in the next phase of the project.

◊ Work on this objective was also informally suspended primarily because of the ambiguity concerning the notion of "hard-to-reach".

◊ The project's co-ordinator did, however, identify places to look for appropriate programs, especially when she had access to a medical library. As she pointed out, "there is a lot out there in the medical journals, a lot of lesson plans and examples such as bingo to teach dialysis patients how to measure phosphate in their dialysis". The project's co-ordinator also suggested that a place to start might be to look at the existing infrastructures in the different units and to target better utilisation of underused assets. For example, there is a partial closed circuit television system in the Dialysis Clinic: "They have the television sets but no system to play the documents."

1.2.4 If possible within the timeframe of the project, identify and purchase the equipment needed to deliver the teaching modules in each unit.

◊ The materials produced during this phase of the project required computer equipment and tape recorders which were duly purchased.

1.2 Issues

a) Conceptual Ambiguities

The Needs Assessment produced during Phase 1 of this project identified different communication needs of hard-to-reach patients but did not develop a specific conceptual framework for the term "hard-to-reach". Instead, hard-to-reach patients were identified by indicators such as: "lack of fluency in either English or French; obvious cultural barriers; socio-economic background; general difficulties in reading and understanding information (e.g. patients who repeat the same questions, or return repeatedly with the same issues, or those who might have a blank look during information sessions); obvious learning difficulties due to cognitive or physical disabilities; education level, if such information was available". Moreover, the expressions "low literate" and "low literacy" were often used as synonyms for "hard-to-reach". This conceptual ambiguity was thus carried forward from the preceding phase. As such, this was not problematic until it became necessary to determine appropriate selection and production criteria for programs and materials in Phase 2. As this phase progressed, it became increasingly clear that the actual notion of what constitutes being "hard-to-reach" could not remain nebulous if teaching modules were to be developed. Although this ambiguity remains today, clarifying the concept of "hard-to-reach" is one of the research objectives for the following phase according to funding proposals submitted to ensure continuity of the Health Literacy Project. Indeed, if setting up teaching modules is retained as an objective in the next phase of this project, the knowledge gathered in the first phase as well as in this one should be collated to produce the foundation for a conceptual framework. Parts of the new teaching modules could then be built around this framework while research could be undertaken — if funding is obtained, of course — to complete whatever is missing.

This conceptual ambiguity did not, however, prevent the production of a print document or more in each unit, adapted to Plain Language in English and French and translated into other languages. This is because the Needs Assessment clearly identified medical jargon and scientific vocabularies as major obstacles to understanding information by patients and lack of proficiency in one or the other of the two official languages as an impediment to communications. Therefore, adapting documents to Plain Language and subsequently translating them with a degree of cultural sensitivity simply made sense in light of the results obtained in the previous phase and did not have to wait for a complete conceptual

framework. Similar work could be performed in the next phase of this project since the needs related to these problems are great. However, only segments (albeit probably significant ones) of hard-to-reach patients will benefit from such tasks.

b) Need for Exploratory Research for Materials and Tools

According to the project's co-ordinator, there exists an abundance of materials in medical journals and on the Internet that could be extremely useful in meeting some of the needs of the Health Literacy Project. However, they are not readily accessible. As she noted, ''don't look for words like 'low literacy'. It's also not across the board; it's very disease specific. […] You know, you have to really dig, really dig, but it's there in a big, big way. In a way, the project, if it continues and it works on this concept of hard-to-reach, it won't be inventing anything new, it will be just pulling together pieces that exist. […] You know, there is lot, I was surprised.'' She also mentioned that this information is available in professional journals and specialised media. For example, ''there is a lot of nutritional information. And that actually might be why some of the nurses didn't see it, because it's the nutritionist that is getting that information.'' Indeed, as she also mentioned, the Health Literacy Project is ''dealing with two things, patient education and consumer health information'', and a great number of documents and tools have been produced elsewhere, especially around the latter theme. It would thus seem warranted to follow her suggestion to do more research before committing resources to the production of completely new materials.

