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The Development and Validation of Measures of "Health Literacy" in Different Populations

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EXECUTIVE SUMMARY

Issues of literacy and health, and '*health literacy'* are of increasingly interest to practitioners, policy makers and researchers in Canada, and elsewhere. In October 2003, the investigators were awarded a grant from CIHR to undertake a project to develop measures of health literacy for different population groups.

The objectives were to: 1) develop a rigorous, systematic and valid measure of health literacy appropriate to the Canadian context; 2) test the application of this measure with three specific population groups (seniors, immigrants, and people with low incomes); 3) further develop a conceptual framework for better understanding health literacy and its role in Canadian society; and 4) develop the foundation for a descriptive and predictive model of the role of health literacy in relation to use of health services, determinants of health and quality of life. For practical reasons, the investigators chose to focus first on older adults. We aimed to develop a measure of health literacy in the English language in order to minimize potential confounders such as ESL. (The present work is part of a larger program of research on health literacy that includes work with school children, street youth and immigrants).

To achieve the above objectives, the investigators proposed three steps: 1) develop a consensus regarding the conceptualization of "health literacy" in the Canadian context; 2) develop and rigorously validate a measure of health literacy appropriate to this context; and 3) test the relevance and utility of the tool with a specific, high-risk population group (older adults). This report summarizes the work that was carried out during the period of funding.

With regard to the first step, the investigators consulted with researchers to develop a conceptualization for health literacy in the Canadian context. This process resulted in the following operational definition of health literacy:

"*The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts to promote and maintain health across the life-course*."

A conceptual framework capturing this definition of health literacy and relating it to possible outcomes and influencing factors was also developed.

In relation to the second step, the investigators developed and tested a set of measures of health literacy suitable for older adults. Two hundred and twenty-nine community-dwelling older adults in Vancouver and Victoria were interviewed using these measures.

We collected demographic data on age, gender, marital status, education, ethnicity, country of birth, language, and income. Participants needed to be comfortable reading, writing, and speaking in English. The characteristics of our sample suggested that the seniors had a fair degree of literacy. This was based on characteristics such as education, country of birth or length of time living in Canada, and language. They had also been well exposed to Canadian culture and the English language. Compared to the National Population Health Survey (NPHS) and Census data, our sample was older, more educated, less likely to be married (were divorced, widowed, or separated), born in Canada or Europe, and English-language speakers. These data raise a caution as to the generalizability of our data.

We asked respondents to define "healthy aging.” They suggested that this was representative of someone who feels well and still functions well enough to be able to do the things one wants and be able to take care of oneself. Respondents suggested that this could be done by accepting aging, living life to the fullest, keeping active, exercising, taking care of oneself, interacting socially, learning, keeping a positive outlook, cleanliness, and getting enough sleep.

Participants were also asked to rate their self-perceived health in general, ranging from "poor" to "excellent." Most (89%) felt that their health was "good" or better. Only 11% felt that their health was "fair" or "poor." Seniors in our sample rated their health more highly than seniors who participated in the NPHS. Commonly identified health concerns were osteoarthritis, heart condition, osteoporosis, diabetes, breast cancer, blood pressure, prostate cancer, and cholesterol. The duration of concerns varied greatly from recently (within the past year) to more than 50 years.

Our interview focused on the perceptions of the respondents with respect to their health information experiences. In our analyses, we tried to distinguish a difference between health literacy *skills* (to access, understand, appraise and communicate health information) and variables that influence the seniors' experiences (health information *context*). This proved to be a challenge, as the seniors did not limit their focus to a specific health information experience.

We also wanted to explore the different types of health information that people seek. Respondents identified a diverse list of interests including causes of conditions, diagnoses, prognoses, treatment options, drugs, supplements, foods, research, prevention, and tests.

Reasons for not actively looking for health information included: already had the knowledge, not interested, not worried, and already had too much information. The respondents were also asked to rate how easy it was overall to find the information they wanted. They appeared to have little difficulty doing so. The distinction between just finding information, and finding information that is of interest or is relevant, was not always salient for the respondents. Some respondents selected the rating "easy" to find, but then later added that the information wasn't what they were looking for. The seniors also commented on some reasons why information was made easier, or not easier, to find. This suggests that context does influence the experience or "success" with which the relevant information is found.

In most cases, the respondents used more than one source for information on a specific health topic. The most frequently identified sources were general practitioners, specialists, books (non-library), and the Internet. These four sources accounted for almost one half (47%) of the total number of sources identified. The seniors had mostly *actively* sought information, except from the following sources, to which they were *exposed* to information – specialists, pamphlets/brochures, research studies, people with similar interests/condition, and the news. We note that there may be a bias in the responses towards sources of information being actively sought, because we interviewed seniors who looked for information. However, the finding that the respondents were sometimes exposed to information suggests that these sources, although not as actively sought, may also be important avenues for communicating information to individuals.

The seniors were generally satisfied with the information they received from a variety of sources. One of the limitations of our question on how "satisfied" the respondents were with the information from the various sources was that the term "satisfied" could be interpreted in different ways (e.g., satisfaction with the doctor-patient rapport, etc.), although we specifically asked about "satisfaction" with "information."

The seniors varied in their degree of trust in the health information they found, ranging from not having thought about trusting information, to trusting the information completely. The seniors commented that their trust depended on the source of the information and on the information itself. Distinctions such as trusting a person vs. information vs. the effectiveness of treatments and procedures were not always salient to the respondents; these concepts were often confused with each other.

Our participants suggested that they had little difficulty understanding the information they found, as 42% reported that it was "very easy" and 47% reported that it was "easy" to understand. The ease with which information was understood was influenced by several variables. These included the immediate clarification of explanations and words, the source, use of lay language, use of visual aids, respondent’s education, and the complexity of information. The comments and responses of the respondents suggest that there were two types of understanding - "technical" understanding and understanding in terms of "making sense" of the situation. "Technical" understanding refers to having knowledge of what specific words mean (e.g., medical terms). "Making sense" refers to the bigger picture of how things work (e.g., physiology, effects of treatment), how they fit in, what it means, etc. and implies an element of critical thinking.

In most instances, the seniors reported having encountered information that conflicted. Only in 33% of the instances did respondents not come across conflicting information. We found a statistically significant positive correlation ($p<0.001$, Kendalls’ tau b) between the frequency of encountering conflicting information and difficulty in making sense of the information. It is difficult to know whether this reflects difficulties in understanding specific or in reconciling conflicting information.

Over one half of the seniors (56%) reported that they never or hardly ever came across words that they did not understand. However, the phrasing of the question may have appeared vague to some respondents. There appears to be a distinction between being unfamiliar with a word (e.g., never seen the word before) vs. not understanding a word, which could be interpreted as being unfamiliar with a word (the former), or it could be interpreted as not knowing what a word meant even after receiving an explanation of the word. Most of the seniors used more than one approach to find out the meaning of unfamiliar words.

The respondents identified different people to whom they told, or did not tell, their concerns. We grouped the types of people, which are not mutually exclusive, into the following categories – family, people in a health (care) profession, friends, and acquaintances. For each group, there were instances where some respondents shared their concerns, while other respondents did not share them. In those instances where the respondents shared their concerns with other people who were not in health (care) professions, a variety of reactions from other people, mostly positive, were reported. The positive experiences were described using phrases such as "concerned," "supportive," "helpful," "encouraging," "sympathetic," and "understanding." People shared information with and offered help to the respondent. Negative experiences were reported as well. Some examples included other people who did not care or were disinterested, other people who could not relate to the respondent's concern, or the respondent having had to calm other people down because they were upset over the respondent's health.

When asked what key points about health or health conditions they would pass on to others, the seniors mostly suggested ways of coping, rather than (technical) health information. Some seniors had shared these key points with others, with some positive results. However, reasons were also given as to why they would not share these key points with other people, such as the negative reactions of other people. For measurement purposes, the responses pointed towards a challenge that needs to be considered in designing "good" measures of communicating (sharing) health information to other people. First, some respondents did not easily "separate" the sharing of concerns (I have a health condition) or the sharing of experiences (I am having a hard time with a health condition) from the sharing of information or key points about the health condition (that the health condition can be managed). The word "share" was selected for phrasing our question, because it connotes communication and collaboration. However, it seems that the word "share" was interpreted in other ways as well, such that the respondents were answering (again) our other question about who they told their health concerns to, rather than this specific question about who they had passed key points and health information on to (although the interviewers often used phrases such as "shared key points" or "shared health information" or "shared what you learned).

When asked what difference health information had made in their lives, most seniors reported positive impacts, such as increased knowledge, and what this increase in knowledge led to (e.g., changes in beliefs, attitudes, how one takes care of one’s health, improved health and well-being). However, the seniors were not always able to distinguish between the impacts of the condition itself (e.g., decreased mobility due to pain or stiffness) vs. the impacts of health information (acquisition of knowledge and the results of having that knowledge). There is also a difference between what one learns by personal experience (e.g., overdoing it makes one fatigued) and what one learns from others (e.g., to eat specific foods because of their nutritional content). Another challenge with respect to measuring outcomes is that self-reported improvements in health and well-being are not necessarily attributed to increased knowledge alone, e.g., improvements in health may be due to medication, which is treatment, not knowledge.

Data from our sample suggest that self-perceived measures may not necessarily correlate well with task-oriented measures of health literacy, although each type of measure appears to have some internal consistency (i.e., correlation of its own items with each other). Therefore, self-perceived measures of health literacy appear to be distinct from task-oriented measures of health literacy.

Self-rated health (as an outcome variable) was not found to be predicted by thirteen variables, that included demographics, beliefs about health and health information, self-reported health literacy, and task-performance health literacy.

Our use of both quantitative and qualitative techniques has enhanced our understanding of what health literacy means and how it can be measured. The main findings can be summarized as follows:

1) the seniors in our sample tended to be fairly educated and exposed to Canadian culture, and perceived their health to be fairly good

2) the respondents rated themselves to be fairly health literate on the self-perceived measures of health literacy (finding, understanding, appraising, and communicating health information, 3 "predictor" questions)
3) the types of information sought by the respondents varied broadly
4) multiple sources of information were often used to find information on a specific topic, most commonly from GPs, specialists, books (non-library) and the Internet
5) the self-perceived measures of health literacy were reported to be influenced by a broad range of variables (context)
6) the acquisition of information made a variety of differences in the respondents' lives, both positive and negative, in terms of increased knowledge and the effects of increased knowledge
7) some respondents had shared health information with other people, and believed that this had made some positive differences in these other people's lives
8) the respondents tended to do fairly well on most of the task-oriented measures of health literacy (REALM, reading passages), with the exception of the 2 most difficult tasks associated with one of the reading passages
9) the measures of self-perceived health literacy that we developed had good internal consistency (Cronbach's alpha=0.852), and therefore a sum scale of these measures was created
10) there was some correlation between self-perceived measures of health literacy with each other, and some correlation between the task-oriented measures of health literacy with each other, but there was minimal correlation between self-perceived measures of health literacy and task-oriented measures of health literacy
11) there may have been (as yet unidentified) underlying processes or "factors" that distinguished between task-oriented measures of health literacy and multiple groupings of self-perceived measures of health literacy
12) the self-perceived measures of health literacy, REALM score, self-rated health, and demographic characteristics were not found to be (strong) predictors of selected task-oriented measures of health literacy
13) self-rated health (as an outcome variable) was not found to be predicted by thirteen variables, which included demographics, beliefs about health and health information, self-rated health literacy, and task-oriented health literacy

There were a few similarities between our study results and what has been published in the literature, with respect to: 1) some (but not high) correlations between self-report health measures and task-performance measures of health literacy; 2) the inaccuracy of demographic characteristics in predicting task-performance measures of health literacy; 3) the inaccuracy of health literacy (and other variables) as predictors of outcome (e.g., self-rated health); 4) fewer respondents being able to correctly answer questions that were more difficult; 5) popular sources of health information (e.g., the Internet and doctors); 6) the importance of a good patient-doctor relationship; 7) suggestions for communicating health information (e.g., use of lay language, and use of visual aids); and 8) the stigma of low literacy. We found one notable difference between our sample of seniors and the published literature. The seniors in our study may have had higher health literacy than anticipated, based on the REALM and self-reported health literacy. Some comparisons were not conducted, because of a lack of greater heterogeneity in our sample of older adults (e.g., ethnicity).

Our study contributed to the articulation of health literacy as a construct – we have developed a definition and conceptual framework of health literacy that moves beyond the health care setting and suggests that health literacy is a shared responsibility. We have also contributed to a better understanding of health literacy, the variables that influence it, and the impacts or outcomes of health information that are not related to traditional measures of health such as morbidity and mortality. In our study, we were also able to clarify how seniors interpreted our health literacy questions; this will lead to better phrasing of measures of health literacy for future research. A variety of internal and external variables were suggested by the respondents as having influenced their health information experiences. These influences may be developed into new measures; this will lead to future research that tests the degree of influence these variables have on health literacy. One variable was reported by the respondents to have positively influenced *all four* health literacy skills, i.e., the seniors believed that having a science, biology, or health background made it easier for them to access, understand, appraise, and communicate health information. The responses of the seniors suggest that this may be an important influence on people's health literacy skills. Future research on health literacy can explore this relationship. If having a relevant background proves to be influential on health literacy skills, this may have implications for the education system as well as adult basic education.

In our study, we were also interested in exploring how health information made a difference in the seniors' lives. The seniors were not always able to discern impacts that resulted from health information vs. the health condition (e.g., decreased mobility) or what they learned by experience (e.g., overdoing it makes one fatigued). Future research on the outcomes of health literacy and health information should take these differences into account. The seniors mostly identified impacts of health information that were positive. A few negative feelings were reported, such as being scared or pessimistic. Most of these impacts are changes that are more immediately apparent and identifiable and are not related to traditional health measures such as morbidity and mortality. Although they are subjective, they can be linked to the respondent's health literacy skills, whereas objective impacts (e.g., health service utilization rates, mortality) at this point in time rarely, if ever, can be linked to health literacy skills. Future research on the link between health literacy and outcomes may benefit from these subjectively reported outcomes. The descriptions of "healthy aging" that our seniors provided may also inform us about what outcomes are of importance to seniors, such as being independent for as long as possible.

We found some (but low) correlation between self-report measures and task-performance measures of health literacy. One possible explanation for this is that the two types of measures are tapping into two different concepts (the results of our factor analysis suggested this) – one's *perception* of one's own health literacy skills and how one *performs* on various health literacy tasks. Both are equally interesting (performance should not be valued over perception), as one's perception of oneself and the world inevitably influences one's actions. Another possible explanation for the low correlation is that the self-report measures were *general* statements, whereas the task-performance measures were more specific. Future research on the measurement of health literacy can further explore the link between self-report measures and task-performance measures of health literacy, and whether there is a stronger correlation between the two types of measures when they are designed to measure the same aspect of health literacy (e.g., both measure reading ability).

In our study, we used a nutrition label reading passage to test task-performance measures of health literacy. We chose a nutrition label for various reasons. The scoring of our questions to be analogous to the IALS proved useful. The more difficult levels (4 and 5) of health literacy generated greater variability in data than other measures of health literacy in our study, including pre-existing measures of health literacy such as the REALM and three predictor self-report questions. This suggests that the questions about the nutrition labels were better able to discriminate differences in health literacy skills, whereas most other measures showed that almost all seniors in our study had relatively high health literacy. Future research can further explore the utility of this approach (questions that reflect the range of IALS difficulty levels), for different populations and for different topics.

Although our study is considered preliminary, the findings have potential applicability for practice and for research purposes. With respect to practice, our measures of health literacy were designed to be adaptable for multiple purposes – the generation of population data, intervention, and research. We strongly encourage that the purpose of measurement be explicitly identified such that appropriate measures are used, and that health literacy isn’t measured just for measurement’s sake. The seniors in our study corroborated the literature that information should be communicated in lay language, and they preferred information communicated with visual aids, such as diagrams. Practising doctors (no longer in medical school) may benefit from continuing education on topics such as low health literacy in patients and how best to communicate information to these patients. With respect to research, our study has expanded knowledge on health literacy and how it can be measured. We found that self-report measures of health literacy and task-performance measures of health literacy appear to be tapping into two different "dimensions" of health literacy. Future research would benefit from the development of more measures that are specific, that reflect a range of difficulty levels, that cover a wider range of health literacy skills than just reading ability, and that extends beyond the health care setting (e.g., health promotion). Qualitative and quantitative data are complementary for this. Some outcomes of health literacy may be more apparent if longitudinal studies are used. Efforts should be made to recruit more diverse study samples to explore differences and similarities in health literacy between population sub-groups. Finally, efforts should also be made to explore the most effective interventions for improving health literacy *skills* (not just health *knowledge*).

Although our study was exploratory, we advanced the objectives we set out to achieve. First, we tried to establish the validity of our measures. Second, we tested the measures in a population sub-group that has been reported to have lower general literacy – seniors. Third, we developed a definition and conceptual framework for understanding health literacy and what influences it, and for guiding its measurement. Fourth, we have established a basis for developing measures of health literacy outcomes that extends beyond traditional measures of health such as morbidity and mortality. Furthermore, our study expands research on health literacy into the Canadian context, whereas most of the published literature is in the U.S. context.

We suggest three future steps that need to be taken if the concept of health literacy is to fulfil its promise. First, we need to better define what constitutes health literacy. Green and Kreuter [1] define evaluation as the comparison of objects of interest against standards of acceptability. In the case of health literacy, we have not sufficiently conceptualized the objects of interest or constituent elements. Second, once these elements are better defined, there remains a need to develop measures of the nature, level, and shape of the distribution of health literacy in specific populations. Finally, we will need to define the standards of acceptability for health literacy in different situations. Standards of acceptability serve to identify the desired level of outcome and allow all parties to agree on how much change should be achieved in return for a given investment of resources. They also serve as targets that signal success, improvement or growth. For health-literacy programs, the standards will be the expected level of improvement in health literacy that is stated in a program's objectives. Our research with older adults suggests that we are still some distance from adequately defining health literacy. We are even further from adequately measuring it or defining 'best practices' or standards of acceptability with respect to specific interventions. However, we believe that this study has helped move us forward in our efforts to measure health literacy.

Although we were unable to address all the health literacy issues that we had identified in our literature review, this does not minimize their importance. We also echo the concerns raised by Shohet and Renaud, [2] who suggested a need for a holistic perspective on health literacy, while at the same time focusing beyond the individual to consider the roles of organizations, health contexts and systems. A parallel need for funding, infrastructure, and policy/legislation to foster a supportive environment for enhanced health-literacy practice and research also exists. Health literacy extends beyond an individual seeking information, and is a shared responsibility with those who provide and/or communicate health information, with those who teach health knowledge and/or health (literacy) skills, and with those who have the authority to develop policies that support health literacy.

TABLE OF CONTENTS

1. INTRODUCTION

The concept of "health literacy" was first used in 1974 in a paper on health education as social policy. [3] Since then, especially during the last decade, interest in the concept has grown among researchers, educators, health care providers, governments and patients. Health literacy is often linked to goals such as improving access to health-related information, improving health outcomes, and empowering people to improve health. Despite these goals, health literacy is a concept that lacks a common framework and definition about what it is, how different factors influence it, and how it affects health outcomes. The development of a conceptual framework and definition of health literacy should contribute to a common understanding of health literacy, help guide research, and help guide the development of policies and programs that enhance health literacy.

However, the conceptualization and measurement of health literacy is still in its infancy and does not capture the richness of recent attempts to define the concept in terms that are consistent with current thinking in the literacy field. The purpose of this project was to address these deficiencies though a process of developing a consensus regarding the conceptualization of "health literacy" in the Canadian context and developing measures that are appropriate to that context and different population groups. To help achieve this purpose, the investigators submitted a proposal to the Canadian Institutes for Health Research and were provided with partial funding in October 2003 to undertake this project

As indicated the proposal to CIHR, the objectives of this project were to:

1) develop a rigorous, systematic and valid measure of health literacy appropriate to the Canadian context;
2) test the application of this measure within with three specific population groups (seniors, immigrants, and people with low incomes);
3) further develop a conceptual framework for better understanding health literacy and its role in Canadian society; and
4) develop the foundation for a descriptive and predictive model of the role of health literacy in relation to use of health services, determinants of health and quality of life.

However, given the fact that insufficient funding was provided to work with three different population groups, the investigators chose to focus on one group, namely older adults. This group was also chosen because it appeared to be at high risk at least in relation to general literacy skills and it was felt that there might be less variability within this group, which might make it easier to develop new measures, and the group would be relatively easy to access.

Although this study focused specifically on the conceptualization and measurement of health literacy, it is a complex topic and other aspects of it are recognized in this report. The report begins with a review of the literature, including: the distribution of general literacy in the population and in specific sub-populations; the importance that health literacy has acquired; how health literacy has been defined; how health literacy has been conceptualized; how health literacy has been measured; the challenges in measuring health literacy; the association of health literacy with other factors; the association of health literacy with outcomes; and the research agenda for health literacy. The methods of the study are then described, including: the development of a definition and a conceptual framework of health literacy; the development of an instrument to measure health literacy; and the testing of the health literacy instrument in a sample of seniors. The Results section reports on the findings of the research, including: descriptive characteristics of the sample; the distribution of health literacy in the sample; factors associated with health literacy; and a comparison of the health literacy instrument with other related instruments. The Discussion section suggests the implications of these findings for further development of the measures.

2. LITERATURE REVIEW

We conducted a critical review of the published literature to gain a better understanding of "health literacy." We first talk briefly about the distribution of general literacy and health literacy in the population. In order to establish some common ground, we reviewed how health literacy has been defined, how it has been conceptualized (frameworks), and how it has been measured (instruments). The challenges of measuring health literacy are identified. To place health literacy in a broader context, we also looked at some of the potential influences that affect people's experiences with health information, as well as the strategies for improvement and potential outcomes related to health literacy. We end the literature review with some key conclusions about what has been published about health literacy to date.

This literature review draws on related literature from various fields of research, including patient education, doctor-patient communication, chronic disease self-management, general literacy, school health education, adult basic education, communication and information science, psychology, and health services research. As mentioned earlier, the term health literacy was first used in 1974, but the concept of health literacy is related to all the fields listed above. Therefore, we can draw on what has been learned in these other fields, with the caveat that most of the published literature is from the U.S.

2.1 The Distribution Of General Literacy In The Canadian Population

Three large-scale surveys have been conducted in Canada since the late 1980s to assess general literacy levels in the adult population, aged 16 and older – the Survey of Literacy Skills Used in Daily Activities (LSUDA) (1989), [4] the International Adult Literacy Survey (IALS) (1994), [5] and the International Adult Literacy and Skills Survey (IALSS) (2003), [6] which is the Canadian component of the Adult Literacy and Life Skills Survey (ALL) (2003). [7] The IALS is considered to be an extension of the LSUDA, while the IALSS are successors to the IALS. All three measure general literacy of different types (e.g., prose, document, quantitative) and at different difficulty levels. The IALSS included a new category of skill – problem solving.

The findings from all four surveys suggest that on average, the literacy skills of adults aged 16 and older have not changed much since 1989. A sizeable number of adults (about 50% or more of those sampled) performed below the "desired level" (Level 3) of competence to adequately function for each of the different types of literacy skills measured.

The distribution of literacy across Canada varies by geography. Higher average proficiency scores (than the national average) were observed for the Yukon, Alberta, Saskatchewan, and British Columbia, while lower averages were observed for New Brunswick, Newfoundland and Labrador, and Nunavut.

The distribution of literacy across Canada also varied by population sub-groups. Younger and more educated adults showed a higher level of literacy proficiency than older adults, and this difference (albeit smaller) was observed even after accounting for differences in the level of education. Other sub-groups that also scored lower on average on one or more of the three literacy skills were Franco-phones, Aboriginals, and immigrants. Lower literacy proficiency was also associated with the following characteristics – those who were either unemployed or not in the labour force, those who reported poorer health, and those who reported lower engagement in various community activities.

2.1.1. Comparison of Canada with Other Countries

Literacy levels at the broad national level have also been compared between countries. Comparisons for all types of literacy were made between Canada and the countries participating in the first round of the IALS, including Germany, the Netherlands, Poland, Sweden, Switzerland (French and German), and the United States, [5] and between Canada and the other countries participating in the ALL – Italy, Norway, Switzerland, United States, Bermuda, and Neuvo Leon state in Mexico.

The IALS data showed that the distributions for Canada and the United States were quite similar. For every country, except Poland, and for all three literacy scales, the highest proportion of adults were found to have Level 3 literacy (31%-44%). Compared to other countries, Canada (and the United States) had relatively higher proportions of adults at the extremes – Levels 1 and 5. This suggests a greater inequality in literacy levels in Canada and in the United States. However, data from the ALL showed that there was less inequality in skill between the highest and lowest performing groups than in the IALS. The ALL data also showed that changes in mean country performance were not substantial, but that there was some improvement among the 5% of adults with the lowest scores.

2.2. The Prevalence of Low Health Literacy In The Population

How does general literacy relate to health literacy? Are the trends observed for general literacy also found for health literacy? In order to answer these questions, health literacy needs to be defined and subsequently measured. We discuss this in more detail later in the literature review, but for now we report on some findings about the distribution of "health literacy" in the population.

2.2.1. Canada

So far, no large-scale assessments of "health literacy" have been conducted in Canada. However, the health-related questions from Canada in the 2003 IALSS are currently being analyzed as measures of health literacy. In addition, there is little in the published literature on the distribution of health literacy in Canada. Findings from various studies in Canada have shown the prevalence of low literacy in patients study samples to range from 5% to 9% using a health literacy measurement instrument called the REALM. [8] [9]

There has been one large-scale assessment of health literacy in the U.S. (which was part of a general literacy assessment), and many studies using various measurement instruments in different sub-populations in different settings and geographic locations.

2.2.2. United States

We report some findings from researchers who reviewed the literature in order to establish some idea of the prevalence of low health literacy in the U.S.

A pooled analysis of 85 studies in the medical literature in the U.S. found that nearly one half of the subjects in the studies had low or marginal health literacy as measured with various instruments (mostly REALM and TOFHLA). [10] The authors suggested that this was a conservative estimate of the prevalence of limited health literacy in the U.S. (e.g., participation bias, etc.).

Another review of English-language peer-reviewed studies that measure literacy or use the instruments REALM or TOFHLA among patients or consumers in a health context found that limited health literacy skills were common in the study samples, and that segments of the U.S. population that could be considered at greatest risk for limited health literacy were those that were reported to have higher rates of limited literacy in the National Adult Literacy Survey (NALS), e.g., older adults. [11]

Although the conclusions that can be drawn about the extent of low health literacy are limited because most studies measured only the print component from a broader set of health literacy skills, it is reasonable to conclude that individuals with limited general literacy (as measured by NALS) probably also have limited health literacy, as basic literacy skills are required for health literacy. [11] However, until we have adequate measures of health literacy, we do not know this for sure. In addition, limited health literacy probably affects more than just those with limited literacy when faced with the complex literacy demands of the health care context.

The health literacy of adults in the U.S. was reported in a recent publication [12] using data from the 2003 National Assessment of Adult Literacy (NAAL). More than 19,000 adults (ages 16 and older, in households or prisons) participated. Items specifically designed to measure health literacy were included. The items were chosen to represent literacy-related tasks that adults are likely to face in their daily lives. Overall, 12% had proficient health literacy, 53% had intermediate health literacy, 22% had basic health literacy, and 14% had below basic health literacy. On average, lower health literacy was found in males, Hispanics, adults who spoke other languages alone or other languages and English before starting school, adults who were ages 65 and older, adults who had never attended or did not complete high school, adults living below the poverty level, adults who reported lower self-perceived health, and adults who received Medicare or Medicaid and adults who had no health insurance coverage.

Thus, the findings from the review papers and the NAAL suggest that low general literacy and health literacy are common in the U.S., and are sometimes prevalent in about one half of the subjects in the study samples. This represents a significant number of individuals, especially when viewed from the perspective of the larger population. Canada and the U.S. appeared to have similar distributions of general literacy levels in the population based on the IALS and the IALSS. Although the U.S. data can not be generalized to the Canadian population, it is reasonable to conclude that there may also be a significant number of individuals in Canada who have low health literacy.

2.3. What Is “Health Literacy?”

An important first step in conceptualizing and measuring "health literacy" is to define it. What do people mean by the term "health literacy?" Rather than leaving the term "health literacy" ambiguous, a definition provides an explicit statement of meaning. It therefore gives guidance as to how health literacy is conceptualized, and thereafter measured.

What is the difference between *literacy* and *health literacy*? There have been discussions over the definition of general literacy. Without going into an exhaustive discussion about what literacy means, it has generally been defined as the information processing skills (e.g., reading, writing, etc.) needed to function in society (e.g., at work, at home, in the community, etc.). What is “health literacy” then, and how does it relate to “literacy?” Health literacy appears to be conceptually distinguishable from, yet related to, general literacy. As mentioned, the term health literacy was first used (but not defined) in 1974 in a paper on health education as social policy. [3] The author emphasized the importance of health education (health literacy) as a policy issue in three systems: 1) education; 2) health; and 3) mass communication.

Since 1974, the literature published about health literacy has grown. However the terms *literacy* and *health literacy* have often been used interchangeably. In an attempt to clarify the terms, various authors have suggested that people who have the requisite literacy skills to access, understand and apply information on some topics may nonetheless lack the health literacy ability to do so when it comes to health information. [13] [14] Therefore the term health literacy is preferred in relation to situations and settings in which individuals or groups receive health-related information and messages. In general, health literacy can be broadly viewed as the application of literacy skills specific to the context of health. Other “types” of literacy have also been referred to, including media literacy, scientific literacy, computer literacy, etc. These specific types of literacy refer to specific modes of communication or specific topics. They appear to be all inter-related, as individuals rarely apply only one type of literacy skill to process information, regardless of the topic (health or some other topic) or medium of communication.

Some definitions of health literacy and functional health literacy are presented in Table 1. The difference between the two terms is not entirely clear. “Functional” implies that an individual can use health information to make decisions and act in ways for his/her own good health. However, definitions of “health literacy” often contain an element of acting or using health information as well.

Several observations about the definitions include: 1) some definitions refer to basic literacy skills such as reading and writing; 2) some definitions refer to the tasks of finding/accessing/obtaining and understanding/comprehending/interpreting health information; 3) only two definitions referred specifically to evaluating or thinking critically about health information; 4) some definitions referred to using or acting on health information; 5) all definitions referred to one or more of the following terms – ability, capacity, and skills; and 6) some definitions refer specifically to the health care setting, while others are unspecified or more broad. These observations suggest that there are commonalities as well as differences across the definitions.

Table 1: Definitions of Health Literacy *(continued on next page)*

Term	Source (in order of year)	Definition
Health literacy	Center for Health Care Strategies, Inc. (1997) [15]	The ability to read, understand, and act on health care information.
	Joint Committee on National Health Education Standards (1998) [16]	The capacity of individuals to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health.
	World Health Organization (1998) [17]	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.
	Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association (1999) [18]	A constellation of skills, including the ability to basic reading and numerical tasks required to function in the health care environment.
	Selden et al. (2000). [19]	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Note: This definition was accepted for: 1) the Institute of Medicine's report titled *Health Literacy: A Prescription to End Confusion*; [20] and 2) the U.S. Department of Health and Human Services' *Healthy People 2010*. [21]
	Nutbeam (2000) [22]	The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health. Note: Three levels of health literacy were also identified: 1) basic or functional health literacy; 2) communicative or interactive health literacy; and 3) critical health literacy.
	NCE (2003) http://nces.ed.gov/NAAL/index.asp?file=AssessmentOf/HealthLiteracy.asp&PageId=12	The ability to use printed and written information associated with a broad range of health-related tasks to accomplish one's goals at home, in the workplace, and in the community (including health care settings).
	Zarcadoolas, Pleasant and Greer (2003) [23]	The evolving skills and competencies needed to find, comprehend, evaluate, and use health information and concepts to make educated choices, reduce health risks, and improve quality of life.

Term	Source (in order of year)	Definition
	Zarcadoolas, Pleasant and Greer (2005) [24]	The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.
	Kickbusch, Wait and Maag (2005) [25]	The ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the health care system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility.
Functional health literacy	Parker et al. (1995) [26]	Being able to apply literacy skills to health-related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care.
	Center for Health Care Strategies, Inc. (1997)	The ability to apply reading and numeracy skills in a health care setting.[b]
	Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association (1999) [18]	Ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient.

[a] This definition was accepted for: 1) the Institute of Medicine's report titled *Health Literacy: A Prescription to End Confusion*; [20] and 2) the U.S. Department of Health and Human Services' *Healthy People 2010*. [21]

[b] This definition was found on the website of the Center for Health Care Strategies in 2003, but has not been found on their web site since.

2.3.1. Strengths and Weaknesses of Definitions of Health Literacy

Some authors have criticized the existing definitions of health literacy. Greenberg praised the definition of health literacy by the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs for its inclusion of numeracy, but criticized the definition for not addressing oral communication skills and cultural belief systems. [27] Another weakness of the definitions of health literacy is that they assume that the onus of responsibility is on the patient, rather than the responsibility being shared with health care providers. Health literacy should be viewed in relation to issues of power (e.g., between patient and doctor), such that health literacy does not focus exclusively on issues of patient compliance. [28] It has been also suggested that some definitions are limited to a focus on medical and health care settings, and that health literacy should also be understood as a key determinant of population health (rather than just as a personal characteristic). In addition, health information is crucial but not sufficient to address the challenges faced by those who are disenfranchised or marginalized. Nevertheless, health literacy is closely related to the concept of empowerment, i.e., it is a means through which individuals can be informed and empowered to participate in their own health and quality of life. [17]

We agree with these criticisms and suggest another. We make a conceptual distinction between what health literacy is (a set of *skills*) and what it aims to do (its *purpose* or potential *outcomes*). We believe that this should also be clearly distinguished in the definition of health literacy. From a measurement perspective, the clearer and more specific a definition is, the easier it is to know what you are measuring and to reliably and validly measure it. As pointed out earlier, some definitions of health literacy included the ability (skills) to use or act on health information to promote and maintain good health, which we consider to be the *purpose* rather than a *skill* of health literacy. Although health literacy can not be viewed in isolation of its purpose, a set of health literacy skills can be measured (e.g., finding information, etc.), as can a set of outcomes of health literacy (e.g., increased knowledge, decreased morbidity, etc.), and associations between the two (skills and outcomes) can be studied.

2.3.2. Summary Definition of Health Literacy

From a review of the definitions identified above, health literacy appears to be the application of a set of *skills* (e.g., general literacy - reading, writing, numeracy) as it relates to the *tasks* of finding, understanding, evaluating and communicating health information for the *purpose* of making decisions and acting in ways that promote and maintain good health and quality of life. Although this may imply an onus of responsibility on the individual, the conceptual frameworks reviewed in the next section suggest that health literacy is situated within a larger context and associated with multiple influences and outcomes.

2.3.3. Health Literacy vs. Health Education

Sometimes the terms "health education" or "health knowledge" have been used interchangeably or synonymously with "health literacy." However, we conceptualize health literacy as being distinct from, but related to, health education. We view health literacy to be one outcome of health education. Health education generally refers to education-driven strategies (e.g., health knowledge) to empower people towards appropriate health decisions and health behaviours that will lead to positive health outcomes. Health education can, but does not necessarily, involve teaching people the health literacy *skills* to find, understand, appraise, and communicate health information. Through both health education and health literacy, people can become empowered to make healthy choices and enjoy positive health outcomes.

2.4. Conceptualizing Health Literacy

We searched the documents for graphical conceptual frameworks of *health literacy* in a broader context, e.g., its relationship to literacy, to other variables, and to outcomes. We also included frameworks that situated *general literacy in relation to health and outcomes*. We found seven such conceptual frameworks, and present them chronologically in order by the date of publication. Table 2 presents a comparison of the frameworks based on information context, development, and testing. A more detailed description of each framework follows.

Table 2: Comparison of Conceptual Frameworks of Health Literacy

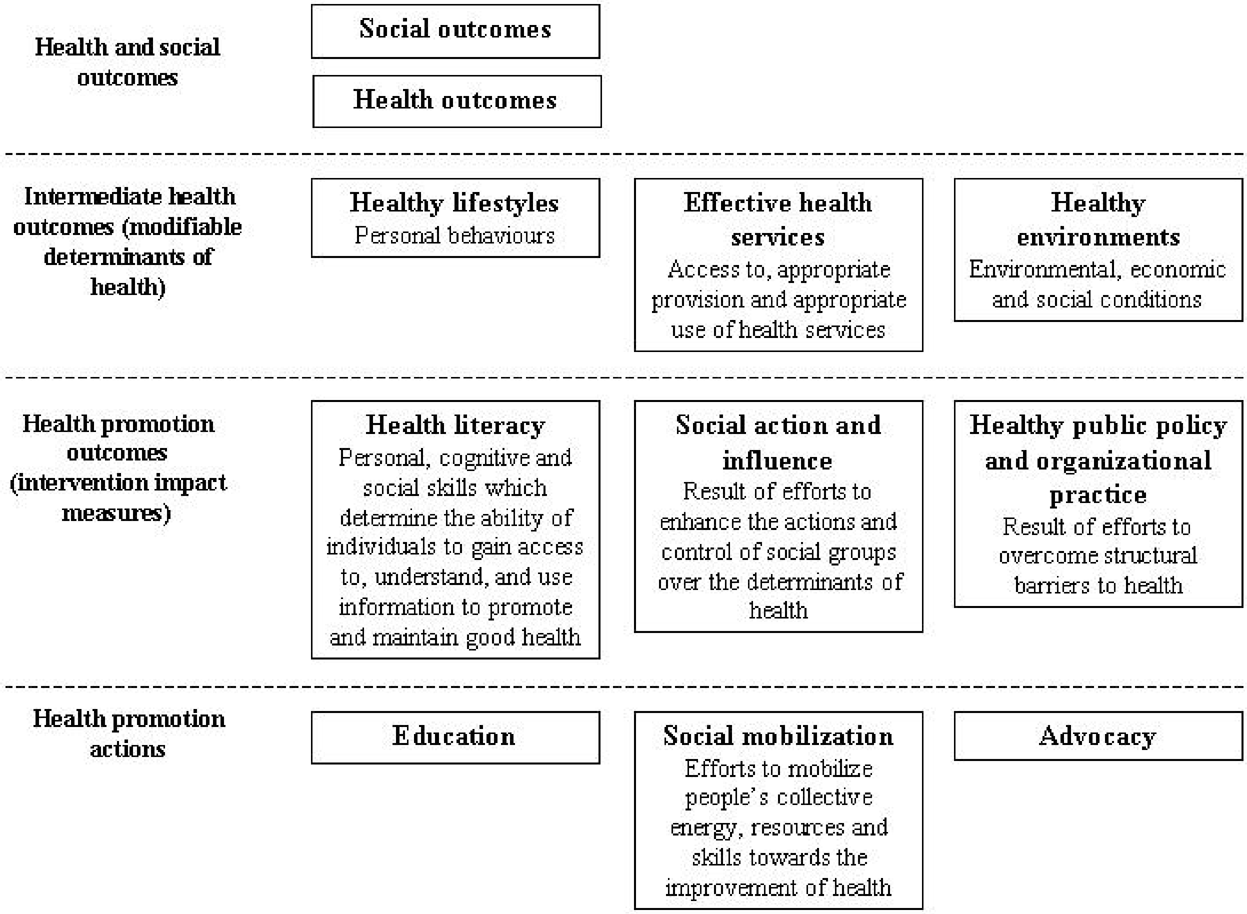
Source	Information Context	Development	Testing
Nutbeam (2000)	Health promotion	Not discussed.	Not conducted or discussed.
Pitkin Derose and Baker (2000)	Access to medical care	Modification of an existing "emerging" access model (by another author).	Found positive correlation between English proficiency and physician visits.
Rootman et al. (2003)	Not specified.	Not discussed.	Conducted focus groups to gather feedback on a draft.
NAAL Health Literacy Framework (2003)	Health-related print information – clinical, preventive, and navigating the health system.	Not discussed.	Not conducted or discussed.
Lee, Arozullah and Cho (2004)	Health service utilization.	Based on cited research evidence that justifies the pathways in the framework.	Not conducted or discussed.
IOM (2004)	Not discussed.	Not discussed.	Not conducted or discussed.
Pawlak's Health Literacy Model (2005)	Health care, health insurance, and "informed consumer."	Not discussed.	Not conducted or discussed.

