Writing

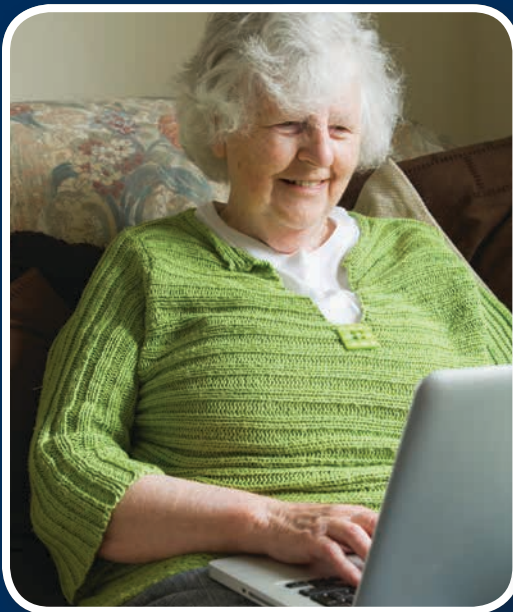## health information
for patients and families

A guide to developing
educational materials that
promote health literacy

Lindsay **Wizowski** • Theresa **Harper** • Tracy **Hutchings**

F O U R T H   E D I T I O N   2 0 1 4

A note to readers from the authors:

The links (URL's) to the websites listed in this book were correct at the time of printing. However, as information on the Internet changes frequently, we cannot guarantee that the links or the content of the websites will remain accurate.

Writing health information for patients and families

Forward to the fourth edition - 2014

The evidence is clear. Using easy-to-read health education materials is a best practice strategy for promoting patient-centred learning and health literacy.

If you want to know how to develop clear and effective education materials for patients and families, this book can be your guide.

- ✓ The first half presents the evidence, guiding principles and techniques. This fourth edition provides new perspectives on health literacy, and links to helpful resources, including our website: www.healthliteracyconnection.ca

- ✓ The second half is a practical guide to writing, designing and producing patient education materials. This step-by-step process can be used to develop materials in print and online.

This book is based on over two decades of experience as Patient Education Specialists at a multi-site teaching hospital and cancer centre. Our goal is to share what we have learned from patients and families, health care providers, and research in the growing field of health literacy.

We hope that you find this book helpful and invite your comments and suggestions.

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Part One

Using patient education materials can make your teaching more effective.

Developing patient education materials has many benefits.

Writing health information for patients and families

What are the benefits of using patient education materials?

Patient education is a planned interaction between a patient and a health care provider. Information is exchanged as the health care provider:

- seeks to understand the patient's learning needs, preferences and values
- strives to facilitate and support the patient's learning, in part by providing accurate and understandable information

Verbal communication is essential to this process, but by itself, it is not enough. Patient education is best accomplished using a combination of methods. When education materials are provided in addition to verbal communication, patient education is more effective (RNAO, 2012; Cancer Care Ontario, 2009; Johnson, Sanford &Tyndall, 2008).

> **For more effective patient education, reinforce verbal information with patient education materials (PEM).**

There are many specific benefits of using patient education materials:

PEM promote learning and increase knowledge

- Exposure to well-designed PEM increases patients' knowledge (You, Wolff, Bailey & Grobman, 2012).

- PEM help people remember important messages. Patients receive information from many different people. Studies examining patients' memory report that 40 to 80% of the information provided by health care practitioners is forgotten immediately, and half of the information patients remember is actually recalled incorrectly (Kessels, 2003).

- Patients have more control over learning. They can read materials at their own pace and refer to them as often as needed. Reviewing printed materials after interaction with health care providers can promote long-term retention of new information (Wilson et al., 2010).

- Patients may find it very difficult to learn at the hospital. The environment can be noisy and distracting. Patients may feel anxious or tired, or be in pain. This interferes with their concentration and memory. Patients can review PEM at home, where privacy and comfort makes the setting more conducive to learning.

- PEM provide accurate information to family members who were not present during teaching.

PEM promote patient engagement and self-management

- Providing quality health information (accurate, accessible and actionable) enables patients to better manage their health and wellbeing, and make fully informed decisions about their treatment and care (Patient Information Forum, 2013; Coulter, 2012; Johnson, Sandford & Tyndall, 2008).

- With interactive features such as questions, journals, and charts, patients can use PEM as tools for monitoring health behaviours and outcomes.

PEM enhance the patient experience

- Providing verbal and written information at discharge from hospital improves patient satisfaction (Johnson, Sanford & Tyndall, 2008).

- PEM can help patients know what to expect before, during and after a procedure, treatment or surgery. This can reduce their anxiety and increase satisfaction with their care and their care providers.

- Providing high quality and accessible health information promotes patient engagement and helps to enhance patients' experience of care (Patient Information Forum, 2013).

PEM provide consistent information

- The content of PEM reflects what the health care team decides are the main messages. This promotes consistency in patient and family education.

PEM save health care providers' time

- PEM reinforce information, so health care providers may not need to repeat teaching.

- PEM can help patients understand information and follow instructions. As a result, they may have fewer questions and less need for follow-up teaching, visits and phone calls.

PEM reduce health care utilization and costs

- Providing patients with quality health information is the key to patient engagement and self-management of long-term conditions. This has a positive impact on services use and costs. (Patient Information Forum, 2013; Mitic & Rootman, 2012; Jack et al, 2009; Goudreau et al, 2008).

Why develop patient education materials?

Many education materials are available to purchase or download from the web. So why spend your time and energy developing your own materials?

From over two decades of experience developing patient education materials, we know this process has significant benefits for health care providers, students in health professions, hospitals and healthcare organizations, as well as patients and families.

Most importantly, the materials you develop will meet the unique needs of your patients and are tailored to your health care setting. However, the development of the materials yields other benefits to staff and students, the organization, and to patients and families.

Benefits to staff and students

The process of developing PEM helps health care providers and students:

- better understand patients' perspectives and needs

- communicate more effectively with patients and families

- keep up to date in clinical practice

- apply knowledge from research

- understand the roles of other health care providers

- facilitate an interprofessional approach

This is supported by one author's study, in which Occupational Therapy students reported that the process of developing materials furthered their understanding of patient-centred education and gave them insight into the importance of teamwork (Edwards & Harper, 2004).

> **Raising awareness of health literacy is recommended as a strategy for improving the health literacy of Canadians.**
>
> (Mitic & Rootman, 2012; Rootman & Gordon-El-Bihbety, 2008)

Benefits to the organization

The development process helps hospitals and health care organizations improve the quality of their services by:

- making patient and family education materials easy to update and consistent across units and programs

- fostering clear communication practices that promote health literacy and patient safety

- establishing a patient-centred approach to education

- promoting interprofessional teamwork

- encouraging collaborative partnerships among hospitals and health care organizations

> **The process of developing PEM improves the effectiveness and coordination of communication among service providers and with the recipients of care.**
>
> **Communication is one of Accreditation Canada's Required Organizational Practices.**
>
> www.accreditation.ca/sites/default/files/rop-handbook-2014-en.pdf

Benefits to patients and families

By developing PEM, you can provide information that is tailored to the needs of patients in your hospital or health care setting. You can make sure the information is easy to read, understand and use.

Developing PEM supports a partnership between patients and families. Health care providers involve patients and families by seeking and using their input to improve educational materials. Patients and families feel valued for their expertise and opinions.

Patients who help improve the readability of patient education materials take pride in having helped others to understand complex health information (Ross, Potter & Armstrong, 2004).

> **Involving patients and families leads to the production of quality information.**

Why develop materials when patients can access health information on the Internet?