Similarly, instead of purchasing new materials, thought should be given to translating some of the deemed excellent existing print and audio-visual materials that are distributed at no cost, by certain foundations, associations and corporations, but often only in English.

SUB-OBJECTIVE 1.3

1.3 Establish a Health Education Centre in each unit.

1.3 Results for each task

1.3.1 Identify the locales for the Health Education Centre in each unit.

◊ Physical spaces where a Health Education Centre could be set up in each unit were examined and some outreach was done with potential partners (such as the Interior Design Department at Dawson College) but work to attain this objective was, for all intents and purposes, suspended during the course of this phase of the project (even though no clear decision was taken not to proceed). On one hand, it was found that health education often occurs when a health care professional is in contact with a patient — in an office that they have access to, in a waiting room, at bedside, in a hallway. On the other hand, unexpected health issues cropped up, such as the possible spread of infection when materials are shared. Thus, the "locale" aspect of the Health Education Centres became much more complex than had originally been anticipated.

1.3.2 Gather task-related information to create a resource that will facilitate future development of the project. Identify potential partners internal and external to the hospital. Identify sources for materials and ideas for programs.

◊ The gathering of task-related information overlapped with the review of existing materials and tools. Evaluation resources were found and used (Fry readability test, Area Health Education Center checklist for assessing the suitability of materials, Hamilton Health Sciences guide to creating patient education materials).

◊ The need for on-going clinical approval of materials being developed became increasingly clear as the project progressed. Including health care professionals in all the activities of the project was a fundamental aspect of the workplan and their collaboration seems to have in fact been readily obtained when time allowed. However, the project's co-ordinator noted that the sporadic nature of this collaboration — generally because of other more pressing demands on the time of the health care professionals involved — made it difficult to plan the production of documents with any degree of precision.

◊ The health care professionals' structures within the MGH — for example, the Department of Nursing Staff Development and the Professional and Quality Improvement Council (PQIC) — were identified as crucial partners of the project. Indeed, maintaining liaison with the PQIC was included in

the job description posted for recruitment purposes of the project's co-ordinator.

◊ As the project evolved and became more widely known throughout the MGH, staff from other services and units were invited to join the Steering Committee or to otherwise keep in touch with the project. These included Clinical Nutrition, Infection Control and the Multicultural program. Other units within the MGH were also identified as warranting closer ties with the Health Literacy Project. For example, ties are deemed essential with the MUHC Communications Department because of its plan to set up a template for patient education materials and to work out a formula for printing that may overlap with some of the Health Literacy Project's work.

◊ Potential external partners, such as the CLSC Côte-des-Neiges, were occasionally identified during Steering Committee meetings. Many others have been noted by the project's co-ordinator in her activity report, notably services in other McGill University Health Centre hospitals such as the Cedars Cancer Centre and its CanSupport program, at the Royal Victoria Hospital.

◊ See Task 1.2.3 for a discussion on sources for materials and ideas for programs.

1.3.3 Promote the Health Education Centres by means of presentations and information bulletins within the hospital.

◊ The focus of this objective changed over the course of the project, switching from the idea of Health Education Centres to Health Literacy.

◊ During this phase, with the exception of activities surrounding Health Literacy Day and International Nursing Week, all promotional activities and materials were related to tasks identified in the workplan.

◊ A Health Literacy web page was also inserted onto the Nursing home page of the MUHC Intranet.