2.4.1. Nutbeam's Outcome Model for Health Promotion (2000)

This paper identifies the failings of past educational programs to address social and economic determinants of health, presents a "health outcome model" that highlights health literacy as a key outcome from health education, and discusses the implications of this for the content and method of contemporary health education and communication. [22]

Nutbeam's outcome model for health promotion illustrates the linkages between health promotion actions, the determinants of health, and subsequent health outcomes (Figure 1). It is postulated that health promotion outcomes (health literacy, social action and influence, and healthy public policy and organizational practice) provide a bridge between an intervention (health promotion actions such as education, social mobilization, and advocacy) and the goal of an intervention to modify the determinants of health, and ultimately to improve health and social outcomes. Health literacy is thus a key outcome of health education. In the model, health literacy has both lateral and vertical relationships with other health promotion outcomes and education. Nutbeam’s model focuses specifically on health promotion and empowerment.

Figure 1: Outcome Model for Health Promotion (adapted from Nutbeam 2000) [22]



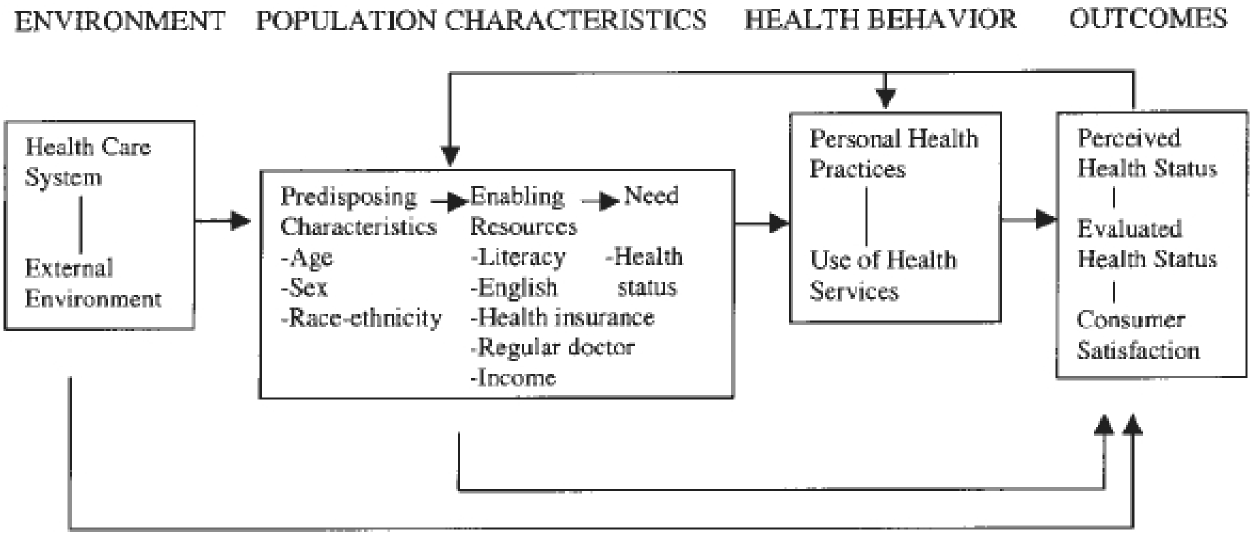
Health and social outcomes	**Social outcomes** **Health outcomes**		
Intermediate health outcomes (modifiable determinants of health)	**Healthy lifestyles** Personal behaviours	**Effective health services** Access to, appropriate provision and appropriate use of health services	**Healthy environments** Environmental, economic and social conditions
Health promotion outcomes (intervention impact measures)	**Health literacy** Personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health	**Social action and influence** Result of efforts to enhance the actions and control of social groups over the determinants of health	**Healthy public policy and organizational practice** Result of efforts to overcome structural barriers to health
Health promotion actions	**Education**	**Social mobilization** Efforts to mobilize people’s collective energy, resources and skills towards the improvement of health	**Advocacy**

Nutbeam also discussed three levels of health literacy: 1) basic/functional health literacy; 2) communicative/interactive health literacy; and 3) critical health literacy. Basic/functional health literacy refers to sufficient basic skills in reading and writing to be able to function effectively in everyday situations, and is broadly compatible with narrow definitions of health literacy. Communicative/interactive health literacy refers to more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. Critical health literacy refers to more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations. The first two types of health literacy focus on benefits to the individual, while that latter type focuses on both individual and community benefits.

2.4.2. Pitkin Derose and Baker's Model of Access to Medical Care (2000)

This study examined whether Latino patients with limited English proficiency use fewer physician services than patients who speak English fluently, controlling for other factors. [29] The study is based on a model for conceptualizing the use of physician services (Figure 2); this model is in turn adapted from an "emerging" access model. Predisposing characteristics are variables that are not controlled by the individual, e.g., age, gender, race or ethnicity. Enabling resources are individual characteristics that enhance one's ability to access and interact with the health care system, e.g., education, literacy, income, English proficiency, health insurance status, and regular source of care. The model focused specifically on medical care, although the determinants of health, such as income and literacy, are also acknowledged. Although this framework does not use the term "health literacy," it presents a relationship between literacy and health outcomes, and was therefore included.

Figure 2: Model of Access to Medical Care [29]



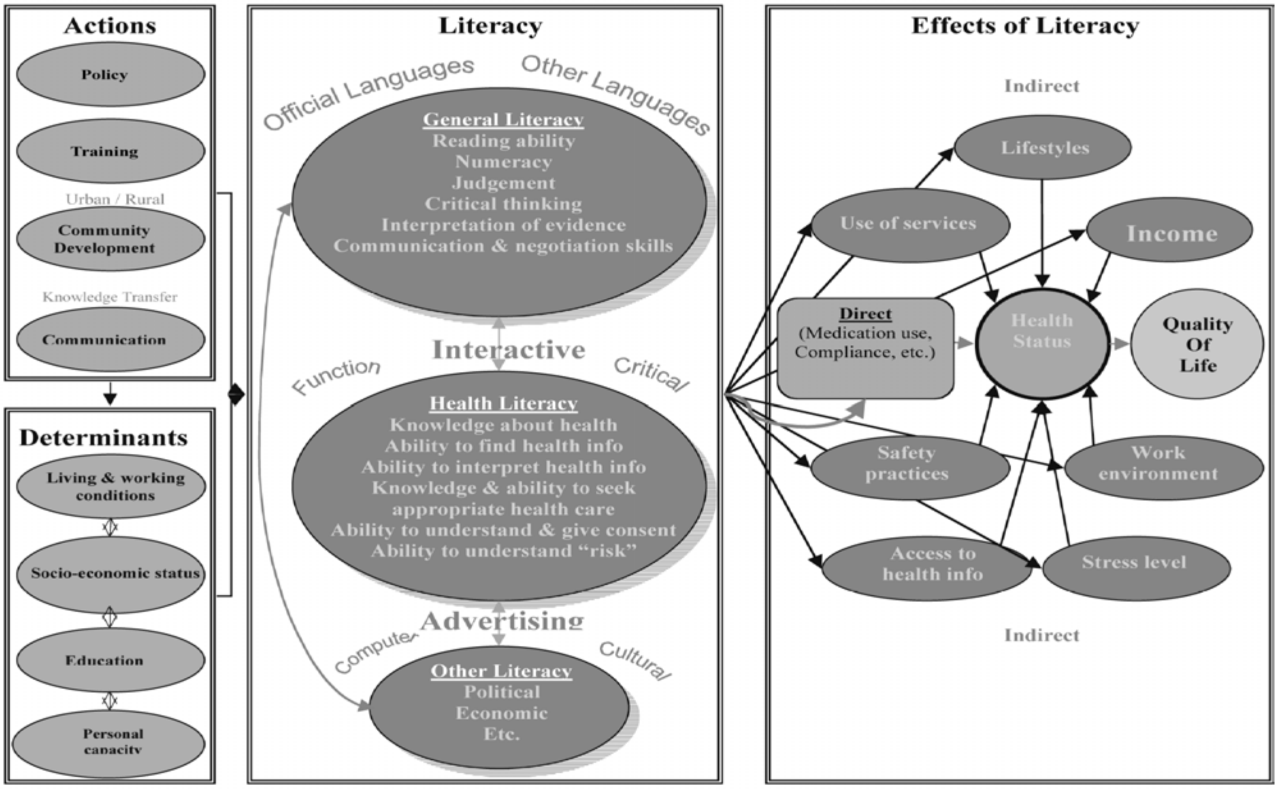
2.4.3. Report - National Literacy and Health Research Program Needs Assessment and Environmental Scan (2003)

This report was part of a project to develop a Canadian Literacy and Health Research Program funded in April 2002 by the Social Sciences and Humanities Research Council in collaboration with the National Literacy Secretariat. [30] The objectives of the environmental scan and needs assessment were to identify: 1) gaps in knowledge in literacy and health research in Canada; 2) current and proposed initiatives in literacy and health in Canada; and 3) resources and opportunities for research in literacy and health in Canada. The report synthesizes the data collected via interviews and focus groups with practitioners, researchers and policy makers involved in literacy and health issues.

Participants in focus groups were asked to comment on a draft conceptual framework of literacy and health. Based on their comments, the framework was revised (Figure 3). In this framework, health literacy is a type of literacy that acts as a bridge between actions and determinants and the effects of literacy, i.e., health and social outcomes.

In this framework, health literacy is characterized by the following: 1) knowledge about health; 2) ability to find health information; 3) ability to interpret health information; 4) knowledge and ability to seek appropriate health care; 5) ability to understand and give consent; and 6) ability to understand “risk.”

Figure 3: Conceptual Framework of Literacy and Health (2002) [30]

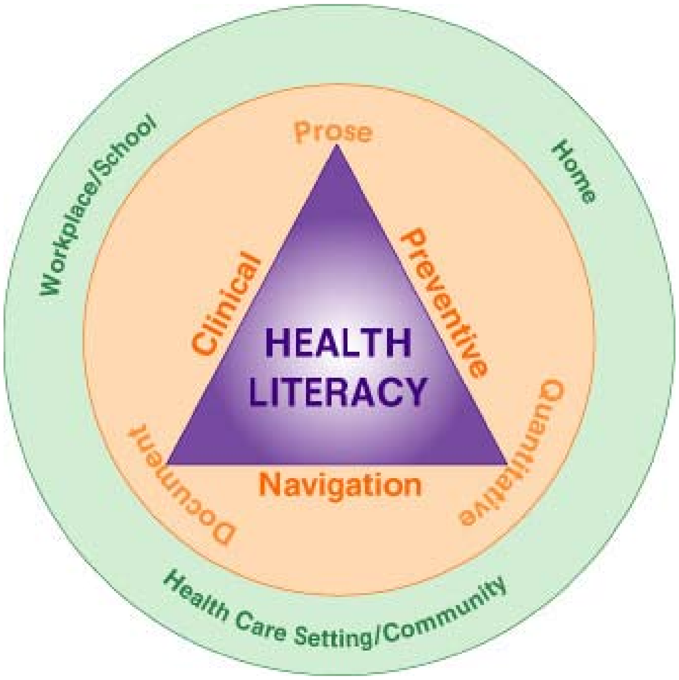


This framework acknowledges the determinants of health as influences in literacy and the effects of literacy. In addition, delineates health literacy as knowledge and a set of skills. Health promotion is reflected in this framework, e.g., the outcomes focus on health in a broader context such as lifestyles and quality of life.

2.4.4. Health Literacy Framework for the 2003 National Assessment of Adult Literacy (NAAL)

(http://nces.ed.gov/NAAL/index.asp?file=AssessmentOf/HealthLiteracy.asp&PageId=12)
The health literacy framework used for the NAAL in the U.S. is comprised of three aspects (see Figure 4). First, the setting is identified – home, workplace and community (including health care settings). Second, the three different types of general literacy are identified – prose, document and quantitative. Third, three types of health literacy tasks were identified – clinical, preventive and navigation. Clinical tasks refer to health care, e.g., following the directions to prepare for a mammogram. Preventive tasks refer to healthy habits and prevention of illness, e.g., understanding what a mammogram is and why it is important. Navigation tasks refer to the bureaucratic demands to get to the health care, e.g., finding the radiology department and later interpreting the bill.

Figure 4: Health Literacy Framework for the 2003 National Assessment of Adult Literacy (NAAL)

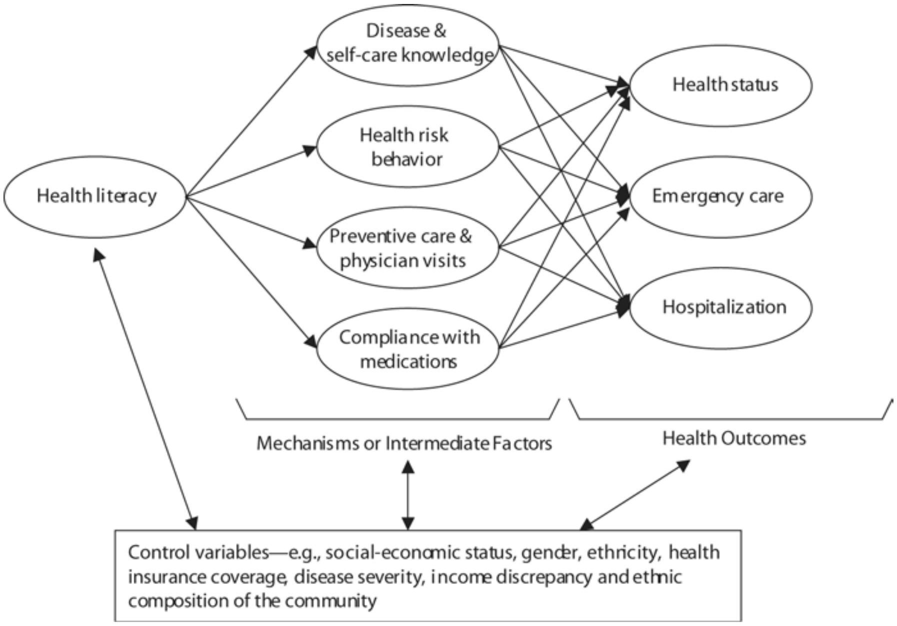


2.4.5. Lee, Arozullah and Cho’s Framework (2004) of Health Literacy and Health Outcomes

In their article, Lee, Arozullah and Cho [31] proposed two research questions to provide useful research directions. First, what are the causal pathways or intermediate steps that link low health literacy to poor health status and high utilization of expensive services such as hospitalization and emergency care? Second, what is the impact of social support on the relationships of health literacy with health status and health service utilization?

A framework that links health literacy to health status and health service utilization was proposed (Figure 5). In the framework, health literacy appears to result in health outcomes through various intermediate factors. “Control variables” influence health literacy, intermediate outcomes, and health outcomes. These “control variables” are factors at the individual and community levels that are considered to be important confounders that need to be controlled for when the framework is tested. For the sake of simplicity, the inter-related nature of the intermediate factors and the feedback loops from health outcomes to intermediate factors and to health literacy were not illustrated. This framework focuses mainly on medical care, but it acknowledges determinants of health such as income.

Figure 5: A Simplified Model of Mechanisms Linking Health Literacy to Health Outcomes



2.4.6. The Institute of Medicine’s (IOM) Health Literacy Framework (2004)

The IOM published a report to define the scope of the problem of health literacy, to identify the obstacles to creating a health-literate public, to assess the approaches that have been attempted to increase health literacy in the U.S. and abroad, and to identify goals for health literacy efforts and to suggest approaches to overcoming the barriers to health literacy in order to reach these goals. [20] In the report, a health literacy framework is presented (see Figure 6). In this framework, literacy is viewed as the foundation of health literacy, and health literacy is viewed as the active mediator between individuals and health contexts. In other words, health literacy is the bridge between literacy and the health context. Health contexts “reflect the many situations and activities relating to health” (p.41). The context of health literacy is composed of three key sectors – culture and society, the health system, and the education system (see Figure 7). These three sectors are points at which interventions are to be targeted.

Figure 6: IOM Health Literacy Framework

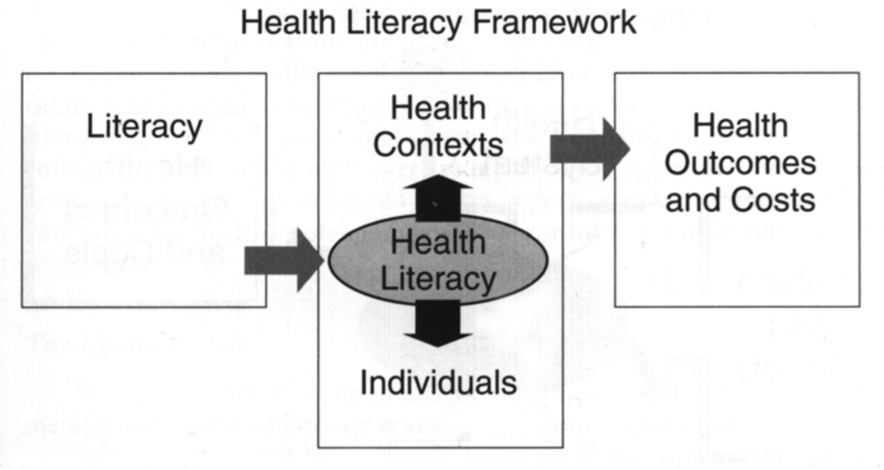
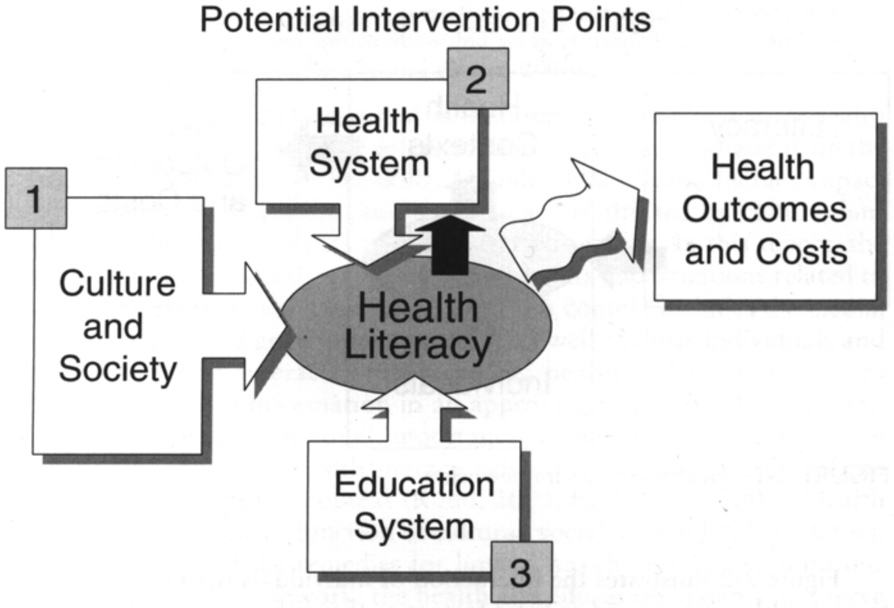


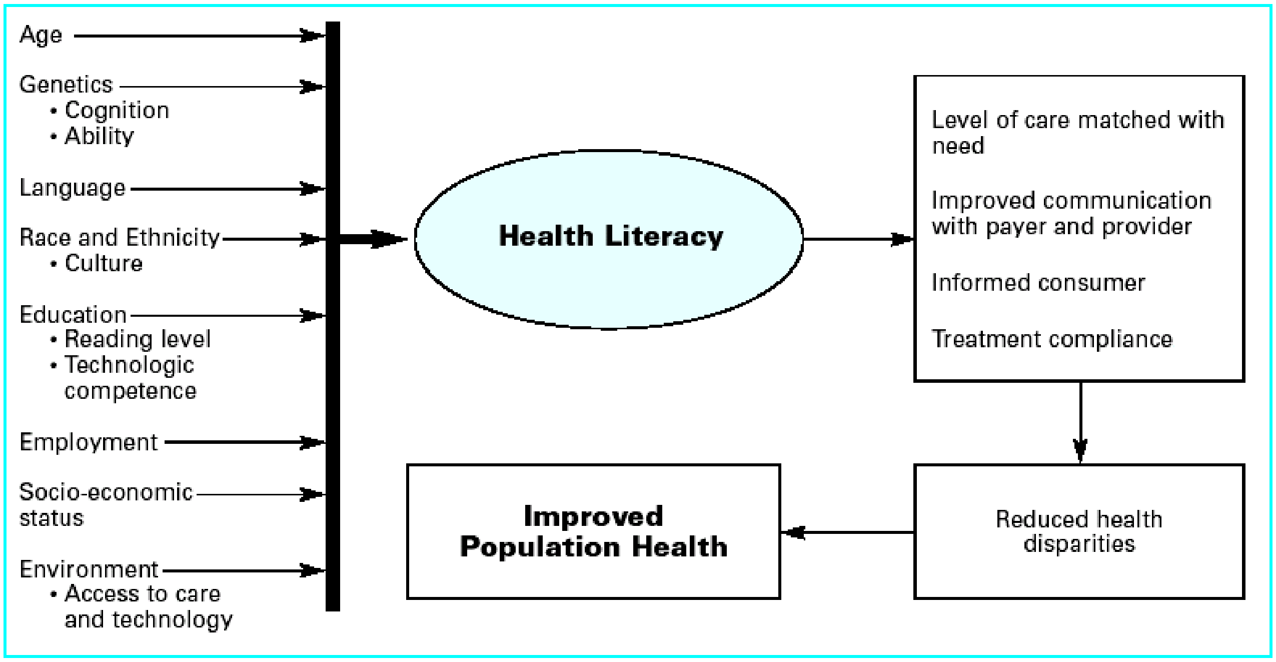
Figure 7: Potential Intervention Points in the IOM Health Literacy Framework



2.4.7. Pawlak’s Health Literacy Model (2005)

This model shows that health literacy is influenced by various determinants (e.g., age, genetics, etc.), and that health literacy in turn is a determinant of health (e.g., level of care matched with need, etc.) (Figure 8).

Figure 8: Pawlak’s Health Literacy Model (2005)



One of the strengths of the model is that it links health literacy to various determinants of health and to health outcomes. Therefore the model can be used to develop strategies for improvement in multiple areas.

One of the weaknesses of the model is that it is a consumer/patient-driven model that focuses on health care and health services in the U.S. It does not appear to include information for prevention or for health promotion purposes. Another weakness of the model is that it does not include how the source of information may influence an individual’s experiences in accessing and understanding information.

2.4.8. Observations on and Summary of Conceptual Frameworks

Two observations about the frameworks are noted. First, most of the frameworks portray health literacy as having a direct influence on health and social outcomes. Health literacy and health and social outcomes are bridged by intermediate outcomes. Second, health literacy is viewed as one of many factors that influence health and social outcomes. The determinants of health are considered an important part of the equation leading to health and social outcomes.

Most of the papers do not discuss the strengths and weaknesses of the frameworks. In addition, except for the IALS framework, limited information is provided about how the frameworks were developed. Pitkin Derose and Baker based their model on someone else’s “emerging” access model. Lee, Arozullah and Cho cited research evidence that justifies the illustration of the pathways in their framework. None of the frameworks were systematically tested, except for the IALS framework. Other frameworks were “validated” (although not systematically). Pitkin Derose and Baker measured a variety of variables and found an association positive correlation between English proficiency and physician visits. Rootman et al. conducted focus groups with practitioners, researchers and policy makers involved in literacy and health issues to gather feedback on a draft of the framework.

In terms of comprehensiveness, the frameworks appear to include, at a broad level, factors that influence health literacy and the intermediate and ultimate outcomes, and the pathways through which this may occur. The contributions of these frameworks to an understanding of health literacy and its influence are yet to be determined. However, the frameworks provide an illustration of the possible pathways (that may be tested) through which health literacy and other factors may act or interact to lead to improved health and social outcomes. Lee, Arozullah and Cho's framework distinguish the variables which may be confounders and which should be controlled during the testing stage. Nutbeam suggests some indicators that may be used to measure the different parts of his framework.

There has been less research on the conceptualization of specific "elements" of health literacy. Some of the frameworks, however, do suggest that health literacy is a resource for the individual (skills and knowledge).

2.4.9. Dimensions/Domains Of Health Literacy

There is a lack of agreement of what dimensions or domains constitute health literacy. This is not surprising given that different definitions of health literacy have been developed. We identified some dimensions or domains that have been suggested. It is quite likely there is overlap between these different dimensions and domains.

Several domains of health literacy were proposed in one model: 1) fundamental literacy (reading, writing, speaking and numeracy); 2) science literacy (levels of competence with science and technology); 3) civic literacy (abilities that enable citizens to become aware of public issues and to become involved in decision-making process); and 4) cultural literacy (ability to recognize and use collective beliefs, customs, world-view and social identity in order to interpret and act on health information). [24]

Speros (2005) [32] conducted a concept analysis of health literacy to clarify its meaning. The following "attributes" of health literacy were identified – reading skills, numeracy skills, comprehension, capacity to use health information in decision-making, and successful functioning in the patient role. The antecedents (events or incidents that must precede the occurrence of the concept) of health literacy were identified as literacy and health-related experience. Literacy refers to the ability to read, the ability to comprehend written words, and numeracy skills. Health-related experience refers to exposure to medical vernacular or some prior experience with illness or the health care system, and some logical context of health information within the individual's cognitive framework. The consequences of health literacy were identified as improved self-reported health status, lower health care costs, increased health knowledge, shorter hospitalizations, and decreased use of health services.

Some research has been organized around various dimensions of health literacy. A study of adolescents and online health information used Nutbeam's dimensions of functional, critical and interactive health literacy and found that the adolescents faced challenges in all three of these dimensions. [33] Some of the self-reported functional challenges faced by the adolescents included difficulty spelling medical words correctly and constructing questions to accurately describe their symptoms. Critical challenges were associated with figuring out what information was relevant and knowing which websites to trust. Interactive challenges were associated with trying to apply information to their personal concerns when the information was not locally specific, e.g., local service providers, local environmental data.

As discussed earlier, the measurement of health literacy as part of the NAAL was based on a framework that identified different types of tasks of health literacy – clinical, preventive and navigation.

Rudd, Kirsch and Yamamoto (2004) suggested five types of health activities (behaviours related to where and why people take health-related actions) for categorizing the health-related items from the NALS and the IALS in the U.S. [34] The five types of health activities were health promotion, health protection, disease prevention, health care and maintenance, and systems navigation. Health promotion refers to "healthy habits" undertaken by individuals for their own health, such as nutrition and physical activity. Health protection refers to the preservation and protection of one's health, such as products. Disease prevention refers to actions undertaken to prevent the onset of an illness or a disease or to detect diseases at early stages, such as immunization, screening, and use of sunscreen. Health care and maintenance refers to seeking care and forming a partnership with health care providers. Systems navigation refers to barriers to programs, services and care, such as application for health insurance and informed consent.

2.5. Health Numeracy vs. Health Literacy

There appears to be a growing body of literature on numeracy in health contexts, or health numeracy. The concept of numeracy is relevant to how people understand "risk," such as the probability of diseases or conditions, prognosis, etc.

Some authors have discussed "health numeracy" as an entity separate from health literacy, [35] or have argued that "health numeracy" should be recognized as an entity that is separate from health literacy because "simply addressing numerical tasks as a part of health literacy does not seem adequate in light of the inherent importance of conceptual and functional quantitative components of health care and health decisions" and because health numeracy is broader than numerical tasks alone. The authors defined health numeracy as "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions." In addition, health numeracy has the following functional categories – basic, computational, analytical and statistical.

However, some authors have found using factor analysis that general numeracy and numeracy in the context of health were tapping into the same central construct of global numeracy, i.e., performing mathematical operations in the context of health risks did not differ from other simple mathematical processes in other contexts. [36] The authors also found that education was an inaccurate predictor of numeracy scores, i.e., even those who were highly educated had difficulty with relatively simple numeracy questions. [36] In addition, being able to calculate mathematical operations does not necessarily translate to knowing what a risk means, in terms of magnitude or consequences or appropriately personalizing the information.

2.6. Measures of General Literacy in Health Settings

Some instruments that were designed to measure general literacy have been used in health settings. We do not discuss these instruments in detail, as we were more interested in instruments that were specifically designed to measure "health literacy." The general literacy measurement instruments have all been used to a fair degree, and have been tested for reliability and validity.

A list of the instruments used to measure general literacy in health settings and to measure health literacy was compiled by Davis et al. [37] The authors reviewed literacy testing in health care settings, and reported that this has occurred through both informal methods (e.g., observation of patient behaviour) and through the use of instruments. The types of instruments used can be classified as reading recognition tests (ability to pronounce words) and reading comprehension tests. Reading recognition tests tend to be more commonly used because they are easy and quick to administer and score. Table 3 shows the different types of instruments that have been used – we have added instruments and a new type of instrument to Davis et al.'s list and will discuss measures of health literacy in more detail in the next section.

Table 3: Instruments used to assess literacy in health care settings (adapted and updated from Davis et al. 2005) [37]

	Reading Recognition Tests	**Reading Comprehension Tests**	**[a]Self-Reported Reading Ability**
General Literacy	Wide Range Achievement Test – Revised 3 (WRAT-R3) Slosson Oral Reading Test – Revised 3 (SORT-R3) Peabody Individual Achievement Test – Revised (PIAT-R), word recognition subtest	Peabody Individual Achievement Test – Revised (PIAT-R), comprehension subtest Instrument for Diagnosis of Reading (IDL) [a]Test of Reading Comprehension (TORCH) [38]	
Health Literacy	Rapid Estimate of Adult Literacy in Medicine (REALM) + short revised version (REALM-R) Literacy Assessment for Diabetes (LAD) Medical Achievement Reading Test (MART) [a]Short Assessment of Health Literacy for Spanish-speaking Adults (SIRACT) (Spanish language) (also has a reading comprehension component) [a]Comprehension of fifty medical terms (instrument not named)	Test of Functional Health Literacy in Adults (TOFHLA) + short version (S-TOFHLA) and very short version [a]Stieglitz Informal Reading Assessment of Cancer Text (SIRACT) [a]Short Assessment of Health Literacy for Spanish-speaking Adults (SIRACT) (Spanish language) (also has a reading recognition component) [a]Newest Vital Sign (NVS) [a]Health Literacy Component of the National Assessment of Adult Literacy (NAAL) [a]Health Activities Literacy Scale using data from the National Adult Literacy Survey (NALS)	[a]Single Item Literacy Screener (SILS) [a]Three screening questions (set of questions not named)

[a] Not included in the original list by Davis et al.

2.7. Measures of General Literacy with Health Content

Health content may also be found within instruments that measure general literacy. An example can be found in the adult basic education (ABE) context. Adult basic education (ABE) refers to the instruction in basic reading, listening, writing, speaking, and math skills to function in society for individuals who are aged 16 or older who are not regularly enrolled full-time pupils.

A paper that reviewed the assessment of health literacy and ABE reported that the addition of a health literacy component to ABE classes in the U.S. is relatively recent. [35] Of the most commonly used ABE assessment tools, only one tool, the Comprehensive Adult Student Assessment System (CASAS), had a section devoted to health-related issues. The CASAS measures 5 health competencies: 1) understand how to access and utilize the health care system; 2) understand medical and dental forms and related information; 3) understand how to select and use medications; 4) understand basic health and safety procedures; and 5) understand basic principles of health maintenance. [39] However, using aspects of the CASAS as a tool to measure health literacy has several limitations. First, multiple versions of the CASAS exist and therefore not all versions contain the same set of health-related questions. Second, the CASAS does not provide scores for the five health competencies or a global health score. Scores are provided only for reading, math, and listening. Only when a student misses a question is the relevant competency referred to, so this could be identified as an area the student needs to concentrate.

2.8. Measures of Health Literacy

We searched for measures of health literacy that met one of the following criteria:

1) it was designed to measure “health literacy”
2) it was designed to measure literacy in a health context

We did not consider measures of “readability” to be measures of “health literacy.” The readability of health-related materials may influence how people understand health information. However, readability is not considered to be an aspect of the individual, whereas health literacy is. Readability is considered to be a characteristic of written materials.

The ways in which health literacy has been measured can be categorized into one of the following categories:

1) health literacy instruments (a group of multiple measures that are meant to be administered as a complete set)
2) other, proxy, or indirect measures of health literacy

2.8.1. Health Literacy Measurement Instruments

Table 4 shows the various health literacy measurement instruments that we found, in order of date of first publication. This is followed by comparisons of the different instruments in Table 5 to Table 18 based on characteristics such as purpose, time to complete, versions, procedure, scoring, reliability, validity, skills measured/not measured, strengths, and limitations.

Table 4: Various Health Literacy Measurement Instruments

Year	Authors	Instrument	Acronym
1961	Samora, Saunders and Larson [40]	Comprehension of fifty medical terms (instrument was not named)	n/a
1991	Davis et al. [41]	Rapid Estimate of Adult Literacy in Medicine	REALM
1995	Parker et al. [26]	Test of Functional Health Literacy in Adults	TOFHLA
1997	Hanson-Divers [42]	Medical Achievement Reading Test	MART
1999	Baker et al. [43]	Test of Functional Health Literacy in Adults, shortened version	S-TOFHLA
2001	Nath et al. [44]	Literacy Assessment for Diabetes	LAD
2003	Bass, Wilson and Griffith [45]	Rapid Estimate of Adult Literacy in Medicine, shortened version	REALM-R
2003	National Center for Education Statistics (NCES) in the U.S.	Health Literacy Component of the National Assessment of Adult Literacy (NAAL)	HLC
2004	Rudd, Kirsch and Yamamoto [34]	Health Activities Literacy Scale using data from the National Adult Literacy Survey (NALS)	HALS
2004	Chew, Bradley and Boyko [46]	Three screening questions (the set of questions was not named)	n/a
2005	Weiss et al. [47]	Newest Vital Sign	NVS
2006	Agre, Stieglitz and Milstein [48]	Stieglitz Informal Reading Assessment of Cancer Text	SIRACT
2006	Lee et al. [49]	Short Assessment of Health Literacy for Spanish-speaking Adults (Spanish instrument)	SAHLSA
2006	Morris et al. [50]	Single Item Literacy Screener	SILS

Table 5: Characteristics of comprehension of fifty medical terms (1961)

Characteristic	Comprehension of fifty medical terms	
Purpose	To obtain a measure of the extent to which patients might be failing to understand the meaning of frequently used medical words.	
Time to complete	Not reported.	
Versions	English only.	
Procedure	An interviewer reads aloud to the subject an illustrative sentence for each of the medical words (do you have a pain in your *abdomen*), and asks the subject for his/her interpretation of the key word (open-ended). The interviewer immediately scores the response. When there is doubt about how to score a response, the interviewer writes down the subject's reply, which is then scored by the principal investigators.	
Scoring	Responses are categorized into one of 4 categories: 1) no understanding (category A); 2) erroneous understanding (B); 3) vague or ambiguous understanding (C); and 4) reasonably clear and complete understanding (D).	
Reliability	Inter-rater reliability – the selected words had to have an average agreement of 96% in scoring by two interviewers who independently scored a number of pre-tests.	
Validity	Content validity – words were from selected based on feedback from patients, doctors, medical residents, and medical students.	
Skills	*Measured* Listening skills Oral skills	*Not measured* Writing skills Reading skills (prose literacy) Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Measures comprehension.	
Limitations	Not that quick to administer.	

Table 6: Characteristics of the REALM (1991) *(continued on next page)*

Characteristic	Rapid Estimate of Adult Literacy in Medicine (REALM)
Purpose	Screening tool to assist physicians in identifying patients with limited reading skills, and in estimating patient reading levels.
Time to complete	No time limit given, but generally takes 3-5 minutes.
Versions	English only. Shortened version of 8 words (REALM-R)
Procedure	66-word recognition.
Scoring	Raw scores converted to grade ranges: below third grade; fourth to sixth grade; seventh to eighth grade; and high school.
Reliability	Test-retest reliability of 0.98 [41] and 0.99 [51] Inter-rater reliability of 0.99 (P<0.0001). [41]
Validity	Concurrent validity: 1) with Peabody Individual Achievement Test) PIAT-R (r=0.94) [41] and (0.97) [51] 2) with comprehension (r=0.81, P<0.0001). [41] 3) with SORT (r=0.95) [41] and (0.96) [51] 4) with WRAT-R2 (r=0.82) [52] and (0.88) [51] 5) with TOFHLA (r=0.298, p<0.01) [38] Content validity – words selected from education materials and forms used in the Louisiana State University hospital clinics. [53] Face validity – based on physician, staff, and patient receptivity to the test and its applicability to medical settings. [53]

Characteristic	Rapid Estimate of Adult Literacy in Medicine (REALM)	
Skills	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Minimal training is required to administer the test. Administration and scoring of the test takes a short time. Has a high concentration of items at lower levels (lower literacy); therefore, this increases the instrument’s discriminatory power when administered to patients with limited reading ability, making it most useful in screening for low literacy.	
Limitations	Does not measure the patient’s understanding of the words. Presence of a ceiling effect (highest score is in the “high school” group), i.e., no discriminatory power for higher levels of education. [54] Requires interviewer administration. [38]	

Table 7: Characteristics of the TOFHLA (1995) *(continued on next page)*

Characteristic	**Test of Functional Health Literacy in Adults (TOFHLA)**
Purpose	To measure functional health literacy, i.e., measures patients' ability to perform health-related tasks that require reading and computational skills.
Time to complete	A time limit of 22 minutes is given.
Versions	English Spanish (TOFHLA-S) Shortened version (S-TOFHLA)
Procedure	Fifty-item reading comprehension and 17-item numerical ability test. A maximum of 22 minutes is given for completing the test.
Scoring	Comprehension: 50 points (50 items). Numeracy: the score (out of 17) is multiplied by 2.941 to create a score from 0 to 50. The sum of the two sections yields the TOFHLA score, which ranges from 0 to 100.
Reliability	Internal consistency: 1) Cronbach's alpha=0.98 for both English and Spanish versions [26] 2) Cronbach's alpha>0.95 within each of 3 patient populations [55] Internal consistency: intercorrelations among the Reading Comprehension and the Numeracy subtests were r=0.79 and 0.70 for the English and Spanish versions, respectively. (also demonstrates the unique contributions of the 2 subtests) [26] Test-retest reliability, Spearman-Brown equal-length coefficient of 0.92 for the English version, and 0.84 for the Spanish version.

Characteristic	Test of Functional Health Literacy in Adults (TOFHLA)	
Validity	Content validity: based on commonly used hospital texts reviewed by a literacy expert. [26] Concurrent validity: 1) Spearman's rank correlation: 0.84 (P<0.001) for REALM, and 0.74 (P<0.001) for WRAT-R. [26] 2) with REALM (r=0.298, p<0.01) [38] Face validity: the materials were drawn from commonly used hospital texts. [26] Pearson's correlation of 0.71 (p=0.0002) for S-TOFHLA and REALM as continuous variables. As categorical variables (both tools) the correlation is 0.52 (p=0.01). [56]	
Skills measured	*Measured*	*Not measured*
	Reading skills (prose literacy)	Listening skills
	Document literacy (more than just text)	Oral skills
	Numeracy skills	Writing skills
	Appraisal skills (critical thinking)	
Strengths	Measures numeracy.	
Limitations	Longer time for completion means the tool is more useful as a research tool than a clinical screening tool. [26] [57] Requires interviewer administration. [38] Feedback from survey administrators in one study suggested that: [58] 1) the dates on the prescription prompt cards should be current 2) the test type was too small 3) the scoring process was cumbersome and time consuming	

Table 8: Characteristics of the MART (1997)

Characteristic	**Medical Achievement Reading Test (MART)**	
Purpose	To allow health care professionals and researchers to assess patient reading ability.	
Time to complete	Not reported.	
Versions	English only.	
Procedure	Pronunciation of 42 medical words, and letter reading (taken from the WRAT).	
Scoring	Raw score (total), which can be converted into a grade-levels based on the conversion chart in the WRAT3 booklet.	
Reliability	Not tested.	
Validity	Modeled after the WRAT, which has been shown to be a reliable and valid measure of literacy. Cronbach’s α of raw scores (0.97) and grade levels (0.98) with WRAT (assumed true score). [42]	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Quick.	
Limitations	Measures word recognition only.	

Table 9: Characteristics of the S-TOFHLA (1999)

Characteristic	S-TOFHLA	
Purpose	Shortened version of the original TOFHLA.	
Time to complete	Maximum of 12 minutes.	
Versions	English and Spanish.	
Procedure	4 numeracy items 36 items in 2 prose passages	
Scoring	Total score out of 100. Each numeracy item was worth 7 points. Each prose item was worth 2 points. 0-53 meant inadequate health literacy. 54-66 meant marginal health literacy. 67-100 meant adequate health literacy.	
Reliability	Internal consistency: 1) Cronbach’s α=0.68 for the 4 numeracy items and 0.97 for the 36 prose items [43] 2) Spearman’s correlation coefficient between numeracy and reading comprehension (0.60) [43]	
Validity	1) Criterion validity – Spearman correlation of 0.80 with the REALM, but there were important disagreements between the two tests [43]	
Skills measured	*Measured* Reading skills (prose literacy) Numeracy skills	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Appraisal skills (critical thinking)
Strengths	Quicker to administer than the original TOFHLA. Measures numeracy.	
Limitations	Still not that quick to administer.	