The Internet offers many advantages for patient education, such as providing:

- a range of information from consumer health articles to medical research

- interactive tools to assess health risks, make decisions about treatment options and promote self-management

- access to support groups and health care professionals

- access from remote locations

- access for people with disabilities

- a variety of media – text, audio, video and animation

- an opportunity for people to learn at their own pace, at a convenient time, and privately

However, there are some issues to consider when using the Internet for patient education.

Internet use is not universal

In 2012, 83% of Canadians age 16 or over used the Internet for personal use. Of Internet users, 67% searched for medical or health-related information (Statistics Canada, 2013).

Reasons for not using the Internet include:

- lack of confidence, knowledge or skill
- lack of a device such as a computer
- the cost of service or equipment
- no need for or interest in it

The "digital divide" persists. This is the gap in the rate of Internet use on the basis of income and age. Older Canadians and those with lower incomes are less likely to use the Internet (Statistics Canada, 2013).

Internet use requires additional skills

An Internet search results in an overwhelming amount of information. This information must be read and analyzed to determine what is accurate and relevant. This is difficult when much of the information is written at a level that the average adult would find hard to read and understand.

Literacy demands can be a barrier to Internet use.

(Risoldi Cochrane, Gregory & Wilson, 2012; Korp, 2006; Schwartzberg, VanGeest & Wang, 2005.)

The Internet is helpful when:

✓ patients have access to a computer or hand-held device and the skills to search for health information

✓ online information is presented in a way that is easy to read and navigate

✓ online information is relevant to the person's needs and location

Tips for using online information during teaching

Ask patients to discuss the health information they have found on the Internet.

Use interactive websites that offer simple text, pictures, and audio such as:

- McGill University Health Centre
  www.muhcpatienteducation.ca/?q=content/general-health-guides
- MedlinePlus Interactive Health Tutorials
  www.nlm.nih.gov/medlineplus/tutorial.html
  Use printed pages from websites you recommend as handouts.

Help people learn how to find good quality health information.
Refer them to websites such as:

- Healthy Canadians: www.healthycanadians.gc.ca/health-sante/index-eng.php
- MedlinePlus:
  www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html
- National Cancer Institute:
  www.cancer.gov/cancertopics/factsheet/Information/Internet

What is the most effective way to use patient education materials?

> **"Health materials are effective only when used as a part of an overall patient education strategy."**
>
> (Agency for Healthcare Research and Quality, 2010, p. 53)

First, use the right material

Based on your assessment of the patient's needs and preferences, use patient education materials that will support the patient's learning. Effective materials are:

- **Accurate** – They reflect current practice and reinforce what you teach. They also match your organization's philosophy and policies.

- **Accessible** – They are easy to read and understand. This enables more people to use the information.

- **Actionable** – They encourage patients and families to take an active part in their health care. They focus on what patients need to know and do. They give action steps with concrete examples.

We recommend that health care providers:

- maintain a collection of patient education materials on the topics most relevant to their practice

- select or develop the materials themselves to ensure readability, accuracy and quality

- are familiar with the content of the materials they use

- ensure that materials are integrated into the patient's plan of care

- make materials easily available to staff – whether they are printed copies or electronic versions to be downloaded from a central database or internal website

> **Health care providers' involvement and familiarity with patient education materials are key to their use in clinical practice.**
>
> (McVea, Venugopal, Crabtree & Aita, 2000)

Second, use the material during teaching

Don't rely on handouts to educate.

- Simply giving a patient a handout is not enough to promote understanding or behaviour change.

- PEM support and reinforce verbal messages. They can facilitate discussion, not replace it.

> **"Handouts don't teach. People teach."**
>
> (London, 2009, p. 91)

Review the material with the patient.

- Emphasize important information (such as warning signs and who to call for help) by circling or highlighting it in the material. This helps the patient find this information easily when they get home.

- Endorse the information. Tell the patient why the information is important for them. Discuss how the key points relate to his or her care.

- Invite questions and encourage the patient to tell you if something is unclear.

Individualize the information

- Personalize materials by adding the patient's name, notes and specific instructions.

- Involve the patient. For example:
  - As you review discharge instructions, ask the patient how he or she will do each step at home.
  - From a list of recommended foods, ask the patient to circle those that he or she eats regularly or might like to try.

- Find out 'where they're at'. Many people do not have a strong understanding of how the human body works. And everyone has their own ideas and experiences, which may or may not fit with the information you are providing.

Writing health information for patients and families

Check understanding

- Confirm that the patient has learned a skill by asking him or her to demonstrate the skill. Give feedback and allow time for extra practice as needed.

- Confirm that the patient understands verbal and written instruction by using the "teach back" method (Schillinger et al., 2003). Use open-ended questions. Ask the patient to restate the information or instructions in his or her own words. Make it clear that you are checking the effectiveness of your teaching, not testing the patient. Clarify or re-teach as needed.

Statements that invite 'teach-back':

- I want to see if I did a good job teaching what warning signs to watch for. Can you please tell me when you would get worried and call the doctor?

- To make sure I explained this clearly, can you tell me what you will do at home?

- We have talked a lot about the importance of exercise, how do you plan to be active this week?

- I noticed that your partner wasn't able to be here today. What will you tell him/her about our discussion?

- These signs are not evidence of understanding:
  - patient is smiling and nodding
  - patient repeats your words
  - patient has no questions

Repeat as needed

- If applicable, refer to materials again in future visits. Focus on different topics as needed.

What is the process for developing patient education materials?

Before developing patient education materials, it is helpful to learn about:

- the concept of health literacy

- the health literacy skills of Canadians

- the consequences of low health literacy

- assessing the suitability of materials for patient education

- writing health information in plain language

- designing materials that are easy to read

Read about these concepts and skills in Part Two of this book.

In Part Three you apply these concepts and skills, using our step-by-step guide to developing patient education materials.

Part Four provides tools, forms, references and resources that you can use.

Part Two

Most people need help to understand health information.

You can help by writing and designing patient education materials that are easy to read, understand and use.

What is health literacy?

Everyday, adults engage in a wide variety of activities that relate to health.

Health activity	Examples
Health promotion Actions to stay healthy	• learn about health, lifestyle, well-being • healthy eating • physical activity
Health protection Actions to protect the health of individuals and communities	• safety in the home • workplace safety • product safety
Disease prevention Actions to prevent disease and to detect disease at early stages	• determine risk • change health behaviours • immunization and screening
Health care and self-management Actions to seek advice or help from health care providers	• learn about illness and treatment • find needed health care services • communicate with health care providers • self-care, monitor symptoms, take medications
Systems navigation Actions to obtain health care services	• navigate to and through health care settings • work in partnership with the health care team • provide informed consent

(Canadian Council on Learning, 2008 and 2007; Rudd, Soricone, Santos, Zobel & Smith, 2005;
Rudd, Kirsch & Yamamoto, 2004)

To do these activities effectively:

1. People need to use a variety of skills, often simultaneously. They use:

    • General literacy skills including listening, speaking, reading, writing, interpreting charts and forms, using basic mathematics, and problem-solving.

    • Skills related to information, communication and technology, including the ability to search for quality health information, use computers and social media.

2. People need environments that are easy to navigate and conducive to learning, and health information that is accurate, accessible and actionable.

> **The extent to which people can access, understand and use information for their health is called 'health literacy'.**

Writing health information for patients and families

Definitions of health literacy

Health literacy generally refers to the ability to access, understand and act on information for health (Canadian Public Health Association, Health Literacy Portal www.cpha.ca/en/portals/h-l.aspx).

As our understanding of health literacy has evolved, many definitions have been proposed. Initially, health literacy was narrowly defined as the ability to read health information. Current definitions acknowledge that health literacy involves more than an individual's skills. **It is the product of the complex interaction between an individual and the health care system.**

Source	Definition of Health Literacy
Berkman, Davis & McCormack 2010	The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions.
Centre for Literacy: Calgary Charter on Health Literacy 2009	Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills.
World Health Organization 2009	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.
Rootman, & Gordon-El-Bibety 2008	The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.