1.3 Issues

a) Confusion about the word "Centre"

The suspension of specific activities related to the establishment of a Health Education Centre in each unit that would occupy a specific place was never the result of a formal decision by the Steering Committee or by The Centre for Literacy. It occurred, instead, gradually as it became increasingly obvious to the Health Literacy Project's leadership that a physical location was less important than the provision of health literacy services through materials for patients and their families and training programs for health care providers. As the project's co-ordinator put it, "Phase 2 came along and analysed where people learn" and the Health Education Centres thus became vehicles for providing services as opposed to actual places that people could see and visit. There nevertheless persists a degree of confusion regarding this objective since some of the persons interviewed feel that the Health Literacy Project has been unsuccessful because specific places were not identified (even though some were investigated) and because "physical" Health Education Centres were thus not set up. This objective needs to be reviewed in light of the information gathered thus far, since it is not clear that it is still relevant.

b) Using Volunteers

As one person interviewed noted, "I think probably the updating of most of the procedure would have to follow the rule of nursing. I don't know that having volunteers there definitely would help." In other words, it must be remembered that the information being produced, adapted or translated during this project, is generally of a medical nature. The use of volunteers to ensure this production has to be harmonised with the imperative of clinical approval over content in the materials. This would seem to indicate that the input by patients and other volunteers, unless they are active health care professionals, should be limited to non-medical information. If and when medical issues are involved in the execution of tasks by volunteers who are not active health care professionals, their work should be reviewed by a health care professional member of the Health Education Committee. Indeed, referring to the imperative of clinical approval of materials being developed in the project as well as to the difficulty in working with health care professionals who are already very busy simply doing their jobs at the MGH, the project's co-ordinator suggested that a line item for this

should be included in future budgets for professional clinical approval. This suggestion seems quite appropriate.

c) Partnering with the MGH/MUHC

Partnering with an organisation as complex as the MGH is not as simple as it sounds. On one hand, in the words of the project's co-ordinator, finding people of like interest is "the key to the next stage" which is "not going to be locations, it's going to be about services". But there are "layers and layers and layers" of management and hierarchies to understand and eventually penetrate. She suggested that The Centre for Literacy try to find a mentor, on either a voluntary or a remunerated basis, to act as a key informant about what is going on in the hospital, how decisions are taken, what the proper channels of communications are, and to be someone that the next project co-ordinator could turn to for such information. And on the other hand, the hospital's organisational structure is in a constant state of flux, as is the case in most complex organisations. For example, some possible mentors simply vanished when their jobs were cut. This means that the Health Literacy Project must be ready to adapt its communications and organisational tactics by building in a certain amount of flexibility into its strategic planning without sacrificing its strategic objectives.

d) Organisational Ownership and Autonomy

Developing partnerships requires a clear definition of the roles and the responsibilities of each potential partner. As regards the Health Literacy Project, a certain organisational ambiguity reigns at many levels that, if allowed to persist, will probably hamper the project's potential for continuity and growth. In particular, the question of ownership is of concern. Who "owns" the Health Literacy Project, The Centre for Literacy or the Montreal General Hospital (MGH)? This is not an abstract issue, but rather one of leadership — or rather, perceived lack of it — and of organisational independence. Generally speaking, the health care professionals interviewed felt the need for more forceful leadership of the project by The Centre for Literacy. Indeed, The Centre for Literacy could more emphatically maintain its present exclusive hold on the project but it also has the option of finding some way to more formally integrate the MGH, perhaps as a joint venture. However, in order to ensure that the literacy component of the project does not become subservient to the health component — which will be omnipresent given the context and the goals of the

project and the number of health care professionals involved —, it must preserve its position of power.

The leadership question is also critical from a practical standpoint. "[In] my position as [the project's] co-ordinator, it was fairly impossible to straddle two organisations and you know, really my direction had to come from [The Centre for Literacy]. The nurses had their own agendas and their own understanding of the project." Indeed, the project's co-ordinator has to be able to communicate the right things to the right people. If this person is stationed in a MGH office, he or she could be perceived as being part of the hospital's staff and therefore under the MGH's orders. If this person is going to be negotiating partnerships both within the MDH and outside of it, there must be no doubt as to which organisation he or she is representing.