Table 10: Characteristics of LAD (2001)

Characteristic	Literacy Assessment for Diabetes (LAD)	
Purpose	To develop a tool for use in the clinical environment that was not only valid and reliable, but also quick and non-stigmatizing. Additionally, this instrument would be diabetes context specific.	
Time to complete	3 to 5 minutes.	
Versions	English only.	
Procedure	60 word recognition with words of graded difficulty.	
Scoring	Raw score that may be converted to grade levels (modeled after REALM).	
Reliability	Test-retest – intraclass correlation coefficient of reliability was 0.86. [44]	
Validity	Concurrent validity (statistically significant correlation coefficients): 1) 0.81 with WRAT3 2) 0.90 with REALM	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Quick	
Limitations	Measures word recognition only.	

Table 11: Characteristics of the REALM-R (2003)

Characteristic	REALM-R	
Purpose	To rapidly screen patients for potential health literacy problems. Shortened version of the original REALM, which had 66 words.	
Time to complete	Less than 2 minutes.	
Versions	English only.	
Procedure	Reading 8 words aloud – osteoporosis, allergic, jaundice, anemia, fatigue, directed, colitis, and constipation (with fat, flu and pill included at the beginning to decrease test anxiety and enhance patient confidence, but not included in the score).	
Scoring	Total out of 8.	
Reliability	Internal consistency, Cronbach’s α=0.91. [45]	
Validity	Criterion validity: 1) with WRAT-R using Spearman rank correlation (0.64). Able to identify a significant number of people who scored poorly on the WRAT-R. [45] 2) with REALM using part whole correlation (0.72) [45]	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Quick. Patients were very open to completing the survey. [45]	
Limitations	Does not measure the patient’s understanding of the words.	

Table 12: Characteristics of the HLC of the NAAL (2003)

Characteristic	**Health Literacy Component (HLC) of the NAAL**
Purpose	National assessment to measure adults' ability to use literacy skills to read and understand health-related information.
Time to complete	Not reported – was completed as part of a larger survey.
Versions	English only.
Procedure	The HLC (28 tasks) is embedded in the main NAAL assessment booklet (152 tasks).
Scoring	4 clinical tasks 14 preventive tasks 10 navigation tasks As part of NAAL prose, document and quantitative scores. As a separate health literacy score.
Reliability	Not tested yet.
Validity	Not tested yet.
Skills measured	*Measured* Reading skills (prose literacy) Document literacy (more than just text) Numeracy skills *Not measured* Listening skills Oral skills Writing skills Appraisal skills (critical thinking)
Strengths	First national-level assessment of health literacy. Measures numeracy.
Limitations	Would not be quick to administer if separated out of the NAAL.

Table 13: Characteristics of the HALS of the NALS (2004)

Characteristic	Health Activities Literacy Scale (HALS) of NALS	
Purpose	Used to estimate the distribution of literacy on health-related tasks among U.S. adults, describe the health literacy skills of at-risk or vulnerable population groups, and demonstrate how health-related literacy is connected to health status, wealth and civic engagement.	
Time to complete	Completed as part of the NALS, which included other non-health items.	
Versions	English only.	
Procedure	The 191 tasks were completed as part of large-scale assessments of general literacy. The number of tasks for the five types of activities was: health promotion – 60; health protection – 65; disease prevention – 18; health care and maintenance – 16; and systems navigation – 32.	
Scoring	Using Item Response Theory (IRT), a new scale of was developed for HALS to reflect different levels of health literacy, ranging from a Level of <1 (lowest) to a Level of 5 (highest). Total HALS scores were used.	
Reliability	Using item response theory, the stability of the HALS item parameters was remarkably good.	
Validity	Content validity based on the ability of several researchers to fit the items into the health activities framework.	
Skills measured	*Measured*	*Not measured*
	Reading skills (prose literacy)	Listening skills
	Document literacy (more than just text)	Oral skills
	Numeracy skills	Writing skills
		Appraisal skills (critical thinking)
Strengths	Uses items from existing large-scale surveys of a nationally representative sample of adults in the U.S. Measures numeracy.	
Limitations	Would not be quick to administer if separated out from the NALS.	

Table 14: Characteristics of Three Screening Questions (2004) *(continued on next page)*

Characteristic	Three Screening Questions
Purpose	To identify clinically useful screening questions to detect inadequate or marginal health literacy among patients.
Time to complete	Not reported, as was completed as part of a larger test.
Versions	English only.
Procedure	Interviewers read aloud sixteen questions to the subjects . Responses were selected from a 5-point Likert scale. The three questions that were reported to be effective screening questions were: 1) How often do you have someone help you read hospital materials? 2) How confident are you filling out medical forms by yourself? 3) How often do you have problems learning about your medical condition because of difficulty understanding written information?
Scoring	Sum of scores on the scales.
Reliability	Not tested yet.
Validity	Comparison with S-TOFHLA as the standard using ROC[a] with 95% confidence interval in parentheses: [46] 1) first question – 0.87 (0.78-0.96) 2) second question – 0.80 (0.67-0.93) 3) third question – 0.76 (0.62-0.90) Better at identifying patients with inadequate health literacy than for patients with marginal health literacy.

Characteristic	**Three Screening Questions**	
Skills measured	*Measured (via self-report)* Reading skills (prose literacy) Document literacy (more than just text)	*Not measured* Listening skills Oral skills Writing skills Numeracy skills Appraisal skills (critical thinking)
Strengths	Quick. Inexpensive. Less likely to induce anxiety and shame, as the questions do not directly assess health literacy through word recognition or comprehension testing. [46]	
Limitations	Not widely tested yet. Only addresses written information. Questions are related to health care and medication only.	

[a] ROC stands for receiver operating characteristic curve. It is a plot of sensitivity (true positive test) against (1-specificy) (false positive test) on the X axis. The area under the curve, which theoretically ranges from 0-100, represents the effectiveness of the test for screening purposes, i.e., the larger the area under the curve the better the performance of the test.

Table 15: Characteristics of the NVS (2005) *(continued on next page)*

Characteristic	Newest Vital Sign (NVS)	
Purpose	To develop a quick and accurate screening test for limited literacy available in English and Spanish.	
Time to complete	About 3 minutes.	
Versions	English and Spanish.	
Procedure	Answering 6 questions about a nutrition label.	
Scoring	Total correct out of 6. Fewer than 4 correct answers indicate the possibility of limited literacy.	
Reliability	Internal consistency – Cronbach’s α>0.76 in English and 0.69 in Spanish. [47]	
Validity	Criterion validity, using TOFHLA as the gold standard (<75 means limited literacy): [47] 1) r=0.59, p<0.001 2) area under ROC curve in English was 0.88 3) area under ROC curve in Spanish was 0.72 Does not have the ceiling effect seen with the TOFHLA and therefore provides better discrimination of skill levels among individuals in the upper part of the distribution of literacy skills. [47]	
Skills measured	*Measured* Reading skills (prose literacy) Document literacy (more than just text) Numeracy skills	*Not measured* Listening skills Oral skills Writing skills Appraisal skills (critical thinking)

Characteristic	Newest Vital Sign (NVS)
Strengths	Measures numeracy. [47] Nutrition labels are familiar items that are important parts of health management for many chronic diseases, and are used for health promotion to achieve healthy eating habits. [47] Quick.
Limitations	Is topical so may not seem applicable in some settings.

Table 16: Characteristics of the SIRACT (2006)

Characteristic	**Stieglitz Informal Reading Assessment of Cancer Text (SIRACT)**	
Purpose	To estimate patients’ instructional level of comprehension when reading cancer-related passages of increasing difficulty.	
Time to complete	No time limit, but generally ranges from less than 10 minutes to as long as 20 minutes.	
Versions	English only.	
Procedure	Reading a list of words to determine an entry point for reading Graded Reading Passages Test, and answer questions about the passages.	
Scoring	Each response is awarded either full, partial, or no credit, and then converted to different levels – instructional (adequate comprehension of 70%-80% correct), independent (little difficulty (>90% correct), and frustration (comprehension of less than 70%).	
Reliability	Not tested yet.	
Validity	Not tested yet.	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	More likely to appeal to patients with cancer because the test is disease-specific. [48] Minimizes feeling of shame associated with low literacy because it feels more like a test of the clarity of the passage. [48] It is grade-level specific. [48]	
Limitations	Longer time for completion (up to 20 minutes). [48]	

Table 17: Characteristics of the SAHLSA (2006) *(continued on next page)*

Characteristic	Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA)	
Purpose	To develop and validate a health literacy test for the Spanish-speaking population that can be used for screening for low (Spanish) health literacy in clinical or community settings.	
Time to complete	3-6 minutes	
Versions	Spanish only.	
Procedure	50-word recognition (translated from REALM) and multiple choice word association (comprehension).	
Scoring	Deemed correct only when the word is pronounced correctly and the right word association is made. Maximum score of 50.	
Reliability	Internal consistency – Cronbach's α=0.92. [49] Test-retest reliability with 40/201 respondents (r=0.86) [49]	
Validity	Concurrent validity: 1) with TOFHLA (r=0.65). [49]	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Fairly quick.	

Characteristic	Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA)
Limitations	Spanish language only. [49] Respondents may guess on multiple choice questions, and still be scored as "correct." [49] Can not be converted to grade-equivalent reading levels (for the purpose of designing appropriate education materials). [49]

Table 18: Characteristics of the SILS (2006)

Characteristic	Single Item Literacy Screener (SILS)	
Purpose	To develop a screening assessment that would cast a broad net to capture all subjects with limited reading ability.	
Time to complete	Was part of a larger questionnaire, but should not take more than 1 minute on its own.	
Versions	English only.	
Procedure	Answer one item as part of a larger questionnaire: “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” – 1=never, 2=rarely, 3=sometimes, 4=often and 5=always.	
Scoring	Use rating from Likert scale as is. Scores greater than 2 were considered as indicators of some difficulty with reading printed health-related material.	
Reliability	Not tested yet.	
Validity	Using S-TOFHLA as the gold standard: [50] 1) moderate ability to identify adults with limited reading ability 2) less ability to identify adults with marginal reading ability	
Skills measured	*Measured* Reading skills (prose literacy)	*Not measured* Listening skills Oral skills Writing skills Document literacy (more than just text) Numeracy skills Appraisal skills (critical thinking)
Strengths	Very brief and therefore practical for use in clinical settings. [50]	
Limitations	An indirect measure of reading ability (or could reflect reading problems due to other reasons, such as vision impairment). [50]	

2.8.1.1. Some Comments on the Existing Health Literacy Measurement Instruments

Several observations can be made about the existing health literacy measurement instruments.

First, there is a trend towards developing health literacy measurement instruments that are quick to administer (for the clinician), while at the same time are effective at identifying those with low health literacy. For example, shorter versions of both the REALM and the TOFHLA have been developed. Some of the more recently developed instruments, such as the SILS and the three screening questions developed by Chew, Bradley and Boyko, [46] are based on self-report for a minimal number of questions, rather than on task-performance such as word recognition or reading comprehension.

Second, there is a trend towards measuring multidimensional aspects of health literacy. Earlier tests, such as the REALM, the MART, or use of general literacy tests in health settings, measured word recognition. These have the advantages of being quick to administer and easy to score, but they do not measure other health literacy skills that have been identified. More recently developed tests, such as the TOFHLA, NVS, and SIRACT, measure reading comprehension and, in some cases, numeracy. However, these latter tests have been criticized for only measuring skills associated with written materials, and not measuring skills associated with verbal communication.

Third, most of the health literacy measurement instruments were developed and tested primarily in the U.S. context. The content of the instruments may be applicable in the U.S., but may not be in other countries (without revisions).

Fourth, each of the REALM, TOFHLA, and S-TOFHLA has been used as a "standard" to which health literacy instruments are compared for validity purposes. These instruments have the advantage of being more frequently used to measure health literacy. However, their use as "standards" of health literacy measurement has rarely been questioned. Every test instrument has its limitations, but to be a good "standard," a test instrument should adequately address five shortcomings of "standards" or criterion indicators that were identified by Thorndike – incompleteness, mis-weighting, intrusion of irrelevant factors, bias, and low reliability. [59]

Incompleteness refers to criterion indicators not covering all aspects of a construct. For example, neither the REALM, TOFHLA, nor S-TOFHLA measure listening and speaking skills associated with health literacy. These skills are also important for information exchange, but are usually considered to be too time-intensive (analysis) and costly to measure. If a more complete picture of health literacy is to be portrayed, indicators of listening and speaking skills that are not as time-intensive or costly need to be developed. For example, are there any proxy measures (not actual task-performance) that correlate well with a task-performance standard(s)?

Mis-weighting refers to a disproportionate amount of weight being placed on different aspects of the construct. However we often do not know the "true" importance of different aspects of a construct. In the case of health literacy, we do not know the importance that the different skills contribute to overall health literacy or to health outcomes.

Intrusion of irrelevant factors refers to giving weight to a factor that really should receive no weight. An example from education would be when a teacher judged the competence of a child as a student of history or science based on the child’s handwriting ability. Another example would be variation in rating or grading standards from different instructors or supervisors. In the case of health literacy, an example would be variability between different people in how open-ended responses on reading comprehension tests are marked (correct or incorrect).

Bias refers to both prejudicial attitudes held by evaluators toward individuals or groups, and to impersonal factors that may alter the score. An example would be volume of sales by an insurance salesperson being biased by the economic level of the surrounding community. It is important to identify what the biases may be, and to seek ways to minimize or circumvent them. In the case of health literacy, the readability of documents may influence how an individual scores on a reading comprehension test. One way to minimize this would be to choose documents that are more easily readable, and modify the difficulty level of the task required.

Low reliability refers to a test item that is inaccurate or inconsistent in what it measures, and therefore results in a loss of sensitivity in validity studies. Sometimes the reliability of a criterion indicator is not known. It is important to generate a sound estimate of the reliability of a criterion score so that obtained validity data can be appropriately interpreted.

2.8.2. Other, Proxy, or Indirect Measures of Health Literacy

In addition to the health literacy measurement instruments discussed in the previous section, various proxy or indirect indicators have also been used or tested as measures of health literacy. These include physicians’ assessment of patients’ health literacy skills, observation of physician-patient interaction, self-reported reading ability, knowledge, self-reported life circumstances and practices (e.g., number of children’s books in the home, etc.), education, and comprehension of nutrition labels (not compared with health literacy measurement instruments). Generally speaking, these measures appear to have some association with scores on health literacy measurement instruments, but none were found to be strongly correlated with, or strong predictors of, health literacy scores.

2.8.2.1. Physicians’ Assessment of Patients’ Health Literacy Skills

Most of the evidence suggests that physicians tend to over-estimate their patients’ health literacy skills. Therefore, physicians’ assessments are not sensitive predictors of patients’ health literacy skills. This has been reported in studies that compared physicians’ and medical residents’ perceptions with patient performance on the REALM, [54] the REALM-R, [60] and the S-TOFHLA. [61] Over-estimation by physicians was also found when comparing the perceptions of patients and their attending physicians on whether the patients understood (yes, no, do not know) aspects of their treatment plan such as the post-discharge medication regimen, the potential side effects of medication, and when to resume normal activities. [62]

One study did find a relatively good overall correlation of physicians’ estimate of their patients’ reading levels and the patients’ score on the REALM. [63] However, the physicians’ ability to discern poorer readers (less than high school level) was significantly less accurate.

One study reported that doctors tended to under-estimate their patients' communication competence compared to patients' self-assessment of communication competence during medical interviews. [64] Communication competence was based on four aspects of information exchange – information giving, information seeking, information verifying, and socio-emotional communication. The authors suggested that the doctors' assessments were probably accurate, and that patients often seek information indirectly and that this may not have been apparent to doctors.

2.8.2.2. Observation of Physician-Patient Interaction

Some evidence from studies where physician-patient interactions were observed and analyzed suggest that patients are not fully comprehending information from medical interviews.

In a study of physician communication with diabetic patients with low health literacy (based on the S-TOFHLA), audiotapes of the physician-patient interaction were observed. [65] In addition to counting the number of new concepts introduced by the physicians (mainly about a change in the patient's medication regimen), the number of times the physicians assessed patient recall or comprehension of the new concepts was recorded (12%, 15/124 new concepts). Physicians only asked patients to restate or interpret 7 of the 15 new concepts, and patients responded incorrectly 47% of the time. However, in none of the cases did the physician perform a second follow-up assessment to ensure a common understanding.

This study assessed comprehension based on oral communication between health care providers and patients. Most studies assess comprehension, knowledge, or literacy based on print materials, and occasionally based on videotapes. The results of the study by Schillinger et al. [65] suggests that physician-patient communication is not necessarily conducive to patient learning. However, the study only assessed the communication from the physician-side of the interaction. Whether patients sought more information during the interaction was not assessed, e.g., number of times the patient asked questions or for more information. This may be an important indicator of patient health literacy in relation to health promotion and empowerment.

2.8.2.3. Self-reported Reading Ability

Some measures of self-reported reading ability (that were designed to be instruments for screening) have already been reported in the Health Literacy Measurement Instruments section. This section reports on other measures of self-reported reading ability that have been studied. Some of these measures include questions about patients' ability to read a newspaper, [57] patients' ability to read forms and other written materials given to them by health providers, [57] [66] [67] and whether help is needed from others to read materials (e.g., from the hospital, [57] instructions such as on a medicine bottle [4] or medical forms. [67]

Based on the research evidence, self-reported reading ability appears to be moderately correlated to, but may not be an accurate measure of, (health) literacy.

Some studies have found positive associations between self-reported reading ability and health literacy. Moderate correlations have been found between self-reported reading ability and health literacy, based on comparisons with either REALM [68] or TOFHLA. [57] [69] Patients tended to report a higher reading ability than was reflected in their responses to the REALM and the TOFHLA. Another study found that self-reported difficulty in reading medical forms was a predictor of TOFHLA score using a multiple regression analysis. [67] One study found a strong correlation between reading ability based on the ABLE (Adult Basic Learning Examination) and how well subjects perceived they understood the patient drug information materials. [70]

Self-reported reading ability has also been found to be an inaccurate measure of general reading performance. A study on general functional literacy (not health literacy) reported that self-reported reading ability was not an accurate measure of difficulty for illiterate adults. [71] Self-reported rating of difficulty in the reading of passages was a small contribution in a discrimimant analysis of different indicators of difficulty for illiterate adults. It is possible that inaccuracies found for general literacy may also be found for health literacy and self-reported reading ability.

There are various explanations for observed differences in people's self-reported skills and their performance, including the ability to read what they need in their daily lives, not being able to recognize that they have poor literacy skills, and providing socially desirable answers which may also be associated with shame. [27] Those who have low literacy may not perceive themselves as such, or may not perceive this to be an issue or limitation in their lives because they have found ways to overcome their difficulties. A qualitative study of 36 patients with low literacy at a public primary care clinic in Hong Kong showed that there were diverse views on whether low literacy was perceived to be a problem. [72] The respondents identified that they were able to overcome their difficulties (and were therefore able to function in society) using various methods. Another study of eight adults with low literacy and their use of the Internet (after some training) showed that although these subjects could not answer the information-seeking questions posed to them, they still did not feel uncomfortable with searching or with not being able to answer the questions correctly (if they were even aware that they were not able to answer the questions). [73] Because the subjects did not perceive that they had problems in seeking information, it was not surprising that they were not hesitant to express that they wanted to receive more instruction about doing searches over the Internet.

2.8.2.4. Knowledge

The research evidence on the correlation between health literacy and health knowledge is mixed. However, health knowledge appears to be positively correlated with health literacy (more so than self-reported reading ability). Some limited evidence suggests that the relationship between health literacy and health knowledge may not be linear.

Strong positive correlations have been found between health literacy and health knowledge, using the REALM, [54] [74] [75] [76] [77] and the TOFHLA or S-TOFHLA. [78] [79] [80] [81] [82] [83] WRAT, [84] The use of a measure of general literacy, the reading test portion of Adult Basic Learning Examination (ABLE), in another study also found strong correlation between ABLE score and comprehension of reading materials. [70] Health literacy was often found to be the strongest predictor of patients' knowledge (if not the only predictor), even after controlling for other variables, such as age, ethnicity, education, etc. In support of the use of knowledge questions to measure health literacy, research on the measurement of general functional literacy has shown that comprehension, based on discriminant analysis, was a valid indicator of difficulty for illiterate adults. [71]

There is also evidence to suggest that health literacy may not be so strongly correlated with health knowledge. A moderate correlation between patients' scores on the Prostate Cancer Knowledge Questionnaire and REALM scores was found in one study. [85] Another study found that the REALM did not predict performance on either of two over-the-counter (OTC) pain reliever knowledge tests, and that the S-TOFHLA test predicted performance on one, but not the other, OTC knowledge test [86]

The evidence about whether a linear relationship exists between health literacy and health knowledge is mixed. In a study of polio information pamphlets given to parents who brought their children in for immunization at clinics, the parents' knowledge after reading the pamphlets was compared with REALM grade reading levels. [87] Only in parents with higher reading levels, i.e., grades 7-8 and grades 9+, were knowledge scores higher. This was not observed in parents with lower reading skills, i.e., grades 1-3 and grades 4-6. On the other hand, another study found no difference in colon cancer knowledge gain after intervention (health information materials) between patients with different literacy levels based on WRAT-2 scores (grade 7 or higher and lower than grade 7). [88] These results are inconclusive, for two reasons: 1) the limited amount of research; and 2) the categorization of literacy into only two levels in the latter study.

2.8.2.5. Self-reported Life Circumstances and Practices

Asking people about their life circumstances and practices related to literacy or health literacy has been suggested as a less intimidating way than task performance for identifying those who are low literate. A limited number of studies found that these types of measures may be correlated with health literacy. However, the practicality of asking these questions across different settings is questionable.

A study of 163 parents of children aged 12 to 24 months presenting for routine care at various clinics tested 7 screening questions for identifying parents with adequate health literacy (S-TOFHLA). [89] Only two were found to be associated with *adequate* health literacy – more than 10 adults' books or more than 10 children's books in the home. Although these conclusions seem persuasive, the authors did not discuss the following limitations. First, the significance levels of the statistical tests for these two screening questions were only marginal ($p=0.02$ – 0.05). Second, the Pearson correlation coefficient between the number of children's books and S-TOFHLA scores was only 0.198, which was a relatively low correlation. Third, the limitations of using these two questions as proxy measures of health literacy were not discussed (e.g., were there older siblings in the family, accuracy of caregivers' estimates about the number of books in the home, practicality of asking these questions at a doctor's office, etc.). Fourth, it may be more practical to identify those who have low literacy rather than those who have adequate health literacy, if the point of screening is to apply interventions for those who have low literacy. Given these limitations, the persuasiveness of the findings is questioned.

In another study of primary caregivers of preschool children seen in a primary care setting, three measures were found to have statistically significant associations (chi-square) with REALM results (dichotomized high/low literacy groups). [90] The three items were: 1) how many years of school have you completed (<12th grade); 2) if parent, does your child’s other parent live with you (no); and 3) do you ever read books (no). The authors suggested that in practice, one may wish to ask items associated with low literacy rather than actually measure literacy per se. This may be useful, not as a diagnostic tool of illiteracy, but as a means of initial risk stratification to be followed by an offer of services.

2.8.2.6. Education

Education level refers to the highest level of education completed, or number of years of school completed. The data are mostly obtained through self-report. A natural assumption is that people with more education will also be more health literate. This assumption has been widely tested in studies that have compared education level and (health) literacy measured using a variety of instruments. Education appears to be positively, but at most only moderately, correlated with health literacy, and is not an accurate measure of health literacy. Self-reported education level overestimates health literacy level, usually by several grade levels.

Many studies have found that education was correlated with health literacy. A statistically significant positive, and often moderate (0.3 to 0.7 range if using a correlation coefficient), association between education level and (health) literacy has been reported in many studies that have compared the two. [54] [91] [92] [57] [93] [78] [94] [95] [96] [69] [43] [79] [80] [97] [98] [99] [100] [8] [101] [55] [34] [102] [103] [67] [38] [104] [8] Education has also been found to be the only background variable that significantly predicted scores for each of the reading comprehension and numeracy components of the TOFHLA. [105] Another study on maternal schooling, literacy skills and health literacy skills (comprehension) in rural Mexico, rural Nepal, and urban Zambia reported that reading skill (from the school years) was retained during the childbearing years (adulthood), and that maternal schooling was correlated with comprehension of health messages. [106] The authors suggested that literacy could be considered part of the pathway through which the schooling of women affected the acquisition of health information and health care practices, and that literacy skills could be acquired even in low-quality schools. Another study of Spanish-speaking Latino parents with limited English proficiency found that higher levels of education were positively correlated with better scores on comprehension questions in either English or Spanish, although the parents did not score well on the comprehension questions in general, whether in English or Spanish. [107] This suggests that comprehension, regardless of language (English or Spanish), was positively associated with education, i.e., education has a cross-language effect. Finally, a pooled analysis of 85 studies in the medical literature in the U.S. found that low literacy was associated with less education [10]

Other studies have found that education was an inaccurate measure of health literacy. Some researchers found that education level alone was not a reliable predictor of (health) literacy. [57] [66] In one study, use of educational level alone as a measure of literacy would have mis-classified more than 10% of the subjects compared to measures such as TOFHLA. [38] Another study of persons living with HIV/AIDS found that measuring education alone without measuring health literacy would have failed to identify more than half of the lower health-literacy persons in the sample. [79] In other studies, self-reported education level was several grades higher (usually by at least 3-4 grades) than grade levels based on performance on reading ability and/or reading comprehension [108] [109] [56] [88] [110] [111] [112] [113] [114] [115] [116] although only in some cases was this tested for statistical significance. [52] [117] [99] [118] [119] [120] [121] [104] A review of literacy testing in health care settings found that patients' education level, although highly correlated with reading grade level and level of functional literacy, could not accurately predict a person's reading level or functional health literacy. [37]

A limited number of studies found no correlation between education level and literacy. A study of 53 outpatients of a psychiatric emergency service found that the last grade completed in school was not correlated with WRAT-3 scores (general literacy). [122]

Some researchers of general literacy have suggested that education level may be a better predictor of oral language skills than of reading comprehension of print materials. [123] It was suggested that this may be due to children acquiring school-based oral language skills, but not necessarily acquiring reading skills because these are more difficult to acquire.

2.8.2.7. Use of Nutrition Labels to Measure Health Literacy

There have been several studies that assessed comprehension of nutrition labels. Although the studies did not use the term “health literacy,” we included these studies because nutrition labels serve as a scenario in which various skills – document literacy, comprehension, and numeracy – can be assessed. In addition, nutrition labels are on almost every food packaging (common), and also provide a health-related scenario that is neither medical nor clinical. The findings from the studies suggest that a variety of tasks, including quantitative tasks, are associated with the interpretation of nutrition labels and that task difficulty influences how people perform. None of these studies used a health literacy measurement instrument such as the REALM, TOFHLA, etc.

Studies in the UK and the US have found that respondents tend to perform well on locating and retrieving information (finding and understanding information), and less well on “manipulating” quantitative information, e.g., simple diet planning calculations. [124] [125] [126] [127] Patients may have been confused between calories per serving and total calories per package, and this confusion was correlated with lower educational levels and with the presence of cardiovascular heart disease. [127] This confusion therefore would not lead to informed dietary choices. A review of research (mostly in North American or northern Europe) on consumer understanding and use of nutrition labeling concluded that the task required of consumers affects how well they can understand and use nutrition labels. [128] Most subjects were able to retrieve simple information and make simple calculations. However, their ability to interpret the label accurately was reduced as the complexity of the task increased.

2.9. Health Literacy in Specific Population Sub-Groups

Findings from large-scale literacy surveys suggest that the distribution of literacy in the population varies based on geographical location and population sub-groups. In this section, we discuss some findings on the distribution of health literacy in population sub-groups, including older adults, gender, and culture or ethnicity and immigrants.

Weiss [14] reviewed multiple studies on literacy and health literacy and concluded that there were some population groups in which limited (health) literacy were most common. These groups were the elderly, minority groups, persons with limited education, immigrants, the poor, the homeless, prisoners, and military recruits. From another perspective, low literacy among adults can be classified into groups using data from the NALS in the U.S. – those who have not acquired basic print skills, those who have not become fluent and automatic readers, those who did not acquire high school levels of knowledge and vocabulary, and non-native speakers of English (which can further be sub-classified as those with adequate native language education, and those with limited native language education). [129] An analysis of English-language peer-reviewed studies that measured literacy among patients or consumers in a health context or used the REALM or TOFHLA found that limited health literacy skills were common in the study samples, and that segments of the U.S. population that could be considered at greatest risk for limited health literacy are those that were reported to have higher rates of limited literacy in the NALS, e.g., older adults.

2.9.1. Older Adults

As mentioned earlier, older adults on average have scored lower than younger adults on tests of general literacy, even after taking into account differences in education level. The evidence for age and health literacy, however, is mixed. Some studies reported significant negative correlations or associations between age and measures of health literacy or general literacy in health settings, sometimes even after various potential confounders (e.g., education) were taken into account. Other studies reported no significant negative correlations or associations at all, or found no correlation after potential confounders were taken into account.

Negative correlations or associations between health literacy and age have been found using the TOFHLA, [57] [93] [95] [69] [100] [103] [78] the S-TOFHLA, [96] [43] [97] [98] [130] the REALM, [75] [102] and the HALS [34] A pooled analysis of 85 studies in the medical literature in the U.S. also found that low literacy was negatively associated with being older. [10] A comparison of self-reported difficulty understanding medical information and literacy, as measured using the Instrument for the Diagnosis of Reading (IDL), showed that low-income older adults with low-literacy were more likely to report having difficulty. [66]

Negative correlations or associations between health literacy and age have been found, even after accounting for potential confounders (e.g., health status, visual acuity, cognitive function, education, etc.), using instruments such as the S-TOFHLA. [131] [55] Age has also been reported to be negatively correlated or associated with education, i.e., older adults tended to have less schooling, [103] which suggests that education may be a potential confounder with age on health literacy.

Some studies found that age was no longer negatively correlated or associated with health literacy after accounting for confounders such as education, using measures such as the TOFHLA, [38] and comprehension of fifty medical words. [40] Although age along with other variables (education, gender, and race) were found to be significant predictors of PIAT-R score, only 39% of the variability in PIAT-R scores could be predicted by these four variables – these variables only inaccurately predicted PIAT-R scores. [104]

Some studies did not find negative associations between education and age, using instruments such as the REALM, [132] [63] [101] [38] [133] and the WRAT-3. [122] Another study that looked at age as one of multiple independent variables (visual acuity, educational level and self-reported difficulty reading medical forms) and TOFHLA as the dependent variable found that age was marginally not statistically significant (p=0.06) as a predictor TOFHLA score. [67]

The mixed findings about the association between age and health literacy is probably due to differences between studies, such as the geographic location and setting, the age range of the study subjects, the potential confounders that were measured, and the measures of health literacy that were used. Education is the most obvious confounder, as older adults in general have been reported to have less formal schooling. The authors of a study on information-seeking behaviour have also suggested that differences in task performance may be explained by age-related changes in information-processing ability. [134] Another longitudinal study using WRAT-3 to assess literacy in 136 older adults found that elders with both high and low levels of literacy declined in immediate and delayed memory over time. [135] However, the decline in low literacy elders was more rapid. The authors suggested that literacy, or learning to read and write, may fundamentally change the functional architecture of the brain such that it may actively compensate for age-related changes. Other authors have suggested that reading skills may be the last to be lost in dementia and therefore dementia as a confounder may be small, although dementia is not usually controlled for in studies. [104]

2.9.2. Gender

The findings about the relationship between gender and health literacy or general literacy in health settings are mixed as well, with some studies finding differences (females generally scored higher than males) and other studies finding none.

Some studies reported that females significantly scored higher than males, using measures such as the PIAT-R [104] and the REALM. [133] One study reported that these differences, measured using the S-TOFHLA, remained even after adjusting for education. [55]

Other studies found no differences between genders, using measures such as the REALM. [102] One study found that these differences, measured using comprehension of fifty medical words, remained even after controlling for ethnic group membership and education. [40] A pooled analysis of 85 studies in the medical literature in the U.S. found no association between gender and level of health literacy [10]

2.9.3. Culture or Ethnicity and Immigrants

Statistically significant differences in health literacy (or general literacy in health settings) have been reported between cultural groups. In some cases, these differences remained even after taking into account confounders such as education. Those who were foreign-born were also reported to have scored lower than those who were not foreign-born. In addition, there may be differences in health literacy scores even amongst “non-White” cultures.

Studies have mostly found that “Anglos” or “Caucasians” or “whites” tend to score higher on measures of health literacy than do other cultural groups, such as “blacks” or “African-Americans” and “Hispanics” or “Spanish Americans” and “non-Whites.” These differences were found using measures such as the PIAT-R [104] and the HALS. [34] A pooled analysis of 85 studies in the medical literature in the U.S. found that low literacy was associated with being black [10] Such differences remained even after taking into account potential confounders such as education, using measures such as the REALM, [102] and comprehension of fifty medical words. [40] Foreign-born adults (immigrants) have also been found to score lower on the HALS than did those born in the U.S. [34] A study in Canada found that patients whose maternal language was neither of the official languages of the country, English nor French (assumed to be immigrants), scored lower on the REALM on average. [8]

Differences in health literacy between “non-White” cultures have also been reported. For example, non-Hispanics (91% African-American) were found to have scored lower on average on the English S-TOFHLA than did Hispanics (93% Puerto Rican). [55]

Some studies found no differences between cultural groups on health literacy scores, using measures such as the REALM. [63] [133]

Culture is relevant to health literacy in a variety of ways. [136] First, cultures differ in the their styles of communication and in the meaning of words and gestures. Second, culture provides a context through with *meaning* is gained from information. Third, culture influences attitudes and beliefs, e.g., what can be discussed regarding the body, health, and illness. It is culture that gives meaning to health communication and therefore health literacy must be understood and addressed in the context of culture and language. Others have also reported on the importance of *meaning* in how people from different cultures conceptualize learning, education, and health, such as for Aboriginals [137] and for immigrants. [138] However, our understanding of different cultures with respect to health literacy, e.g., information-seeking practices, remains limited. [139]

2.9.4. Persons with Low Income

The findings about whether income and health literacy are positively correlated or associated are mixed. Some researchers have found a correlation, while others have not.

Positive correlations or associations between income and health literacy have been reported in studies using the REALM, [92] the S-TOFHLA, [96] [97] and the HALS. [34] One study found that poor reading skills were prevalent in low-income (older) persons, whose average grade level 5.5 was on the Instrument for the Diagnosis of Reading (IDL). [66]

Other studies found no correlation between income and health literacy, using measures such as the REALM [63] and the TOFHLA. [79]

2.10. Various Influences on Health Information Experiences

Earlier, we concluded that the various definitions of health literacy included several skills associated with health information experiences – finding, understanding, evaluating, and communicating health information. There is a vast amount of literature that addresses these skills, but often do not use the term "health literacy" although they may be specific to a health topic. In this section, we highlight some of the influences (e.g., practices, attitudes, etc.) that may affect health information experiences with respect to these skills. The research evidence suggests that these skills are not necessarily mutually exclusive, nor are the various influences that affect health information experiences. For example, various factors that contribute to limited health literacy have been suggested, including system factors (medications, time, self-care, fragmentation of care, and insurance and paperwork), provider factors, and patient factors. [14]

2.10.1. Finding or Being Exposed to Health Information

In a paper that used theories from psychology and sociology to provide a framework for understanding consumer health information-seeking behaviour, various influences were highlighted. [140] Information-seeking behaviour has been found to be influenced by how people deal with stress, who they get information from, and the meaning of the information for the individual seeking the information.

Some insights can also be gained from the literature on the use of the Internet for health information, which may be an important source of health information. An ethnographic study of Internet usage (not limited to health information) in 24 adults with low literacy found that the most frequently identified type of information these adults would use the Internet for was health information. [141] However, using the Internet for health information poses some challenges. Mismatches have been reported between the terms used by consumers and those used on health-related websites, ranging from more basic issues such as spelling to more complex issues such as the mental model of how problems are approached (e.g., consumers view them more anatomically while clinicians view them as a specialty or pathophysiology). [142]

A frequently used and therefore significant source of health information is doctors. However, the exchange of information (related to health literacy) is only one aspect of doctor-patient communication, which also includes creating a good inter-personal relationship and medical decision-making. [143] In one study on doctors' and patients' perceptions of their own and the other party's communication competence, both doctors and patients agreed that doctor competence was based on the ability to adequately explain aspects of the medical problem, verify that patients understood the information, and explain technical information that patients can understand. [144] However, patients placed more weight on obtaining information about their medical problem than doctors placed on providing such information. Although relational (affective) aspects of the doctor-patient interaction are not information exchange per se, both doctors and patients felt that communication competence was affected by relational aspects (but not to the extent as information exchange aspects) such as a friendly trusting atmosphere, doctors showing care and interest. However, patients placed more emphasis on these relational aspects than did the doctors. Patients also placed more emphasis on explaining their health conditions and seeking information than did doctors. Neither doctors nor patients included relational aspects as part of their competence judgments of patients. This suggested that both doctors and patients felt that the onus of relational work falls on the doctors rather than the patients. There seems to be both agreements and disagreements between the doctors and patients on what aspects of doctor-patient communication are important and how important they are. This in turn may affect how doctors and patients behave during medical visits.

Health literacy itself has also been suggested as a predictor of information-seeking practices. In one study, S-TOFHLA score was found to be a patient-related predictor of their interest in both reading and seeking written information about their prescription medicines. [145] Other patient predictors of interest in reading information were patients’ coping style and occupation, while other predictors of interest in seeking information were their disease state (pain/rheumatology condition vs. hypertension) and health locus of control.

There is also variation in how people prefer information to be communicated to them. Research on the preferences for health information by 140 cancer patients using complementary and alternative medicine found Caucasian patients preferred written scientific information while non-Caucasian patients preferred verbal person-to-person communication. [146] In addition, a higher educational level was closely associated with written scientific information, while a lower educational level was associated with verbal interpersonal communication.

There is some evidence to suggest that self-perceived health literacy (vs. task-oriented health literacy) may influence an individual’s information-seeking practices. A study of Internet use in eight adults with low literacy reported that although the subjects did not perform well on the tasks (seeking information over the Internet to answer some questions), they nevertheless did not perceive that they did not perform well (self-perception) and were not daunted to receive even more instruction on how to search for information on the Internet. [73]

The findings discussed above suggest that finding (or being exposed to) written information may be influenced by multiple person-related variables, including health literacy, as well as variables external to the individual. It is possible that self-perceived health literacy may influence information-seeking practices, e.g., someone who believes that he/she has low health literacy may not be motivated to seek information.

2.10.2. Understanding Health Information

Whether health information is understood is broader than just technical reading ability. Dray and Papen (2004) [147] proposed a rethinking of the concept of health literacy, which is dominated by narrow notions of a set of technical skills (such as reading and understanding) in isolation of context. They suggested that attention should be shifted to people’s meaning-making abilities (as an active participant) rather than their skills deficits, and that health literacy should be thought of as being situated within institutional structures that both shape and are shaped by each other. Therefore, health literacy should be thought of in light of the practices and social relationships around (written) health information. The authors report the findings from an exploratory study using ethnography (studying social phenomena in real life contexts) and linguistic textual analysis of a celiac information leaflet. The data provided insights into health literacy practices such as the role of health texts in health care settings (e.g. purpose, as mediators of communication between patient and doctor), the patient’s information-seeking activities, and the patient’s engagement with and reaction to the content of written information. These findings align with the concept of culture and the meanings that individuals from different cultures derive from health information.

The research evidence also suggests that informational *content* influences comprehension. In a paper that reviewed the literature on comprehension monitoring (mainly of text), various content- or message-specific influences on comprehension monitoring were found. [148] Comprehension monitoring refers to one’s knowledge about cognition of one’s reading comprehension. Message-specific influences on comprehension monitoring included the words and clauses used, the degree of detail of the information, and inconsistencies in the information presented. The literature that was reviewed was drawn from the fields of education, psychology, and literacy. Insights from the literature on risk communication suggest that how patients interpret verbal probability terms (related to health numeracy) is associated with age (older patients perceive risks to be greater), outcome (death is perceived as being more rare), and the numerical scales used. [149] A review of the literature on risk perception in patients who face substantial treatment risks found reported that risk perception (understanding) was guided by various influences, such as how easily an event is brought to mind, immediacy of an effect, novelty, how catastrophic an event would be, optimism bias (more risk for other people than for oneself), coding risks as simply dangerous or safe (but not in-between), whether risks were presented with a degree of uncertainty (range of possible values), whether risks are presented in terms of survival data or mortality data, format in which risk is presented (absolute risk, relative risk, number need to treat), and the meaning or significance of the risk for the patient. [150]

There are many studies that have compared the health literacy or general literacy levels of individuals with the readability of written materials on a variety of health topics. The reading level of materials has often been assessed using one or more of the instruments, such as the SMOG Readability Formula, the Flesch(-Kincaid) Index, the Fry readability method, and the Gunning-Fogg Index.