Zarcadoolas, Pleasant & Greer 2005	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. Health literacy is characterized by four domains: • Fundamental literacy (reading, writing, speaking and numeracy) • Science literacy • Civic literacy • Cultural literacy
Nielsen-Bohlman, Panzer & Kindig 2004	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
Nutbeam 2000	Nutbeam's model of health literacy has three levels: Basic/Functional health literacy: • The reading and writing skills needed to use health information in everyday situations. Communicative/Interactive health literacy: • The communication and social skills needed to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. Critical health literacy: • The advanced literacy, cognitive and social skills needed to critically analyze health information, make informed decisions, and exert greater control over life events and situations.

For an in-depth review of health literacy in Canada, refer to Hoffman-Goetz, Donelle and Ahmed, 2014.

What influences health literacy?

> Health literacy is the ability to access, understand and use health information. It emerges from the interaction between a person, his or her environment and the health care system.

Personal factors → **Health Literacy** ← **System factors**

Personal factors (Skills and abilities, environment)	System factors (Demands and complexity)
• literacy skills • cognitive skills, such as reasoning and memory • motivation to learn and self-manage • physical and emotional health • experience with the health care system • knowledge about health and health condition • language proficiency, cultural beliefs and practices regarding health • social and community supports • education and parents' education • birthplace (born in Canada or immigrant)	• health care providers' communication skills (speed of dialogue, extent of jargon, use of visual aids, degree of interactivity) • time pressures upon the health care providers • accessibility and complexity of health information • physical setting (noise, privacy, interruptions, space) • system demands and expectations (self management, partnering with activated and informed patients)

(Canadian Council on Learning, 2008; Paasche-Orlow & Wolf, 2007; Schillinger, 2007; Weiss, 2003)

> "There are many factors that contribute to an individual's health literacy.... Of these factors, perhaps the most important patient factor is the individual's general literacy."
>
> (Weiss, 2003, p. 6)

What is the difference between literacy and health literacy?

Literacy is the ability to read, write, communicate, use numbers and solve problems well enough to function in society and achieve one's goals (Rootman & Gordon-El-Bihbety, 2008).

A significant proportion (48%) of Canadian adults has low literacy skills (Statistics Canada, 2005a).

Appendix A provides detailed information about literacy in Canada and its connection to health.

"While general literacy skills are a necessary foundation for health literacy, health literacy is more than being able to read health information and complete medical forms. Health literacy involves the integration of a wide variety of individual skills, health-care professional communication skills, health-care practices and system processes." (RNAO, 2012. p. 16)

Even individuals with strong literacy skills may not be able to cope with the demands of learning in the health care context, especially when they are made more vulnerable by poor health (Nielsen-Bohlman, Panzer & Kindig, 2004; The Joint Commission, 2007).

Anyone can experience "low health literacy".

How 'health literate' are Canadians?

To define the extent of health literacy in Canada, data from an international literacy survey (Statistics Canada, 2005a) were analyzed with the Health Activities Literacy Scale (Rudd, Kirsch & Yamamoto, 2004). This scale provides a valid and reliable measurement of adults' ability to deal with health-related tasks. While not a complete assessment of health literacy skills (skills such as oral communication and problem-solving were not measured), the Canadian Public Health Association's Expert Panel on Health Literacy (Rootman & Gordon-El-Bihbety, 2008) believes this scale provides the best available information.

Low health literacy is even more prevalent than low literacy

- 48% of Canadian adults have low literacy
- 60% of Canadian adults have low health literacy

(Canadian Council on Learning, 2008; Rootman & Gordon-El-Bihberty, 2008; Statistics Canada, 2005a)

Who is most at risk?

Health literacy skills differ among population sub-groups within Canada. Some groups score below the national average.

Groups that are more vulnerable than others are:

- adults over the age of 65
- immigrants, especially those who do not speak either English or French
- adults with low income or those who are unemployed
- adults with low education

(Simich, L., 2009; Rootman & Gordon-El-Bihbety, 2008; Canadian Council on Learning, 2008 and 2007)

Other findings about health literacy

Health literacy varies with age

- 55% of Canadian adults 16 to 65 years of age have low health literacy
- 88% of Canadian adults over the age of 65 have low health literacy

(Rootman & Gordon-El-Bihberty, 2008; Canadian Council on Learning, 2008; Statistics Canada, 2005a)

Health literacy changes with experience

As people face different situations, their health literacy skills change over the course of their lives (Rootman & Gordon-El-Bihbety, 2008). Through learning and experience, people can improve their health literacy skills, which helps them in new situations.

Health literacy depends on the situation

A person may have adequate health literacy skills for getting a flu shot, but not for managing diabetes. Health literacy is "whatever one needs to successfully navigate their health care environment" (Jensen, King, Davis & Guntzviller, 2010. p. 807).

Why does health literacy matter?

> **"Health literacy is critical to Canadians' capacity to manage their health."**
>
> (Mitic & Rootman, 2012, p.3)

Health literacy enables people to use information to manage their health and effect change for healthier communities.

There is moderate evidence that people with low health literacy are more likely to experience negative health outcomes (Agency for Healthcare Research and Quality, 2011; Berkman, Sheridan, Donahue, Halpern & Crotty, 2011).

Low health literacy is associated with:

- poorer health
- chronic illness such as diabetes and hypertension
- poor ability to interpret health messages and labels
- medication errors
- lower use of preventative services such as mammography and vaccination
- more use of emergency services
- increased risk of hospitalization
- increased risk of mortality among seniors

It is important to note that in this research, health literacy was measured primarily by assessing reading and numeracy skills.
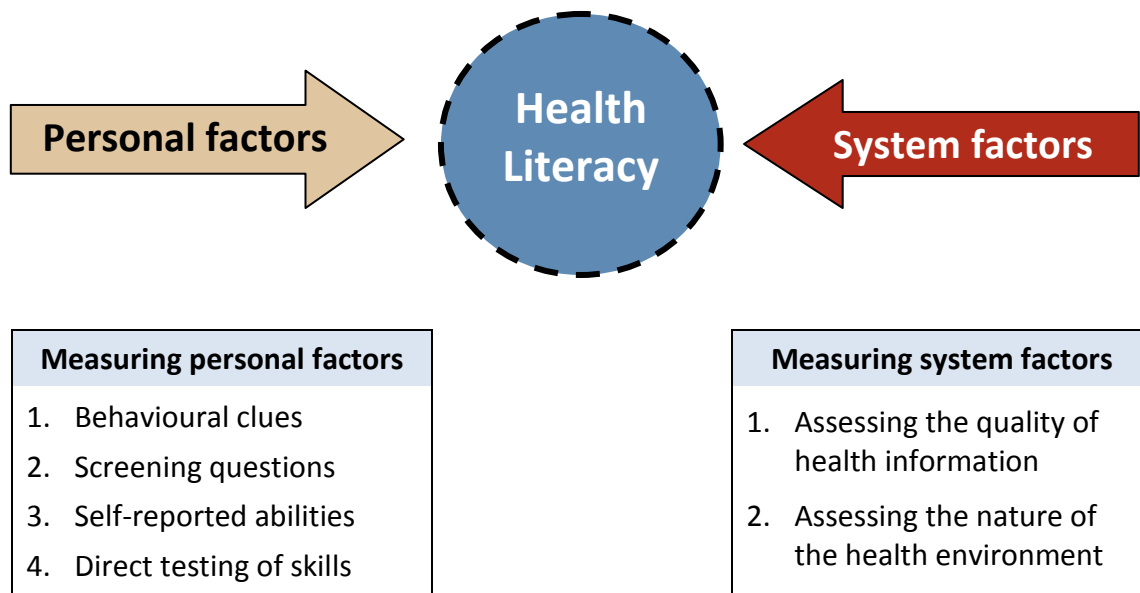
Low health literacy may have significant economic consequences. Researchers estimate that three to five percent of total healthcare costs are due to low health literacy (Eichler, Weiser & Brügger, 2009). Based on forecasts of total spending on health care in Canada (Canadian Institute for Health Information, 2012), that translates into $6.2 to 10.4 billion for 2012. Further research is needed to evaluate the impact of low health literacy on healthcare costs.