This brings up the related question of the Health Literacy Project's autonomy. Should it remain a project of The Centre for Literacy or should it become an autonomous organisation? If it becomes autonomous, who will be its members? What is at stake here are questions of credibility and power. Does the Health Literacy Project have concerns and objectives that go beyond those of The Centre for Literacy? If so, to what degree do these concerns and objectives dovetail with those of other organisations or institutions, in particular with those of the MGH? Where these concerns and objectives do, in fact, dovetail with those of other organisations, to what degree is the Health Literacy Project prepared to share decision-making power with them over its own activities? In other words, is the Health Literacy Project looking for external partners or potential members? All of these questions need to be clarified as soon as possible.

SUB-OBJECTIVE 1.4

1.4 Ensure continuity of the project.

1.4 Results for each task

1.4.1 Hold and facilitate meetings of the Steering Committee. Record their activities and decisions.

◊ The Steering Committee has a core of six members: the director of The Centre for Literacy (who is not a health care professional), three active

health care professional (a nurse from each of the three units involved) and two persons representing patients (one of whom is a nurse who is no longer active because of illness). Throughout Phase 2 of the project, a number of other persons were invited to participate, generally staff of other MGH departments. Their attendance was usually sporadic and dropped off as the project evolved. On the other hand, "core" members did not miss many meetings that were usually held monthly. All participants have been women.

◊ Meetings were chaired by the director of The Centre for Literacy. She generally developed the agenda on site at the beginning of the meeting.

◊ Reports of each meeting were drafted and e-mailed to members. These were not formal minutes, however.

◊ Decision-making processes were generally informal and sought consensus. They were inclusive in that every person present could freely participate in all decisions taken. Not everyone expressed themselves during meetings, however, and consensus was more often passive (absence of opposition) than active (expressed agreement by everyone). Generally, many of the documents supporting decisions (such as draft budgets) were sent to members before the meetings.

1.4.2 Identify sources for funding and submit proposals.

◊ A number of meetings were held during the course of this phase of the project with the MGH Foundation. The MGH Foundation granted the Health Literacy Project $10,000 for the year 2002-2003.

◊ The Centre for Literacy of Québec has committed $10,000 of its own funds to match the MGH Foundation grant but for specific purposes such as training for nurses and the cost of a "one day a month" editor for the Nursing Department to review the language, organisation and layout of new written documents. "This activity is not focused on the hard-to-reach, but should benefit a large segment of the overall patient population."

◊ A Web search of sources of funding was performed and proposals were submitted by the Centre for Literacy of Québec to various potential funding sources: Max Bell Foundation, Pfizer Canada Inc., Webster Foundation.

1.4 Issues

a) Recruitment:

In general, the same issues related to recruitment noted for sub-objective 1.1 are relevant here: sensitivity to the communication needs of patients and families as a selection criteria when possible, and combined with appropriate training when it is not; the need for specific support from the Project's leaders for the Steering Committee members without a background in a health care profession to assist them in voicing their opinions; the need for members whose principal concern would be literacy; the need for less gender imbalance. However, regular attendance of meetings does not seem to be a problem and there is no apparent call for an increased number of committee members.

b) Procedural Issues

Steering Committee procedures need more rigour. While there are minutes of meetings, these reflect the informality of the discussions and of the decision-making processes. They are not formally approved and signed. The meetings' agendas are generally not developed and sent out to members beforehand although some items are known in advance when members receive supporting documents. More formal procedures would send out a message that The Centre for Literacy is very serious about this project and would provide all Steering Committee members with documented evidence of discussions and decisions. At the same time, they might also encourage greater participation by the non health care professionals of the Steering Committee, since their right to be heard would have to be taken into consideration by the person chairing the meetings. However, as noted for the Health Education Committees, procedures should be kept simple given the limited amount of time that most of the members can devote to meetings.