Most studies have found that the reading level of materials, which were mostly at grade 9 reading level or above, on average were higher than the reading ability of many of the individuals studied. [84] [52] [151] [115] [117] [110] [119] [111] [152] [87] [99] [112] [153] [154] [114] [122] One study reported that most of the study subjects, who had higher overall reading level measured using the REALM, would be able to read all of the sampled written clinic materials. [155] The research evidence is mixed on whether readability affects the responses of participants on health literacy test instruments. Comprehension/knowledge appears to improve when materials are written at lower reading levels. However, the influence of the readability of materials on knowledge gain for subjects at different literacy levels remains unclear. Some studies have reported greater improvements in knowledge in subjects with higher literacy than in those with lower literacy, assessed using the WRAT [118] and the REALM. [108] [156] Other researchers found greater understanding in subjects with higher literacy levels than those with low literacy (assessed with ABLE), but only for materials written at a higher reading level, and not for materials written at a lower reading level. [70] On the other hand, one study found the greatest improvement in comprehension in subjects with low literacy, assessed using self-reports (e.g., assistance required, frustration). [157] Another study found no difference in subjects’ comprehension of two consent forms written at different reading levels. [156] The contribution of reading ability (assessed using ABLE), grade level of the materials, and the interaction of the two factors, on comprehension of patient package inserts has been tested. [70] Although both factors are significant, comprehension depended most on reading ability (24% of the variance explained), and less so on grade level of the materials (8% of the variance explained). The interaction of the two factors was not significant.

There is evidence to suggest that comprehension may also be influenced by how informational content is presented visually. Printed materials are more than just text on paper, are formatted differently (e.g., text size, spacing, font, etc.) and may include pictures or charts, or use different types of paper. The significance of how written health information is presented is that it may aid in attracting people to read the materials in the first place, and in helping people to remember what they read. The use of illustrations has been shown to increase the likelihood by 1.5 times that patients would score at or above the median in their understanding of emergency discharge instructions. [158] Other studies have reported on patients' preferences on the presentation of written health information. In addition to reading ease, preferences have been based on colourful printing, illustrations (which aided memory recall of information), the question-and-answer format, and the thickness of the paper (which wasn't easily torn). [87] Another study found that most respondents preferred a sans serif (Arial) font style) and larger font-size (14-point), regardless of their age, gender, REALM grade equivalent, reported education or income (based on logistic regression). [159] On the other hand, illustrations have been found to have little to no effect on improving patients' comprehension of medication labels. [9]

Comprehension may also be influenced by individual factors. For example, a study of cancer outpatients reported that misunderstanding about cancer and its treatment appeared to be predicted by patient denial (of having the disease and of its impact) and by patient ratings of the clarity of the information received, which the authors suggested was related to the doctors' ability to communicate effectively. [160]

The findings described above highlight the importance of how information is communicated, and the meaning that individuals derive from the information, rather than focusing primarily on the technical skills of the individual seeking information.

2.10.3. Appraising Health Information

Some studies have thrown some light on the process of appraising health information. Although limited to online health information, one study found that the assessment of credibility was higher if the author of the web site was more of an expert (expert, moderate expert, low expert), and if the respondent was already knowledgeable about the health topic (no interaction effect was found). [161] This suggests that individuals may use the perceived expert level of the source of information as a means of appraising the credibility of health information. This also suggests that the one's assessment may also be affected by how much one already knows about the health topic.

2.10.4. How Do Individuals with Low Literacy Find, Understand, Appraise, and Communicate Health Information?

There is evidence to suggest that the process of finding, understanding, appraising and communicating health information by those who have low literacy may be fairly superficial or not as detailed. In a study of Internet usage by eight adults with low literacy, the subjects were limited in how they articulated their search for information using a think-aloud procedure. [73] In addition, they did not search for information beyond the first page of search engine-generated results, and they selected ad-sponsored sites over search engine-generated links. Doak and Doak [162] suggested that there are two reading characteristics about individuals with low literacy that are often overlooked – that they skip over words rather than looking them up, and that they take information literally rather than interpreting them in context.

Another study on Internet usage (not limited to health information) in twenty-four adults with low literacy reported different approaches that the respondents used to determine their trust of online information. [141] Some of the approaches were based on common sense or logic, such as comparing online information with other sources (e.g., books) or verifying online information with personal experience. Other methods included the level of detail in the information, the number of links to other information and websites, whether the information sought was discovered, and the assumption that the information was from a professional because it was available on a website. The subjects rarely based their trust on the actual informational content, and used other indicators (e.g., number of links to other websites) on which to base their trust. The researchers did not assess the “accuracy” of the informational content.

Some researchers have suggested that patients’ assessment of physicians’ communication may be positively correlated with the patients’ level of health literacy (based on S-TOFHLA). [98] Patients with poor health literacy tended to report the quality of their interaction with the physicians to be lower, especially with respect to physicians’ explanations of the condition and care, and physicians’ elicitation of the patients’ understanding of the explanations. The possibility that the physicians’ communication (sub-consciously) may have varied depending on the patients’ literacy level was not measured. Nevertheless, these findings suggest that patients with low literacy may *perceive* their interactions with physicians to be of lower quality than do more patients with higher literacy skills.

2.10.5. Association of Other Variables with Health Literacy

Associations have been reported between health literacy (measured using the HALS) and several variables related to health status, reading practices, and civic engagement. [34] The authors found that adults who reported that they did not have any health conditions that restricted their ability to work or attend school (health status) on average had higher HALS scores than adults in any of the other health status groups. Adults who reported little prose reading and no document reading (reading practices) on average had the lowest average HALS scores. Adults who tended not to vote or use a library (civic engagement) on average had lower HALS scores than adults who did. In addition, adults whose primary source of information was TV on average had lower HALS scores than adults who got information from a broad range of sources.

Another study reported that the perceived overall health of patients with low literacy in the study sample was poorer on average than that of high-literate patients based on the REALM, although this difference was not statistically significant. [8]

2.11. Health Literacy And Outcomes

Studies on health-related outcomes associated with literacy and health literacy have used two approaches. The first and more common approach uses statistical techniques to find significant associations between (health) literacy levels and different outcome variables (which may be self-report, but the respondents were not asked to directly state how health information made a difference in their lives). The second less commonly used approach is qualitative and solicits self-reports of how health information has made a difference. We present conclusions about health literacy and outcomes from several review papers from 2004 and 2005. The findings about whether health literacy is associated with outcomes have been mixed – some outcomes have been associated with health literacy while others have not. The pathways between health literacy and outcomes remain unclear.

A review of English-language peer-reviewed studies that measure literacy or use the REALM or TOFHLA among patients or consumers in a health context found that: 1) patients with chronic illness who had lower health literacy scores had less knowledge of their chronic illness and its management than those with higher scores; 2) patients with lower health literacy scores had higher hospitalization rates than those with higher scores; 3) patients with lower health literacy scores were more likely to report their health as poor (self-reported health status); and 4) patients with lower health literacy scores were less likely to use preventive services. [11] In addition, more recent results suggest that higher health-care costs of patients with limited literacy may be associated with their higher rate of hospitalization and use of emergency services. It has been suggested that low literacy magnifies health disparities and places an additional cost burden to the health care system. [163]

Weiss [14] concluded that findings from various studies have demonstrated that individuals with limited literacy have less health knowledge, lower health status, higher utilization of health services, and higher health costs than their more literate counterparts, and may jeopardize personal safety (e.g., errors in self-administration of medications).

In a critical review of the literature on literacy and health outcomes, DeWalt and Pignone [164] concluded that literacy is related to knowledge and comprehension, hospitalization, global measures of health, and outcomes of some chronic diseases. They caution however that in many cases, the evidence is mixed and depends on the study design and method of analysis. In addition, the relationship between literacy and health outcomes became weaker and often statistically non-significant after controlling for potential confounders such as education or socioeconomic status. Most of the studies were cross-sectional and thus a cause-effect type of relationship between literacy and health outcomes could not be concluded. Therefore, the authors suggested that the specific avenues between literacy and those health outcomes need more exploration.

We found one study that provided stronger empirical evidence of a link between health literacy and outcomes. A randomized control design was used to examine the relationship between communication skills training for patients (n=150) and their compliance with recommended treatment (medications, behaviour, follow-up). [165] The patients were randomly assigned to one of three groups: 1) trained group who received a training booklet that included instructions on communication for information provision, seeking, and verifying; 2) informed group who received a brief written summary of the training booklet; and 3) untrained group who received no communication skills intervention. The authors found that trained patients were significantly more compliant overall than untrained or informed patients, and that informed patients were more compliant overall than untrained patients. This study differs from many health education efforts in that it focused on *communication skills* (which are considered to be an aspect of health literacy) rather than on the uptake of *health knowledge*.

When self-reported outcomes as a result of health literacy were explicitly solicited from study subjects, positive outcomes have been identified. A study on adolescents in the US and UK and their use of the Internet for health information reported that the adolescents themselves identified the following ways in which acquiring health information had made a difference in their lives – not taking performance enhancers after finding information about their pros and cons, and starting healthier regimes after finding information about diet and exercise. [33]

2.12. The Experiences of Individuals with Low Levels of Literacy

There are a few studies that have explored the experiences of individuals with low literacy, from their own perspectives. These studies sought to throw light on the difficulties these individuals face, how they are affected by their low literacy skills, and how they cope with their low literacy. Individuals with low literacy are not necessarily people with English as a second language.

Individuals with low literacy skills may feel shame or embarrassment that they can not read health-related materials, and in turn feel intimidated or anxious when seeking medical care. [166] [167] [168] In addition, low literacy may be mis-interpreted by other people as stupidity. [167] [168] Some patients with low literacy have expressed the fear that exposure of their low literacy skills would result in decreased self-esteem, self-concept and social acceptance. [168] One of the main findings of the IOM report on health literacy was that the shame and stigma associated with limited literacy skills are major barriers to improving health literacy. [11] This shame may be reinforced by health care providers who become frustrated or angry when patients with low literacy can not complete a form or read instructions. [166]

Most studies on health literacy and outcomes have tested for correlations or associations at a cross-section in time, or have used interventions that relate to how information is presented, rather than improving the *skills* of the study subjects. Therefore, these studies can not claim to provide evidence of a cause-effect relationship of health literacy on outcomes – only associations can be reported. This gap in knowledge may be supplemented by qualitative data such as the first-hand experiences of individuals with low literacy or others involved in the health of the individuals with low literacy, e.g., physicians. Low literacy has been reported by individuals with low literacy skills themselves to be a cause of negative health-related outcomes. For example, patients with low literacy have reported that they have had serious medication errors because they could not read labels [166] or prolonged their illness because it had not been dealt with appropriately. [167] In addition to problems with reading written materials, individuals with low literacy have also reported difficulties explaining their health conditions to their doctors (verbal communication skills). [167] Some of the methods that individuals have used to deal with their low literacy have been deterrents to appropriate care or excluded the individual as a decision-maker in their own care, such as avoiding going to the doctor because of difficulties associated with completing paperwork, making up answers to questions on medical forms, signing forms without really understanding them, and not asking questions when information was not understood. [167] [168]

Patients with low literacy often rely on non-written information to deal with their inability to read, such as verbal explanations, visual cues, demonstrations of tasks, using a friend or family member as a surrogate reader, having health care providers who were sensitive to their low literacy, or making the most of it themselves (e.g., using their own symbols or comparing with their own experiences). [166] [72] However, relying on others may also bring a sense of dependency on others. [167]

2.13. Approaches to Improving Health Literacy and Outcomes

Health and access to health care are, in principle, rights that all individuals should have. Health literacy is an essential life skill for individuals, is a public health imperative, is an essential part of social capital, and is a critical economic issue. [25] There are also legal arguments as to why health literacy should be improved. [169] From the health system context, several emerging themes and issue are relevant to health literacy: 1) chronic disease care and self-management (patients need to learn and understand how to manage and treat chronic disease); 2) patient-provider communication (failure to communicate can lead to unfavourable outcomes); 3) patient safety and health-care quality; 4) access to health care and preventive services; 5) provider time limitations; 6) health expenditures; and 7) consumer-directed health care. In addition, legislators and courts are beginning to respond to issues raised by limited health literacy. Two areas of health law and health care that are particularly important to health literacy are the standard of reasonable care (care rendered in accordance with the standards of the profession, e.g., lack of patient understanding would expose the patient to an unreasonable risk of harm) and the informed consent process (physicians are obligated to inform patients of the risks, benefits, and alternatives to undergoing or refusing to undergo the treatment recommended by the physician).

The improvement of health literacy and outcomes can be approached from various (not necessarily mutually exclusive) perspectives: 1) from immediate influences such as the individual seeking or being exposed to health information, and the communicator (source) of health information, and 2) from other important influences such as the determinants of health (e.g., education, culture, social environment, etc.), the health system, communication technology, etc.

Different approaches to health literacy in the health system have been identified: 1) provision of simplified/more attractive written materials (the most commonly reported approach); 2) technology-based communication techniques (e.g., videos, CD-ROMs, and interactive multimedia programs); 3) personal communication and education (e.g., classes or health education sessions for patients, etc.); 4) combined approaches; 5) tailored approaches (e.g., culture); and 6) partnerships. [169] In addition, the training of educators and providers, which cuts across all the categories of approaches listed above, is also an important area of activity for health literacy. The samples of interventions that were reviewed suggested that the effectiveness of the interventions on outcomes was mixed (e.g., knowledge, comprehension, adherence, etc.).

A non-extensive review of some studies in the English-language peer-reviewed health literature that investigated the effect of an intervention in a community-based setting found that results of the interventions were mixed. [136] The interventions in the studies reviewed included both those aimed at improving the health-related skills of individuals (e.g., patient education) and those at improving how information was communicated (e.g., modified written materials). Generally, the interventions were reported to have been effective on some of the outcomes measured, but not on others, or not at all.

Although the health system seems to be the most obvious place for strategies to improve health literacy and outcomes, health literacy is broader than the health system and therefore health literacy strategies outside the clinician-patient relationship have been proposed. [170] The following entities can also play a role – insurers, employers, advocacy organizations, governmental and social service agencies, and others. For example, insurers (in the U.S.) could provide insurance premium discounts to non-high school graduates who successfully complete graduate equivalency diploma (GED) programs. Employers could expand workplace literacy education programs to include an emphasis on health literacy. Advocacy organizations could provide health education courses. Governmental and social service agencies could provide health education videotapes for residents of public housing facilities for the poor. Others could include cell phones display screens that provide a “health tip of the day.”

Many health literacy initiatives are often not reported in the academic peer-reviewed literature, especially given that outcome evaluations are often not conducted due to various challenges (e.g., changes may not be evident in limited time frames, etc.). However, these initiatives may be shared within formal and informal networks, as well as at conferences. For example, health literacy initiatives have been shared at both the First (2000) and Second (2004) Canadian Conference on Literacy and Health hosted by the Canadian Public Health Association. [171]

A critical analysis of best practices in literacy and health that were presented at the Second Canadian Conference on Literacy and Health concluded that: 1) some practices assumed to be “best” have not been tested with target populations who are not well served by the health care sector; 2) that most efforts were project-based and had not been absorbed into standard practice; and 3) most examples of “best practice” were for health communication and materials. [2] Thus, it seems even “best practices” have been limited in scope and effect.

Public policies may be developed to promote health literacy. From the Canadian perspective, the following public policies have been suggested: 1) to improve literacy outcomes (e.g., early childhood education and family literacy programs, reduce high school drop out); 2) to improve health literacy; and 3) to reduce disparities by strengthening levels of literacy and health literacy among vulnerable groups. [172]

2.13.1. The Individual

There is general acceptance that the onus of responsibility does not fall solely on the individuals who seek health information, and that the health care of these individuals is a shared responsibility with their health care providers. Being informed is a right and individuals are not passive players. However, this does not necessarily mean that individuals will be motivated to be informed or take an active part in their own health. Although individuals do have different personalities, their beliefs, attitudes, and motivations are often shaped by a complex array of social and cultural influences. In addition, even if an individual is highly literate, he/she may still encounter bureaucratic challenges that make being informed difficult. Nevertheless, individuals should (be encouraged to) take an active role in being informed and taking care of their own health. However, this alone is not appropriate as it places the onus of responsibility on the individual. Therefore, supports for the individual should be provided at the same time (e.g., materials that are easily readable, easier access to information, etc.).

2.13.1.1. K-12 Education

The educational system offers an important point of intervention to improve literacy and health literacy. [173] However, there are significant barriers to successful health literacy education for grades K-12, such as a lack of continuity in health education programs across the age groups and inadequately prepared teachers. In addition, at the post-secondary level, few colleges and universities require or provide education about health for its students. Two strategies that have been suggested for improving health education and literacy in the education system is to invest in preparing teachers to teach health education and literacy, and to incorporate health literacy content into basic literacy teaching. The assessment of health literacy in educational settings can be done through two types of assessments – formative (to inform and shape ongoing instruction) and summative (to determine how well students learned what was taught).

The education system has been identified as one of the most important barriers to improved health literacy, yet it is largely out of the control of health professionals. [14] The education system does not always effectively teach its students to read or have basic knowledge of science concepts. It then becomes difficult for these individuals to achieve health literacy.

2.13.1.2. Adult Basic Education (ABE)

Adult basic education (ABE) generally refers to instruction in reading, writing, and math skills from basic through high school level for individuals over 16 years of age. The addition of health literacy or health content in ABE has been increasing [35] [173] and a role of ABE in providing instruction in basic skills as it relates to the health context has been suggested. [27] ABE plays a particularly important role with respect to health literacy for individuals with limited literacy or limited English proficiency. [173]

Health content in ABE must be relevant and culturally not offensive to the individual, and should consider the student's prior knowledge and what the student wants to know, i.e., learner-centred. [27] [174] Unless health literacy training is cast within a problem-solving context, its effect may be loss, as adult education theory maintains that people prefer information that is relevant to their current situation, and that people tend to learn better in an open and encouraging environment. [173] There appears to be support for contextual health information in ABE from both learners and instructors. [174] However, there is little empirical evidence to suggest that contextual information in ABE (at least for cancer control) leads to improved knowledge, behaviour, or outcomes. This is an area that future research can help us better understand the role of health literacy in ABE.

There are two advantages to recognizing an increasing role of ABE and health literacy with each other. First, from a research perspective, ABE provides a practical real-world experience rather than a study setting created by researchers. Second, ABE provides opportunities for improving health literacy *skills* (intervention), especially for those who are more likely to be have low literacy, e.g., people who did not complete high school, immigrants.

2.13.1.3. Self-Expression and Empowerment

The concept of empowerment is inherent in health literacy and health education. While *knowledge* uptake is an important aspect of many health education efforts, there are also examples where improving the information and communication *skills* of individuals are a primary focus. The premise of such efforts is that individuals will develop the skills and confidence to be active and critical participants in their own health and health care. Various approaches have been used, but all give control to the participants to express themselves, and provide an opportunity for both the participants as well as others (e.g., clinicians, etc.) to learn from the experience.

The development of learner-developed materials is one approach to empowering learners. A report of four case examples of this approach in various locations in northeastern U.S. suggested that this approach was feasible and led to positive outcomes for both the learners who helped develop the education materials, as well as other members of their communities who were able to identify with the materials produced. [175] Facilitators of the process and learners should both be cognizant of the following aspects of the approach: 1) initiation (who will participate and what authority will they have over the form of the material): 2) design (form and content); 3) production (decisions about the final product and its distribution); 4) utilization (who controls the distribution); and 5) evaluation (reflection on what was done and learned from the experience). Although this study was focused on health education, the learner-developed approach has the potential to enhance the skills (including health literacy) of learners, and to improve the communication of health information to other community members who are able to better identify with the content of the materials.

Another study reported on the use of Video Intervention/Prevention Assessment (VIA), where young people with chronic medical conditions used visual illness narratives to teach clinicians about their experiences and needs. [176] Young people learned to express themselves through media and became more observant of how they managed medical conditions and lifestyle choices (critical self-reflection). The documented experiences captured important information and insights (e.g., social and environmental influences) that were not accessible to traditional research techniques. It was suggested that VIA increases the health literacy of both its participants and the clinicians who serve them.

2.13.1.4. Lifelong Learning

Learning does not end once individuals are finished formal or institutional education. Learning is a lifelong process. Not only do we need to better understand the links between education and health, but also between lifelong learning and health and how we can build and support adult education and training systems that support lifelong learning. [172] Although health literacy may be related to highest level of education, health literacy skills may also be improved via lifelong learning experiences although they are not considered to be formal education.

2.13.2. Providers and Communicators of Health Information

Approaches to health literacy can also focus on providers of health information (access), as well as communicators of information (content and presentation), which are not necessarily mutually exclusive.

2.13.2.1. Doctors

Health care providers are an important and frequent source of information for many people. How aware are health providers and professionals of health literacy issues that patients may have? Some researchers have studied this aspect with respect to health literacy. In general, health care providers and professionals have some awareness about issues of low literacy in patients. Training may help raise more awareness amongst health care providers and professionals. However, the benefits of increased awareness have been questioned, especially if health care providers and professionals do not have the supports to address issues of low literacy in patients.

In a study that included a survey of 64 physicians in California, most of the physicians believed that adults with low literacy generally experience lower quality care than other patients. [167] It was also recognized that low literacy in patients may lead to decreased compliance, increased risk for patients, and increased liability for physicians. However, few physicians felt that they were equipped to effectively respond to patients with low literacy, and reported some negative outcomes (such as death or delayed care) as a result of patients not being able to read. In the same study, a survey of 16 hospital administrators found that these hospital administrators were concerned about low health literacy, but few of them indicated that they fully grasped how much this affected both health care providers and patients with low literacy.

Without training, awareness of low literacy in patients may be limited. One study examined 98 Internal Medicine and medical residents’ recognition of low literacy as a potential factor in patient adherence and hospital readmission using two case scenarios – one with clues to suggest limited patient literacy skills (that the patient relied upon his daughter to read his pill bottles and appointment slips) and one without this clue. [177] Few of the residents raised the possibility of low patient literacy even when clues were provided (25%) and even less so when clues were not provided (4%). Only 14% suggested low patient literacy as a factor in readmission or non-adherence, and few recommended educational strategies for those with low literacy.

Training has been shown to raise awareness to improve practices related to health literacy in medical students. A study of 24 family medicine students showed that their knowledge, attitudes and practices with respect to literacy were improved after receiving a total of 4 hours of training in literacy assessment and guidance, including didactic sessions, role-playing and peer feedback. [178] The residents’ average knowledge scores increased, they reported a greater sense of comfort in counseling about childhood and adult literacy, and more reported usually or always asking about literacy milestones and patient-child reading during well-child visits.

However, as mentioned, the benefits of raising awareness of low literacy in patients have been questioned. Notifying physicians about their patients’ health literacy skills may not lead to patient benefits. [61] In addition, physicians may actually feel less satisfied with visits and perceive themselves to be less effective in the visit after being informed of their patients’ health literacy skills. This suggests that even if physicians are aware of their patients’ health literacy skills, this may only serve to point out the barriers that physicians’ may face in communicating with patients with low literacy. Generally, health care providers and health professionals have limited education, training, continuing education, and practice opportunities to develop skills for improving health literacy. [173] In the U.S. and Canada, there are few official requirements or curricula that address health literacy in schools of medicine, public health, nursing, dentistry, or pharmacy, although health literacy may be, but are not systematically, addressed under topics such as patient communication. Health professional associations, such as the American Medical Association, can and have developed programs in professional continuing education in health literacy.

2.13.2.2. Libraries

Both public and medical libraries can be a source of information for individuals. There is a growing body of literature on this topic. Partnerships between medical librarians, public librarians, consumers, and organizations and agencies are possible with communication and collaboration. [179] Medical library outreach projects have included the training of health professionals, public librarians, and consumers to access health information for their own health as well as for the health of others. These have focused on information-searching skills, as well as increasing access to information (e.g., larger book collection, install of computers with Internet access).

2.13.2.3. Strategies For Improving Communication of Information To Individuals

There are some resources that provide practical ideas for improving how health information is communicated, sometimes for specific health topics, especially to individuals with low literacy. [180] [181] [182] [183] [184] Some of the ideas are similar, e.g., use of plain language, use of media other than written materials. Greenberg’s review of health literacy found that various methods have been suggested for improving communication of health information to individuals, including use of an interpreter/reader, development of easy to read user-friendly materials, and non-text based media such as videos and pictures. [27] Greenberg also questioned whether it is necessary to make a distinction between low and high literate patients. Would it not be safe to assume that all patients would benefit from easy to understand and read directions?

2.14. Conceptual and Methodological Considerations in Measuring Health Literacy

Our understanding of health literacy is still limited. Different definitions of health literacy have been used, and various graphical models of health literacy have been proposed. There is no consensus on what health literacy really means, although there seems to be agreement that it is not limited to the reading of written materials or to the health care setting. There seems to be a lack of discussion in the published literature on the conceptualization of health literacy, especially as it relates to measurement. This is not surprising, given past experiences with other emerging concepts. However, if our understanding of health literacy is to advance, we need to develop a better conceptual model and understanding of health literacy, as this guides our work. In this section, we discuss some of the less commonly raised conceptual and methodological considerations in the measurement of health literacy. We also summarize the challenges encountered in trying to measure health literacy.

2.14.1. Health Literacy as State (Ability) or Trait (Capacity)?

Thorndike [59] referred to two types of attributes – one type intended to refer primary to *states* of the individual and another type intended to refer primarily to *traits* of individuals, keeping in mind that many attributes refer in some degree to both. An example of a state attribute is a person’s level of anxiety, which may change radically from one time to another. There is also a trait aspect to anxiety, as some people seem to typically operate at a high anxiety level while other people typically operate at a low anxiety level. State attributes are the ones that should primarily be sensitive to intervention and for which the modification of prior or current conditions should be expected to modify test scores.

Health literacy that refers to skills (ability) to find and understand information in order to make appropriate health decisions and actions can be viewed primarily as a health literacy *state*. This view suggests that individuals interact with and are influenced by the information context when trying to find and understand information. For example, an individual with low literacy may have no difficulty reading a pamphlet written at grade 5 reading level, but may not understand a pamphlet of the same topic written at college level.

Health literacy can also be viewed as a trait (capacity). This suggests that there is a set of skills that an individual possesses (i.e., has but is not necessarily using). This view of health literacy is in line with the concept of capacity, which Kickbusch [28] suggested was what people are able to do or be, vs. how they function or perform. An individual may possess a set of skills (trait), but we can not really measure these skills unless they are applied (state). However, these skills may not always be applied as a complete set. In addition, the skills that an individual possesses may expand as the individual learns and experiences more during the course of his/her life.

Health literacy is probably both a state and trait attribute. If state attributes are the ones primarily sensitive to interventions, this suggests that the context (which can be modified) plays a significant role in how people use their health literacy skills. Indeed, most health literacy interventions have focused on the context, such as how information is communicated to individuals who seek it. This includes interventions such as writing in plain language, and providing information using media other than printed material (e.g., videos, etc.). There is limited literature published about interventions that aim to improve the set of health literacy skills that an individual's possesses. Health literacy skills training (vs. health knowledge) may or may not occur during the schooling years or at adult basic education programs. Health-related content in education varies from school to school, as there generally is no standardized health literacy curriculum.

A maximum level of health literacy skill could theoretically be attained. However, we do not know what this maximum level of achievement might be. Nevertheless, the concept of a maximum level of health literacy and of individuals gaining knowledge and skills as they gain life experiences suggest that individuals are operating at sub-maximum capacity (of health literacy). This does not suggest that people are lazy or "stupid." Rather, it means that various *opportunities* for gaining health literacy skills have not been available. The opportunities available to individuals are affected by a complex set of individual, familial, societal, and cultural influences that often are not well understood, nor effectively modified by intervention.

2.14.2. Relationships and Discrepancies Between Different Types of Literacy Skills

There is some evidence to suggest that some literacy skills are correlated with each other, while others are not. Quite likely this applies to health literacy skills as well.

Low reading comprehension was associated with low listening comprehension in children in one study. [185] There also appeared to be a difference between the reading practices and attitudes of good readers (higher comprehension) and poor readers. Poor readers were more likely to choose watching TV over reading, while good readers were more likely to choose reading. Good readers also reported having read more than the poor readers. In addition, the good readers also judged themselves better readers than did the poor readers.

Another study in patients found that scores on reading comprehension (one type of skill) were lower than those for word recognition (another type of skill), measured using the PIAT. [115]

2.14.3. Validity

Do health literacy instruments measure what they claim to measure? In this section we discuss content validity, criterion-related validity, and construct validity. Although many studies can be classified as having tested for one of these types of validity, the authors did not necessarily explicitly state that they were testing validity.

Content validity refers to whether the questions on a test (content) represent the domain they are purported to represent. For example, does the TOFHLA measure health literacy? In studies that assess reading ability, content validity is often determined by using materials that are found in the study setting, e.g., words in the REALM. Content validity has also been determined by using "experts" to review the content of a test to make sure it reflects the real world setting. Content validity is easier to determine than the other types of validity, and is an important part of test development.

Criterion-related validity refers to whether the scores on a test correlate with an indicator of success or with some other well-established measure of the construct. In the case of health literacy, the REALM, the TOFHLA, the S-TOFHLA, or a general literacy test have served as the more “well-established” measures for comparison. However, as mentioned previously, the validity of these instruments should be questioned as well. Health literacy instruments have also been correlated with various “indicators of success.” such as knowledge, health services utilization, etc. The evidence is mixed on whether and how much health literacy is associated (contributes to) these indicators of success.

Construct validity refers to the extent to which the underlying construct is really measured by a test. Construct validity is difficult to determine, yet is the most important. We can not assess the underlying construct (e.g., health literacy) directly. Many constructs, such as health literacy, are also difficult to define or there may a lack of agreement on the definitions. The determination of construct validity is an ongoing process. Thorndike suggested four types of evidence on the construct validity of a measure: [59]

1) judgmental comparison of the nature of the task with our conception of the construct. Does the test match our conception of the trait (e.g., health literacy)? It is generally acknowledged that current measures of health literacy tap mainly into reading ability, and are limited in their assessment of other skills related to health literacy. Health literacy has also mainly been measured in patient populations related to specific health conditions, e.g., cardiovascular disease. Thus, health literacy has mostly been measured in a medical health care context. This does not represent the possible universe of health information, which also includes health information related to health promotion, etc. People also seek information through avenues outside of the medical encounter.
2) correlational data, showing correlations between the test under study and other measures (tests or life events) believed to reflect or depend on the attribute in question. Correlations have been found between different health literacy tests, and between health literacy tests and general literacy tests. Findings about correlations between health literacy and other measures, such as demographic characteristics, outcomes and proxy measures are mixed – some researchers have found correlations whereas others have not. It is also remains unclear what and how confounders influence health literacy.
3) group difference data, comparing test scores of subgroups that might be expected to differ on the attribute. There is some evidence to suggest that there are differences between subgroups that were expected, e.g., older adults and non-Whites have been reported to have lower health literacy.
4) data showing the effects of treatments or experimental interventions that might be expected to influence expression of the attribute. There is some evidence to suggest that interventions that address how information is communicated have had some success in improving some outcomes, e.g., knowledge.

Thus it appears there has been some evidence in support of health literacy as a construct using the existing tests. However, the current tests have limitations. There are also gaps in our knowledge about what influences health literacy and how health literacy influences outcomes.

2.14.4. Purpose of Measurement

We identified three main purposes for measuring health literacy, which are not necessarily mutually exclusive. First, measuring health literacy can provide a *population profile*, such as census data or large-scale literacy surveys. Population-level data can be used to develop policy, e.g., writing in plain language. It is also useful for decisions about the allocation of funding for priorities (such as literacy). Trends over time can also be observed, to see whether health literacy skills are decreasing, remain unchanged, or are increasing. A second purpose for measuring health literacy is to identify where *interventions* should be targeted. For example, patients with low literacy can be identified so health care providers can better communicate with them to work towards improved health. Those identified as having low literacy can also be directed to skills training programs. A third purpose for measuring health literacy is for *research* to expand our knowledge and understanding of health literacy. For example, what influences health literacy? What is the influence of health literacy on outcomes? What are “good” measures of health literacy?

Kickbusch provided some guidance for measuring health literacy at the population level. [28] For example, the three literacy domains in the IALS (prose, document and quantitative literacy) could be adopted. There also needs to be agreement on key domains of health literacy, such as the domains suggested by Nutbeam (functional, interactive and critical health literacy). Further, a set of indicators or scales would need to be developed for each of the identified domains. The new measure of health literacy would complement existing measures such as disability adjusted life years (DALYs) and morbidity and mortality data.

In their review of literacy testing in health care settings, Davis et al. [37] suggested that literacy skills are best assessed using brief, simple tests. However, these tests can not determine the cause or type of reading or learning difficulty, and thus can really only be used to detect low literacy, rather than to diagnose specific reading, learning, or health literacy problems. Unless specific health education interventions are being tailored for the patient or there is support available for patients with limited literacy skills, screening for literacy may not be very useful. In addition, there is no evidence that literacy testing results in improved delivery of health care or improved health outcomes, and this is less likely to be so if interventions or supports are not linked with screening. On the other hand, screening may be useful for providing aggregate profiles of the literacy skills of the patient population in clinics or health systems. However, health care providers/administrators need to be sensitive to the concerns of patients with low literacy and potential embarrassment, and confidentiality must be ensured.

2.14.5. What Makes a Useful Measurement Instrument?

In their review of literacy screening in health care settings, Davis et al. [37] identified general, patient, and test characteristics that need to be considered before selecting and administering a test. General considerations include the purpose, time available, test location, how health care providers will use the results, training required to administer and score the test, and confidentiality. Patient characteristics include age, language, vision, hearing, cognitive function, presence/absence of acute illness, and timing (e.g., has the patient just been given bad news?). Test characteristics include cost, validity and reliability, ease of administration and scoring, acceptability to patients, acceptability to providers, and reports in the literature.

What types of health literacy scores are useful? For example, conversion into grade reading levels is useful as this allows for comparison with education level as well as readability levels. Another useful type of score is an index for health literacy overall, as well as for each dimension or domain of health literacy. Is there a single-item measure of health literacy that would be analogous in utility to self-reported health?

Even if a measurement tool is found to be valid and reliable in the English language, translation of the tool into other languages raises multiple challenges related to how the written language is read as well as to grammar and language-specific phrases or idioms. For example, pronunciation of the Spanish language is mostly phonetic and may pose a problem for tests of word recognition such as the REALM. [186]

2.14.6. Special Methodological Considerations in Designing Measures of Health Literacy for Individuals with Low Literacy

The range of health literacy skills can not be fully measured using only low-level tasks. A range of tasks of varying difficulty would need to be included, especially if the purpose of measurement is a population profile. In order to assess health literacy in individuals who potentially have low literacy, special considerations need to be taken into account when designing and administering health literacy instruments.

In a descriptive study of the translation of an English version of diabetic self-efficacy for an urban Puerto Rican population who had limited English-speaking ability, the following methodological considerations were identified as being of importance: 1) more than four points on a Likert-type scale created confusion in the respondents; 2) respondents found it difficult to grasp the more abstract agree/disagree statements (e.g., strongly agree) and needed more concrete anchors (I feel very sure); 3) one-on-one administration by an interviewer vs. self-administered; and 4) use of visual aids helps. [187]

In a qualitative study of the perceptions of being screened for literacy using the REALM, eight patients who were also enrolled in a community college literacy program found that most of the patients reported a negative response to screening, such as feeling frightened, anxious to get it over with, and embarrassed at being unable to read many of the words. [168] Only one patient reported the experience to be positive in enhancing her self-esteem, because she was able to read more words correctly than she had expected she would. Nevertheless, all eight patients supported the principle of literacy screening in hospitals, and suggested that the responsibility for initiating discussions about reading ability rest with the health care provider rather than the patient, who may be reluctant to volunteer that they have low literacy, based on their social conditioning to hide illiteracy. On the other hand, health care providers may be reluctant to do so because they fear offending the patient or may not have time to do so. [178] Another study showed that only 2% of the physicians who were informed of their patients' results on the S-TOFHLA had actually discussed these results with their patients, and 27% stated that they would discuss these results with their patients in the future. [61] Both patient and physician support of health literacy screening were also found.

Health literacy instruments do not have to be administered using traditional routes, e.g., printed on paper or face-to-face interviews. More interactive media could be used for purposes of measurement. One study showed that patients with low literacy and without previous computer experience could be instructed to use a computer to complete one of the three reading passages of the TOFHLA. [188] It has been suggested that standardized interviews and paper-and-pencil questionnaires may not yield valid information when administered to those who have low literacy. [189] In addition, individuals with low literacy may check off answers on written tests and surveys without understanding them, just like they may sign forms without understanding them or make up answers to questions on medical forms. [167] [168]

2.15. Challenges in the Measurement of Health Literacy

A variety of challenges are encountered in the measurement of health literacy. These relate to: 1) the definition and conceptualization of health literacy; 2) whether people participate in completing health literacy surveys; and 3) the reliability and validity of health literacy surveys.

2.15.1. Challenges Related to the Definition and Conceptualization of Health Literacy

Can one measure something without having a clear definition or conceptualization of it? One of the challenges to measuring health literacy is a lack of a conceptual framework on which the measurement is based. Different definitions of health literacy exist, and various graphical conceptual models have been proposed. There appears to be an implicit consensus: 1) that health literacy is a type of literacy; 2) that health literacy is a resource for individuals (e.g., skills); and 3) that many variables influence health literacy and outcomes related to health and quality of life. On the other hand, the specific dimensions or domains of health literacy remain unclear (e.g., types of task, types of skills, etc.). This lack of clarity presents a challenge in the development of an instrument for measuring health literacy. Defining and conceptualizing health literacy is also related to issues of reliability and validity.

2.15.2. Challenges Related to Whether People Participate in Completing Health Literacy Surveys

Several variables appear to influence whether people, especially those who have low literacy, participate in completing health literacy instruments. Low literacy may be associated with shame and with appearing “stupid” to other people. Those who have low literacy may not disclose this to others, such as health care providers. [168] Therefore, individuals who have low literacy may not participate in research on (health) literacy; this may lead to the under-reporting of the prevalence of low literacy.

2.15.3. Challenges Related to the Reliability and Validity of Health Literacy Surveys

Two important concerns in the development of test instruments are the reliability and the validity of the test instrument. Reliability relates to the stability or repeatability of the measures. Validity relates to how well an assessment actually measures what it is supposed to measure. Several challenges related to reliability and validity in measuring health literacy are: 1) performance confounders (e.g., test-taking ability of participants); 2) test instrument variables (e.g., grade reading level of the test instrument); 3) limited sample sizes; and 4) the scope of health literacy skills being measured.

2.15.3.1. Performance Confounders

Most health literacy measurements instruments are task-oriented. They measure *performance* on a variety of tasks that are supposed to represent health literacy. However, performance on health literacy tests may be influenced by several confounders, such as test-taking ability, memory recall, cognitive ability, and day-to-day functioning (e.g., hearing, visual acuity).

It has been suggested that people who score higher on tests, such as the REALM and the TOFHLA, may simply be better at taking tests than people who score lower. [78]

However, it has also been shown that the effect of test-taking ability as a confounder may be minimized. In a study of the effect of reading ability (measured by WRAT3, reading scale only) and response formats on patients’ abilities to respond to a Patient Satisfaction Scale, it was possible to gather essentially the same data using different response formats, regardless of reading level. [190] This suggests that written questionnaires may be designed to maximize comprehension and response time.

When trying to measure comprehension (or knowledge), the answers may be influenced by memory recall. This limitation has been noted. [156] Questions about comprehension have been asked up to one month after the information was conveyed. [191] One way to bypass the issue of memory recall is to provide the written information (if this was originally provided) to the respondent while the questions are being asked. In this way, the respondent may refer to the written information, rather than responding by using memory recall.

There is no doubt that there is an association between health literacy, cognition, and intelligence, although we do not know how they are associated psychometrically. The American Psychological Association defines cognition as “processes of knowing, including attending, remembering, and reasoning; also the content of the processes, such as concepts and memories. Intelligence is defined as “the global capacity to profit from experience and to go beyond given information about the environment.” [192] Cognition and intelligence are concepts that are general and unrelated to specific topics, similar to general literacy. However, health literacy calls on the various skills and processes of both cognition and intelligence in relation to health information. Knowledge (health- and non-health-related) is essential for health literacy, especially for understanding new concepts and for making sense of various concepts in relation to each other. In addition, health literacy skills (and knowledge) may evolve as an individual encounters different health information experiences. Measures of health literacy most likely capture elements of both cognition and intelligence as it relates to health information.