> **Health literacy matters because it can have an impact on the social and economic well-being of individuals and of Canada.**
>
> (Canadian Council on Learning, 2008)

How can health literacy be measured?

There are no comprehensive tools to measure health literacy as we currently understand it. However, there are tools to assess some of the personal and system factors associated with health literacy.

Personal factors → **Health Literacy** ← **System factors**

Measuring personal factors
1. Behavioural clues
2. Screening questions
3. Self-reported abilities
4. Direct testing of skills

Measuring system factors
1. Assessing the quality of health information
2. Assessing the nature of the health environment

Measuring personal factors

1. Behavioural clues

It is not possible to predict low health literacy from a person's behaviour. However, certain behaviours may be clues that point to low health literacy.

These behaviours **may** indicate a patient has low health literacy (American Medical Association Foundation & American Medical Association, 2007; Weiss, 2003):

- filling out forms incompletely or inappropriately

- unable to name medications or explain what they are for

- not taking medication as prescribed

- missing appointments

- bringing someone to do the reading

- avoiding having to read in front of others, by saying "I forgot my glasses", "I'll read this later" or "Let me take this home to read"

- being quiet or passive

- clowning around and using humour

- becoming angry or demanding

Writing health information for patients and families

2. Screening questions

Screening questions are a brief and practical way to estimate health literacy. They are often used when time and resources are limited.

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Appendix B provides detailed information about health literacy assessment tools.

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Health literacy screening has been studied in hospitals and primary care settings, where the questions are asked routinely as part of the patient's registration or admission. The results are intended to alert health care providers to an individual patient's need for clear communication strategies.

Some studies suggest the screening question **"How confident are you filling out medical forms by yourself?"** may be effective in clinical research and practice settings. The responses "somewhat", "a little bit" or "not at all" identify patients with inadequate health literacy. (Sarkar, Schillinger, López, & Sudore, 2011; Miller, Allison, Schmitt, Ray & Funkhouser, 2010; Wallace, Rogers, Roskos, Holiday & Weiss, 2006).

When compared with other screening questions, this question performed best in identifying patients with inadequate health literacy (Ohi, Harris, Nurudtinova, Cai, Drohobyczer & Overton, 2010; Sakar, Schillinger, López & Sudore, 2011; Powers, Trinh & Bosworth, 2010; Chew et al, 2008).

3. Self-reported abilities

Several scales are available to measure a person's self-reported health literacy and numeracy:

- Health Literacy Management Scale (HeLMS)
  (Buchbinder et al., 2011; Jordan, Buchbinder & Osborne, 2010)

- Health Literacy Questionnaire (HLQ)
  (Osborne, Batterham, Eslworth, Hawkins & Buchbinder, 2013)

- 3-Level Health Literacy Scale
  (Ishikawa, Takeuchi & Yano, 2008; van der Vaart et al., 2012)

- Subjective Numeracy Scale (SNS)
  (Zikmund-Fisher, Smith, Ubel & Fagerlin, 2007)

4. Direct testing of skills

The most commonly used methods of assessing health literacy are:

- **REALM - Rapid Estimate of Adult Literacy** in Medicine (Davis et al., 1993)
- **TOFHLA - Test of Functional Health Literacy in Adults** (Parker, Baker, Williams & Nurss, 1995)
- **NVS - The Newest Vital Sign** (Osborn et al., 2007; Weiss et al., 2005)

In a critical appraisal of health literacy indices, REALM and TOFHLA had the strongest psychometric properties (Jordan, Osborne & Buchbinder, 2011).

Measuring system factors

1. Assessing the quality of health information

The language and design of printed and online health materials directly affects how well a person can understand and use the information. Our guidelines for plain language and clear design are described on pages 31 to 53.

There are many ways to assess the quality of health information, including:

- involving people from the intended audience
- using a checklist to see if the material meets recommended criteria (for example, the **Checklist for patient education materials** on page 106)
- using a readability formula to assess the difficulty of the words and sentences

More information about assessing the quality of patient education materials is on pages 64 to 68.

2. Assessing the nature of the health care environment

The characteristics of the health care setting can also affect how well people can navigate, understand and use health information and services.

Ten attributes that exemplify a 'health literate' health care organization are described in a discussion paper written by participants in the Institute of Medicine's Roundtable on Health Literacy (Brach et al., 2012).

Ten Attributes of Health Literate Health Care Organizations
(Brach et al., 2012)

A health literate health care organization:

1. Has leadership that makes health literacy integral to its mission, structure, and operations.

2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.

3. Prepares the workforce to be health literate and monitors progress.

4. Includes populations served in the design, implementation, and evaluation of health information and services.

5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.

6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.

7. Provides easy access to health information and services and navigation assistance.

8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.

9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.

10. Communicates clearly what health plans cover and what individuals will have to pay for services.

Health literacy audits are practical tools to assess the:

- quality of verbal communication
- accessibility and navigation of the physical environment
- usability of forms, print and online information
- use of patient-friendly policies and support systems

Examples of health literacy audits:

- **Health Literacy Universal Precautions Toolkit** (Agency for Healthcare Research and Quality, 2010)
- **Health Literacy Audit** (Literacy Alberta, 2008)
- **The Health Literacy Environment of Hospitals and Healthcare** Centers (Rudd & Anderson, 2006)

> **"Our health system continues to place greater expectations and demands on patients and families. In response, we must pay attention to how patients access, understand, and use health information provided to them to promote, protect and manage their health. This is the embodiment of 'health literacy' and why it is increasingly a recognized goal in discussions about quality, disparities and cost."**
>
> (Parker & Ratzan, 2010, p. 29)

What health literacy measures do you recommend?

We recommend measuring system factors to assess the clarity of health care providers' verbal and written communication, and the nature of the health care environment. The results can identify areas for improvement that will benefit patients and families.

We believe that measuring an individual's health literacy can be helpful in research, with acknowledgment that all assessment tools have limitations.

We **do not** recommend measuring patients' health literacy skills in clinical settings for these reasons:

- Anyone can experience low health literacy. System factors can contribute to low health literacy, regardless of a person's skills and abilities.

- Health literacy testing has the potential to cause feelings of shame or embarrassment, and fear of labelling. Patients may feel dissatisfied or upset at being tested when they are ill, anxious and in need of medical care.

- Little is known about the influence of health literacy assessments on health care providers' communication or patients' health outcomes. Without demonstrated benefits of screening, we have to be mindful of the time and resources required for this practice.

We do not support health literacy screening or testing in clinical practice.

**We recommend using clear communication with all patients and families.
This is a 'universal precautions' approach.**

What is a 'universal precautions' approach to health literacy?

It is impossible to tell who has low health literacy, and anyone can experience it, so it is best to use clear communication with every patient.

Using a standard approach to communication with all patients to prevent misunderstandings is similar to using standard precautions with all patients to prevent infection. This is called "universal precautions".

> **A universal precautions approach shifts the focus of health literacy from patients' skills to the health care providers' and systems' abilities to communicate effectively.**

Universal precautions includes these strategies to improve health literacy:

- Anticipate that patients may have difficulty understanding health information and navigating the health care system.