b) Operational Autonomy

How much autonomy does the Steering Committee actually have? What is the relationship between the Steering Committee and the Health Education Committees? For the latter to properly act in either an advisory role or a more active one, lines of authority and responsibility have to be fixed along with corresponding channels of communication. As things stand now, the limits in terms of authority and responsibility are not clear for most participants, nor is it

clear that any of the committees, including the Steering Committee, have anything to say in budget allocations or similar management decisions. The Centre for Literacy should, as soon as possible, establish guidelines regarding the levels of authority and responsibility for both the Steering Committee and the Health Education Committees. Indeed, if committee members are to become true stakeholders of the Health Literacy Project, they must believe that they have something to contribute — even if it is only an opinion — while participating in decisions that have an effect on the project.

OBJECTIVE 2: INCREASE THE AWARENESS AND SKILLS LEVEL OF HEALTH CARE PROFESSIONALS WITH REGARD TO ISSUES SURROUNDING HEALTH LITERACY AND, MORE SPECIFICALLY, THE HEALTH INFORMATION AND EDUCATIONAL NEEDS OF HARD-TO-REACH PATIENTS.

SUB-OBJECTIVE 2.1

2.1 Offer training to the health care professionals participating in the Health Literacy Project to provide them with certain skills, knowledge and tools needed to be actively involved with either the project's Steering Committee or the Health Education Centres or both.

2.1 Results for each task

2.1.1 Awareness training: visit to the Hospital for Sick Children and the Princess Margaret Hospital Health Education Centres, Toronto, Ontario.

◊ The main result of this training for the five health care professionals who went to Toronto (accompanied by The Centre for Literacy's director) is that there is now a basis for comparison. It was "an eye-opener". "I was totally unaware that there is so much available. I was greatly impressed, especially with the computer program to teach people about their illnesses, with the videos that are available, with the written material that's available, and the thing most surprisingly, for the volunteers that were available. For people who are complete illiterate or who just need extra explanations." However, the individuals interviewed who participated in these visits believe that emulating the centres visited is unrealistic because of the lack of resources, financial ones, especially, at the MGH.

2.1.2 Skills development: training in Plain Language Writing, Albequerque, New Mexico.

◊ The main result of this training for the two health care professionals who went (accompanied by The Centre for Literacy's director) seems to have been a greater sensitivity to the communication needs of hard-to-reach

patients and their families. "I realise now, by watching some patients and by being exposed to the idea and low literacy or hard-to-reach patients, you know, we overwhelm them so, we give out information but we are realising that it's maybe not tailored to the hard-to-reach."

2.1.3: Knowledge gathering: visit with Harvard School of Public Health's Health Literacy Research Team to increase awareness of the research underpinning health literacy work.

◊ The director of The Centre for Literacy was the sole participant. The main result seems to have been an increased awareness of the research on health literacy that the project can draw on in the future.

2.1 Issues

a) Training

The awareness training visits and skills development workshops seem to have produced excellent results. As noted by the project's co-ordinator, ''[nurses] have expressed a keen interest in Plain Language and Clear Communication training''. But even more significantly, each health care professional who participated (with one exception) is actively engaged in both the Steering Committee and the Health Education Committee of her unit. Furthermore, each one demonstrates a remarkable sensitivity to the communication needs of patients and their families in general and to those of hard-to-reach patients in particular. According to one health care professional interviewed, this training even sparked a paradigm shift of sorts among some of the personnel in her unit, going from a paternalistic attitude when communicating with patients to a more empowering one. The appropriateness of the training offered is such that it should be offered to anyone playing a leadership role on either the Steering Committee or the Health Education Committees as well as to any future management staff.

SUB-OBJECTIVE 2.2

2.2 Offer training to the health care professionals working throughout the Montreal General Hospital and who are not currently involved in the Health Literacy Project, in order to broaden their awareness of the issues surrounding health literacy and the communication needs of hard-to-reach patients.

2.2 Results for each task

2.2.1 Three 45-minute presentations to the nurses who were interviewed or who participated in focus groups during Phase 1, summarizing the results of the Needs Assessment.