2.15.3.2. Test Instrument Variables

As discussed earlier, the grade reading level of written materials may potentially influence how well subjects comprehend the materials, and that the subjects’ comprehension may be associated with the subjects’ reading ability (literacy level). It is possible that this translates to the grade reading level of the health literacy test instrument as well – the readability of the health literacy test questions may influence how well subjects (at different health literacy levels) respond or perform. However, this has not been tested.

Earlier we also discussed the influence of visual presentation of the informational content on study subjects’ comprehension of written materials. This may also translate to the visual presentation having an effect on responses on health literacy test instruments. This has not been tested, but it would be advantageous to design health literacy test instruments that would visually appeal to study participants.

2.15.3.3. Limited Sample Sizes

Smaller sample sizes in studies may influence whether a significant link between health literacy and other variables, or health outcomes, is detected. [78] Studies with smaller sample sizes have less power to make conclusions about comparisons within the study and generalizations beyond the study.

2.15.3.4. The Scope of Health Literacy Skills Measured

Most health literacy tests measure the reading skills of the respondents, i.e., of printed materials. This has been noted as a limitation. [156] People obtain information from sources and in ways other than the reading of printed materials. Research on people’s acquisition and preferences for health information have shown this to be the case. [66] [117] [193] Other methods for obtaining health information include television, movies, individual instruction, audiocassettes, group learning, videos, posters, and hotlines. Measuring reading skills primarily neglects other skills (e.g., verbal) associated with finding, understanding, appraising, and communicating health information.

2.16. Concluding Remarks

Although research on health literacy is in its infancy, a lot has still been learned. There is no consensus on a definition or a conceptual framework of health literacy, but some have been proposed. The domains of health literacy also remain unclear. The research to date tends to support the validity of health literacy as a construct, e.g., variables (such as education and outcomes) that are anticipated to correlate with health literacy do show some correlation, etc. A variety of health literacy instruments have been developed, some of which (the REALM, the TOFHLA) have been tested more than others. Results using these instruments suggest that low health literacy is prevalent in the population (most studies were done in the U.S.). These health literacy instruments have mostly measured reading ability, and miss measuring other health literacy skills such as verbal communication, which tends to be costly to administer. The use of self-reported health literacy and the inclusion of numerical tasks are emerging measures of health literacy. While attempting to measure health literacy, one must keep in mind that health literacy is influenced by a host of variables that influence health information experiences. This, along with other methodological challenges, must be addressed when measuring health literacy, especially in those who are less literate. A variety of approaches have been used to improve health literacy and outcomes.

3. METHODS

A first and important step towards measuring a construct, such as health literacy, is to develop a clear definition of it and situate it in a framework to understand it in context.

Both our definition and framework of health literacy were based on: 1) a review of the literature, including non-academic publications; 2) discussions within the research team; and 3) feedback from external experts in health promotion, self-management, and seniors. The definition and framework guided the development of the interview questions.

3.1. Literature Retrieval and Review

An initial search of the literature was conducted using the terms "health literacy" and a combination where both the terms "health" and "literacy" were present in the abstract and/or text of the document. These were intended to focus our search on health literacy, or literacy in a health context (rather than general literacy). The search term “health information” was also used.

The following bibliographic databases were accessed: 1) EMBASE; 2) Medline; 3) ABI/Inform; 4) Canadian Periodical Index; 5) CBCA Fulltext Education; 6) CINAHL; 7) Education Index Full Text; 8) JStor Collection; 9) MD Consult; 10) National Academies Press; 11) The National Library of Medicine; and 12) specific major publishers of journals, e.g., Blackwell Synergy, Elsevier, Kluwer.

Literature was also obtained via other methods. The research team and colleagues of the research team were asked to suggest or provide documents about health literacy. In addition, the references in the documents were searched for additional documents that may not have been found using the other strategies.

3.2. Discussions within the Research Team and Feedback from External Experts

The research team met several times to brainstorm what health literacy means, what influences it, how to measure it, and what its potential outcomes may be. The team has expertise with respect to seniors, education and literacy, health promotion, psychology, and psychometrics. Several external experts (outside the research team) who had expertise in health promotion and health literacy also attended one or more of the brainstorming sessions. These brainstorming sessions served the purpose of developing a better understanding of health literacy, and of developing an operational definition and initial framework for health literacy.

An operational definition of health literacy was developed to address the criticisms of existing definitions that they were not comprehensive enough, e.g., that definitions only addressed written health literacy or only addressed health literacy in medical or clinical situations. A framework was developed to reflect our current understanding of health literacy, the factors that influenced health literacy, and the potential outcomes of health literacy. This is a work-in-progress, and it was anticipated that the framework would be revised as new knowledge about health literacy is gained.

3.3. Interview Development

The definition and framework of health literacy developed by the research team served as a guide for composing the interview questions.

The interview was semi-structured and consisted of both quantitative and qualitative questions. The quantitative questions were developed for the purpose of measuring (or quantifying) health literacy, while the qualitative questions were developed for the purpose of conceptualizing (or defining) health literacy. As much as possible, any text that the seniors would need to read was displayed in larger font (size 14).

Two types of measures of health literacy were included in the interview – self-perceived and task-oriented. Self-perceived measures were developed by the research team, and asked the respondents to rate their own health literacy skills, while task-oriented measures asked the respondents to “perform” specified tasks. The task-oriented measures included one existing tool for measuring health literacy – the REALM (vs. the TOFHLA due to practicalities in administering an interview that would not be too taxing on the respondent as to turn them off), and answering questions related to two reading passages (see end of Appendix E). The two reading passages were taken from existing published pamphlets – one was about the Chronic Disease Self-Management Program and the other was about fats and health. The first passage was text only (prose literacy), while the second passage on fats contained an example of a food nutrition label (document literacy and numeracy). The questions on the two passages were developed by the research team to reflect questions that one might ask if one was interested in reading these passages, i.e., the questions were developed to reflect real-life situations (vs. academic test situations) as much as possible. The questions on the two passages also reflected different “levels” of health literacy, based on estimated IALS levels calculated using the approach outlined in *Assessing the Complexity of Literacy Tasks: A Guide to Analysis*. [194] The levels range from the simplest level 1 to the most difficult level 5. The respondents were not given a time-limit for answering questions on the two passages, nor were they required to recall what they read, i.e., they were allowed to refer to the passages.

With the help of staff at a seniors’ residence, the interview protocol was pilot-tested with four seniors. The interviews were audio-taped and transcribed. The results of these pilot interviews were used to inform revisions to the interview protocol.

3.4. Training of Interviewers

Six individuals (4 in Vancouver, 2 in Victoria) with interviewing experience were recruited to conduct the interviews. All the interviewers received a half-day training session, which outlined the purpose of the project and the methods used, and included a practice session with various parts of the interview. As the interviews were under way, the Coordinator gathered feedback from the interviewers on how the interviews were proceeding, and whether the interviewers used approaches or prompting questions that were effective. This was then shared with all the interviewers via e-mail.

3.5. Recruitment of the Study Sample

Subjects were recruited in the cities of Vancouver and Victoria. The following two criteria were outlined in all recruitment materials:

1) must be 65 years of age or older (but we were willing to accept 55 years because some organizations use that as the age for classifying seniors, although this was not stated in the recruitment materials)
2) must be comfortable reading, writing, and speaking English
3) must be interested in being interviewed for 45 minutes to 1 hour in person

We did not test for visual acuity, based on the assumption that vision was not a problem for those who could see and read our recruitment materials. We also did not test for cognitive function, based on the assumption that those who were organized and remembered to contact and speak with the Coordinator, schedule an interview with an interviewer, and follow through on meeting for the interview and completing it probably did not have significantly decreased cognitive ability.

The following four methods were used to recruit seniors for the study:

1) *posters* at civic community centres, seniors’ housing, and seniors’ organizations. These places were obtained through an Internet search including the City’s website and the Red Book, a directory of community, social and government agencies and services. The posters were from mid-February to May 2006 to the appropriate staff at these locations, with the request to put them on the poster board or somewhere else that would be visible to seniors.
2) *letters* placed at seniors’ housing and seniors’ organizations. These letters were sent during the same period as the posters to staff at the seniors’ housing and at seniors’ organizations, although the letters were addressed to seniors. The staff was asked to place the letters in a visible location so that seniors could pick them up, or give copies of the letter to seniors that might be interested in participating in our study.
3) *advertisements* in two local newspapers and three community newspapers. We ran one-day ads in the Health section of the newspapers, or if it existed, the Seniors’ section.
4) *by word of mouth*. Seniors who were interviewed were asked at the end of their interview to tell other seniors about the study, and were given copies of the poster to pass on.
5) *seniors’ radio show* in Victoria.

Seniors who were interested in participating or had questions about the study were instructed to phone or e-mail the Research Coordinators in the respective cities. An honorarium could not be offered due to budget contingencies.

A total of 251 seniors contacted the Coordinators; 229 met the inclusion criteria and were interested in being interviewed. The following are the numbers of seniors who contacted the Coordinators but, for one reason or another, were not interviewed:

> *Nine* seniors – could not be reached by the interviewer to schedule an interview during the data collection period after initial contact, or contacted us after the data collection period was over already.
>
> *Five* seniors – called the Coordinator to find out more about the study but not necessarily with the intent to participate, or were not interested in participating after finding out more about the study, e.g., didn’t think they could contribute much to the study.
>
> *Three* seniors – were interested in participating but chose not to due to inconvenience, e.g., did not want to be interviewed in the home and/or did not want to travel to be interviewed.
>
> *Two* seniors – cancelled after initially expressing interest in being interviewed (reasons not given).
>
> *One* senior – phoned to ask for information about seniors’ services because they couldn’t find the information from other sources (did not call to participate).
>
> *One* senior – was interested in being interviewed, but was not interviewed because the Coordinator did not believe the senior was an appropriate subject, e.g., the senior could not focus enough to answer a few sample questions from the interview during two separate phone calls.
>
> *One* senior – cancelled due to unforeseen circumstances (e.g., a death in the family).

3.6. Data Collection

After ensuring that the seniors understood the purpose of the study and what would be involved (e.g., time required, consent to participate, withdrawal from participation at any time), the Coordinators distributed the names of interested seniors amongst the interviewers, based on geography (ease of travel for the interviewers) and on the availability of the interviewers. The interviewers contacted the seniors to arrange a time and location for the interview. The interviews were conducted at a mutually agreed upon location, e.g., at home, at the university, etc.

Interviews were conducted starting at the end of February until the beginning of July 2006. They were audio-taped and transcribed by three transcribers. In a few cases the interviews were not audio-taped, either at the request of the interviewee, because of technical difficulties with the equipment, or because there was too much background noise for a good recording – the interviewers took notes during these interviews. At the beginning of each interview, the interviewers reminded the seniors about the purpose and procedures of the interview, and the seniors were asked to sign a consent form.

The interviews were conducted orally in person. The only written texts that the seniors were required to read were the REALM, the passages, and the questions about the passages. They also had the option of seeing the rating scales in written format (if they wished to point or to see all the ratings in front of them).

3.7. Data Analysis

Quantitative data were analyzed using SPSS® 12.0. Frequencies and charts were produced for all the questions. An exploratory factor analysis was conducted to test for underlying “factors” in the various measures of self-perceived health literacy and the task-oriented measures. Internal consistency in the self-perceived measures of health literacy was conducted using Cronbach’s α. A logistic regression with demographic variables and self-rated health as the independent variables and selected task-performance measures was conducted to test for predictors of health literacy. A more detailed description of the factor analysis, Cronbach’s α, and logistic regression can be found in the Results Section. Statistical significance was established at $p \leq 0.05$ for all tests.

Qualitative data were analyzed using NVivo® 2.0. The transcribed interviews (and notes from interviews that were not audio-taped) were imported into the software program. Coding nodes were created to reflect each of the questions in the interview. Additional nodes were created to reflect emerging themes in the responses. All the interviews were coded in NVivo® using these nodes. The analysis of qualitative data is time and labour intensive, and requires an understanding of the topic of interest. Given these parameters, inter-rater reliability was assessed in the following way. The Coordinator analyzed four interviews and identified the themes from each interview. The research team was provided with the original transcript of each of the four interviews, as well as the identified themes for each interview. The team was asked to review the themes to see if they made sense, and to see if any themes were missing. None of the members of the research team identified any missing themes; the identified themes were felt to have reflected what was in the original transcripts. The Coordinator analyzed and coded the rest of the interviews.

4. WORKING DEFINITION OF HEALTH LITERACY

The latest version of the working definition of health literacy developed by the research team is:

> *"The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts to promote and maintain health across the life-course."*

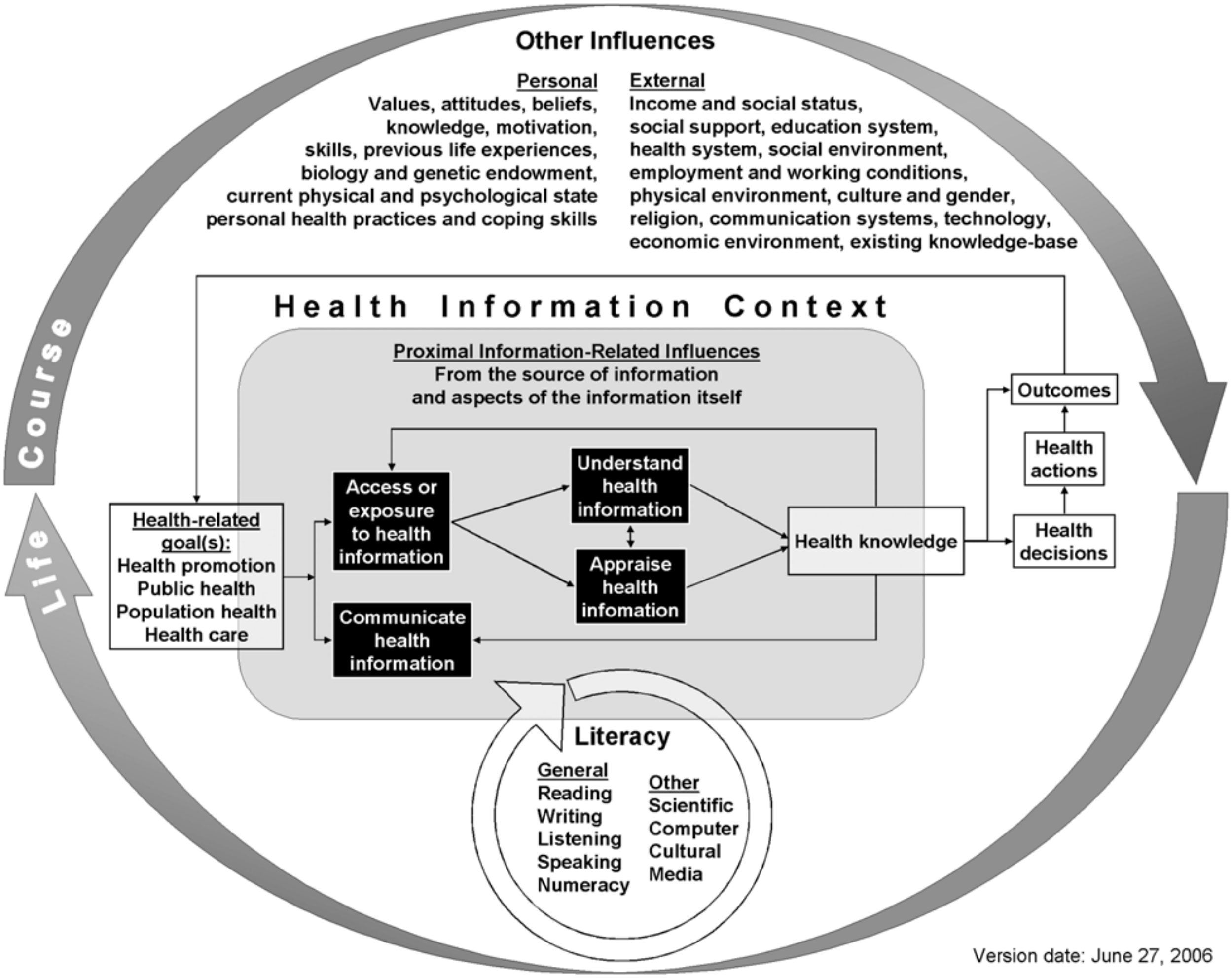
We would like to emphasize the following about our definition: 1) it identifies an *appraisal* or critical thinking aspect to health literacy (the meaning of health information in people's lives); 2) it identifies a *communication* aspect to health literacy (sharing of health information); and 3) it positions health literacy skills in different contexts at different points in one's life. Our definition does not place the onus of responsibility for health on the individual. Rather, it suggests that individuals are not passive recipients of health information because they "engage" in different health contexts.

5. FRAMEWORK OF HEALTH LITERACY

The latest version of our framework of health literacy is shown in Figure 9. Definitions to various aspects of the framework follow. Although the framework is presented before the Results Section, data from the interviews did guide revisions to the original framework. Our framework is a two-dimensional representation. However, we emphasize that neither health literacy nor the context in which it is situated is static – they occur over the "life course" and build on past experiences and events. For example, an individual may gain health literacy skills through skills training or learning from others, or through one's personal experience in trying to find, understand, appraise, and communicate health information. The skills gained from one experience may be used for another situation. Another example is an innovation in technology, such as the Internet, that may influence access to and appraisal of health information.

Theoretically, the different elements (variables) of the framework can be measured, and relationships between these different elements can be elucidated. For example, which variables are strong predictors of health literacy skills? How well do health literacy skills predict health outcomes? The development of a definition and framework of health literacy help us to better understand it and develop better measures of it.

Figure 9: Health Literacy Framework



Version date: June 27, 2006

5.1. Definitions

Literacy

The reading, writing, listening, speaking, and numeracy skills required to engage with the information processing demands of different circumstances.

Health Literacy

(Only the black boxes are considered to be health literacy *skills*.)

Access (or exposure) to health information
“Access” refers to the ability to find health information that is relevant – it is the *conscious* effort of an individual to find such health information. “Exposure” refers to health information that is presented to an individual by happenstance, without that individual making a conscious effort to look for that health information.

Understand health information
The ability to (technically) comprehend health information (e.g., words, etc.), and to grasp its meaning and make sense of it with respect to one’s life.

Appraise health information
The ability to assess the credibility of sources of health information and the merit of the information itself.

Communicate health information
The ability to inform others about health information, e.g., the symptoms of an illness, the nutrients in a particular food, etc. This could be for the purpose of obtaining health information or health care for oneself, or for sharing health information that may be of help to others, e.g., someone who is newly diagnosed with diabetes.

Health Information Context

This is the shaded rectangle in the middle of the framework, and represents the circumstances under which an individual encounters (actively or exposed to) health information, and in which information processing demands are placed upon the individual. This context includes proximal influences such as the source of the information and aspects of the information itself (e.g., presentation, content, etc.). The health information context is linked with the health-related goals of the individual (the intended use of the information). The health information context is also linked to the health knowledge derived from the information.

Health-related Goals

The health-related goals are the purposes for which the health information will be used (intent). The four categories of health-related goals are health promotion, public health, health care, and population health. These goals are not necessarily mutually exclusive.

Health promotion
Empowerment for personal control and public responsibility for health matters.

Public health
Prevention of disease or injury to oneself (or to others).

Health care
Use of the health system to take care of one’s health (or the health of others).

Population health

Health of the *population as a whole* (broad determinants of health) and reduction of health inequities.

Other Influences

These "other influences" permeate across an individual's life in different contexts and across time, and have an effect on health literacy and health outcomes (but also on aspects of life other than health). The determinants of health are included under "other influences." These variables may occur before, during, after, or throughout the process of an individual accessing (or being exposed to), understanding, appraising, and communicating health information. The variables may be personal (related to the make-up of an individual due to life circumstances and genetics) or external (forces that are outside of an individual but with which an individual may interact).

Personal Influences

This includes an individual's values, attitudes, beliefs, knowledge, motivations, skills, previous life experiences, biology and genetic endowment, personal capacity, physical and psychological state, and personal health practices and coping skills.

External Influences

This includes income and social status, social support, the education system, the health system, the social environment, employment and working conditions, the physical environment, culture and gender, religion, communication systems, technology, the economic environment, and the existing knowledge-base.

Health Knowledge

Health *knowledge* is related to but distinct from health *information*. Health information is translated into health knowledge when an individual understands health information. Health knowledge is related to health literacy, but is not considered to be a health literacy *skill*. Health knowledge is considered to be an *intermediate outcome* of health literacy.

Health Decision

The choice of an individual to act, or not act, as it relates to that individual's health. This includes deciding whether to have medical treatment, deciding to start an exercise regime, etc.

Health Action

The behaviour of an individual as it relates to that individual's health. This includes getting medical treatment, eating a balanced diet, making changes in the home to prevent falls, etc.

Outcomes

The results of what an individual decides and how he/she behaves, on his/her own personal health and quality-of-life, on other people, and on the surrounding environment. Outcomes do not have to be limited to physical health. Outcomes include use of health services, morbidity and mortality, quality-of-life, etc.

6. RESULTS

The Results section begins with a description of the study sample, and some background information about the respondents, such as their definition of "healthy living" and their self-rated health. This is followed by the experiences (self-perceived) of the respondents in finding, understanding, appraising and communicating information on a specific health topic, and for health information in general. We also report on task-oriented measures of health literacy, such as the REALM, and reading comprehension of two passages. A further exploration of the data was conducted with statistical techniques, such as reliability analysis (for creating sum scales), correlations (between different types of measures of health literacy), factor analysis (underlying processes), and logistic regression (variables that predict health literacy). Finally, we summarize the results into some key findings.

The data in our study were both quantitative and qualitative. Quantitative data are presented as frequencies, charts, or other statistical calculations. Qualitative data are presented as themes. For each question, we also reviewed the respondents' comments for methodological considerations, such as how the respondents interpreted the questions and what was reported to have influenced their responses. These methodological considerations are important for building the construct of health literacy, for guiding the development of better measures of health literacy, and for gaining a better understanding of health literacy.

6.1. Description of the Sample (Demographics)

A total of 229 seniors were interviewed – 196 in Vancouver-Mainland and 33 in Victoria. This was considered to be of insufficient sample size for meaningful comparisons based on location, or for inferences about the general population of seniors in these locations. There were 18 husband-and-wife couples (n=36) who participated in our study and whose interviews were conducted independently of each other and with the same interviewer per couple. This also was considered to be of insufficient sample size for meaningful comparisons between participant-couples, or between participant-couples and participant-non-couples. Therefore, descriptive statistics are presented for the sample population as a whole. Table 19 shows the demographic characteristics of the sample of seniors that were interviewed, such as age, gender, marital status, education, ethnicity, country of birth, language, and income.

Table 19: Description of the Sample (Demographics) *(continued on next page)*

Age	Mean = 76 years (s.d. 8 years) Range = 60 to 96 years [a] 50% Ages 60 to 74 35% Ages 75 to 84 15% Ages 85 and above
Gender	65% Female 35% Male
Marital status	35% Married 30% Widowed/widower 24% Divorced 7% Single (never married) 3% Separated 1% Living with a partner
Education, highest level completed [b]	11% Less than secondary school graduation 27% Secondary school graduation/some post-secondary 62% Post-secondary graduation
Education completed, country	69% Canada 19% European country 7% United States 5% Other
Ethnicity (multiple origins could be identified) [c]	64% British Isles 13% Western European 11% Eastern European 7% Other European 6% French 6% North American 6% Northern European 5% Southern European (not listed if <5%)

Country of birth	58% Canada 31% European country 4% Asian country 3% United States 4% Other
Year moved to Canada to live (non-Canadian born)	10% Before 1945 26% From 1945 to 1954 32% From 1955 to 1965 20% From 1965 to 1974 4% From 1975 to 1984 7% From 1985 to 1994 1% From 1995 on
Language first spoken	76% English 3% English plus other language 4% German 2% Dutch 2% Non-English multiple languages 13% Other (<5 respondents/language)
Language spoken most often at home at time of interview	95% English 2% English plus other language 3% Other
Gross annual household Income	4% From $0 to $10,000 27% From $10,001 to $20,000 19% From $20,001 to $30,000 13% From $30,001 to $40,000 10% From $40,001 to $50,000 28% More than $50,000

[a] There was only senior who was 60 years of age, and three who were 64 years of age.

[b] These are the same categories that have been used in the analysis of data from the National Population Health Survey (Statistics Canada).

[c] These categories are based on the classification of ethnic origins used in the Statistics Canada 2001 Census. The question was "to which ethnic or cultural group(s) did your ancestors belong?"

One of the criteria for self-selection into our study was whether a senior felt comfortable reading, writing, and speaking in English. Our sample reflected this criterion for self-selection, i.e., the seniors in our sample had a fair degree of literacy based on education, country of birth or length of time living in Canada, and language. Our sample was fairly well educated. Most of the respondents had completed high school, and continued with post-secondary education (whether they completed it or not). Only 11% of the respondents had less than high school graduation. Our sample had also been well exposed to Canadian culture and the English language. Over one half of the respondents were born in Canada (58%), while 69% had completed their education in Canada. Most of the respondents who were not born in Canada had lived in Canada for more than 20 years (92%). Most respondents had learned English as their first language (76%), or English in conjunction with another language (3%). English was also the language spoken most often at home (93%) or with another language (2%) at the time of the interview, for almost all the respondents.

6.2. Comparison of the Sample with the Population

We compared our sample with data on seniors aged 60 and older in the Vancouver area from both the 1998/1999 Canada National Population Health Survey (NPHS) and the Canada Census 2001 obtained via special access through data services at the University of British Columbia library. Given that the sampling procedures and criteria were different, only rough observations can be made (not statistically tested).

On average, the following described our sample compared to the NPHS and Census data:

- older
- more educated
- more were no longer married (either divorced, widowed, or separated)
- more were born in Canada or Europe
- more non-Canadian-born had been in Canada longer (NPHS data only)
- more spoke English as the first language and speak English most often at home at the time of the survey (Census data only)

Our sample and the sample from the NPHS differed from the Census sample on two variables:

- our sample and the NPHS sample had income that was more bimodal than the Census sample, which also had more income
- our sample and the NPHS sample had a greater proportion of females (over 60%), which was higher than in the Census sample (54%)

Thus, based on demographics alone, our sample may have been more educated, been in Canada longer (non-Canadian born), and first spoke and frequently use (at home) the English language. Based on geographic neighbourhoods in Vancouver, Vancouver residents in our sample were distributed throughout all 23 neighbourhoods, except for one neighbourhood (South Cambie), which contained only 2% of the seniors’ population in Vancouver.

6.3. Definition of "Healthy Aging"

The term "healthy aging" has sometimes been used with respect to seniors. We wanted to find out what this term meant to the seniors in our study. We asked the respondents, in open-ended format, to define this term. Two aspects of "healthy aging" were observed in the responses – the "what" and the "how" of healthy aging.

The "what" of healthy aging refers to a description of someone who represents healthy aging. The respondents suggested that this was someone who feels well and still functions well enough to be able to do the things one wants and be able to take care of oneself. Therefore, healthy aging means, in some of the respondents' words, "not suffering" or "being free of pain," and being "mobile" or "independent." It means being able to continue doing the things one has been doing. A few respondents added that healthy aging does not start once someone becomes a senior, and that it is no different being healthy as a senior than being healthy before one became a senior. Many respondents also suggested that the "what" of healthy aging refers to being well in four general aspects of living: 1) the mind (e.g., intellect, being alert); 2) the body or the physical; 3) the spirit, such as one's soul, religion, or interconnectedness with the world; and 4) the emotions.

The "how" of healthy aging refers to how one can look after oneself in order stay healthy, and was also referred to as "healthy living." The respondents suggested that this could be done through the following ways (in no particular order):

1) accept aging as a natural process that is a part of life
2) live life to the fullest – e.g., go on holidays, have fun, relax, slow down
3) keep active or busy – e.g., volunteer, be occupied
4) exercise
5) eat well
6) take good medical care of oneself – e.g., be informed of medications and their side effects, get regular check-ups
7) interact socially with others – e.g., support system, family, friends
8) keep learning – e.g., read, be aware of what is going on in the world
9) keep a positive outlook – e.g., have a sense of humour
10) maintain cleanliness – e.g., hygiene, clean living
11) get enough sleep

Although not considered part of the definition of healthy aging, some respondents pointed out that one's financial situation influences how well one can live. When seniors retire, their financial means can become more limited, and they may face financial stress in trying to support themselves and live well.

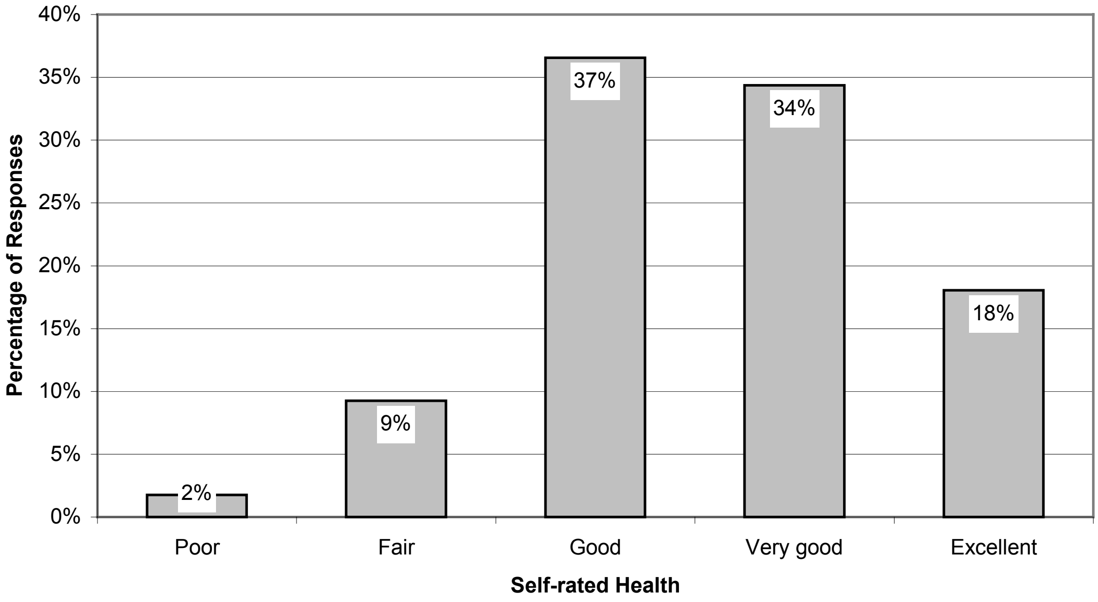
> *"I think healthy aging consists of being able to be mobile, to follow the interests that you have, and also not to suffer pain. And to be mentally alert."*

> *“Means keeping active, enjoying life. I guess keeping alert, both physically and mentally.”*
>
> *“Well I think I didn't start soon enough, that's one thing that's the matter is I think it could begin when we're very young and shouldn't change that much.”*
>
> *“Remaining viable in the community, continuing to be a functioning citizen for as long as possible.”*
>
> *“…you accept the aging; the acceptance of aging is the beginning of healthy aging.”*

6.4. Self-Rated Health

We wanted to find out how people rate their own health. The respondents were asked to rate their self-perceived health in general, ranging from “poor” to “excellent.” The question, and the scale used, corresponds with that used in the Statistics Canada National Population Health Survey. (http://www.statcan.ca/english/concepts/nphs/index.htm). Figure 10 shows the distribution of responses from the seniors in our study. Most of the seniors (89%) felt that their health was “good” or better. Only 11% felt that their health was “fair” or “poor.” This finding is not surprising, given that someone who does not feel well is less likely to self-select him/herself to be interviewed.

Figure 10: Self-rated Health



Compared with data from the NPHS for Vancouver, more seniors in our sample reported having good, very good, and better health. Thus, the seniors in our sample may have rated their health more highly than seniors who participated in the NPHS.

6.5. Health Concerns, Conditions and Interests

We asked the seniors in our study to tell us what health concerns, conditions, or interests they had, and to pick one of these topics to be the focus of the interview. The selection of one topic only (although many respondents had multiple health concerns and conditions) was used to help make the questions less abstract for the respondent. In some cases, a topic was discussed, but the respondent was not asked the complete set of questions. There were 238 instances of a *specific* topic being discussed (excluding health information in general, which were discussed in 59 instances). The most commonly selected topics are shown in Table 20, and included osteoarthritis, heart condition, osteoporosis, diabetes, breast cancer, blood pressure, prostate cancer, and cholesterol. As much as possible, the respondents were also asked how long their selected topic(s) had been of interest to them. The duration of their interests varied greatly from recently (within the past year) to more than 50 years. In about one half of the instances (50%), the topic had been of interest for more than 5 years.

Table 20: Some Selected Topics

Topic	Number Who Selected Topic
Osteoarthritis	22
Heart condition	20
Osteoporosis	12
Diabetes	10
Breast cancer	8
Blood pressure	8
Prostate cancer	7
Cholesterol	6

There were many other topics that were also of interest, but which were not discussed as much, including back problems, nutrition, cataracts, stability and balance, thyroid problems (hyper- or hypo-), dental health, etc.

6.6. Respondents' Experiences with Health Information – Specific to a Health Topic(s)

The questions in the first part of the interview focused on the perceptions of the respondents with respect to their experiences in finding, understanding, appraising, and communicating health information for a specific health topic(s).[1] The measures of health literacy in this first part of the interview were therefore *self-perceived* measures of health literacy. Later we will present the results of *task-oriented* measures of health literacy.

In our framework of health literacy (Figure 9, page 81), we identified four health information contexts, which are not necessarily mutually exclusive – health promotion, health care, public health, and population health. Our definition of health literacy specifies that an individual's level of health literacy is influenced by the health information context. Although our categorization of four health information contexts makes theoretical sense, they could not be used in our analysis for two reasons. First, the frequent overlapping of health information contexts (e.g., health promotion and health care) makes distinct analyses difficult. Second, most of the experiences of the respondents often did not fall into either the public health or the population health information contexts, and therefore analyses could not be done on incomplete data. Neither could we analyze the data based on a categorization of health information contexts based on the health topics discussed by the respondents, because the topics were too many and therefore there were not many respondents per topic.

On the other hand, in the few instances when a respondent discussed more than one topic, he/she answered the same question differently, depending on the topic. This suggests that the concept of a "health information context" may be identifiable. If the health literacy skills of a specific individual are static, then health literacy should not change across different situations. However, our finding (albeit based on limited data) that an individual's responses differed for different topics suggests that health literacy may be a function of the individual and the "health information context."

In trying to better define the "health information context" and "health literacy," we developed questions to explore the experiences that seniors have had with health information. In our analysis of the seniors' responses, we tried to distinguish a difference between the health literacy *skills* of the individual (to find, understand, appraise and communicate health information) from variables that influence the seniors' experiences (health information context). In many instances, this proved to be a challenge, as the seniors often talked about their experiences as a whole (e.g., with seeking treatment from their GP, rather than information), or commented on the health system (e.g., doctors are influenced by pharmaceutical companies to prescribe drugs), rather than limiting their focus to a specific *health information* experience. Thus, one of the challenges of measurement is to distinguish health literacy *skills* from the health information context, and to develop questions that are specific to each.

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[1] The analysis includes the instances where respondents discussed health information in general, rather than a specific topic, like cholesterol or osteoarthritis.

6.6.1. What Did Respondents Want to Find Out About These Topics?

We wanted to explore the different types of health information that people seek. We asked the respondents, in open-ended format, to identify what they wanted to find out about their topics of interest. The process of seeking information is not static. Therefore, an individual respondent may seek more than one kind of information over the course of time. The types of information that were sought are shown in Table 21 (in no particular order).

Table 21: Types of Information Sought By Respondents *(continued on next page)*

Type of Information Sought	Examples
The cause of a condition	Why do I have this condition?
Obtaining a diagnosis	What exactly do I have?
Description of a condition	Stages Types Prognosis
Identifying the treatment options	What can be done for me? Drugs Procedures Supplements Foods Physical activities
Description of the treatment options	Effects How treatments work
The latest news	Research Equipment Procedures
How to prevent a condition from recurring	
Locating a desired health care provider	A doctor who understands seniors
The cause of an unusual symptom while monitoring a condition	
Test results (OK or not) while monitoring a condition	
The meaning of test score results	What do the numbers mean?

Type of Information Sought	Examples
Other	Locating health-related equipment Locating a support group Wait times for procedures Application process for financial support for equipment Whether insurance covers a procedure How to maintain health in general

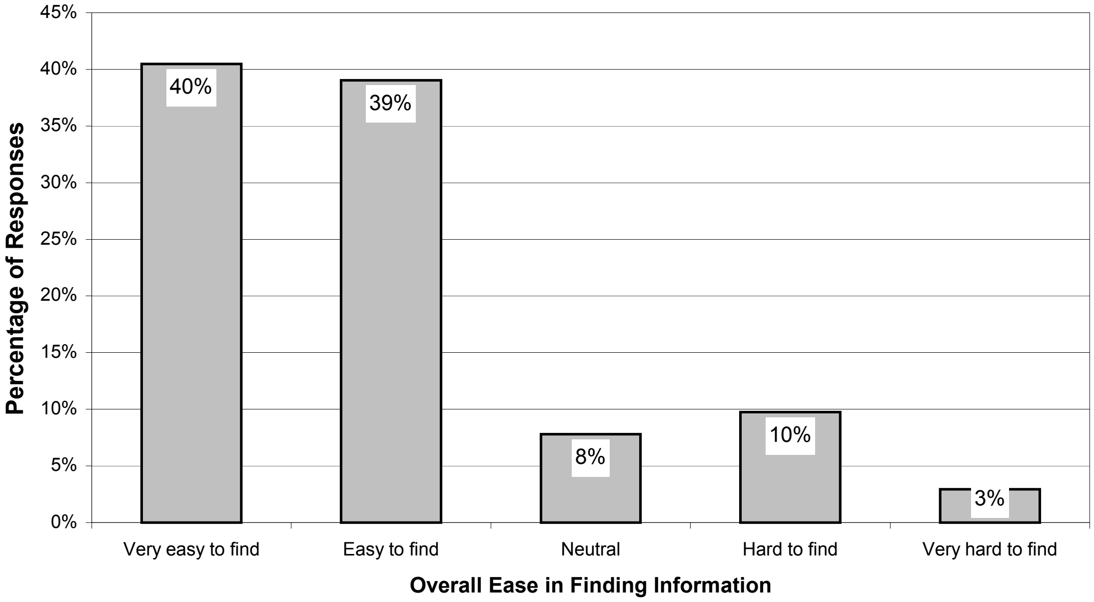
While identifying the kinds of information that were sought, some respondents also identified some reasons for *not* actively looking for health information. These reasons may potentially influence whether an individual actively seeks health information. We did not explicitly ask for these reasons, and therefore the responses can not be considered exhaustive. However, the responses are valuable in suggesting some important influences on whether an individual actively seeks health information, and in the kinds of information sought. The reasons that the respondents identified as to why they did not actively seek (particular kinds of) information included (in no particular order):

1) already had the *knowledge*
2) not interested in having the information, e.g., about a specific aspect such as what caused the condition, because the information wouldn't be of use in dealing with the condition (wouldn't act on the information anyway)
3) was given information without having to actively seek it
4) the condition was not that worrisome (to warrant actively seeking information)
5) already had so much information (and don't want even more)

6.6.2. Overall Ease in Finding Health Information

We wanted to explore people's experiences in finding health information. The respondents were asked to rate how easy it was overall to find the information they wanted, ranging from "very easy to find" to "very hard to find." The distribution of responses for all selected topics is shown in Figure 11. The respondents appeared to have little difficulty finding the information they wanted, as 40% reported that it was "very easy" and 39% reported that it was "easy" to find.

Figure 11: Overall Ease in Finding Sought for Information



Rating the ease of finding information overall may at first glance seem like an easy question to answer. However, it introduces several variables that a respondent might consider before coming up with a response for the "overall" situation rather than for specific instances, e.g., for specific sources, at different points in time, etc.

> *"…first couple…months…I was really, really digging for information…but after I found out about…it got very easy after that…"*
>
> *"I used to get a lot of information, but I don't now."*

There is also a distinction between just finding information, and finding information that is of interest or is relevant. Some respondents selected the rating "easy" to find, but then later added that the information wasn't what they were looking for, although the question asked respondents to rate the ease in finding information they *wanted*, and not for all the information they found.