- Create an environment where patients feel welcome to ask questions or bring someone with them. Offer help with forms. Ensure staff and signage help patients find their way.

- Communicate clearly. Speak and write in plain, non-medical language. Give a simple explanation of the medical or technical words that patients need to know. Be mindful of how quickly you are speaking. You may need to slow down.

- Limit the amount of information patients receive in one encounter. Focus on what is critical for the patient to know and do. Repeat these key points often.

- Confirm patients' understanding at each step of their care. Use the "teach back" technique. Ask patients to explain in their own words what they have understood and what they will do. This is not a test of patients' knowledge.
  It is a way to confirm that you have explained what patients need to know in a way they can understand.

(RNAO, 2012; Agency for Healthcare Research and Quality, 2010; American Medical Association Foundation and American Medical Association, 2007; Brown et al., 2004)

> **In this book, we focus on using patient education materials written in plain language as a key strategy for improving health literacy.**

What is plain language?

Plain language is a way of writing information so that it is easy for people to read, understand, and use. In health care, plain language can help people understand health information. It is most helpful for those who do not read well.

As plain language makes health information more accessible, it is an effective communication strategy for promoting health literacy (Mitic & Rootman, 2012; U.S. Department of Health and Human Services, 2012; Rootman & Gordon El-Bihbety, 2008; Stableford & Mettger, 2007).

> **"Clear communication, in plain language, about health information and services will help create and promote health literacy."**
>
> Plain Language Action and Information Network (PLAIN)
> www.plainlanguage.gov/populartopics/health_literacy/index.cfm

Plain language is a patient-centred approach to writing. All decisions regarding the content, organization, writing style, format, and design are made with the readers in mind. Your readers, patients and families, are the intended audience. The more you know about your audience and their needs, the better you will be able to communicate with them.

Plain language uses familiar words, not jargon, and a conversational style (the everyday language of the intended audience) to convey information clearly. This minimizes the effort required to understand information.

Plain language writing is a process that involves patients and families. When you begin developing patient education material, you consult your audience to find out what they want and need to know. When you have finished writing, you evaluate your materials with your audience and make changes to better meet their needs. After the material is implemented, patients and families should regularly evaluate it.

> **A commitment to plain language is a commitment to clarity.**
>
> Plain language is essential for:
>
> ✓ printed materials (Mitic & Rootman, 2012; U.S. Department of Health and Human Services, 2010b)
>
> ✓ websites (U.S. Department of Health and Human Services, 2006 and 2010a)
>
> ✓ health apps – mobile health application software (Broderick, Devine, Langhans, Lemerise, Lier & Harris, 2014)
>
> ✓ portals – patient accessible electronic medical records (Zarcadoolas, Vaughon, Czaja, Levy & Rockoff, 2013)

Begin by learning about the intended audience

Learning to use plain language starts with a commitment to learn about the people who will receive and use your material. Think about your topic from their point of view.

Find out as much as you can about your intended audience:

- What are the demographics of the patient population?
- When and how will patients and families get the material?
- What do they already know?
- How will they be feeling?
- What decisions will they have to make?
- What actions are required?

Sometimes, you don't have a specific audience in mind. You need to communicate health information to patients across the hospital or to the public. The goal is to be inclusive; you want your message to be understood by as many people as possible.

> **"Your document is in plain language when your target audience understands it."**
>
> Canadian Public Health Association. Plain language service. www.cpha.ca/en/pls/faq.aspx

Writing in plain language is a highly skilled activity

The simplicity of plain language makes it look easy to do. In reality, writing health information in plain language is a skill that takes effort to learn and time to practice.

Plain language writing is an evidence-based process that requires specific knowledge, skills, and attitudes. The theory base draws from adult learning, cognitive psychology, social marketing, and document design. Plain language involves a thorough understanding of the readers' needs and the ability to explain complex medical information in a clear and meaningful way.

Many health care providers, accustomed to writing for their colleagues, use complex vocabulary and a formal writing style. Although they may think this writing style will sound "professional" to patients, it is actually a barrier to communication. Communicating effectively for the purpose of patient education requires a patient-focused attitude.

Learning to communicate health information straightforwardly in the everyday language of patients is a new skill for many health care providers. They usually find that it is harder to do than they had thought. Health care providers also tell us that learning to write in plain language improves their verbal communication too.

Technical support

Software programs can help with part of this process. They quickly identify complex words, lengthy sentences and paragraphs, and suggest alternatives based upon plain language principles. Examples include:

- Health Literacy Advisor (HLA) is an add-on to Microsoft Word from Health Literacy Innovations. www.healthliteracyinnovations.com/home

- Readability Studio from Oleander Software. http://oleandersolutions.com/readabilitystudio.html

People prefer plain language

Some health care providers may be concerned that plain language will offend patients who read well. This has been proven to be a misconception.

Skilled readers are not insulted by clear, concise writing that is designed to meet their needs (Holmes-Rovner et al., 2005; Davis et al., 1998). In a study of health literacy at a pediatric surgery outpatient clinic at McMaster Children's Hospital, parents expressed satisfaction with patient education materials written in plain language, regardless of their health literacy skills (Otal et al., 2010).

Plain language:

- ✓ Enables people to quickly read and use essential health information.

- ✓ Accurately explains medical concepts and health information in a way that minimizes the effort required for understanding. This helps patients apply the information to their lives.

- ✓ Engages readers. It is not oversimplified, childish or "dumbed down" information.

Research shows that people prefer easy-to-read materials.

- In public and private pediatric clinics, parents at all reading levels preferred a simplified pamphlet about vaccines (Davis et al, 1996).

- In a randomized trial, patients at all literacy levels overwhelmingly preferred and completed an advance directive written in plain language (at a Grade 5 level) compared to a standard form written at a Grade 12 level (Sudore et al., 2007).

Using plain language demonstrates respect for your audience.

Plain language techniques

Use a conversational writing style.

Plain language materials are an extension of your clinical practice. Write in a friendly and respectful tone as if you are speaking with a patient. Your writing should not sound formal, clinical or condescending.

To check your writing style, read aloud what you have written and ask yourself: Is this what I would say to a patient?

Use words that are familiar to your intended audience

'Everyday' or 'living room' language uses common words without jargon.

Whenever possible, replace unfamiliar words with familiar words.

Unfamiliar words	Replace with	Familiar words
physician	→	doctor
approximate	→	about
consume	→	eat
onset	→	start
modify	→	change
utilize	→	use
implement	→	do
administer	→	give
hospitalization	→	hospital stay

Explain unfamiliar words that patients need to know

Patients may need to know some medical, scientific or technical terms to communicate with their health care providers and take an active role in their health care. These words cannot be replaced by simpler ones.

Define the terms patients need to know in everyday language, with real-life examples. If you have many terms to explain, consider adding a glossary.

> **For example:** Osteoporosis
>
> Osteoporosis is a disease that makes your bones thinner and weaker, causing them to break more easily.

Some words may be unfamiliar or confusing because they have more than one meaning. You may need to explain words such as:

- report
- stable
- discharge
- admission
- monitor
- acute
- positive results
- negative results

Explain abbreviations and acronyms

Patients may need to know the short forms of some medical terms.

The first time the term appears, write out the full version and follow it with the short form. Later in the document, you may just use the short form.

> **For example**:

- Blood pressure, or BP
- Cardiopulmonary Resuscitation is also called CPR.

Use terms consistently

Use the same terms throughout a document. For example, decide if you are going to use the word medication, medicine or drug. Then use this word consistently.

You may need to ask patients which words they prefer. For example: Do they wish to be called patients, clients or consumers?

Use inclusive language

Be respectful when referring to individuals and groups. Avoid stereotyping or excluding people based upon their sexuality, gender, marital status, ethnicity or physical ability. For example, not all doctors are men, not all nurses are women.