- ◊ Odette Langlais, the researcher responsible for the Needs Assessment, presented the findings from Phase 1 in December, 2001, to staff of two of the three targeted units: two 30-minute sessions in the Dialysis Clinic, and one 30-minute session in the Haematology/Medical Oncology Clinic.
- ◊ Attendance: 17.

2.2.2 One-day Clear Communication Skills workshop (collaboration with the Practice and Quality Improvement Council).

- ◊ This activity was held in March. It was deemed appropriate but the main criticism was that it lacked depth: "But regrettably, it didn't really give us enough time to go into the detail on how to prepare material that would reach the difficult-to-reach people, hard to reach people. We just sort of got started and I would have like to have continued, that would have been a great value to myself." Said another participant: "Absolutely appropriate, yes, because it involves all of us."
- ◊ Attendance: 27 (including two non health care professional members of two Health Education Committees).

2.2.3 Awareness training in Clear Communication: three 45-minute presentations for nurses in each unit who will not have attended the one-day workshop.

- ◊ Michelle Black, the trainer who gave the One-day Clear Communication Skills workshop (see Task 2.2.2), gave these presentations to staff who did not make it to the workshop of two of the three targeted units: two sessions in the Dialysis Clinic, and one in the Haematology/Medical Oncology Clinic.

- ◊ Attendance: 9.

- ◊ Indirect feedback was positive.

2.2.4 Presentation to the Practice and Quality Improvement Council (PQIC).

- ◊ The project's co-ordinator made three presentations: one in January to the PQIC Patient Education Work Group (attendance: 8), one in April to the PQIC general assembly (attendance: 15) and one in May with the PQIC Patient Education Work Group (attendance: 40-50).

- ◊ The results of the presentation are not known but the fact that the project's co-ordinator made more than one presentation is an indication of some degree of interest by PQIC in the Health Literacy Project.

2.2.5 Disseminate information bulletins within the Montreal General Hospital.

- ◊ This task was replaced by the development of a Health Literacy page on the Nursing Web Site on the MUHC Intranet. A text on health literacy has been produced and has been posted.

2.2 Issues

a) Training

Short, strategically focussed presentations seem to have had a twofold effect. First, they allow for greater interaction between the health care professionals who actively participate in the Health Literacy Project and other staff and volunteers working throughout the MGH, since they now have a common understanding of some of the rudiments of health literacy. Second, they seem to have been an excellent promotional tool for the Health Literacy Project. Offering such training should continue.

b) Dissemination

A true dissemination strategy is lacking. While the idea of piggy-backing onto PQIC activities is excellent and while using the Intranet makes sense, there does not seem to be an overall plan to use the information gathered in both phases of the Health Literacy Project to position it as an essential partner of the MGH where healthcare is concerned. The objectives pursued by disseminating information need to be more clearly defined. This would allow to better target the specific groups of people to be reached by the dissemination.

OBJECTIVE 3: TO GATHER AND DISSEMINATE INFORMATION AND FINDINGS CONCERNING HEALTH LITERACY IN GENERAL.

SUB-OBJECTIVE 3.1

3.1 Ensure liaison with key partners within the hospital system and outside of the hospital system in order to build a pool of resources and data as well as to communicate the purpose, activities and results of the pilot project.

3.1 Results for each task

3.1.1 Create a list of resources and partnerships pertinent to the Health Literacy Project.

◊ This task has been discussed with Task 1.3.2.

◊ No actual list of resources and partnerships was created as such.

3.1.2 Disseminate the findings of the Health Literacy Project to key partners.

◊ An article written by the director of The Centre for Literacy on health literacy was posted on the Web site of the ALNARC (Adult Literacy and Numeracy Australian Research Consortium)[2].

◊ Another article, also written by the director of The Centre for Literacy on health literacy and hard-to-reach patients, was published in an issue of *Literacy Across the Curriculum* (Vol.16, N° 1, pp. 15-16), a newsletter published four times a year by The Centre for Literacy.