The ease with which some respondents found information was reported to have been influenced by several variables. When the variable existed, the ease of finding information was increased. When the variable did not exist, the ease of finding information was decreased. The comments of the respondents about finding health information suggest that context does influence the experience or "success" with which relevant information is found. The influences identified by the some of the respondents included (in no particular order):

1) whether the information existed
2) whether the individual had existing research skills

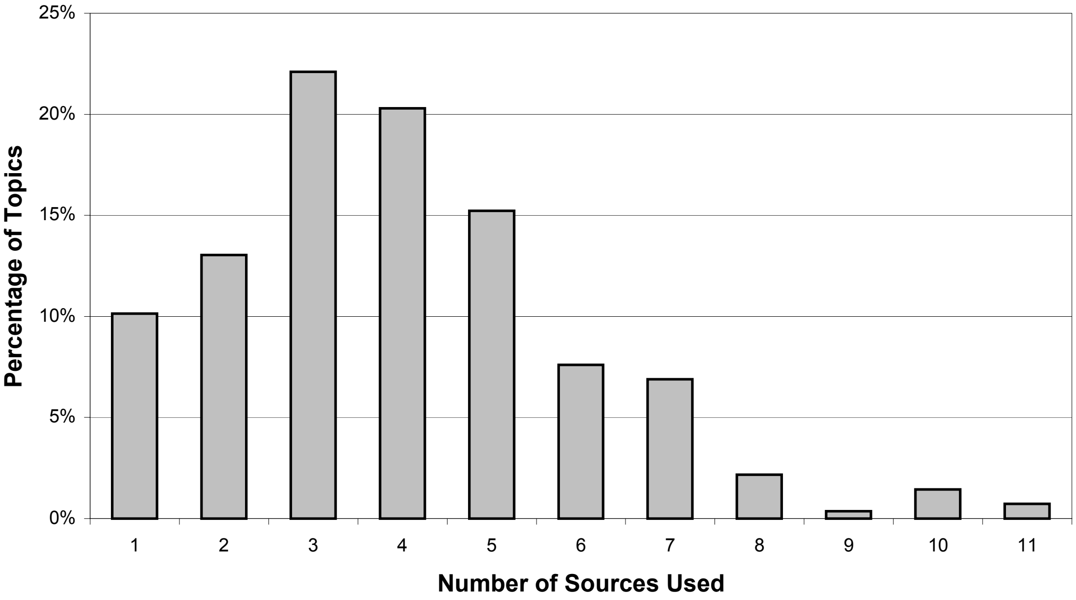
3) whether the individual had some previous knowledge of the topic of interest
4) whether the individual was given information without having to actively seek it
5) whether the source (e.g., doctor, pamphlet, etc.) had the information of interest
6) whether the source was willing to give information
7) whether the source was easily accessible (e.g., one’s personal medical books)
8) whether the individual had to filter the information (e.g., to find information that was reliable)

6.6.3. Sources of Information Used

We wanted to explore which sources people use to find health information, how useful these sources were, and how satisfactory these sources were with respect to providing information. The respondents were asked to identify the sources of information they used and which of these sources was first, and to rate their level of satisfaction with the information that they got from each of these sources (very dissatisfied, dissatisfied, neutral, satisfied, very satisfied).

In most cases, the respondents used more than one source for information on a specific health topic. The total number of times a source was identified was 1,095. Figure 12 shows the distribution of the number of sources that respondents identified per topic discussed, ranging from one source up to 11 sources. Although the data are incomplete, because some topics were not discussed in as great detail as were other topics, the main finding is that for most topics, the respondents used multiple sources of information.

Figure 12: Percentage of Number of Sources Used Per Topic



Out of 277 instances (by topic discussed), a first source of information was identified in 198 instances. Table 22 lists the types of sources used, how often each source was identified as a first source, and the median level of satisfaction for each type of source that was rated and for which n>30 (sufficient size n). The most frequently identified sources were general practitioners, specialists, books (non-library), and the Internet. These four sources accounted for almost one half (47%) of the total number of sources identified.

Table 22: Types of Sources of Information *(continued on next page)*

Type of Source	**Number of times identified (out of 277 instances)**	**Number of times as a first source (% of 198 instances)**	**Median rating of level of satisfaction** [a]	**Range of level of satisfaction**
General practitioner	210	119 (60%)	4 (n=165)	1-5
Specialist (generic or specific)	155	23 (12%)	4 (n= 112)	1-5
Books (non-library)	78	9 (5%)	5 (n=62)	1-5
Internet	72	3 (2%)	4 (n=50)	1-5
Pamphlets/brochures	45	0	n<30	3-5
Newsletters/periodicals/magazines	41	0	n<30	2-5
People (generic)	40	4 (2%)	n<30	3-5
Special-focus program or clinics (e.g., Healthy Heart, etc.)	39	0	5 (n=32)	2-5
Read (generic)	37	1 (1%)	n<30	2-5
Library, public	30	2 (1%)	n<30	3-5
Newspaper	26	1 (1%)	n<30	1-5
Doctor, type unspecified	26	7 (4%)	n<30	1-5
Health care providers with conditional Medical Services Plan coverage [b]	26	2 (1%)	n<30	2-5
People with health (care) background, e.g., son who is a doctor	25	6 (3%)	n<30	3-5
People with similar interest/condition	22	2 (1%)	n<30	3-5

Type of Source	Number of times identified (out of 277 instances)	Number of times as a first source (% of 198 instances)	Median rating of level of satisfaction [a]	Range of level of satisfaction
Pharmacist	22	4 (2%)	n<30	1-5
BC Health Guide	21	1 (1%)	n<30	3-5
Associations/foundations/societies	16	0	n<30	4-5
Television	16	0	n<30	3-5
Media (generic)	10	0	n<30	3-5
Seminar/lecture	10	0	n<30	3-5
Radio	8	0	n<30	4-5
Nurse (generic or specific)	9	2 (1%)	n<30	4-5
Research study	8	3 (2%)	n<30	4
Drug label	8	1 (1%)	n<30	4-5
General practitioner, not regular one	7	1 (1%)	n<30	3-5
Support group	7	1 (1%)	n<30	2-5
Health store	7	0	n<30	3-5
News (generic)	6	0	n<30	n/a
Other [c]	61	5 (3%)	4 (n=38)	1-5

[a] Not all sources were rated and only those where n>30 was the median calculated.

[b] This includes chiropractors, naturopaths, massage therapists, and physiotherapists.

[c] This includes sources where n≤5, such as videos, health lines, community/seniors' centres, health fairs, government, etc.

For most of the sources that were rated and had larger n, the ratings tended to be skewed towards the satisfied (ratings of 4 and 5) end of the scale (bar charts not shown). This suggests that respondents were generally satisfied with the information they received from a variety of sources. However, it should also be noted that some sources also received notable ratings of dissatisfaction (ratings of 1 and 2), such as general practitioners (9% of ratings), and specialists (21%).

Although not asked for explicitly, the respondents sometimes identified whether they actively sought information from the sources, or whether the sources provided the information without the respondent having to actively look for it (exposed to information). For the majority of each type of source, the respondents said that they actively sought information, with the exception of the following sources, for which the respondents were mostly exposed to the information: specialists; pamphlets/brochures; doctors (type unspecified); research studies; people (generic); people with similar interest/condition; special-focus programs or clinics; and news (generic). It is noted that there may be a bias in the responses towards sources of information being actively sought, because we interviewed seniors who looked for information. However, the finding that the respondents were sometimes exposed to information suggests that these sources, although not as actively sought, may also be important avenues for communicating information to individuals.

Some of the respondents also provided comments about specific sources of information. We present some of the comments for the major sources of information – general practitioners (GPs), specialists, books (non-library), the Internet, and pamphlets.

The respondents had both positive and negative experiences with their GPs. We view these experiences as interactive exchanges between GPs and respondents. Although we only have the perspectives of the respondents and not the GPs, we categorized the respondents' comments as to whether they pertain to the GP or to the respondent (Table 23). The respondents made fewer comments about the specialists, but the comments were largely similar to some of those made about GPs.

Table 23: Respondents' Comments about Variables that Influenced Their Interaction with General Practitioners *(continued on next page)*

	About the GP (Respondent's Perspective)	**Respondent's Perspective as a Patient**
Attitudes	Whether the GP cares about the respondent Whether the GP is supportive (e.g., listens to the respondent's ideas) Whether the GP is interested in the topic (e.g., nutrition) Whether the GP is open to non-drug routes of dealing with a health condition Whether the GP is open to the respondent looking up information first	*(positive attitudes)* The respondent trusts the GP The respondent has a good rapport with the GP The respondent appreciates the GP not wasting time (e.g., socializing)
Beliefs	That the respondent should follow the GP's orders	That the GP's role is one of referral That patients should not take up the GP's busy schedule to ask questions That the GP is the expert That the GP is not all knowledgeable That the GP's role is in prescribing drugs, not in explaining the situation

	About the GP (Respondent’s Perspective)	Respondent’s Perspective as a Patient
		That good GPs don’t prescribe drugs right away That the GP is doing the best possible
Knowledge	Whether the GP is knowledgeable about the topic	
Skills	Whether the GP explains well	Whether the respondent can communicate effectively with the GP
Actions	Whether the GP gives information without the respondent having to ask for it Whether the GP gives information when the respondent asks for it Whether the GP makes time for the respondent Whether the GP is on time for appointments Whether the GP works together with others (e.g., specialists) Whether the GP refers the respondent to other sources of information (e.g., book) Whether the GP admits to not being all knowledgeable	Whether the respondent asked the GP questions Whether the respondent brings written questions to the GP Whether the respondent finds information to bring to the GP

The respondents’ comments about books as a source of information were less detailed than their comments about doctors. They talked about the types of books, the accessibility of books, and the content of books. Two types of health books were referred to – medical books (written in medical language) and non-medical books (written in lay language). In many cases, the respondents actually owned the medical books and could refer to them in the convenience of their own home. Although one respondent appreciated being able to peruse books at one’s own pace, another commented that books did not have a human touch (e.g., face-to-face with a doctor). In terms of the content found in the books, the respondents had both positive and negative comments. Positive comments included: the book was easy to read; the book was helpful; the book was complete or comprehensive; and the book was concise. Negative comments included: the information in the book was too complicated; the book was interesting but not useful; the book was outdated; the book didn’t give the respondent any new information; and the book was general and not “tailored” to the respondent’s own situation.

The respondents’ comments about the Internet as a source of information were categorized as such: beliefs; attitudes; accessibility; and informational content. The only belief that a few respondents mentioned was self-perceived computer or Internet “illiteracy” – that they did not have adequate computer or Internet skills. Several respondents reported their attitudes towards computers or the Internet. One positive attitude about using the Internet was that one does not have to be embarrassed about asking questions. Several negative attitudes were mentioned, such as distaste for computers (e.g., don’t want to sit and look at a screen), frustration with having to spend time looking for relevant information on the Internet, and that the computer is scary. In terms of accessibility, some respondents either did not have a computer, or had a computer but no Internet access. For those who used the Internet, some respondents liked having access to information and being able to get information quickly (vs. a book), and being able to get information on one’s own time without time pressures such as at a doctor’s office. On the other hand, there is so much information on the Internet that one has to spend time sifting through it all for information that is relevant. This is especially emphasized when one’s computer is slow. In terms of informational content, the respondents had both negative and positive comments. Negative comments about content included: that you can’t trust all the information; that people are trying to sell you all sorts of things (rather than giving information); and that sometimes the information is not relevant to the respondent. Positive comments included: that the information is up-to-date; and that the respondent found the information they sought and therefore the information was “useful.” In some cases the respondents believed the Internet to be the most useful of all the sources they had used.

The respondents’ comments about pamphlets and brochures as a source of information were categorized as such: attitudes; accessibility; and informational content. A few respondents expressed the (negative) attitude that information from pamphlets (vs. treatment) would not help with one’s condition. With respect to accessibility, the respondents appreciated the convenience of pamphlets and brochures, because one can pick them up and read them on one’s own time or use it as a good reference after visiting the doctor (e.g., in case one forgets something). Some respondents commented that they would pick up pamphlets to read them just because they were interested, although they did not have the health condition discussed in the pamphlets. Most of the comments about the informational content of pamphlets were positive, such as: was useful (in some cases, the most useful of the sources used) or informative; provided relevant information; was comprehensive or thorough; was concise; and was written in lay language. The few negative comments about informational content included that the language was too technical, and that the information was not relevant or specific enough to the respondents’ situation.

For measurement purposes, one of the limitations of our question on how “satisfied” the respondents were with the information from the various sources was that the term “satisfied” could be interpreted in different ways, although we specifically asked about “satisfaction” with “information.” For example, some respondents talked about satisfaction with a source overall (not just for information), or satisfaction with specific aspects of interaction with some sources, e.g., how health care providers treated them as individuals, how well health care providers dealt with the respondents’ health condition, etc.

6.6.4. Trusting Information

We wanted to learn more about people’s degree of trust, and how they determine that trust (skills in appraisal of health literacy), in the health information that they find or to which they are exposed. We considered the process of determining one’s trust in health information to be an aspect of the health literacy skill of *appraising* health information. We asked the respondents, in open-ended format, to tell us their thoughts on how much they can trust the information they found, and more specifically on which sources they trusted (the most) and what made them trust these sources.

In some instances, we were able to discern the respondents' overall degree of trust in the information they found:

1) the respondent's trust depended on the source of the information

   "It depends on who wrote it and how it's written and how it's handled."

2) the respondent trusted all the information found or to which he/she was exposed

   "I trust it completely."

3) the respondent did not think about whether the information could be trusted (only two respondents)
4) the respondent reported a percentage on the degree to which they trusted information (e.g., 70%)

The respondents used a variety of criteria, which were not necessarily mutually exclusive, on which to base their degree of trust in the information that they found or received (see Table 24). The criteria are phrased in the positive, i.e., information was trusted if the state existed.

Table 24: Criteria That Respondents Used to Base Their Trust of Health Information *(continued on next page)*

Trust In	Criteria	Examples
A person	The source had the relevant knowledge, skills, and/or experience	The source was "knowledgeable" The source had personal experience with the same health condition
	The source did not have (hidden) motives	Trying to sell something to the respondent
	The source was open to explaining to the respondent	The source was not "evasive"
	The source cared about the respondent	
	The respondent trusted the source (and therefore trusted information from the source or any referrals made by the source)	
	The source was reputable	
	The respondent respected the source	

Trust In	Criteria	Examples
In information	The information made sense to the respondent	The information was “reasonable”
	The information was current	
	The information has been “proven”	The information was not “far out”
	The information was thorough or comprehensive	
	The information was corroborated by multiple sources	
	The information was based on research that was adequate and valid	Not just one study Not a small sample size
Mixed (person and information)	The respondent had a gut feeling that the source/information could be trusted	
	The information was based on some kind of accountability	The Internet was not trusted because anybody could put anything up on it

In a few instances, respondents felt that they had to trust the information because they themselves did not know anything about the topic. On the other hand, a few believed that they had the skills to discern whether information could be trusted, based on their own background in science or in research.

In some instances, respondents identified which sources they trusted, or did not trust. They tended to trust those in the health care profession (GP, specialists, nurses, pharmacists), books, pamphlets, and newsletters published by reputable sources. The respondents had little, or conditional, trust in the Internet and in media such as TV and newspapers.

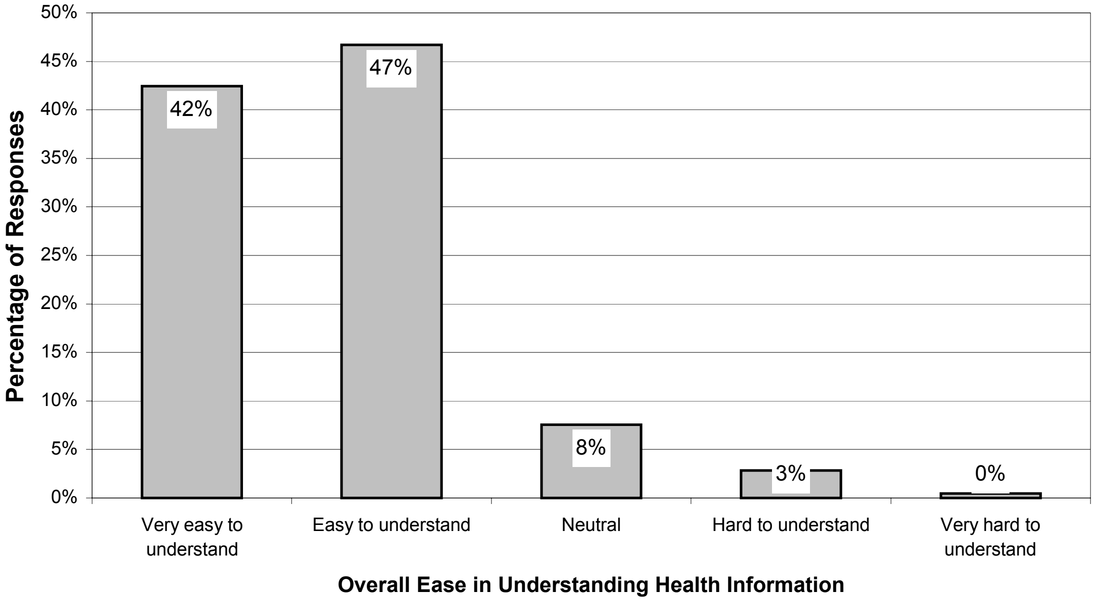
Based on some of the comments from the respondents, we observed different conceptualizations of trust, of which only the first two were of interest for the purposes of our research on health information:

1) trust in a *person*, such as a GP
2) trust in *information*, e.g., one can trust his/her GP (a person) but not necessarily trust information given by the GP if the GP is not as knowledgeable about the topic
3) trust in the *effectiveness of treatments or procedures*, such as drugs or surgery

6.6.5. Overall Ease in Understanding Health Information

We wanted to learn more about people’s experiences in trying to understand health information. The respondents were asked to rate how easy it was overall to understand the information they found, ranging from “very easy to understand” to “very hard to understand.” The distribution of responses for all selected topics is shown in Figure 13. The respondents appeared to have little difficulty understanding the information they found, as 42% reported that it was “very easy” and 47% reported that it was “easy” to understand.

Figure 13: Overall Ease in Understanding Health Information



Although the respondents were not asked to explain how they arrived at their ratings, some elaborated on their answers. The ease with which respondents understood health information is a process and is therefore not static and may change over time. The ease with which information was understood appeared to be influenced by the following variables, positively if the variable was present, and negatively if the variable was not present (in no particular order):

1) whether immediate clarification of explanations and words was possible, e.g., face-to-face vs. written information
2) whether the source (e.g., doctor) first understood the information/situation
3) whether the source (verbally) explained well
4) whether lay language was used
5) whether visual aids were used, e.g., diagrams, models
6) whether the respondent had a health or biology background

7) whether the source was willing to take time to explain
8) whether the information was simple (vs. complex)
9) whether the respondent sought specific sources that would provide simple information

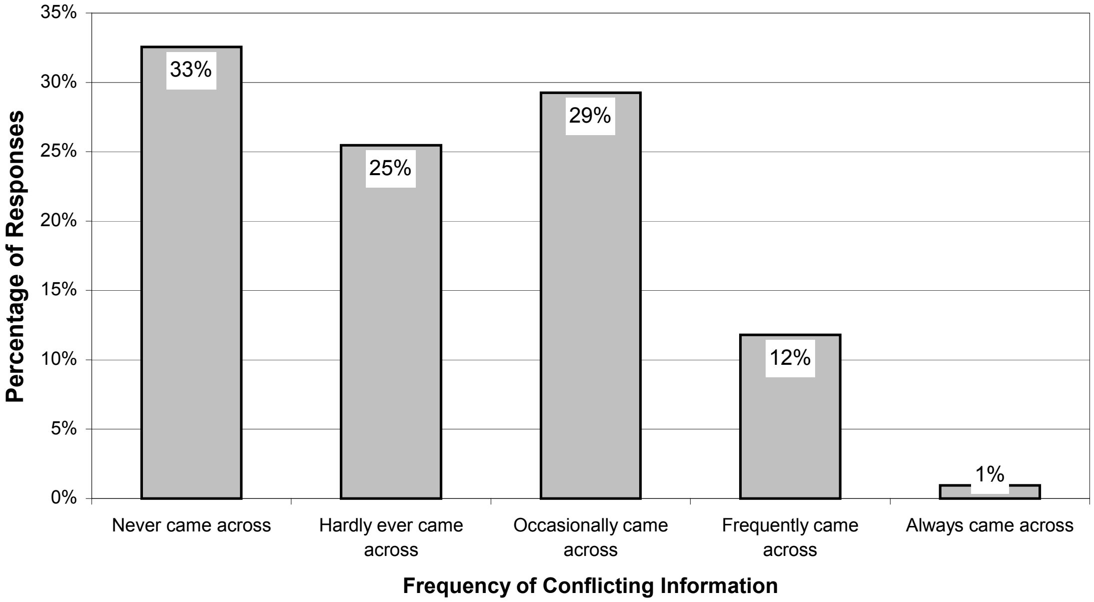
The comments and responses of the respondents suggest that there were two types of understanding – "technical" understanding and understanding in terms of "making sense" of the situation. "Technical" understanding pertains to having knowledge of what specific words mean (e.g., medical terms). "Making sense" pertains to the bigger picture of how things work (e.g., physiology, effects of treatment), how they fit in, what it means, etc. and implies an element of critical thinking.

6.6.6. Frequency with Which Conflicting Information was Encountered

We wanted to find out how people make sense of information that does not agree with each other, i.e., how people determine what is "good" or "correct" information when information conflicts. The respondents were asked to rate how often they encountered information that did not agree with each other (ranging from "never" to "always" came across), and how easy it was to make sense of such information (ranging from "very easy to make sense" to "very hard to make sense").

The distribution of responses for how often conflicting information was encountered for all selected topics is shown in Figure 14. In most instances, the respondents reported having encountered information that did not agree with each other. Only in 33% of the instances did respondents not come across conflicting information. Although there were some instances where respondents reported coming across conflicting information often – 12% for "frequently" and 1% for "always" – in most instances this was only encountered now and then – 25% for "hardly ever" and 29% for "occasionally."

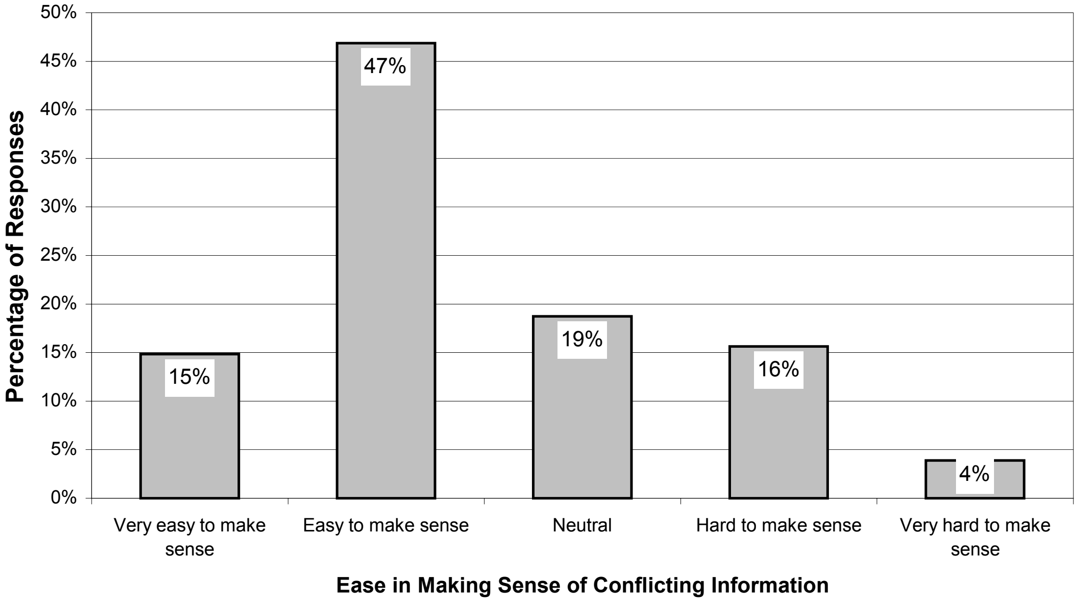
Figure 14: Frequency with Which Conflicting Information was Encountered



Some of the respondents gave examples of conflicting information that they had encountered, such as disagreements on whether a supplement should be taken, whether specific foods should be eaten, what the best treatment option was, or what the actual diagnosis was. A few added that whether they encountered conflicting information depended on the sources they used, and on the amount of information they found (i.e., less conflicting information if less information was found).

Figure 15 shows the distribution of the responses as to how easy it was to make sense of conflicting information for those instances where such information was encountered. In most instances, the respondents had little difficulty making sense of conflicting information – 15% found it “very easy” and 47% found it “easy” to do. However, in a considerable percentage of instances (39%), the respondents did not easily make sense of conflicting information, i.e., ratings of “neutral,” “hard” or “very hard” to make sense.

Figure 15: Ease with Which Sense was Made of Conflicting Information



Some respondents commented on how they made sense of conflicting information, such as by asking someone that was knowledgeable and trusted (e.g., doctor), just using one’s common sense about which information seemed “correct,” and by going with the most recent information. A few reported that they did not need to make sense of conflicting information, especially if the information was not important. Some believed that their health or medical background increased the ease with which they made sense of conflicting information. A few others reported that they had neither the interest nor the time to try and make sense of conflicting information.

We wanted to explore whether the ease with which one made sense of conflicting information was associated with how often one had encountered conflicting information. In those instances where respondents encountered conflicting information, we compared the responses with their ratings of how easy it was to make sense of the conflicting information (n=127). We used Kendall’s tau b for ordinal data to test the correlation between the two sets of responses. We found the correlation (Kendall’s tau b=0.298) to be statistically significant ($p<0.001$). This suggests that the more frequently a respondent encountered conflicting information, the harder the respondent found it to make sense of the conflicting information.

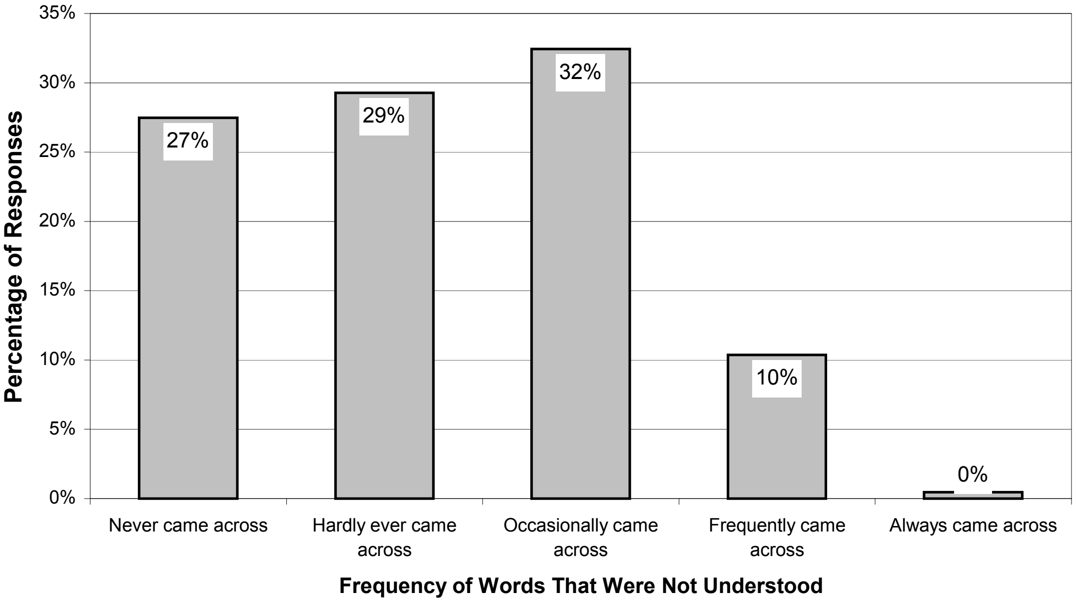
The phrases “information that did not agree with each other” and “make sense” in the questions triggered different scenarios in the minds of the respondents, although in some cases the interviewers were able to focus the respondents back to what we really wanted to know. Some respondents started talking about information that they did not trust, or information that did not seem common sense to them (rather than about information that they found and that did not agree with each other). Some respondents talked about being able to just comprehend or “make sense” of information, or about trying to make a sensible decision about treatment after weighing the benefits and costs (rather than making sense of conflicting information). This suggests that our questions may have been too vague, or that we may have used terms that were too closely associated with other scenarios.

6.6.7. Frequency of Encountering Words That Were Not Understood

We wanted to find out how often people come across words that unfamiliar to them, and how they dealt with such words. We first asked the respondents to rate the frequency of encountering words that they did not understand (ranging from "never" to "always" came across), and then asked them, in open-ended format, what they did when they came across such words.

Figure 16 shows the distribution of the frequency of encountering words that were not understood. The distribution of responses is similar to that observed for the frequency of encountering conflicting information, except that there were fewer instances where the respondents "never came across" words that they did not understand, and more instances of respondents encountering such words now and then – 29% for "hardly ever" and 32% for "occasionally" came across.

Figure 16: Frequency of Encountering Words That Were Not Understood



Sometimes respondents provided additional comments while attempting to rate the frequency with which they came across words that they did not understand. For example, the types of words that respondents did not understand were those that were not in everyday usage, such as medical terms, drug names, chemical terms, and other "scientific" or "technical" terms. Rarely did the respondents report that it was non-medical words that they did not understand.

Some believed that they hardly ever came across words that they did not understand, because they had a background in medicine, chemistry, or anatomy (positive influence). The respondents’ comments also suggested that understanding words was a process – as one learns more about a health condition over time, the frequency with which one comes across words that one does not understand becomes less often.

For measurement purposes, the phrasing of the question may have appeared vague to some respondents, and future research would benefit from clarifying this. There appears to be a distinction between being unfamiliar with a word (e.g., never seen the word before) vs. not understanding a word, which could be interpreted as being unfamiliar with a word (the former), or it could be interpreted as not knowing what a word meant even after receiving an explanation of the word.

6.6.8. How Respondents Dealt with Words They Did Not Understand

We wanted to find out what respondents did about words that they did not understand. We asked them, in open-ended format, to describe what they did when they came across such words.

A few reported that they did not try to find out what the words meant. Most of the respondents did and often used more than one approach to find out what the words meant, such as looking up the words, asking someone, and figuring out the meanings of the words based on the context. The types of sources that the respondents used to look up words included medical books and dictionaries, non-medical dictionaries, the Internet, encyclopedias, and glossaries in books. The types of people that the respondents asked included doctors, pharmacists, nurses, and family or friends who had a medical or health background.

Some of the respondents also suggested some variables that they believed had influenced whether they tried to find out what a word meant. If a respondent believed a word to be important, he/she was more likely to find its meaning. Sometimes there was no need for a respondent to actively find out what a word meant, because the source (e.g., doctor) provided a good explanation of the word immediately after introducing the word, or because they had a background that helped with understanding the word (e.g., Latin or Greek roots of words, health or medical background). Some respondents also suggested some variables that had inhibited them from finding the meaning of a word, including:

1) the respondent’s life was too busy to allocate time to find the meaning of a word
2) the respondent did not believe in taking up more of the doctor’s (or pharmacist’s) time to have a word explained
3) the respondent did not want to appear ignorant (so did not ask anyone)
4) the respondent did not have ready access to a dictionary (e.g., doesn’t own one, misplaced it)
5) The respondent did not have anyone to ask

6.6.9. To Whom Did Respondents Tell Their Concerns/Interests?

We wanted to learn more about the process through which the respondents' concerns were communicated to other people, especially to those people who were not in health (care) professions. We asked the respondents, in open-ended format, to identify to whom they told their concerns, and then to comment on these experiences. It should be noted that telling someone about one's concerns is not the same as going to someone for information or advice, i.e., one can tell someone that one is concerned without seeking information or advice.

The respondents identified different people to whom they told, or did not tell, their concerns. We grouped the types of people, which are not mutually exclusive, into the following categories. For every group type of people, there were instances where some respondents shared their concerns, while other respondents did not share their concerns.

1) family, e.g., spouse, children, grand-children, niece, nephew, parent, sibling
2) people in the health (care) profession, e.g., GP, specialists, nurses, pharmacists
3) friends
4) acquaintances, e.g., neighbours, co-workers

In those instances where the respondents shared their concerns with other people who were not in health (care) professions, a variety of reactions from other people, mostly positive, were reported. The positive experiences were described using phrases such as "concerned," "supportive," "helpful," "encouraging," "sympathetic," and "understanding." People shared information with and offered help to the respondent. On the other hand, negative experiences were reported as well. Some examples included other people who did not care or were disinterested, other people who could not relate to the respondent's concern, or the respondent having had to calm other people down because they were upset over the respondent's health.

The respondents also identified some reasons that made them feel like they could or did not want to tell people about their health concerns. These reasons are shown in Table 25 (in no particular order).

Table 25: Reasons That Respondents Felt They Could Not Tell People About Their Health Concerns

Reason	Examples
The unwanted reaction of other people	Unwanted advice from people Being treated differently because one is ill People are not interested or don’t care People can’t deal with hearing about a serious illness People don’t understand or can’t relate People might feel sorry for the respondent People (other seniors) start worrying about their own health more
Telling other people doesn’t help oneself	
Telling other people doesn’t help these people	Respondent did not want to burden or alarm other people
Telling other people would mean the respondent would have to face the reality of how serious the illness was	
There was no one to tell	Respondent lived an isolated life
The respondent believed in a sense of his/her own personal strength and independence	
The health condition was not socially well accepted	Embarrassing Stigma
The health condition was not a big deal	
The respondent was not interested in talking about health problems	“Boring”

In most instances where the respondents commented on whether they faced any difficulties in communicating, no difficulties were reported. Only two respondents identified skills- or knowledge-related variables that hindered them from communicating their health concerns to other people – that language (English) was a barrier, and that a lack of knowledge on the topic made it hard to talk to other people about it.

Sharing concerns with other people reflects skills in communicating health information, such as symptoms. One limitation to this question was that one could share concerns with someone else (e.g., I am concerned about my heart) without actually communicating information about the health topic/condition. However, the concept of sharing concerns with other people is still of interest, because it is also a way through which one can acquire additional health information (passively). Future attempts at measurement should consider the distinction between expressing concern to, communicating health information to, and seeking health information from someone who is not a health care provider.

6.6.10. Key Points That Seniors Should Know about the Topic(s)

We wanted to find out what people learn from their experiences and the information they find, whether they pass this information on to other people, and how other people's lives are subsequently influenced. We asked the respondents, in open-ended format, to tell us what they thought were the key points that other seniors should know about specific health topics/conditions (or health in general), who they shared these key points with, and how they think this made a difference in other people's lives.

In some cases, the respondents passed written health information, such as a book, on to other people (indirect sharing). Mostly, when respondents did share information, they directly talked to other people face-to-face or over the phone. We categorized the key points suggested by the respondents into the types shown in Table 26 (in no particular order).

Table 26: Key Points That Respondents Suggested Seniors Should Know About Health or Specific Health Conditions *(continued on next page)*

Key Point	Examples
Learn as much about the relevant health condition as one can	Symptoms Prognosis How it can be treated or dealt with Side effects and effectiveness of various treatments Family history of the health condition
Modify one's behaviour and practices to minimize discomfort, or to prevent a health condition from worsening	Don't smoke Eat well Do appropriate physical activity

Key Point	Examples
Find a good GP and keep up a relationship with this GP	If one experiences symptoms go immediately to one's GP (or emergency, depending on the symptoms) Follow the advice of the GP Tell the GP how you feel and about your health behaviours and practices Ask the GP for information Make sure the GP listens and responds to what one has to say Get a check-up even if there are no symptoms
How to cope with the relevant health condition	Accept that one has the health condition Accept that one's life and lifestyle will change with the health condition That having the health condition is not as bad as one might believe it to be (that it can be managed or controlled) That the discomfort from specific procedures or physical examinations are worth it That one can do something to help oneself (vs. medication only) That one should not get too stressed out about having the health condition
That we as individuals have a responsibility to maintain our health	
Keep "active"	Socialize (don't isolate oneself) Keep one's mind active Keep up with the news Volunteer Maintain one's mental health in general
Other	Don't share one's pills with other people Explain to one's family about the relevant health condition

The respondents generally shared key points with people who were interested, such as people who had health conditions similar to the respondent. Key points were shared with friends, family, and acquaintances. In only one case did a respondent report having shared what he/she learned with a health care provider (e.g., GP). In some cases, the respondents had not shared their key points with anyone.

Some respondents offered explanations as to why they felt they could not share information with people. Because we did not explicitly ask them for these explanations, this is not exhaustive but provides valuable insight into disincentives for sharing health information:

1) the respondent believed that other people would rather hear health information from a health care provider than a lay person, such as the respondent
2) the respondent believed that other people would not be interested
3) other people already had the information
4) the respondent reported him/herself to be socially isolated from other people (no one to share information with)
5) the respondent generally prefers not to talk about health conditions with other people
6) the respondent believed that sharing information with other people won’t make a difference in other people’s lives, because people don’t listen and will do what they want to do anyway
7) the respondent reported that it just wasn’t in his/her nature or consciousness to share health information with people
8) the respondent will only share health information if other people explicitly asks the respondent for it
9) the respondent had not shared information with other people because the health condition was only recently discovered, and the respondent was still learning about it
10) the respondent did believe it was his/her place to “give advice,” e.g., they were not experts, people are different so how can you really give advice
11) the respondent believed the information was irrelevant to other people, because other people did not have a health condition similar to the respondent’s
12) the respondent believed the information might upset some people

A few respondents also suggested some reasons why health information should be shared with other people. First, sharing information with someone else shows that one cares about the other person. Second, sharing information with someone else can help ease the other person’s mind, because they are more informed about the health condition and how to deal with it.

In those cases where the respondents shared their key points with other people, some reported that the sharing of key points made no difference in the other people’s lives. Sometimes, the respondents reported that they did not know whether by sharing health information they had made a difference in other people’s lives, either because the other people did not explicitly say that it had made a difference or the respondent did not follow up with other people. The positive differences that the respondents believed they had made in other people’s lives by sharing health information with them are shown in Table 27 (in no particular order).

Table 27: Positive Differences That Respondents Believed They Had Made in Other People's Lives by Sharing Information with Them

Positive Difference in Others' Lives	Examples
Other people became more informed (and empowered to make decisions), and some started seeking more information on their own	
Other people became more aware and conscious of health and health conditions (they had not thought much about it before)	
Other people were influenced to make appropriate health decisions and practice better health behaviours	Friends were able to keep each other accountable for a healthier lifestyle Other people went to see their doctor and were subsequently diagnosed with the health condition (or some other health condition)
Other people's health and well-being were improved	
Other people were better able to cope with their health conditions	Other people became less stressed about their health conditions Other people felt supported and encouraged (sharing itself was a positive experience)

For measurement purposes, the responses pointed towards several challenges that need to be considered in designing "good" measures of communicating (sharing) health information to other people. First, some respondents did not easily "separate" the sharing of concerns (I have a health condition) or the sharing of experiences (I am having a hard time with a health condition) from the sharing of information or key points about the health condition (that the health condition can be managed). The word "share" was selected for phrasing our question, because it connotes communication and collaboration. However, it seems that the word "share" was interpreted in other ways as well, such that the respondents were answering (again) our other question about who they told their health concerns to, rather than this specific question about who they had passed key points and health information on to (although the interviewers often used phrases such as "shared key points" or "shared health information" or "shared what you learned). The second challenge lies in how much of the differences that the respondents observed in other people's lives could be attributed to the sharing of health information by the respondent vs. attributed to other variables, such as the respondent's other family members also urging an individual to adopt healthier eating habits. Some of the respondents noted this challenge as well.

6.6.11. Impacts of Health Information

We wanted to learn more about how health information makes a difference in people's lives. We asked the respondents, in open-ended format, to tell us how the health information they found had changed their lives, no matter how small, specifically with respect to understanding the health topic/condition, how they felt about the health topic/condition, and how they took care of their health.

The changes that occur in people's lives as a result of health information is a process – it is not static and different changes may occur at different points in time. Nevertheless, two "stages" of impacts emerged from our analysis: 1) the acquisition of knowledge and understanding of health and health conditions; and 2) the difference that this acquisition of knowledge and understanding makes in people's lives. Some respondents reported that health information made no difference in their lives, because the information was not new to them, i.e., they already had the knowledge. However, in most cases, respondents reported at least one difference that health information had made in their lives. The types of impacts that emerged from the responses are shown in Table 28, and included increased knowledge and understanding, a change in beliefs (e.g., that exercise is important), a change in attitudes, a change in feelings (e.g., concern – either increased or decreased, hope), a change in taking care of one's health (e.g., diet, exercise), improved health and well-being (as a result of putting knowledge into practice), and "other." It should be noted that knowledge is not necessarily always put into practice, due to various influences, and that sometimes just the acquisition of knowledge alone makes one feel "better." Although in some cases the impact of health information was initially negative (e.g., concerned about how serious a health condition was), the respondents talked mostly about the benefits of health information. Essentially, the respondents were mostly happy to have gained additional knowledge, which helped them to better cope or deal with their health conditions (empowerment), in the hope that health and well-being would be improved, which in some cases it did.