You may need to ask members of your intended audience what words they prefer.

> **Instead of writing:** Marriage counselling.
>
> **Write**: Couples counselling.

> **Instead of writing**: Diabetics
>
> **Write**: People with diabetes.

Use personal pronouns

'Talk' directly to the reader.

Use pronouns (you, I and we) to make your writing more personal and friendly.

> **Instead of writing**: Patients should report to the receptionist upon arrival.

> **Write**: When you arrive at the clinic, please see the receptionist.

Use the active voice

Make it clear who (actor, subject) is doing what (action, verb). Writing in the active voice sounds more clear and engaging, and less formal than the passive voice. You can use grammar and readability software to check the percent of passive sentences in your writing.

> **Instead of writing**: This medication should be taken with breakfast.

> **Write**: Take this medication with your breakfast.

Use strong verbs

For clear and direct writing, avoid nominalizations. This is when a verb is used as a noun.

> **Instead of writing**: Caused a reduction

> **Write**: Reduced

> **Instead of writing**: The doctor will conduct an examination

> **Write**: The doctor will examine

Vary sentence length

Aim for an average sentence length around 10 to 15 words. Some sentences will be shorter, some longer. This makes your writing interesting.

If all your sentences are short, your writing will sound choppy and childish.

If your sentences are long (over 20 words), the material is much more difficult to read and understand.

Give specific, realistic instructions

Clearly state what actions patients are to take.

Avoid using terms that are open to interpretation or require judgment to take action, such as normal range, adequate rest, heavy lifting or excessive bleeding.

If you use category words, always give concrete examples.

> **Instead of writing**: Notify your doctor if you develop a fever.
>
> **Write**: If you have a fever greater than 38°C (100.4°F), call your surgeon's office.

> **Instead of writing**: Get adequate rest.
> **Write**: Try to get 8 hours sleep at night and take a nap during the day.

> **Instead of writing**: Poultry.
> **Write**: Poultry, such as chicken, turkey, duck or goose.

> **Instead of writing**: Take one pill twice daily.
> **Write**: Take 1 pill in the morning and 1 pill in the evening.

Use positive wording

As a general rule, use positive wording. Tell patients what to 'do' rather than what to avoid doing ('do not'). Negatively worded statements are more likely to be remembered incorrectly, especially by older adults (Wilson & Wolf, 2009; Wilson & Park, 2008).

> **Instead of writing**: Do not remove the bandage unless it gets dirty or wet.
>
> **Write**: Keep the bandage on as long as it is clean and dry.

However, when an action has serious consequences, negative wording may be clearer (U.S. Department of Health and Human Services, 2006).

> **For example**: Do not give your baby to anyone who is not wearing an identification badge.

Write with a positive tone.

This makes your writing sound inviting and motivates patients to continue reading. People are usually more receptive to positive messages.

> **Instead of writing**: Some forms of arthritis are very serious and, if left untreated, can result in substantial or complete disability.

> **Write**: Treatment for some forms of arthritis can help prevent serious disabilities.

Present the context first to introduce new information

> **For example**: To prevent constipation, eat foods that are high in fibre. Foods that are high in fibre are fruits, vegetables, and whole-grain cereals and breads.

Use generic and brand names of medications

When you refer to a medication, use the generic name first and then give the common brand or trademark names. Using the symbol ® designates the brand name.

> **For example**: acetaminophen, such as Tylenol®

Use numerals

In general, numbers are easier to read as numerals (99), rather than words (ninety-nine).

Use metric and imperial measurements

Some patients use imperial measurements; other are more familiar with the metric system. It is usually best to include both.

Knowing your audiences' preferences may help you decide which to put first.

> **For example**: ½ cup (125 ml), 5 ml (1 tsp), 5 cm (2")

Organize your writing to meet patients' needs

Write an introduction that describes the purpose of the material. State what the patients can expect to gain from reading the material.

Write the information in a logical order, from the patients' perspective. Some ways of organizing information are:

- putting the most important information (action points) first
- chronological order
- starting with general information and moving to specific information
- starting with what patients already know and moving to new information

Limit the amount of information to what is reasonable for the intended audience to know and do.

Write short paragraphs that are 'chunks' of information. Give each chunk a meaningful subheading. Starting a heading or subheading with a verb is a good practice when writing actionable content (U.S. Department of Health and Human Services, 2010b).

Summarize the most important points.

Tell readers where to get more information and how to get help. Consider giving a contact person and phone number for follow-up.

Summary

What is plain language?		
Plain language is a way of writing and presenting information.	→	It makes information easy to find, read, understand, remember and use.
Plain language is inclusive.	→	It helps your message reach as many people as possible.
Plain language focuses on the readers.	→	It respects readers and meets their needs. It is not "dumbed down" or condescending.
Plain language focuses on action.	→	It helps people know what to do.
Plain language involves more than just the words we use.	→	It is a process of planning, writing, designing and testing communication.

Plain language techniques
❑ Use a conversational writing style
❑ Use words that are familiar to your intended audience
❑ Explain unfamiliar words that patients need to know
❑ Explain abbreviations and acronyms
❑ Use terms consistently
❑ Use inclusive language
❑ Use personal pronouns
❑ Use the active voice
❑ Use strong verbs
❑ Vary sentence length
❑ Give specific, realistic instructions
❑ Use positive wording
❑ Write with a positive tone
❑ Present the context first, before new information
❑ Use generic and brand names of medications
❑ Use numerals
❑ Use metric and imperial measurements
❑ Organize your writing to meet patients' needs

What is clear design?

Clear design refers to the layout or the way you put words on paper or a webpage. The design features for education materials are deliberately chosen to make the information look attractive, simple and easy to read. Writing to educate looks different from writing to market a product or entertain a reader. Colour and graphic elements are not decorative; they are used to help explain the text.

Clear design is simple, well organized, and consistent throughout the material. This invites readers into the content and guides them through the material so they can find information quickly.
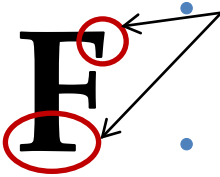
> **Evidence-based, clear design techniques make text easier to read.**
> **This is a key step in making health information accessible.**
>
> **Clear design is recognized nationally as the standard for people with low vision.**
>
> (Russel-Minda, 2006)

Clear design techniques

Choose a simple font that is easy to read.

There are two main types of fonts; serif and sans serif.

Serif font	Sans serif font
F • Serifs are extra strokes at the ends of each letter. • This letter has 4 serifs. Example: **Family**	**F** • 'Sans' means 'without'. • This letter has no serifs. Example: **Family**

Research has shown there are no definite benefits (in reading speed or reader preference) for serif or sans-serif fonts (U.S. Department of Health and Human Services, 2006). However, some guidelines recommend a serif font as 'highly readable' for large amounts of text (U.S. Department of Health and Human Services, 2010c).

A familiar font makes reading easier. Using unfamiliar fonts slows reading speed.
(U.S. Department of Health and Human Services, 2006).

<div style="border:1px solid">

Examples:

A serif font, like this one (Times New Roman) is familiar. Most newspapers are printed in serif fonts.

A sans-serif font, like this one (Arial) is also popular.

Do not use italics as this font style is harder to read.

Do not use script style fonts as they are harder to read.

Do not use reverse type (light font, dark background) as it is harder to read.

</div>

Use no more than 2 fonts.

Keep things simple, by using one font for headings and subheadings, and another for body text. A serif font is recommended for body text and a sans serif for headings (U.S. Department of Health and Human Services, 2010c).

Having many different fonts on a page can be confusing and distracts readers from your message.

Choose a font size that readers can see easily.

Font size is measured by the number of points. A font of at least 12 points is recommended for patient education material (Doak, Doak & Root, 1996).