[2] See: http://www.staff.vu.edu.au/alnarc/onlineforum/AL_pap_shohet.htm#Abstract.

3.1 Issues

a) Partnering

See item 1.3 Issues for a discussion on the theme of partnership building, both internally (MGH) and externally.

b) Dissemination

See item 2.2 Issues for a discussion on the theme of disseminating information.

SUMMARY OF RECOMMENDATIONS

BASIC CONCEPTS

- Attempt to clarify the notions of "hard-to-reach" and "health literacy" as soon as possible, using the knowledge gathered in the first two phases of the project to produce the foundation for a conceptual framework and undertaking research (if funding is obtained) to complete whatever is missing.

- Clearly define the meaning of a health education centre and establish whether or not those being set up by the Health Literacy Project will occupy a specific space in each unit.

ORGANISATION

- The standing of the Health Literacy Project should be clarified as soon as possible: legal status, and, if autonomous of The Centre for Literacy, mission, membership and governance mechanisms to be determined in such a way as to ensure the predominance of its literacy objectives.

- Find a mentor, on either a voluntary or a remunerated basis, within the Montreal General Hospital's management to act as a key informant about what is going on in the hospital

- Integrate into the project's strategic planning a certain amount of flexibility in order to accommodate the hospital's ever-changing organisational structure.

STEERING COMMITTEE

- Determine the roles and responsibilities of the Steering Committee, including its relationship with the Health Education Committees, and communicate these to its members.

- Establish more formal meeting procedures while keeping them as simple as possible.

- Foresee appropriate training and support when sensitivity to the communication needs of patients and families is not a selection criterion of committee members.

- Provide all non health care professional committee members with particular support to assist them in voicing their opinions during meetings.

- Consider recruiting "external" members whose principal concern is literacy, especially for hard-to-reach patients and their families.

- Make an effort to recruit at least one man on the Steering Committee.

HEALTH EDUCATION COMMITTEES

- Determine the roles and responsibilities of the Health Education Committees, including their relationship with the Steering Committee, and communicate these to their members.

- Establish more formal meeting procedures while keeping them as simple as possible.

- Foresee appropriate training and support when sensitivity to the communication needs of patients and families is not a selection criterion of committee members.

- Consider increasing the number of non health care professional committee members to ensure attendance and continuity.

- Attempt to include at least one member who is or has been a patient in the relevant unit and who is not and who has not been a health care professional, and provide all non health care professional committee members with particular support to assist them in voicing their opinions during meetings.

- Consider recruiting "external" members whose principal concern is literacy, especially for hard-to-reach patients and their families.

- Make an effort to recruit at least one man per committee.

- When meetings of the Health Education Committees are held during lunch hours, if attendance becomes a problem, look into defraying the cost of meals to encourage participation.

- If and when medical issues are involved in the execution of tasks by volunteers who are not active health care professionals, have their work reviewed by a health care professional member of the Health Education Committee.

- Include, in future budgets, a line item for professional clinical approval of materials being developed in the project.

- Until the organising of the Health Education Committees is completed, avoid attempts to measure the effectiveness of the strategies used to improve patient education.

ACTIVTIES

- If setting up teaching modules is retained as an objective in the next phase of this project, build as much of the new teaching modules as possible upon the conceptual framework produced with the knowledge gathered in the first two phases of the project and with whatever research is available.

- In the next phase of this project, consider the production of a print document or more in each unit, adapted to Plain Language in English and French and translated into other languages, without waiting for a complete conceptual framework.

- Do research in medical journals and on the Internet before committing resources to the production of completely new materials.

- Consider translating some of the existing print and audio-visual materials that are given out at no cost by certain foundations, associations and corporations, but often only in English.

TRAINING

- Offer awareness and skills development training to anyone playing a leadership role on either the Steering Committee or the Health Education Committees as well as to any future management staff.