Table 28: Impacts of Health Information *(continued on next two pages)*

Category of Impact	Specific Impact
Increased knowledge	Of the condition (e.g., symptoms, physiology, prognosis) Of treatments, procedures, or management of a condition (e.g., options, effects)
Effects of increased knowledge…	
Change in beliefs	Came to believe in the importance of exercise for health Came to believe that the mind and body works together
Change in attitudes	Did not think anymore that it was bad to throw out food at the Indian temple because it was beneficial to one's health not to overeat the wrong foods)

Category of Impact	**Specific Impact**	
Change in feelings (+/-)	*Negative feelings* Shocked to learn that one had a "major" health condition Increased concern after learning about the condition Became scared after learning about the details of a procedure (e.g., angiogram) Became more pessimistic that the condition could be helped or cured Became confused after finding conflicting information	*Positive feelings* Decreased concern after learning about the condition (e.g., peace of mind, that one would not be debilitated) Became more confident that one could deal with other health conditions as well (as a result of applying knowledge and seeing the effects of improved health) Became more hopeful that the condition could be helped or cured Became more confident (as a result of having knowledge) Was grateful to have learned Felt "better" just being able to have gained knowledge Felt "better" to have learned that many other people also have the same health condition (one is not alone) Felt good to know that one was practising a healthy lifestyle Increased empathy towards other people with the same condition (as a result of knowing more about the condition)

Category of Impact	Specific Impact
Changes in taking care of one's health	Dealt with the condition accordingly (through change in habits and practices) Did not go to the doctor needlessly because one knows the symptoms Increased physical activity (e.g., special exercises) Modified diet (e.g., ate less fatty foods, consumed less sugar, consumed less alcohol, consumed less caffeine) Applied what one learned to other aspects of health (other than the condition of interest) Avoided stress Other (e.g., made a medical bracelet to identify one's health condition in case of an emergency) Stopped smoking (e.g., prior to surgery) Started taking supplements/vitamins Expressed one's concern to the GP about a specific health condition after first learning more about the condition Stopped taking a medication after learning about its side effects Started taking a medication after learning about its effects Got screened (preventative) or monitored (existing condition) regularly Got proper sleep
Improved health and well-being	Improved health in general (e.g., as a result of dietary changes, exercises, etc.) Decreased blood sugar (diabetes) Lost weight (as a result of dietary changes) Decreased pain (as a result of exercises)
Other	Increased ability to deal with a condition because you know more about the condition and how to deal with it Increased consciousness or mindfulness of being healthy and living a healthy lifestyle (e.g., diet, physical activity, became a more responsible individual, etc.) Wanted to learn even more after learning some [motivation] Accepted that one had a health condition and had to deal with it (as a result of knowing more about the condition and about one's prognosis) Passed one's knowledge on to others (and therefore made one feel a little bit worthwhile) Enjoyed life more (as a result of knowing one's prognosis)

For measurement purposes, the responses pointed towards several challenges that need to be considered in designing "good" measures of the impacts or outcomes of health information (health literacy). First, there is a difference between the impact of the condition itself (e.g., decreased mobility due to pain or stiffness) and the impact of health information (acquisition of knowledge and the results of having that knowledge). Second, there is a difference between what one learns by personal experience (e.g., overdoing it makes one fatigued) and what one learns from others (e.g., to eat specific foods because of their nutritional content). Third, many inter-related variables influence both knowledge uptake, and whether that knowledge is put into practice, and the pathways of influence have not yet been elucidated. Fourth, improvements in health and well-being are not necessarily attributed to increased knowledge alone, e.g., improvements in health may be due to medication, which is treatment, not knowledge.

6.7. Self-Rated Measures of General Health Literacy

We wanted to find out the respondents' opinions of their own health literacy and their attitudes on being healthy. The respondents were asked to rate their agreement or disagreement on various statements. The rating scale included the following ratings: 1=strongly disagree; 2=disagree; 3=neutral; 4=agree; and 5=strongly agree. Table 29 presents the results of the responses.

Table 29: Respondents' Self-Perceived Health Literacy and Their Attitudes on Being Healthy *(continued on next page)*

Statement	**Mean (with standard deviation)**	**Range**	**% Not in agreement** [a]
Beliefs about Being Healthy			
It is important for me to stay healthy as I age.	4.9 (0.4)	2-5	0.4%
I am responsible for my own health.	4.7 (0.6)	1-5	3%
Beliefs about Health Information			
The health information that I want exists somewhere.	4.2 (0.7)	2-5	10%
Finding Health Information			
I have the skills to FIND the health information I want.	4.2 (0.8)	2-5	13%
I have the skills to ASK others for the health information that I want.	4.3 (0.7)	1-5	7%
Understanding Health Information			
...skills to UNDERSTAND the health information that I find.	4.3 (0.6)	2-5	6%

Statement	Mean (with standard deviation)	Range	% Not in agreement [a]
...skills to ASK others to clarify any health information that is unclear.	4.4 (0.7)	1-5	5%
Appraising Health Information			
...skills to MAKE SENSE of health information that is inconsistent.	3.9 (0.8)	1-5	22%
...skills to PICK OUT the health information that I want.	4.2 (0.6)	2-5	6%
...skills to JUDGE which health information can be trusted.	3.8 (0.8)	1-5	24%
Communicating Health Information			
...skills to DESCRIBE my health concerns to others.	4.2 (0.7)	1-5	9%
...skills to SHARE with others the health information that I have learned.	4.2 (0.7)	2-5	9%

[a] Those who were "not in agreement" means those who rated either "strongly disagree," "disagree," or "neutral" – it means they did not "agree" or "strongly agree."

Overall, the respondents tended to be in agreement with most of the statements – the means of the responses were relatively high (around 4 or higher) and the standard deviations were all less than 1. This means that the respondents generally believed it was important to stay healthy as they aged, and that they were responsible for their own health. They also believed that the health information they want exists, and that they have the health literacy skills to find, understand, appraise, and communicate health information. Based on the results shown in this table, it is worth noting that the results of two statements under "appraising health information" tended to differ slightly from those of the other statements – the means were lower (less than 4), and a higher proportion of respondents did not agree with the statements (over 20%). This suggests that the seniors in our sample may have perceived themselves to be less skilled in appraisal skills.

After our interviews had already started, we were informed of a study that had concluded that three questions were good predictors of health literacy. [46] We decided to include these questions in our interview for comparison purposes, adapting the questions to refer to health in general rather than referring to medical situations specifically (except one question which referred to medical forms). The rating scales were left unchanged. Table 30 shows the responses for the statements.

Table 30: Respondents' Ratings on Three Suggested Predictors of Health Literacy

Question	**Mean (and standard deviation)** [c]	**Range**
How often do you have someone help you read health-related materials? [a]	1.5 (0.8)	1-4
How often do you have problems learning about your health because of difficulty understanding written information? [a]	1.6 (0.8)	1-5
How confident are you filling out medical forms by yourself? [b]	1.6 (0.8)	1-5

[a] The rating scale included: 1=never; 2= occasionally; 3= sometimes; 4= often; and 5=always.

[b] The rating scale included: 1=extremely; 2=quite a bit; 3=somewhat; 4=a little bit; and 5=not at all.

[c] The mean is reported although the responses were skewed towards the lower ratings, because the low mean suggests that the responses on average were of lower ratings.

The low means and small standard deviations suggest that the respondents tended to be in general agreement towards the lower ratings, i.e., little difficulty was faced in performing the respective tasks in the questions. The respondents generally reported that they rarely have someone help them read health-related materials, and that they rarely have problems learning about their health because of difficulty understanding written information. In addition, the respondents reported being confident in filling out medical forms on their own.

Although we had changed the wording of two of the questions to reflect "health" rather than medical situations, we could not tell whether this had any impact on the responses, because we did not know how the respondents interpreted the word "health," e.g., did some respondents interpret "health" to be synonymous with medical care.

6.8. Task-Oriented Measures of Health Literacy

In addition to questions that asked about the respondents' self-perceptions, we included some task-oriented (performance) measures of health literacy, including the Rapid Estimate of Adult Literacy in Medicine (REALM) and reading comprehension of two passages.

6.8.1. REALM

The REALM is a reading test of 66 words that patients may commonly encounter in medical settings. The respondents read the words aloud and the interviewer checks off whether each word is pronounced correctly. The respondents do not have to know what the words mean. A score out of 66 is tallied.

The scores ranged from 45 to 66, with an average of 65 (s.d. 2.5). The scores were further grouped into REALM "grade range" equivalents. Ninety-four percent of the respondents were classified in the "high school" grade range (score of 61-66), meaning that they would be able to read most patient education materials. The remaining 6% of the respondents fell in the 7th to 8th grade range, meaning that they would struggle with most patient education materials. None of the respondents fell into the other grade ranges – grade 4 to 6, and grade 3 and below.

6.8.2. Reading Comprehension

The respondents were given two passages to read (not aloud) (see end of Appendix E), and were then asked to answered some questions (written, not verbally). The first passage was text only, and described a Chronic Disease Self-Management Program. The second passage described good and bad fats, and included a food label (http://www.bchealthguide.org/healthfiles/hfile68f.stm). Table 31 shows the estimated level of difficulty for each question, and the percentage of responses that were correct. The required tasks were developed to reflect different levels of health literacy. The questions for Passage #2 were more difficult than the questions for Passage #1. Out of a total of 9, the average number of correct answers for both passages together was 7.7 (standard deviation of 1.1), which translates to about 85% correct. The median of correct responses was 8 (range from 5 to 9 correct responses). The distribution of correct responses was skewed towards a higher number of correct responses.

Table 31: Reading Comprehension Questions – Level of Difficulty and Percentage Correct *(continued on next page)*

Question	**Estimated IALS Level** [a]	**% Correct**
Passage #1		
1. What is the name of the patient education program?	1	99%
2. Who teaches the program?	1	99%
3. For how many weeks does the program last?	1	96%
4. Other than a patient with a chronic condition, who else can attend the program?	2	98%
5. If you were to complete the program, how many hours would you have spent at the program?	2	77%
Passage #2		
1. Why are some fats good for your health?	3	83%
2. Saturated and trans fats are poor fat choices. It is important to eat less of the foods that contain these fats. Many examples of these foods are listed in the passage. List any THREE of these foods.	4	85%
3. In the example of the FOOD LABEL shown, what is the total number of grams of fat in 10 crackers?	4	55%

Question	Estimated IALS Level [a]	% Correct
3a. Could these crackers be labeled "low fat" (yes or no)? Please explain your answer.	5	45%

[a] The estimated IALS level is based on calculations as suggested in a guidebook authored by Evetts and Gauthier. [194] These were calculated to give an idea of the level of difficulty for each question (task), where 1 meant an easy task and 5 meant a difficult task.

The respondents did well on the level 1 questions (easy) – each of these questions was answered correctly by more than 95% of the respondents. On the other hand, the level 5 question (difficult) was answered correctly by less than one half of the respondents (45%). The results in Table 31 at first glance suggest that the more difficult a question is, the less likely it will be answered correctly. This observation in turn suggests a utility in designing a set of questions that reflect different levels of difficulty (e.g., estimated IALS level), and that this set of questions may in turn be useful in differentiating between different levels of health literacy.

6.9. Reliability Analysis and Correlations Between Different Types of Measures of Health Literacy

We wanted to find out whether: 1) our measures of self-perceived health literacy could be combined into a single sum scale of self-perceived health literacy; and (if yes) 2) how well the different types of measures correlated with each other (self-perceived health literacy, 3 predictor questions, the REALM, and 2 reading passages).

First, we conducted a reliability analysis with the 9 measures of self-perceived health literacy that we had developed (e.g., "I have the skills to…"). The Cronbach's alpha was 0.852, and removal of any of the measures from the analysis reduced Cronbach's alpha slightly to varying degrees, down to 0.832. This suggests that there is relatively good internal consistency between these 9 measures of self-perceived health literacy in our data set, and that these 9 measures have potential to be added together to create a sum scale of these measures. The newly created sum scale was then used to test correlations between the different types of measures of health literacy.

Correlation analyses (Spearman's rank correlation for ordinal and skewed data) were conducted between the following: 1) the sum scale of our 9 measures of self-perceived health literacy; 2) each of the 3 self-perceived predictors of health literacy; [46] 3) the REALM raw score; 4) number of correct answers on Passage #1; and 5) number of correct answers on Passage #2. Some statistically significant correlations were observed (see Table 32). The highest correlation coefficient of 0.511 (moderate correlation) was found between our sum scale and predictor 3. The other correlation coefficients were less than 0.5 (low to limited correlation).

Table 32: Statistically Significant Correlations (Spearman's rho, α=0.05) Between Different Types of Measures of Health Literacy

	Self-perceived Measures				**Task-oriented Measures**		
	Sum Scale	**Predictor 1** [a]	**Predictor 2** [b]	**Predictor 3** [c]	**REALM**	**Passage 1** [d]	**Passage 2** [e]
Sum Scale	n/a		0.411 (p<0.001)	0.511 (p<0.001)			
Predictor 1		n/a	0.335 (p<0.001)			0.173 (p=0.049)	
Predictor 2	0.411 (p<0.001)	0.335 (p<0.001)	n/a	0.495 (p<0.001)			0.206 (p=0.020)
Predictor 3	0.511 (p<0.001)		0.495 (p<0.001)	n/a	0.183 (p=0.039)	0.175 (p=0.050)	0.184 (p=0.040)
REALM				0.183 (p=0.039)	n/a	0.193 (p=0.004)	0.213 (p=002)
Passage 1		0.173 (p=0.049)		0.176 (p=0.050)	0.193 (p=0.004)	n/a	0.177 (p=0.009)
Passage 2			0.206 (p=0.020)	0.184 (p=0.040)	0.213 (p=0.002)	0.177 (p=0.009)	n/a

[a] How often do you have someone help you read health-related materials?

[b] How often do you have problems learning about your health because of difficulty understanding written information?

[c] How confident are you filling out medical forms by yourself?

[d] Total number of correct answers on Passage #1, out of 5.

[e] Total number of correct answers on Passage #2, out of 4.

The following observations were made:

1) the self-perceived measures were mostly correlated with each other, but not with any of the task-oriented measures
2) the task-oriented measures were all correlated with each other
3) predictor 2 correlated with both predictors 1 and 3, but predictors 1 and 3 did not correlate with each other
4) predictor 3 and predictor 2 (self-perceived measures) had the highest number of correlations with the other measures, regardless of whether these other measures were self-perceived or task-oriented

These results suggest that there is some correlation between the self-perceived measures of health literacy with each other, as well as some correlation between the task-oriented measures of health literacy with each other. Predictors 2 and 3 appeared to have had some correlation with both self-perceived measures and task-oriented measures of health literacy.

For measurement purposes, the data from our sample suggest that self-perceived measures may not necessarily correlate well with task-oriented measures of health literacy, although each type of measure appears to have some internal correlation of its own items with each other. Therefore, the self-report measures of health literacy appear to be distinct from task-performance measures of health literacy in our study.

6.10. Use of Factor Analysis to Elucidate Underlying Processes

Our measures of health literacy can be grouped into two broad types of measures: 1) self-perceived health literacy; and 2) task-oriented health literacy. We wanted to find out if there were underlying processes, or "factors," that could contribute to categorizing the measures in this way, or to categorizing our measures in some other way. To do this, we used exploratory factor analysis with our data. We used factor analysis on 15 variables that related to health information in general, i.e., not relevant to a specific health condition. Rating scales were re-coded to be in parallel with each other, i.e., the low end of all the rating scales reflected a lower level of health literacy, while the high end of the scales reflected a higher level of health literacy. The following factor analyses were conducted:

1) *With 15 variables initially.* An initial glance of correlations between the relevant variables showed that there were some correlations over 0.3, some of which were statistically significant ($p \leq 0.05$). This suggested that the factor analysis technique may be used with this data set. Only 113 respondents were included in the factor analysis, because the three questions that were suggested as good predictors of health literacy [46] were added mid-interview period and we wanted to include these questions in the analysis.

   Four "factors" were extracted with both varimax and promax rotation. However, the results did not suggest a strong distinction of these 4 factors amongst the 15 variables included in the factor analysis. The first factor accounted for only 28.5% of the total variance while the second factor accounted for 11.7% of the total variance, and the four factors together only accounted for a cumulative 58.8% of the total variance.

2) *With 15 variables, but specifying the number of factors to extract.* Most of the 15 variables in the initial factor analysis had relatively higher loadings on the first and second factors. We ran further factor analyses to see if these 15 variables could be loaded on either one factor only or on two factors only. The results of loading on only one factor suggested that 11 of the 15 variables tended to load higher on the one factor. The remaining four variables had low loadings, ranging from 0.014 to 0.163. These 4 variables were how often do you have someone help you read health-related materials, REALM raw score, total correct on Passage #1, and total correct on Passage #2. The results of loading on only two factors suggested that there were two factors, similar to the distinction between the 11 variables and the four variables as observed with the one-factor loading analysis.

3) *With 11 variables.* We conducted a factor analysis with the 11 variables that loaded relatively highly on the first factor. An analysis with loading on only one factor showed that there were several variables that had relatively lower loadings, although the loadings themselves were not low (between 0.5 and 0.6). Another factor analysis where the number of factors to be extracted was based on eigenvalues rather than on a pre-specified number of factors showed that there were three factors, and not one factor only. This suggests that the 11 variables probably should not be loaded on to only one factor.

These results suggested that there may be up to four factors that can be extracted, although this should be interpreted with caution, because the factors in all the analyses accounted for less than 65% of the total variance, and the loadings for individual variables sometimes showed relatively higher loadings on more than one factor. Although the results did not suggest that there were only two factors that could distinguish between self-perceived measures of health literacy and task-oriented measures of health literacy, they did suggest that there may be factors that could distinguish between task-oriented measures of health literacy and multiple groupings of self-perceived measure of health literacy.

We emphasize that the factor analysis technique was used purely for exploratory purposes, and the results are not to be interpreted as confirmatory. In addition, our study was not designed specifically for factor analysis, and therefore, there are limitations to using the factor analysis technique with our data set. First, twelve variables represented self-perceived health literacy, but only three variables represented task-oriented health literacy (each anticipated factor should have at least three representative variables). As expected, we also did not find that the factors clearly distinguished the four different aspects of health literacy in our definition – finding, understanding, appraising, and communicating health information. These aspects of health literacy were not represented by at least three variables per aspect. Second, our study was exploratory and therefore we phrased our questions to be broad (rather than specific), so that we could collect qualitative data to help refine our measures of health literacy. Therefore, the variables included in the factor analysis may have had multiple and overlapping underlying processes, and the results become more difficult to interpret with clarity. Third, the respondents tended to report a fairly high degree of health literacy overall, and therefore the distribution of the responses was not highly varied nor necessarily normally distributed. Low variability in the data may contribute to increased difficulty in interpreting the results of the factor analysis, because factor analysis is based on calculations using variability.

The results of the factor analysis suggest that there may be underlying processes, or factors, that could be elucidated. However, more measures of health literacy would first need to be developed. In addition, such questions need to be more specific than broad. If possible, the sampling technique should capture greater variability in the data.

6.11. Use of Logistic Regression to Elucidate Predictors of Health Literacy

We wanted to explore whether there were variables in our study that could discriminate between different groups or “levels” of health literacy in our sample. Logistic regression (which is analogous to discriminant function analysis for 2 groups when the independent variables are not necessarily normally distributed, linearly related, nor equal variance within each group) was used for this purpose.

The first step was to choose the (dependent) variables for which data would represent different “levels” of health literacy. We considered the task-oriented measures of health literacy, based on the assumption that these measures would be a better representation of “actual” health literacy than would self-perceived measures of health literacy. We narrowed these 10 task-oriented measures of health literacy (i.e., REALM generated reading level and the 9 questions on the reading passages) down to 5 measures to be included in the regression. This paring down of the number of measures was based on the size of the groups or “levels” of health literacy for each variable – the variables that were included had groups of 26 or larger. The other variables were excluded, because almost all the respondents (≥97%) were classified into one group, i.e., the higher “level” of health literacy group. The variables that were included were one question from Passage #1, and all four questions from Passage #2. These variables were dichotomous, as the respondents who answered the question either answered correctly or incorrectly. The 22 independent variables that were selected were three statements about beliefs, nine statements about self-perceived health literacy, REALM raw score, self-rated health and demographic characteristics (age, gender, marital status, highest level of education, country of birth, length of time in Canada in years, first language, and income). In order to maintain sufficient group sizes for analysis, the three questions that were inserted mid-interview period were excluded, and some variables were regrouped (e.g., “other” category). The following analyses were conducted:

1) *With 22 variables initially.* The results of the logistic regression analyses for each of the five dependent variables suggested that none of the independent variables were particularly strong predictors of whether the respondents answered the selected task-oriented measures of health literacy correctly. None of the omnibus tests of model coefficients were statistically significant at $\alpha=0.05$, even though some of the individual predictor variables were statistically significant in the regression equation.

2) *With selected predictor variables ($p<0.15$ in the initial logistic regression).* For each of the five dependent variables, a further logistic regression analysis was conducted with selected variables that may be predictors because they were statistically significant or near statistical significance. No statistically significant predictors were found for the following dependent variables – question 5 from Passage #1, and questions 2 and 3a from Passage #2. Statistically significant predictors were found for questions 1 and 3a from Passage #2 (omnibus test=0.011 and 0.010 respectively). Question 1 from Passage #2 reflected an IALS level of 3 (moderate level of literacy) and question 3a reflected an IALS level of 5 (higher level of literacy).

   Three selected predictor variables were entered into the analysis for question 1 in Passage #2 (why are some fats good for your health). One predictor variable was not found to be statistically significant – I have the skills to make sense of health information that is inconsistent. The other 2 predictor variables were found to be statistically significant: I have the skills to ask others for the health information I want ($p=0.023$, $B=0.626$); and the marital status of being a widow or a widower ($p=0.021$, $B=-1.558$). The negative effect of being a widow or widower on question 1 is puzzling, and may have been due to an age-cohort effect that would need to be further explored.

Five selected predictor variables were entered into the analysis for question 3a in Passage #2 (could these crackers be labeled "low fat" (yes or no)? Please explain your answer.). One predictor variable was not found to be statistically significant – years lived in Canada. The other four predictor variables were found to be statistically significant: I have the skills to ask others to clarify any health information that is unclear (p=0.009, B=0.649); age (p=0.019, B=-0.063); having been born in Canada or the U.S. (p=0.024, B=-1.447); and first language was not English (p=0.035, B=-1.056). The negative effect of having been born in Canada or the U.S. on question 3a is puzzling and what this may be attributed to is unclear and needs to be further explored or clarified.

3) *With selected predictor variables for question 3a.* For question 3a, two variables (country of birth and first language) were similar and therefore may have been confounded. We entered them into separate regression analyses to account for this. The omnibus tests were statistically significant for both analyses (p=0.035 for country of birth only, and p=0.20 for first language). However, neither country of birth nor first language was found to be a statistically significant predictor of whether the respondents answered question 3a correctly – this suggests that the two variables may be confounded. In both analyses, only one of the various predictors entered was statistically significant – I have the skills to ask others to clarify any health information that is unclear (p=0.012 and B=0.611 when country of birth is entered, and p=0.014 and B=0.585 when first language is entered). The reason for this one variable being statistically significant as a predictor is unclear and needs to be explored further (e.g., are people who feel confident asking for clarification more likely to understand certain concepts?).

The results of the logistic regressions suggested that none of the 22 variables that were entered into the analyses were strong predictors of whether the respondents correctly answered the selected task-oriented measures of health literacy (omnibus tests were not statistically significant), although some variables were more "predictive" than others (individually statistically significant). In general, self-perceived measures of health literacy, the REALM raw score, self-rated health, and demographic characteristics were not found to be strong predictors of the selected task-oriented health literacy measures.

The limitations of using logistic regression for our analysis included: little variability in data for some variables; small groups sizes for variables, and therefore the exclusion of variables in the analysis or the combination of groups within a variable. These all affect the analyses and their interpretation.

6.12. Use of Multiple Regression to Elucidate Predictors of Self-Rated Health

The only potential *quantitative* outcome variable in this study was self-rated health. The impacts identified in the *qualitative* part of this study may be used to develop measures of outcome in the future.

Multiple regression was used to explore potential predictors of self-rated health. Self-rated health was the dependent variable. The following thirteen independent variables "appropriate" for use with multiple regression (ratio, interval, or ordinal scale, or dichotomous) were used (or were recoded): age; gender; education (less than post-secondary graduation vs. post-secondary graduation); language first spoken (English vs. not English); income; three previously identified predictor questions; [46] self-reported ease in finding health information; self-reported ease in understanding health information; self-reported ease in making sense of conflicting health information; self-reported frequency of encountering unfamiliar words; three beliefs about health and health information (see Table 29 on page 119 for the statements); the sum total of the ratings of disagreement/agreement with statements of self-reported health literacy (see Table 29); REALM raw score; and the sum total of the number of correct answers on the two reading passages.

There was no a priori theoretical reason to assume that any of the independent variables should influence self-rated health more so than any other independent variable. Therefore, the "simultaneous" method ("Enter" method in SPSS®) was used – all thirteen variables were entered into the model in a single step. This model was not statistically significant (ANOVA, p=0.108), and the Adjusted R Square was 0.174, which meant that only 17.4% of the variance in self-rated health was accounted for by the model.

6.13. Main Findings

Our use of both quantitative and qualitative techniques has enhanced our understanding of what health literacy means and how it can be measured. The main findings can be summarized as follows:

1) the seniors in our sample tended to be fairly educated and exposed to Canadian culture, and perceived their health to be fairly good
2) the respondents rated themselves to be fairly health literate on the self-perceived measures of health literacy (finding, understanding, appraising, and communicating health information, 3 "predictor" questions)
3) the types of information sought by the respondents varied broadly
4) multiple sources of information were often used to find information on a specific topic, most commonly from GPs, specialists, books (non-library) and the Internet
5) the self-perceived measures of health literacy were reported to be influenced by a broad range of variables (context)
6) the acquisition of information made a variety of differences in the respondents' lives, both positive and negative, in terms of increased knowledge and the effects of increased knowledge
7) some respondents had shared health information with other people, and believed that this had made some positive differences in these other people's lives
8) the respondents tended to do fairly well on most of the task-oriented measures of health literacy (REALM, reading passages), with the exception of the 2 most difficult tasks associated with one of the reading passages

9) the measures of self-perceived health literacy that we developed had good internal consistency (Cronbach's alpha=0.852), and therefore a sum scale of these measures was created
10) there was some correlation between self-perceived measures of health literacy with each other, and some correlation between the task-oriented measures of health literacy with each other, but there was minimal correlation between self-perceived measures of health literacy and task-oriented measures of health literacy
11) there may have been (as yet unidentified) underlying processes or "factors" that distinguished between task-oriented measures of health literacy and multiple groupings of self-perceived measures of health literacy
12) the self-perceived measures of health literacy, REALM score, self-rated health, and demographic characteristics were not found to be (strong) predictors of selected task-oriented measures of health literacy
13) self-rated health (as an outcome variable) was not found to be predicted by thirteen variables, which included demographics, beliefs about health and health information, self-rated health literacy, and task-oriented health literacy

7. DISCUSSION AND IMPLICATIONS

The Discussion and Implications section is organized into the following sub-sections: 1) comparison of the study results with the literature; 2) contributions understanding and measuring health literacy; 3) potential application of the study results; 4) limitations of the study; and 5) conclusion.

7.1. Comparison of the Study Results with the Literature

There were a few similarities between our study results and what has been published in the literature. For example, we also found some (but not very high) correlation between self-report health literacy and task-performance measures of health literacy. Other variables that have been reported to show mixed results in association with health literacy were not found to be predictors of selected task-oriented measures of health literacy in our study – education, gender, and income. Mixed results have also been reported in the literature on health literacy and health outcomes. In our study, no predictors of self-rated health (an outcome measure) were found. Like previous studies on the comprehension of nutrition labels, fewer respondents in our study were able to correctly answer the more difficult questions than the easier questions. Popular sources of health information are the Internet and doctors; this was apparent in our sample of seniors as well. The responses of the seniors in our study corroborated the importance of a good patient-doctor relationship. The seniors in our study recommended two strategies that are commonly mentioned in the literature on health education and health communication – use of lay language, and use of visual aids (not just text). Finally, some seniors in our study corroborated the published experiences of people with low literacy – that they did not want to be stigmatized by low literacy, and that they sometimes asked someone else, like a family member or friend, to help them understand health information.

We found one notable difference between our sample of seniors and the published literature. The seniors in our study may have had higher health literacy than anticipated, based on the REALM (none were at grade 6 or below reading level) and self-reported health literacy. Findings in the published literature suggest that older adults have lower literacy in general than do adults who are younger.

Some comparisons were not conducted, because of a lack of greater heterogeneity in our sample of older adults (e.g., ethnicity).

7.2. Contributions to Understanding and Measuring Health Literacy

Our study contributed to the articulation of health literacy as a construct – we have developed a definition and conceptual framework of health literacy that moves beyond the health care setting and suggests that health literacy is a shared responsibility. It is important to articulate a construct well in order to develop good measures for it. We have also contributed to a better understanding of health literacy, the variables that influence it, and the impacts or outcomes of health information that are not related to traditional measures of health such as morbidity and mortality. The qualitative data from our study has shown the complexity of what influences health literacy and health information experiences. The data has also broadened our understanding of how individuals find, understand, appraise, and communicate health information (these are the four aspects identified in our definition of health literacy). Health literacy occurs in different contexts, and is not static over time. In our study, we were able to clarify how seniors interpreted our health literacy questions; this will lead to better phrasing of measures of health literacy for future research. The influences on health literacy that were identified by the seniors may be developed into new measures; this will lead to future research that tests the degree of influence these variables have on health literacy.

With respect to *finding* health information, most of the seniors in our study *actively sought* health information of different types, e.g., causes, treatment, prevention, etc. However, a sizeable number of information sources were not actively sought, or what we called being *"exposed"* to health information, e.g., being given pamphlets and brochures. The seniors in our sample often used multiple sources of information, of which doctors (both general practitioners and specialists), books, and the Internet were popular. The seniors in our study also reported some internal (personal) and external influences on how easy it was for them to find the information they wanted (this data was used to inform the development of our framework). The internal influences included existing research skills and previous relevant knowledge. The external influences included whether the information existed, whether the information was given to them, whether the source was easily accessible, and the content of the information itself (e.g., reliable). One topic we did not explicitly inquire about in our study was people's information-seeking beliefs and practices. The link between these beliefs and practices and skills in finding health information can be explored in future studies.

With respect to *understanding* health information, the seniors distinguished two interpretations of what it means to understand information. First, there is a "technical" type of understanding, which pertains to familiarity with or having knowledge of specific words, e.g., medical terms. There is a difference between never having seen a word before, and having seen it but still now knowing its meaning. Future research should consider this when health literacy measures are phrased. Although some seniors did not look up what words meant, most did and used more than one approach. Some internal variables that were reported to have influenced whether respondents sought the meaning of words included the perceived importance of the word, how busy the respondents' lives were, whether the respondent had a health or medical background, not wanting to appear ignorant, and lack of access to a dictionary or someone to ask. An external variable included whether the word was explained immediately (e.g., face-to-face). The second type of understanding is "making sense" of information in context (e.g., how, why) and attaching meaning to the information. This latter type of understanding suggests than an element of critical thinking is involved. The seniors also reported some internal and external influences on how easy it was for them to understand the information they found. The internal influences included whether the respondent had a health or biology background, and whether the respondent actively sought sources that would provide simple information. The external influences included whether immediate clarification of explanations and words was possible (e.g., face-to-face), source-related influences (e.g., how well the source of information understood and could communicate information, whether the source was willing to take the time to explain), and the content of the information itself (e.g., whether the information was simple vs. complex, whether visual aids were used).

With respect to *appraising* health information, we asked the seniors about trusting information and about making sense of information that did not agree with each other. The seniors varied in the degree to which they trusted the information they found, ranging from not even thinking about whether the information could be trusted to trusting the information completely. Although we asked the seniors to talk about their trust in *information*, they frequently referred to trust in a *person* or trusting in the *effectiveness of treatments or procedures*. This suggests that the word “trust” has multiple interpretations, and that future research should carefully consider how questions about health literacy appraisal skills are phrased. The responses of the seniors suggest that there is some overlap in what is trusted (information, person, or effectiveness). For example, some seniors trusted health *information* if the source of the information (e.g., a *person*) could be trusted. Sources that were trusted more (e.g., those in the health care profession, etc.) may be better modes of communicating health information to seniors than through less trusted modes (e.g., media). The seniors used a range of criteria on which to base their trust in the information they found. The internal influences on trust that the seniors identified included whether they already had some background knowledge of the topic or background in science or in research. The external influences included source-related variables (e.g., whether the source of information was reputable, etc.) and content-related variables (e.g., whether the information was current, etc.). Another aspect of health literacy appraisal skills that we asked about was making sense of information that did not agree with each other. This question also elicited multiple interpretations for the respondents, which suggests again that caution should be used in how future measures are phrased. For example, some seniors talked about making sense of information in general (when no conflicting information was present), while other seniors talked about making good decisions (about treatment) based on the information they found. The seniors who interpreted the question correctly identified various strategies for making sense of conflicting information. The also suggested that the ease with which they made sense of conflicting information was influenced by internal variables such as whether the information was important enough to them to warrant the effort to make sense of it, whether they had the time to devote to it, and whether they had a health or medical background. The seniors did not identify any external influences on the ease with which they made sense of conflicting information. We found a statistically significant positive correlation between how often the seniors encountered conflicting information and the ease with which they made sense of this information. This suggests that the more often a senior came across conflicting information, the harder it was for them to make sense of this information. Our questions did not explore potential explanations for this finding; however, future research could explore this further. For example, do people find it more difficult to make sense of conflicting information when they come across it more often because this is overwhelming (like an overload of information), or do they believe that they have encountered conflicting information more often because they lack the background knowledge to understand the information they find?

With respect to *communicating* health information, we asked respondents to identify to whom they told their health concerns, and what key points about health (topics) they would pass on to other people and whether they had communicated these key points. While some respondents did not share their health concerns, other respondents did and with multiple individuals, including family, people in the health profession, friends, and acquaintances. The seniors experienced both positive (e.g., people were encouraging) and negative experiences (e.g., people did not care). Only two seniors identified skills- or knowledge-related variables that hindered them from communicating their health concerns – that language (English) was a barrier, and that a lack of knowledge on the topic made it difficult to talk to people about it. Most of the other identified influences related to the respondents’ own beliefs and attitudes (e.g., telling other people doesn’t help oneself, the health condition was not a big deal, etc.) and how people would react (e.g., the health topic was not socially well accepted, etc.). We were also interested in what the respondents had learned and thought should be passed on to other people. The key points that the seniors suggested refer mostly to *how to cope* with health conditions (e.g., learn about the health condition, modify one's behaviours, etc.), rather than descriptive health information (e.g., symptoms, prognosis, treatment). Some seniors did not share these key points with other people. Other seniors shared key points mainly with people who were interested. The seniors identified internal variables that influenced whether they shared the key points with other people, including whether the respondent was socially isolated from other people, the respondents' usual practices (e.g., not in the respondent's nature to share information), and the respondents' beliefs (e.g., sharing information won't make a difference in other people's lives). External influences included the interests and reactions of the other person. Whether by sharing key points the respondents had influenced other people's lives was more difficult to ascertain. However, the seniors were able to identify some positive impacts.

One variable was reported by the respondents to have positively influenced *all four* health literacy skills, i.e., the seniors believed that having a science, biology, or health background made it easier for them to access, understand, appraise, and communicate health information. The responses of the seniors suggest that this may be an important influence on people's health literacy skills. Future research on health literacy can explore this relationship. If having a relevant background proves to be influential on health literacy skills, this may have implications for the education system as well as adult basic education.

In our study, we were also interested in exploring how health information made a difference in the seniors' lives. However, some seniors talked about how a *health condition* affected their lives (e.g., decreased mobility) or what they learned by experience (e.g., overdoing it makes one fatigued), rather than how *health information* affected their lives (e.g., increased knowledge). Although it may require some effort on a respondent's part to discern the difference, future research on the outcomes of health literacy and health information should take these differences into account. The seniors mostly identified impacts of health information that were positive. A few negative feelings were reported, such as being scared or pessimistic. Positive impacts included the acquisition of knowledge, and the difference this acquisition of knowledge and understanding makes, such as changes in beliefs, attitudes, feelings (positive), how one takes care of one's health, and improved health and well-being. Most of these impacts are changes that are more immediately apparent and identifiable and are not related to traditional health measures such as morbidity and mortality. Although they are subjective, they can be linked to the respondent's health literacy skills, whereas objective impacts (e.g., health service utilization rates, mortality) at this point in time rarely, if ever, can be linked to health literacy skills. Future research on the link between health literacy and outcomes may benefit from these subjectively reported outcomes. We found no predictors (demographic characteristics, self-report measures of health literacy, task-performance measures of health literacy) of self-rated health (an outcome) in our study; this may have been due to a lack of greater variability in our study sample. The descriptions of "healthy aging" that our seniors provided may also inform us about what outcomes are of importance to seniors, such as being independent for as long as possible.

Although most health literacy instruments have been based on task-performance, more recent developments have included another type of measure, i.e., self-report. These have been shown to have concurrent validity with task-performance measures such as the REALM and the TOFHLA. Therefore, in our study we explored the link between the two types of measures. We found some (but low) correlation between self-report measures and task-performance measures of health literacy. One possible explanation for this is that the two types of measures are tapping into two different concepts (the results of our factor analysis suggested this) – one’s *perception* of one’s own health literacy skills and how one *performs* on various health literacy tasks. Both are equally interesting (performance should not be valued over perception), as one’s perception of oneself and the world inevitably influences one’s actions. Another possible explanation for the low correlation is that the self-report measures were *general* statements, whereas the task-performance measures were more specific. For example, the REALM includes words that are commonly found in *medical* settings. Our reading passages were also topical, such as chronic disease and nutrition. In addition, task-performance measures primarily test reading ability, which is only part of a set of health literacy skills. In our review of the literature, we found that some have questioned whether different health literacy skills levels run parallel to each other. For example, does having high skill in finding health information mean that one has high skill in appraising health information? Therefore, future research on the measurement of health literacy can further explore the link between self-report measures and task-performance measures of health literacy, and whether there is a stronger correlation between the two types of measures when they are designed to measure the same aspect of health literacy (e.g., both measure reading ability). Self-report measures, if they correlate highly with task-performance measures, may be more relevant (vs. reading a list of words) and useful in busy clinical settings.

In our study, we used a nutrition label reading passage to test task-performance measures of health literacy. We chose a nutrition label for various reasons: 1) we could design questions to measure prose literacy, document literacy (the actual nutrition label), and numeracy; 2) we could design questions to be scored in a way that is analogous to the levels of difficulty in the large-scale IALS; and 3) the topic was believed to be of interest to a broad audience. None of the seniors in our study explicitly expressed disinterest in the nutrition label reading passage. Indeed, some explicitly expressed interest in the passage. The scoring of our questions to be analogous to the IALS proved useful. The more difficult levels (4 and 5) of health literacy generated greater variability in data than other measures of health literacy in our study, including pre-existing measures of health literacy such as the REALM and three predictor self-report questions. This suggests that the questions about the nutrition labels were better able to discriminate differences in health literacy skills, whereas most other measures showed that almost all seniors in our study had relatively high health literacy. Future research can further explore the utility of this approach (questions that reflect the range of IALS difficulty levels), for different populations and for different topics.

7.3. Potential Application of the Study Results

Although our study is considered preliminary, the findings have potential applicability for practice and for research purposes.