<div style="border:1px solid">

Examples:

This line of type is set in 12 point Arial.

This line of type is set in 14 point Arial.

This line of type is set in 16 point Arial.

</div>

We use a 14 point font for most patient education materials at our hospital.
In a Hamilton, Ontario study (Eyles, Skelly & Schmuck, 2003), 83% of patients preferred a 14 point size. A 16 point font may be helpful if your intended audience includes people with visual problems.

If you are not sure which font size to use, show patients identical paragraphs in different font sizes and ask them which one is easiest to read.

Use font size to guide readers

Headings and subheadings act as signposts to guide readers through printed material. Make subheadings larger than text and headings even larger.

Use font size to give your material a clear hierarchy. This helps readers skim the page to see how it is organized and find important information.

For example, in this book:

Headings are 20 points

Large subheadings are 14 points

Small subheadings are 12 points

Body text is 12 points.

Use upper and lower case letters

The ascending and descending lines give letters their characteristic shape, which helps people recognize words.

Mixed case	All caps
Shape	SHAPE

WORDS WRITTEN IN CAPITAL LETTERS HAVE THE SAME, RECTANGULAR SHAPE. THIS MAKES THE WORDS HARDER TO READ. WRITING IN ALL CAPITAL LETTERS MAKES THE TEXT LOOK UNINVITING. PATIENTS SAY IT LOOKS LIKE SHOUTING.

Use a comfortable line length

Make lines an appropriate length for easy reading. Short lines, such as narrow columns with 3 to 4 words, make the reader's eye jump back and forth too quickly. Lines longer than 14 words or 5 inches are harder to follow. A medium line length of about 60 characters is best (U.S. Department of Health and Human Services, 2010b and 2010c).

For webpages, a long line length (75 to 100 characters) helps people read faster. However, users generally prefer shorter line lengths (about 50 characters), even though this slows reading speed (U.S. Department of Health and Human Services, 2006).

Writing health information for patients and families

Use extra space between lines

The space between lines of text is called leading (pronounced 'ledding'). It gets its name from the thin strips of lead that a printer inserted by hand between lines of metal type. Most word processing software applies a standard leading based on the size of the font.

Adding more leading can help the reader move more easily from one line of text to another. The CNIB's Clear Print Accessibility Guidelines recommend that leading be at least 25 to 30% of a font's point size (Russell-Minda, 2006).

To change leading in Microsoft Word, select the Paragraph group, then Indents and Spacing, then Line Spacing. You can set the space between lines, as measured in lines or points.

Standard leading	Extra leading
This paragraph has 7 lines of 12 point Calibri font with standard, single line spacing. Standard leading is about 20% more than the point size of the text. Changing the leading affects the legibility of text. Using less leading makes the text look too crowded.	This paragraph has 7 lines of 12 point Calibri font with line spacing set at exactly 16 points (30% more than the point size of the font). The lines are slightly further apart, making the text easier to read, especially for people with low vision.

Use left justification

Left justified text is easier to read than fully justified text that is straight at both margins.

Left justified	Fully justified
This paragraph is left justified. The left margin is straight; the right margin is "ragged". This helps to distinguish one line from another. The spacing between letters and words is even, which makes reading easier. Left justified text is best for patient education materials.	This paragraph is justified. To make the text line up at both margins, the computer inserts hyphens and/or irregular spacing between words. These techniques can make the text a little harder to read. Most newspapers use justified text to make sharply defined columns.

Break up material into "chunks"

Chunks are short sections of related information. Minimize the number of sentences in a paragraph. A paragraph should not contain more than six sentences (U.S. Department of Health and Human Services, 2010c).

Give each section a meaningful heading. This helps people skim the page and scan for information. Headings should be complete ideas not a word or two.

> **Instead of**: "Hygiene"
>
> **Use**: "Keep your skin clean and dry"

Questions make good headings. They help people find information and make materials more interactive.

Use a table of contents to help readers find information quickly.

When writing for the web, split up a long page into several shorter pages. Users may prefer moving through shorter pages (paging) to scrolling down lengthy pages.

Use plenty of white space

White space is the unused or blank space on the page, at the margins and in between paragraphs and sections. White space shows how the material is organized and allows the reader's eyes to rest between sections.

When there is little white space, the page looks dense and crowded. This can make the materials look difficult to read or boring. People with poorer reading skills perceive dense text as intimidating and frightening (Smith, Trevena, Nutbeam, Barratt & McCaffery, 2008).

Use bold and simple lines to add emphasis

When you need to draw attention to key information, put it in bold letters or use simple lines for visual interest.

Avoid using underlining, all capitals or italics for emphasis as this makes the information harder to read.

Here are three ways to emphasize a block of text. The first example is the best option (U.S. Department of Health and Human Services, 2010c).

1.	2.	3.
Use simple lines for emphasis. **It is best to use black print on white background.**	**Use a simple border.** **Keep the text box in the same vertical flow of the page.**	**Use very light shading (screen).** **Keep strong contrast between text and paper.**

Use lists with bullets

A list of items is easier to read and remember when presented vertically using bullets rather than embedded in a paragraph.

- Use bullets that are simple, solid shapes. Using colour can emphasize the bullets.

- Indent the list slightly and add space between lines.

- Keeps lists short. For long lists, try to group items together under subheadings.

- Place the most important items at the top of the list.

- Number a list only when an order is required, such as a list of steps in a procedure.

- Capitalize the first letter and use a period after every bullet point that is a sentence. If bullet points are words or fragments, use of capitals and punctuation is a matter of preferred style. Use the same style throughout your material.

Here are three ways to format bullets:

1. Call your doctor if you have:
     • increased pain or swelling
     • bleeding or drainage from the wound
     • a temperature over 38.5°C or 101°F
     • numbness in your arm or hand

2. Call your doctor if you have:
     • Increased pain or swelling
     • Bleeding or drainage from the wound
     • A temperature over 38.5°C or 101°F
     • Numbness in your arm or hand

3. Call your doctor if you have:
     • Increased pain or swelling;
     • Bleeding or drainage from the wound;
     • A temperature over 38.5°C or 101°F; or
     • Numbness in your arm or hand.

Use dark text on plain, light paper or background

The contrast between black text on white or light-coloured paper or background makes it easy to read.

Do not use shading or watermarks behind text as this reduces the contrast, making the text harder to read.

Use a non-glare paper

Coated papers are not suitable for patient education as the glare can be distracting to the reader.

Use colour sparingly

A little colour can grab attention, help navigation, or make headings or key points stand out. Too much colour can be distracting to the reader.

Writing health information for patients and families

Use visuals to explain the text

Visuals are more than decoration, they facilitate learning.

Visuals help explain information and are especially helpful for people with low literacy (Houts, Doak, Doak & Laoscalzo, 2006). In general, visuals grab attention and are easier to remember than text.

Visuals include:
• Photographs
• Illustrations (Line drawings)
• Graphics (icons and pictographs)
• Clip art and cartoons

Research suggests that using visuals can:

- Increase patient attention, comprehension, recall and adherence (Houts, Doak, Doak & Loscalzo, 2006).

- Contribute to a better comprehension and use of medical devices (Kools, van de Wiel & Kok, 2006).

- Improve medication assessment and education, especially for patients with communication barriers such as limited English proficiency and limited health literacy (Schillinger, Wang, Rodriguez, Bindman & Machtinger, 2006; Machtinger et al., 2007).

Age may affect the comprehension of visuals. In one study (Liu, Kemper & McDowd, 2009), younger adults seemed to use illustrations as 'advance organizers', glancing at them before reading text then, actively integrating the illustration with the text. Older adults had more difficulty integrating illustrations with text.