- Continue to offer short awareness and skills development training sessions to health care professionals and volunteers working throughout the MGH and who are not actively involved in the Health Literacy Project.

APPENDIX I

EVALUATION METHODS

INTERVIEWS

In all, eight in-depth interviews with key informants were conducted at the end of May and during the month of June.

As planned, three were held with one non health care professional from each committee. However, because of the very small number of committee members, random sampling was not feasible and persons were selected according to their willingness to participate and their availability. An explanatory letter was drafted and presented to each person before the interview began. In the letter, I introduced myself, explained the objectives of the project and of my task as evaluator, and listed the subjects to be discussed, indicating that the interview would be limited to them. I specified that I would ask no questions related to a person's health situation or to the medical treatments that he or she is receiving at the hospital or elsewhere, and that participation in the interview was strictly voluntary. I also asked permission to record the interviews using a small tape recorder. Finally, I noted that I foresaw including citations in my final report but that I would not attribute one of these citations to a specific person's name. I proceeded with the interview only when the individual confirmed having understood the content of the letter. All of these interviews were held in person at the MGH and explored the following topics: a) the sensitivity of committee members to the communication needs of patients and families (1.1.1); b) member participation in decisions on advice to give (1.1.2); the appropriateness for hard-to-reach patients of existing materials retained (1.2.1)

Three interviews were also held with one health care professional from each committee, two in person at the MGH and one by telephone. I asked permission to record each interview. Each one focussed on: a) the appropriateness for hard-to-reach patients of existing materials retained (1.2.1); b) the appropriateness for hard-to-reach patients of programs and interactive activities identified for the next phase (1.2.3); c) the appropriateness of the training offered to them and on the results of their participation (2.1.1, 2.1.2, 2.1.3); d) the appropriateness of the training offered to targeted health care professional groups, the degree of participation and the results of their participation (2.2.1, 2.2.2, 2.2.3); e) the

results of the presentation to the Practice and Quality Improvement Council (2.2.4).

An in person interview was held at another location with the project's co-ordinator and also recorded. It explored: a) the criteria used to ensure the appropriateness for hard-to-reach patients of existing materials retained (1.2.1); b) the criteria used to ensure the appropriateness for hard-to-reach patients of programs and interactive activities identified for the next phase (1.2.3); c) the process of locale selection and on the appropriateness of the locale identified for the Health Education Centre in each unit (1.3.1); d) the relevance of information gathered to facilitate future development of the project and on information which will still be lacking (1.3.2); e) the process of promoting the Health Education Centres within the hospital (1.3.3); f) the dissemination strategy within the Montreal General Hospital (2.2.5); g) the dissemination strategy of the findings of the Health Literacy Project to key partners (3.1.2).

The planned in person interview with The Centre for Literacy's director could not be held because of unexpected health problems followed by incompatible vacation and travel schedules between the director and myself. However, we did have an in-depth discussion of the issues contained in this report on September 18th, 2002, following the director's review of my draft report and this led to the correction of one factual error.

An interview guide was used (as opposed to a questionnaire) for each interview.

EXAMINATION OF DOCUMENTS

The following documents were examined:

- list of members of the Health Education Committees (diversity);
- reports of meetings of the Health Education Committees (advisory role);
- one print document adapted to Plain Language in English and French in each unit (posters and flyers in English and French edited for plainer language in the Dialysis Clinic, a series of posters in the Hematology/Medical Oncology Clinic, a flyer in the Pre-Operative Centre illustrated and edited for plain language);

- the work in process on these print documents to translate them into Spanish and, for two of them, into basic Chinese;
- evidence of promotional activities and materials;
- reports of meetings of the Steering Committee;
- funding proposals submitted to four different funding sources;
- lists of participants in training activities offered to health care professionals participating in the Health Literacy Project;
- evidence of dissemination of key findings (3.1.2).