With respect to practice, our measures of health literacy were designed to be adaptable for multiple purposes – the generation of population data, intervention, and research. For example, our reading comprehension passages were designed to be analogous to the difficulty levels found in the IALS (population profile purpose). We also designed our questions to be relevant in different settings (not just medical settings) for identifying those with low health literacy skills who may benefit from health literacy interventions, e.g., referral to a literacy resource (intervention purpose). On a practical level, there is little point to screening people for low health literacy if no resources or interventions are provided. For research purposes, we explored different types of measures of health literacy (self-report and task-performance) and different skills related to health literacy. We strongly encourage that the purpose of measurement be explicitly identified such that appropriate measures are used, and that health literacy isn't measured just for measurement's sake. The seniors in our study corroborated the literature that information should be communicated in lay language. They also suggested that they preferred information communicated with visual aids, such as diagrams. The more commonly used sources of information (e.g., doctors, Internet, etc.) suggested by the seniors in our study may be effective modes for communicating information to (fairly health literate) individuals who seek it. Although some seniors in our study had positive experiences with doctors and health information, others had negative experiences. This suggests that practising doctors (no longer in medical school) may benefit from continuing education on topics such as low health literacy in patients and how best to communicate information to these patients.

With respect to research, our study has expanded knowledge on health literacy and how it can be measured. This can inform future studies on health literacy. We found that self-report measures of health literacy and task-performance measures of health literacy appear to be tapping into two different "dimensions" of health literacy. A possible explanation is that the self-report measures were general statements, whereas the task-performance measures were specific to a context and/or skill. Therefore, future research would benefit from the development of more measures that are specific, that reflect a range of difficulty levels, that cover a wider range of health literacy skills than just reading ability, and that extends beyond the health care setting (e.g., health promotion). Qualitative and quantitative data are complementary for this. Qualitative data provide an understanding of health literacy in context and can be used as the basis for the development of quantitative measures. Quantitative data can be used to explore (latent) relationships between health literacy, influencing variables, and outcomes. For example, what variables have the most influence on health literacy? Some outcomes of health literacy may be more apparent if longitudinal studies are used. Efforts should be made to recruit more diverse study samples (e.g., education level, cultural background, etc.) to explore differences and similarities in health literacy between population sub-groups. Finally, efforts should also be made to explore the most effective interventions for improving health literacy *skills* (not just health *knowledge*). Our review of the literature and the findings from this study suggest that health literacy is context-dependent, and that many variables influence health literacy. Future studies can explore which external variables have more influence on health literacy and therefore should be the target of interventions. Although external variables are more immediately amenable to change than internal variables, the influence of the latter on health literacy, and effective interventions for these, may also be explored.

7.4. Limitations of the Study

Our work is limited in several aspects – conceptualization, measurement, the sample and sampling strategy, and the analysis. We were working with a concept (health literacy) that is neither well defined nor extensively researched. This hinders work on developing valid measures of health literacy. Our sample was largely a convenience sample and our results indicate that our respondents were more educated and may have had higher health literacy skills than the general population. This raises a cautionary note with respect to measurement of literacy and health literacy. As such, they may not represent the full range of health status and concerns in seniors. The low variability in the quantitative data also precluded the use of some statistical analysis that would help elucidate predictors of health literacy or variables that discriminate well between different levels of health literacy. Our results were based largely on self-report and are therefore open to the usual biases of subjective data, such as memory recall and socially acceptable responses.

7.5. Conclusion

Although our study was exploratory, we advanced the objectives we set out to achieve. First, we tried to establish the validity of our measures. Content validity was established based on a literature review and feedback from internal and external experts. We tested concurrent validity with existing measures such as the REALM (task-performance) and three self-report measures. [46] Second, we tested the measures in a population sub-group that has been reported to have lower general literacy – seniors. Other vulnerable populations may be studied in the future. Third, we developed a definition and conceptual framework for understanding health literacy and what influences it, and for guiding its measurement. Fourth, we have established a basis for developing measures of health literacy outcomes that extend beyond traditional measures of health such as morbidity and mortality. Furthermore, our study expands research on health literacy into the Canadian context, whereas most of the published literature is in the U.S. context.

We suggest three future steps that need to be taken if the concept of health literacy is to fulfil its promise. First, we need to better define what constitutes health literacy. Green and Kreuter [1] define evaluation as the comparison of objects of interest against standards of acceptability. In the case of health literacy, we have not sufficiently conceptualized the objects of interest or constituent elements. We need to define the universe of health literacy. Our exploratory research suggests that different tasks may tap into different elements of health literacy. Second, once these elements are better defined, there remains a need to develop measures of the nature, level, and shape of the distribution of health literacy in specific populations. Such measures may be qualitative or quantitative depending on their purpose and context. Finally, we will need to define the standards of acceptability for health literacy in different situations. Standards of acceptability serve to identify the desired level of outcome and allow all parties to agree on how much change should be achieved in return for a given investment of resources. They also serve as targets that signal success, improvement or growth. For health-literacy programs, the standards will be the expected level of improvement in health literacy that is stated in a program’s objectives. Standards may be based on perceived needs and priorities, or objective data, or largely on existing policies and the availability of resources. [195] Our research with older adults suggests that we are still some distance from adequately defining health literacy. We are even further from adequately measuring it or defining ‘best practices’ or standards of acceptability with respect to specific interventions. However, we believe that this study has helped move us forward in our efforts to measure health literacy.

Although we were unable to address all the health literacy issues that we had identified in our literature review, this does not minimize their importance. For example, little has been published about the experiences of people with low health literacy. However, health literacy studies have the potential to involve these individuals, e.g., using a participatory research approach. Such efforts should not be done in a vacuum. They should incorporate an ecological perspective that considers the social, cultural, economic and physical environmental contexts in which health-literacy efforts may occur. More specifically, the health context (health promotion, health care, public health, population health) should also be considered. We also echo the concerns raised by Shohet and Renaud, [2] who suggested a need for a holistic perspective on health literacy, while at the same time focusing beyond the individual to consider the roles of organizations, health contexts and systems. Many fruitful areas for research exist including communications between patients and professionals, the training of healthcare professionals, non-written means of communication and action-research. A parallel need for funding, infrastructure, and policy/legislation to foster a supportive environment for enhanced health-literacy practice and research also exists. We applaud the initiatives led by the Canadian Public Health Association, through its National Literacy and Health Program. Health literacy extends beyond an individual seeking information, and is a shared responsibility with those who provide and/or communicate health information, with those who teach health knowledge and/or health (literacy) skills, and with those who have the authority to develop policies that support health literacy.

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APPENDIX A: LETTER SENT TO SENIORS’ RESIDENCES, ORGANIZATIONS, COMMUNITY CENTRES, AND NEIGHBOURHOOD HOUSES

[printed on letterhead]
[date]

[contact name]
[organization]
[address]

Re: Study on Measuring Health Literacy – Seeking Seniors to Participate

Dear [name],

You were suggested as the person to whom we could send this letter to ask for help in recruiting seniors to take part in our study. We will first give you some background information and tell you why we are doing the study, and then describe our recruitment process.

The study is titled “Measuring Health Literacy” and is being conducted by The University of British Columbia (UBC) and The University of Victoria (UVic), with funding from The Canadian Institutes of Health Research. The Principal Investigators of the study are Drs. Jim Frankish (UBC) and Irv Rootman (UVic) .

The concept of “health literacy” was first used about 30 years ago. More recently, researchers working in health care, health promotion, and adult education have called greater attention to health literacy. Health literacy is a concept that has great potential in improving the public’s access to health care services, to health information needed to make informed decisions, and to other resources that people need to improve their health. However, this is challenged by a current lack of clarity on what health literacy means and how health literacy can be measured. The purpose of this study is to explore how health literacy can better be defined and measured. In particular, we are interested in health literacy in different groups of people, such as seniors.

To this end, we developed a 45-60 minute face-to-face interview to measure health literacy with respect to “healthy aging” in seniors. By “seniors,” we mean individuals who are 65 years of age or older. We are interested in how seniors find, understand, and communicate information on health.

We are asking organizations to help us recruit seniors for our study. We are not asking you or your organization to act as a “go-between” for us. Seniors who are interested in taking part are being asked to contact us directly; they are not being asked to contact your organization. All our recruitment materials specify this. We are only asking you to help us spread the word, through one or more of the following ways.
If you have any questions about the recruitment process, or would like additional copies of the materials, please contact the Research Coordinator, Brenda Kwan at 604-822-9214, or brendakw@interchange.ubc.ca.

1) Put up the enclosed **recruitment posters** in locations at your organization where it would be visible to seniors. You may also ask us for additional copies (or an electronic version) of the poster.

2) Pass the enclosed **letters of invitation** on to seniors served by your organization, e.g., members, seniors enrolled in programs or access services. The letter asks seniors to participate in an interview with one of our trained interviewers. Copies of the letter are enclosed for your distribution. If you would like additional copies, please feel free to photocopy the letter, or you may ask us for more copies.

3) Advertise our poster in any of your organization’s **newsletters** that would be read by seniors in particular. This could be done using the text from the enclosed recruitment poster. You may also ask us for an electronic version of the text.

For your information, all information that identifies individual seniors will be kept confidential. The results of the interviews will be made available, only in summary form, to interested organizations and interviewees.

Thank you for your time and support. If you have any questions about the recruitment process or about the study, you may contact Brenda Kwan at 604-822-9214, or brendakw@interchange.ubc.ca. You may also contact Dr. Jim Frankish (phone 604-822-9205; e-mail frankish@interchange.ubc.ca).

Sincerely,

Jim Frankish
Associate Director
Institute of Health Promotion Research
Faculty of Graduate Studies

Co-Investigators (UVic)	Co-Investigators (UBC)	Co-Investigators (SFU)
Deborah Begoray	Arminee Kazanjian	Michael Hayes
Jennifer Mullett	Bruno Zumbo.	

Co-Investigators (UNBC)
Karen Kelly

APPENDIX B: LETTER TO SENIORS

[printed on letterhead]
[Date]

Re: Study on "Measuring Health Literacy" – Seeking Seniors to Participate

Dear [First Name],

The Canadian Institutes of Health Research is funding the University of Victoria (UVic) and the University of British Columbia (UBC) to conduct a study on how people find, understand, and communicate health information. How this occurs in different groups of people, such as seniors, is of particular interest. The Principal Investigators of the study are Drs. Irv Rootman (UVic) and Jim Frankish (UBC).

By "seniors," we mean people who are 65 years of age or older. We are looking for seniors who are comfortable speaking, reading and writing in English. We would like to hear the opinions of as many seniors as possible in Vancouver and in Victoria. Your participation will help us learn how to better provide information on health to seniors.

Taking part in the study will involve a 45-60 minute face-to-face interview with a trained interviewer. The interview would be at a location convenient for you, like in your home or at UBC; this will be arranged between you and the interviewer. At the time of the interview, you will be asked to sign a consent form; one copy will be for your records, and another will be for our records. You will be asked some questions about your health and how you find, understand, and communicate information on "healthy aging." You will also be asked to read some materials (some out loud), and to answer some questions about it. With your consent, the interview will be audio-taped.

You do not have to take part in this study if you do not want to. You may choose not to answer any question during the interview. You may also stop at any time and have us erase all your answers, without any consequences.

Any information that you give to us will not be given to anyone else. The information will only be used for the purposes of this study. Only the research team will have access to the information; these will be stored in locked filing cabinets, or be password-protected on computers. Your name will not appear in any reports or presentations from this study. All data files will be destroyed 5 years after completion of the research.

You have already given us an address and phone number where you can be reached. An interviewer will call you soon to arrange an interview. **If you have any questions before or after being interviewed, please call the Research Coordinator, Brenda Kwan at 604-822-9214.**

If you have any questions about this study, you may also contact Dr. Jim Frankish (phone 604-822-9205; e-mail frankish@interchange.ubc.ca). If you wish to verify the ethical approval of this study, or if you have any concerns about your treatment or rights as a participant in this study, please contact the Research Subject Information Line in the UBC Office of Research Services (604-822-8598), or the UVic Associate Vice-President of Research (250-472-4545 or ovprhe@uvic.ca). Thank you for your time and support.

Sincerely,

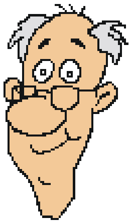
Jim Frankish, Associate Director
Institute of Health Promotion Research
Faculty of Graduate Studies

Co-Investigators (UVic)	Co-Investigators (UBC)	Co-Investigators (SFU)
Deborah Begoray	Arminee Kazanjian	Michael Hayes
Jennifer Mullett	Bruno Zumbo	

Co-Investigators (UNBC)
Karen Kelly

APPENDIX C: RECRUITMENT POSTER

Please post until May 31, 2005.



In collaboration with

SEEKING SENIORS
for
A STUDY ON HEALTH INFORMATION

Measuring Health Literacy

Principal Co-Investigators
Dr. Irv Rootman
Dr. Jim Frankish

Co-Investigators
Deborah Begoray
Arminee Kazanjian
Michael Hayes
Karen Kelly
Jennifer Mullett
Bruno Zumbo

What is the Study About?

We are interested in how seniors find, understand, and communicate information on “healthy aging.”

The study is being conducted by the Institute of Health Promotion Research at the University of British Columbia, together with the University of Victoria.

Who Are We Looking For?

People who:

- are 65 years of age or older,
- are comfortable speaking, reading, and writing in English,
- live in the city of Vancouver or Victoria, AND
- are interested in being interviewed for 45-60 minutes in person.

If You Are Interested in Participating...

In **Vancouver**, call **Brenda Kwan** at **604-822-9214**.
In **Victoria**, call **Melanie Talson** at **250-472-4102**.

If you have any questions about the study, you may also contact Dr. Jim Frankish by phone (604-822-9205) or by e-mail (frankish@interchange.ubc.ca).

APPENDIX D: CONSENT FORM

[printed on letterhead]

Consent Form
MEASURING HEALTH LITERACY

You, (print your name) ___________________________________, agree to participate in a study titled “Measuring Health Literacy.” The study is funded by the Canadian Institutes of Health Research, and is being conducted by the Institute of Health Promotion Research at the University of British Columbia, in collaboration with the University of Victoria. The Principal Investigators are Dr. Irv Rootman and Dr. Jim Frankish (phone 604-822-9205; e-mail frankish@interchange.ubc.ca).

The purpose of the study is to develop a measure of how people find, understand, and communicate health information about “healthy aging.” How this occurs in different groups of people, such as seniors, is of particular interest. You have been asked to participate in this study because you are a senior with experience related to health information. The findings of the study will provide knowledge about how better health information can be given to seniors.

Your participation will involve the completion of a 45-60 minute face-to-face interview with a trained interviewer. With your consent, the interview will be audio-taped.

Any information that you give to us will not be given to anyone else. The information will only be used for the purposes of this study. Only the research team will have access to the information; these will be stored in locked filing cabinets, and be password-protected on computers. Your name will not appear in any reports or presentations from this study. All data will be destroyed 5 years after completion of the research.

You will not be harmed in any way by participating in the study. You may refuse to participate, or withdraw from, the study at any time without any consequences, and have your answers erased. You have the right to ask questions related to the procedures of the study, and to receive answers for your questions. If you have any concerns about your treatment or rights as a participant in a study, you may telephone the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at 604-822-8598. You may also verify the ethical approval of this study, or raise any concerns you might have, by contacting the UVic Associate Vice President of Research at 250-472-4545 or ovprhe@uvic.ca.

You have received a copy of this consent form, and have read and understood the procedures described in the consent form. Your signature below may be taken as evidence of your consent to participate in this study. You keep a copy of the signed consent form, and another copy of the signed consent form will be kept for the records of the project.

Signature: ____

Date: ____

APPENDIX E: INTERVIEW PROTOCOL AND FORMS

Date of Interview:
Start Time:

Health Literacy Instrument

INTERVIEW FORM

ID #: ☐☐☐☐

Begin

This interview will take 45-60 minutes. I will ask you some questions about your experiences with finding, understanding, and communicating information on health. Your responses are important in helping us learn how to provide health information to seniors. With your consent, the interview will be recorded on audio-tape. Please note that you may leave the study at any time, or choose not to answer a question, without any consequences. If you have any questions during the interview, feel free to ask me. Do you have any questions before we begin?

____

____

Consent Forms

Before I start asking you questions, you need to sign a consent form that states that you understand the procedures of the study, and that you are willing to be interviewed. There are two copies of the same form. One copy is for you to keep. The other copy is for our records.

(Give the "interviewee copy" to the interviewee. Allow time to read it. Make sure BOTH copies are signed – interviewee copy and project copy.)

(If the interviewee does not mind, set-up the tape recorder while he/she reads and signs the consent forms. Test the recorder with both your voice and the interviewee's voice.)

Contextual Information

I will begin by asking you some questions to get some background information.

F1. Our interview is about information on "healthy aging." In your own words, please tell me what you think "healthy aging" means. (CT1)

____

____

Page 1 of 17 Version date: April 26, 2005

F2. **During the past month, what has been your biggest health concern?** (CT2, C1)

____
[biggest health concern]

F2a. **What other health concerns have you had during the past month?**

____
____

F2b. **For this interview, we would like you to choose a health concern and tell us about your experiences in finding, understanding, and communicating information on this health concern. You mentioned that your biggest health concern was *[biggest health concern]*. Would you like to talk about *[biggest health concern]* or about another health concern?**

____
[health concern]

F2c. **How long has *[health concern]* been a concern for you?** _______________

Access Health Information

I will now ask you some questions about the experiences you have had in trying to FIND information on *[health concern]*.

F3. **What did you want to find out about *[health concern]*?** (AF1, CT2)

(Or, if necessary, prompt with:)
What questions did you have about *[health concern]*?

____
____

F4. **When you tried to find information on *[health concern]*, which source did you go to FIRST?** (A1)

____
[first information source]

(Flip to appropriate scale for question F4a in the Interviewee Binder.)

F4a. **Please refer to this scale to answer the next question. OVERALL, how satisfied were you with the information on *[health concern]* that you got from *[first information source]*?**
(Mark the appropriate response.)

1 ○ Very dissatisfied with the information
2 ○ Dissatisfied with the information
3 ○ Neutral (neither dissatisfied nor satisfied with the information)
4 ○ Satisfied with the information
5 ○ Very satisfied with the information

F4b. **Please tell me more about what it was like trying to get information on *[health concern]* from *[first information source]*.**

(Or, if necessary, prompt with:)
How well do you think *[first information source]* told you what you wanted to know about *[health concern]*?

____
____

F5. **Aside from *[first information source]*, which OTHER sources did you go to for information on *[health concern]*?** (A2, C2)

1 ○ Did not go to any other sources for information *(Go to F6.)*
(Or list sources in the lines provided below.)

	Very dis-satisfied	Dis-satisfied	Neutral	Satisfied	Very satisfied
2 ____________________	1 ○	2 ○	3 ○	4 ○	5 ○
3 ____________________	1 ○	2 ○	3 ○	4 ○	5 ○
4 ____________________	1 ○	2 ○	3 ○	4 ○	5 ○

F5a. **Referring to the same scale that we just used, how satisfied were you with the information on *[health concern]* that you got from each of these OTHER sources?**
(Mark the appropriate circle(s) above in question F5.)

F5b. **Please tell me more about what it was like trying to get information on *[health concern]* from each of these OTHER sources.**

(Or, if necessary, prompt with:)
How well do you think each of these OTHER sources told you what you wanted to know about *[health concern]*?

and

Of the sources that you used to find information on *[health concern]*, which ONE source did you find to be the most useful? What makes this ONE source the most useful to you?

____

____

F6. **What are your thoughts on how much you can trust the information that you found on *[health concern]*?** (A1)

(Or, if necessary, prompt with:)
Of the sources that you used to find information on *[health concern]*, which ONE source did you trust the most? What makes you trust this ONE source of information the most?

____

____

(Flip to appropriate scale for question F7 in the Interviewee Binder.)

F7. Please refer to this scale to answer the next question. OVERALL, how easy was it for you to find the information that you wanted on *[health concern]*? (A3)
(Mark the appropriate response.)

1 ○ Very easy to find
2 ○ Easy to find
3 ○ Neutral (neither easy nor hard to find)
4 ○ Hard to find
5 ○ Very hard to find

Understand Health Information

We have been talking about your experiences with FINDING information on *[health concern]*. I will now ask you some questions about your experiences with UDNERSTANDING the information that you found on *[health concern]*.

(Flip to appropriate scale for question F8 in the Interviewee Binder.)

F8. Please refer to this scale to answer the next question. OVERALL, how easy was it for you to understand the information that you found on *[health concern]*? (U1)
(Mark the appropriate response.)

1 ○ Very easy to understand
2 ○ Easy to understand
3 ○ Neutral (neither easy nor hard to understand)
4 ○ Hard to understand
5 ○ Very hard to understand

(Flip to appropriate scale for question F9 in the Interviewee Binder.)

F9. Please refer to this scale to answer the next question. Thinking back on all the information that you found on *[health concern]*, how often did you come across information that did not agree with each other?
(Mark the appropriate response.)

- 1 ○ Never came across
- 2 ○ Hardly ever came across
- 3 ○ Occasionally came across
- 4 ○ Frequently came across
- 5 ○ Always came across

(Flip to appropriate scale for question F9a in the Interviewee Binder.)

F9a. Please refer to this scale to answer the next question. How easy was it for you to make sense of information that did not agree with each other?
(Mark the appropriate response.)

- 1 ○ Very easy to make sense
- 2 ○ Easy to make sense
- 3 ○ Neutral (neither easy nor hard to make sense)
- 4 ○ Hard to make sense
- 5 ○ Very hard to make sense

(Flip to appropriate scale for question F10 in the Interviewee Binder.)

F10. Please refer to this scale to answer the next question. Thinking back on all the information that you found on *[health concern]*, how often did you come across words that you did not understand?
(Mark the appropriate response.)

1 ○ Never came across
2 ○ Hardly ever came across
3 ○ Occasionally came across
4 ○ Frequently came across
5 ○ Always came across

F10a. What did you do when you came across words that you not understand about *[health concern]*?

____
____

Communicate Health Information

We have talked about your experiences with FINDING and UNDERSTANDING information on *[health concern]*. I will now ask you some questions about your experiences with COMMUNICATING about *[health concern]* with other people.

F11. Who did you tell that you were concerned about *[health concern]*?
(Or, if necessary, prompt for the following: family doctor; and family or friends.)

____
[person(s)]

F11a. How did it go when you told *[person(s)]* that you were concerned about *[health concern]*? (UF1-3)

(Or, if necessary, prompt with:)
What difficulties did you face in trying to tell *[person(s)]* that you were concerned about *[health concern]*?

____
____

F12. Of all the things you have learned about *[health concern]*, what do you think are the key points that other seniors should know about *[health concern]*?

____

____

F12a. With whom have you had a chance to share what you have learned about *[health concern]*?

____

____

F12b. By sharing what you have learned about *[health concern]*, how do you think this has made a difference in other peoples' lives?

____

____

Impacts of Health Information

We have talked about FINDING, UNDERSTANDING, and COMMUNICATING information on *[health concern]*. I will now ask you some questions about how the information that you found on *[health concern]* has made a difference in your life, no matter how small.

F13. How has the information that you found on *[health concern]* changed your understanding of *[health concern]*? (I1)

____

____

F14. How has the information that you found on *[health concern]* changed how you feel about *[health concern]*? (I2)

____

____

F15. **How has the information that you found on *[health concern]* changed how you take care of your health?** (I3)

____

____

F16. **In what other ways has the information that you found on *[health concern]* made a difference in your life?** (I1-3)

____

____

Attitudes and Beliefs

So far, we have talked about your experiences with information on *[health concern]*. For this next part, I would like you to not just think about *[health concern]*, but to think back on ALL your experiences with trying to find, understand, and communicate information on health. We are interested in your opinions OVERALL.

(Flip to appropriate scale for question F17 in the Interviewee Binder.)

F17. Please refer to this scale to answer the next question. I will read you some statements. For each statement, I will ask you how much you agree or disagree with it.
(For each statement, mark the appropriate circle.)

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a) It is important for me to stay healthy as I age.	1 ○	2 ○	3 ○	4 ○	5 ○
b) I am responsible for my own health.	1 ○	2 ○	3 ○	4 ○	5 ○
c) The health information that I want exists somewhere. (AF2)	1 ○	2 ○	3 ○	4 ○	5 ○
d) I have the skills to FIND the health information that I want. (AF2)	1 ○	2 ○	3 ○	4 ○	5 ○
e) I have the skills to ASK others for the health information that I want. (CF1)	1 ○	2 ○	3 ○	4 ○	5 ○
f) I have the skills to UNDERSTAND the health information that I find.	1 ○	2 ○	3 ○	4 ○	5 ○
g) I have the skills to ASK others to clarify any health information that is unclear. (CF1)	1 ○	2 ○	3 ○	4 ○	5 ○
h) I have the skills to MAKE SENSE of health information that is inconsistent.	1 ○	2 ○	3 ○	4 ○	5 ○
i) I have the skills to PICK OUT the health information that I want.	1 ○	2 ○	3 ○	4 ○	5 ○
j) I have the skills to JUDGE which health information can be trusted.	1 ○	2 ○	3 ○	4 ○	5 ○
k) I have the skills to DESCRIBE my health concerns to others. (CF1)	1 ○	2 ○	3 ○	4 ○	5 ○
l) I have the skills to SHARE with others the health information that I have learned. (CF1)	1 ○	2 ○	3 ○	4 ○	5 ○

General Questions About Health Information

For the next few questions, please again think about ALL your experiences with health information, not just about *[health concern]* only.

(Flip to appropriate scale for question F17i and F17ii in the Interviewee Binder.)

F17i. Please refer to this scale to answer the next question. How often do you have someone help you read health-related materials?
(Mark the appropriate response.)

1 ○ Never
2 ○ Occasionally
3 ○ Sometimes
4 ○ Often
5 ○ Always

F17ii. Using the same scale, how often do you have problems learning about your health because of difficulty understanding written information?
(Mark the appropriate response.)

1 ○ Never
2 ○ Occasionally
3 ○ Sometimes
4 ○ Often
5 ○ Always

(Flip to appropriate scale for question F17iii in the Interviewee Binder.)

F17iii. Please refer to this scale to answer the next question. How confident are you filling out medical forms by yourself?
(Mark the appropriate response.)

1 ○ Extremely
2 ○ Quite a bit
3 ○ Somewhat
4 ○ A little bit
5 ○ Not at all

REALM (Rapid Estimate of Adult Literacy in Medicine)

The next part of the interview will help us learn about how familiar people are with various health-related words.

(Give the interviewee a laminated copy of the REALM word list. Hold your score sheet on a clipboard at an angle so that the interviewee is not distracted by your scoring procedure.)

I want you to read as many words as you can from this list. Begin with the first word and read aloud. When you come to a word you can not read, do the best you can or say “blank” and go on to the next word.

(If the interviewee takes more than 5 seconds on a word, say “blank” and point to the next word, if necessary, to move the interviewee along. If the interviewee begins to miss every word, have him/her pronounce only known words.)

LEGEND: (+) = Correct (-) = Word not attempted (/) = Mispronounced word

List 1			List 2			List 3		
fat	__________	(R1)	fatigue	__________	(R23)	allergic	__________	(R45)
flu	__________	(R2)	pelvic	__________	(R24)	menstrual	__________	(R46)
pill	__________	(R3)	jaundice	__________	(R25)	testicle	__________	(R47)
dose	__________	(R4)	infection	__________	(R26)	colitis	__________	(R48)
eye	__________	(R5)	exercise	__________	(R27)	emergency	__________	(R49)
stress	__________	(R6)	behavior	__________	(R28)	medication	__________	(R50)
smear	__________	(R7)	prescription	__________	(R29)	occupation	__________	(R51)
nerves	__________	(R8)	notify	__________	(R30)	sexually	__________	(R52)
germs	__________	(R9)	gallbladder	__________	(R31)	alcoholism	__________	(R53)
meals	__________	(R10)	calories	__________	(R32)	irritation	__________	(R54)
disease	__________	(R11)	depression	__________	(R33)	constipation	__________	(R55)
cancer	__________	(R12)	miscarriage	__________	(R34)	gonorrhea	__________	(R56)
caffeine	__________	(R13)	pregnancy	__________	(R35)	inflammatory	__________	(R57)
attack	__________	(R14)	arthritis	__________	(R36)	diabetes	__________	(R58)
kidney	__________	(R15)	nutrition	__________	(R37)	hepatitis	__________	(R59)
hormones	__________	(R16)	menopause	__________	(R38)	antibiotics	__________	(R60)
herpes	__________	(R17)	appendix	__________	(R39)	diagnosis	__________	(R61)
seizure	__________	(R18)	abnormal	__________	(R40)	potassium	__________	(R62)
bowel	__________	(R19)	syphilis	__________	(R41)	anemia	__________	(R63)
asthma	__________	(R20)	hemorrhoids	__________	(R42)	obesity	__________	(R64)
rectal	__________	(R21)	nausea	__________	(R43)	osteoporosis	__________	(R65)
incest	__________	(R22)	directed	__________	(R44)	impetigo	__________	(R66)
# of (+) Responses in List 1: __________			# of (+) Responses in List 2: __________			# of (+) Responses in List 3: __________		

Raw Score: REALM generated reading level:

Page 12 of 17 Version date: April 26, 2005

Reading Comprehension

The next part of the interview will help us to learn how to provide information to people. I will show you two short passages taken from pamphlets published by the BC Ministry of Health Services. Please read each passage, and answer the questions that follow.

(Hand the laminated Text Passage #1 to the interviewee.)
This is the first passage I would like you to read. When you are finished reading the passage, please read the questions and write your answers on this sheet.
(Hand the Text Passage #1 Answer Sheet to the interviewee as you tell them the instructions.)

(Turn the tape recorder off while the interviewee completes the task.)

(When the interview is finished with Text Passage #1, take both the laminated passage and answer sheet from the interviewee. Fill in the interviewee's ID# in the shaded box at the top right corner of his/her answer sheet.)

(Hand the laminated Text Passage #2 to the interviewee.)
This is the second passage I would like you to read. When you are finished reading, please read the questions and write your answers on this sheet.
(Hand the Text Passage #2 Answer Sheet to the interviewee as you tell them the instructions.)

(When the interview is finished with Text Passage #2, take both the laminated passage and answer sheet from the interviewee. Fill in the interviewee's ID# in the shaded box at the top right corner of his/her answer sheet.)

(Turn the tape recorder back on.)
F18. What are your thoughts on the two passages?

____
____

Demographics

I will now ask you some final questions about yourself. Your answers will be combined with answers from other people to give us an overall description of the people we are talking to in our study.

(Flip to appropriate scale for question F19 in the Interviewee Binder.)

F19. Please refer to this scale to answer the next question. I'll start with a question concerning your health IN GENERAL. Would you say your health is... (VS3) (This question, and the scale used, corresponds with that used in the Statistics Canada National Population Health Survey.)
(Read categories, and mark the appropriate circle.)

1 ○ Poor
2 ○ Fair
3 ○ Good
4 ○ Very good
5 ○ Excellent

F20. What is your age? (VS1) __________ years

(Alternatively, ask.)
F20a. What is your birth date? _____ / _____ / __________
mm dd yyyy

F21. What is your gender? (VS1)
(It is not necessary to ask this. Look at the interviewee and mark the appropriate circle.)

1 ○ Male
2 ○ Female

F22. What is your marital status? (VS1)
(Mark the appropriate circle. Read categories only if necessary.)

1 ○ Married
2 ○ Common-law
3 ○ Living with a partner
4 ○ Single (never married)
5 ○ Widowed
6 ○ Separated
7 ○ Divorced

F23. What is the highest level of education you have EVER completed? (VS1)
(Mark the appropriate circle. Read categories only if necessary.)

1 ○ Did not complete elementary school
2 ○ Elementary school
3 ○ High school
4 ○ Trade school
5 ○ College
6 ○ University, undergraduate
7 ○ University, graduate
8 ○ Other – *Specify* ____

F23a. In what country did you complete your education?

____

F24. To which ethnic, or cultural group(s) did your ANCESTORS belong? For example, French, Scottish, Chinese, etc. (VS1) (This question is taken from the Statistics Canada National Population Health Survey questionnaire.)

____

F25. In which country were you born? (This question is taken from the Statistics Canada National Population Health Survey questionnaire.)

____

(If the country is not "Canada," then ask. Otherwise, go to F26.)

F25a. In what year did you first come to Canada to live? __________
(This question is taken from the Statistics Canada National Population Health Survey questionnaire.)

F25b. Before coming to Canada, in which country did you live?

____

F26. What language did you FIRST speak as a child? ____________________________
(This question is taken from the IALS.)

F27. What language do you speak MOST OFTEN at home? _______________________
(This question is taken from the IALS.)

F28. We recognize that many people consider the next question, which is about income, to be private. You can choose to answer it or not. However, your answer would be helpful in giving us an idea of who we talked to in our interviews. Please be assured that you will not be individually identified, nor will this information be passed on to anyone else.

What is your best estimate of your TOTAL HOUSEHOLD income in the past 12 months (before taxes and deductions)? (VS1) (This question is adapted from the Statistics Canada National Population Health Survey questionnaire.)
(Mark the appropriate circle. Read categories if necessary, and flip to appropriate scale for question F28 in the Interviewee Binder.)

$ _______________

1 ○ $0 to $10,000
2 ○ $10,001 to $20,000
3 ○ $20,001 to $30,000
4 ○ $30,001 to $40,000
5 ○ $40,001 to $50,000
6 ○ More than $50,000

Final Comments and Second Interview

We have reached the end of this interview. Thank you for taking the time to answer our questions. Your responses will help us learn about how people find, understand, and communicate information on health.

F29. Is there anything else you would like to add to your responses, or do you have any comments on the interview itself?

____

____

F30. Finally, we may conduct a second interview about 3-6 months from now, to learn even more about how people find, understand, and communicate information on health. Please note that completing the interview today does not mean that you have to complete a second interview later. The choice is up to you. Would you be interested in a second interview?

1 ○ Yes
2 ○ No
3 ○ Maybe

(If "no" or "maybe", then ask:)

F30a. Would it be OK for us to call you again in 3-6 months, to ask you then if you would be interested in having a second interview?

1 ○ Yes
2 ○ No

F31. Finally, would you be interested in receiving a copy of our final report for this study, when it is ready about a year from now?

1 ○ Yes
2 ○ No

Good-Bye

Thank you for taking the time to help us with our study. If you know any seniors who might be interested in being interviewed, please feel free to let them know about our study. *(Give copy of poster.)* **Good-bye.**

End Time:

Page 17 of 17 Version date: April 26, 2005

PASSAGE #1

The Chronic Disease Self-Management Program (CDSMP) is a patient education program taught by trained lay leaders. It is given once a week for 2 ½ hours, for six consecutive weeks.

The leaders are trained volunteers and work in pairs following a standardized course outline. Many of the leaders have chronic conditions themselves and have successfully adopted the techniques taught in the program.

If you have a chronic condition such as hypertension, arthritis, heart disease, diabetes, asthma, bronchitis, emphysema, fibromyalgia or others, you will benefit from participating in the CDSMP.

Your spouse, family member or friend is encouraged to attend the program with you. As a participant in the class, they too will benefit from learning about your condition and how it affects you.

PASSAGE #1 – ANSWER SHEET

PO1. What is the name of the patient education program?

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PO2. Who teaches the program?

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PO3. For how many weeks does the program last?

__________ weeks

PO3a. If you were to complete the program, how many hours would you have spent at the program?

__________ hours

PO4. Other than a patient with a chronic condition, who else can attend the program?

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PASSAGE #2

Healthy Fat Choices

Fats are not all the same. Some fats are good for your health, while others are not.

Good choices are *monounsaturated* fats, which help to lower blood cholesterol levels. Monounsaturated fats are found mainly in olive and canola oils and foods containing these ingredients, and in nuts and avocado.

***Polyunsaturated* fats also help to lower blood cholesterol levels. Two special polyunsaturated fats – omega 3 and omega 6 – are very important for your health. Omega 3 fats are found in fish, flax seeds, walnuts and canola oil. Good sources of omega 6 fats are seeds, safflower, sunflower, corn, and soybean oils, and foods that contain these ingredients.**

***Saturated* and *trans* fats are poor choices mainly because they can increase blood cholesterol levels. It is very important to eat less saturated and trans fats.**

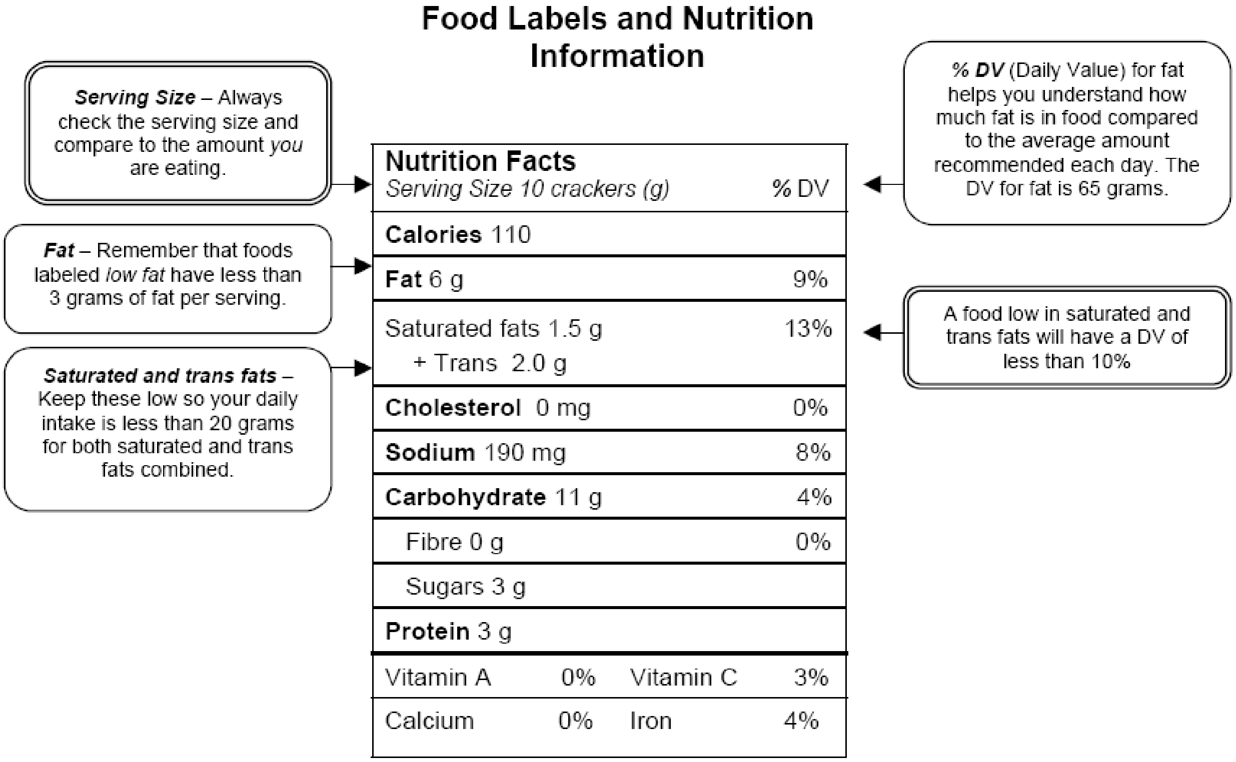
Saturated fats are mostly found in animal products, especially fatty meats like sausages, and products with high amounts of dairy fat like butter, whipping cream, sour cream, cream cheese and chip dips.

Trans fats come mostly from vegetable oils that have been made solid through hydrogenation. Examples of foods that contain trans fats are hard margarine, shortening, donuts, Danish pastries, cookies, crackers, chips, and many fast foods.

Use the Information on Food Labels

Look for the claims

- **Low fat – means that the food must have less than 3 grams of fat per serving**
- **Fat free – means that the food must have less than 0.5 grams of fat per serving**



Food Labels and Nutrition Information

Serving Size – Always check the serving size and compare to the amount *you* are eating.

Fat – Remember that foods labeled *low fat* have less than 3 grams of fat per serving.

Saturated and trans fats – Keep these low so your daily intake is less than 20 grams for both saturated and trans fats combined.

% DV (Daily Value) for fat helps you understand how much fat is in food compared to the average amount recommended each day. The DV for fat is 65 grams.

A food low in saturated and trans fats will have a DV of less than 10%

Nutrition Facts *Serving Size 10 crackers (g)*			**%** DV
Calories 110			
Fat 6 g			9%
Saturated fats 1.5 g + Trans 2.0 g			13%
Cholesterol 0 mg			0%
Sodium 190 mg			8%
Carbohydrate 11 g			4%
Fibre 0 g			0%
Sugars 3 g			
Protein 3 g			
Vitamin A	0%	Vitamin C	3%
Calcium	0%	Iron	4%

PASSAGE #2 – ANSWER SHEET

PT1. Why are some fats good for your health?

____

PT2. Saturated and trans fats are poor fat choices. It is important to eat less of the foods that contain these fats. Many examples of these foods are listed in the passage. List any THREE of these foods.

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PT3. In the example of the FOOD LABEL shown, what is the total number of grams of fat in 10 crackers?

__________ grams

PT3a. Could these crackers be labeled “low fat” (yes or no)? Please explain your answer.

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