Tips for using visuals
✓ Show desired actions. It is better to show what people should do, rather than what not to do. If you must show the "wrong" action, put an X over it.
✓ Place visuals beside the related text. Visuals are not helpful if their meaning is not integrated with the content (Houts, Doak, Doak & Loscalzo, 2006).
✓ Tell people what to look at. Use captions or arrows to direct attention to what the visual is trying to convey.
✓ Test visuals with your intended audience. Make sure the message is clear and the visuals are acceptable.

Tips for using different types of visuals follow on the next few pages.

Line drawings

Simple, black and white line drawings are good for patient education.
Use realistic images with simple lines and few distracting details.

The Clam Shell exercise

Push your knees apart.

Let your heels slide together
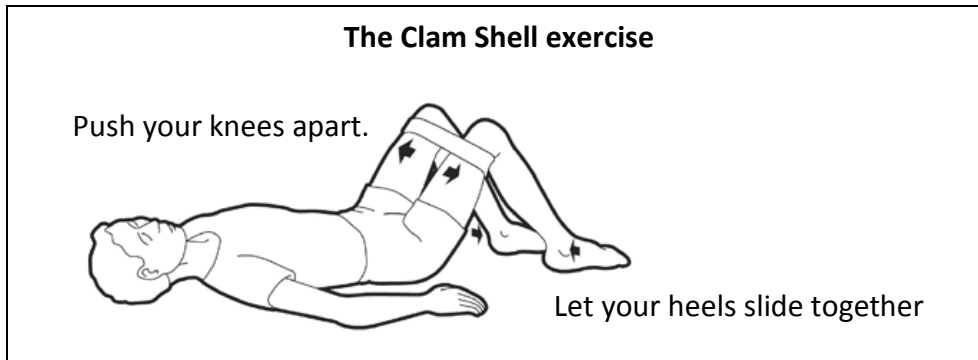
If you need to show a body part, show where it is in the body..

Uterus

Fallopian tube

Ovary

Vagina
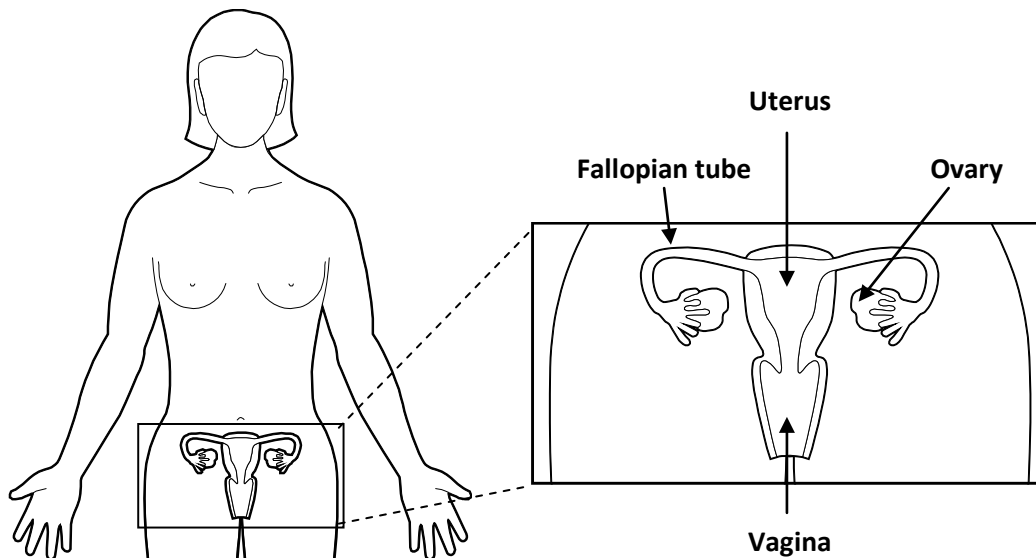
Graphic images

Use graphics such as icons to draw attention to important messages and break up blocks of text.

In this example, a caution symbol draws attention to important safety instructions.

- PCA is your pump!
- Only you should push the button.
- Family members and friends should never push the button.
- If someone other than you pushes the button, you may become too sleepy and stop breathing.

Writing health information for patients and families

Cartoons and humour

Cartoons are best when writing for children.
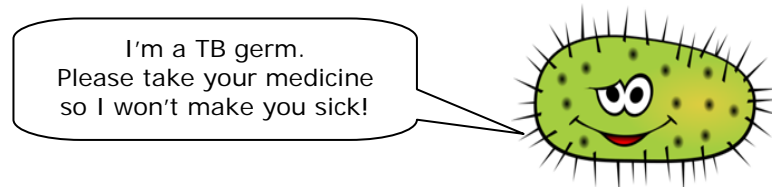
Cartoons may trivialize a topic for adults.

Humour is pleasing and can help people remember information. However, we do not recommend using humour in patient education materials. You cannot tell what statements or circumstances a patient will find funny. Not everyone will share your sense of humour; some may be offended.

Photographs

Photographs are good for showing people and real-life events. Use photos of people who represent your intended audience.

Where to get photos:

- You can buy commercial stock photography on the Internet. Searching for the right images can take a lot of time. Choose the file size that suits your purpose. Purchase higher resolution for posters; lower resolution for a small photo in printed material.

- Search Internet sites for free photos. For example, with Microsoft Office Clipart and Media Library, you can use any image without restriction (as long as you don't offer the image for sale). If you choose clipart, try to use the same style of images throughout your material.

- Take your own photos. Be sure to obtain the consent of those participating.

Test how well the photo reproduces on paper or displays on your webpage.
It needs to be clear, with few distracting details.

Use simple charts

Create charts with simple headings that are easy to read across.

If the reader is to fill out a chart, show an example.

Fever diary

Use this chart to keep track of your child's temperature and symptoms.
Please bring it with you to your clinic visits.

Date	Time	Temperature	Illness/Symptoms	Medication given
Example: *Nov 21*	*8 am*	*38.7°C*	*Chills, coughing*	*1 Junior Strength Tylenol* *160 mg*

Summary

Clear design techniques
❑ Choose a simple font that is easy to read
❑ Use no more than 2 fonts
❑ Choose a font size that readers can see easily
❑ Use font size to guide readers
❑ Use upper and lower case letters
❑ Use a comfortable line length
❑ Use extra space between lines
❑ Use left justification
❑ Break up material into "chunks"
❑ Use plenty of white space
❑ Use bold and simple lines to add emphasis
❑ Use lists with bullets
❑ Use dark text on plain, light paper or background
❑ Use a non-glare paper
❑ Use colour sparingly
❑ Use visuals to explain the text
❑ Use simple charts

What is important to consider when writing for the web?

Just as you would for print materials, start by focusing on the people who use your website. When the public is your intended audience, consider the prevalence of low literacy and low health literacy skills when making all decisions related to your website.

To make your information accessible to as many people as possible, use the plain language and clear design techniques described on pages 31 to 53. These guidelines are most important when writing for the web. Additional resources are listed on page 57.

How do people read online?

Rather than reading every word, most people:

- Scan a page for less than 30 seconds to see if the information looks helpful.
- Read the first words and sentences, and then scan headings and lists.
- Only continue reading if the information meets their needs. If not, they go to another site.

Users with low literacy, however, do read word-by-word. They are unable to understand text or navigate a page simply by glancing at it. When reading gets difficult, they skip over the text and start clicking on links, to try and find the information they are looking for. Skipping may cause them to overlook important information and settle for information that merely "suffices".

Skipping is triggered by:

- text with long or unfamiliar words
- text that contains a lot of numbers
- text in small fonts
- long or complex sentences
- long paragraphs of text
- long pages that require a lot of scrolling

Even content in plain language can be overwhelming if too much text is together in one paragraph.

Adults with limited literacy skills are able and willing to use the computer to find health information. Help them to be successful by making your site easy to read and navigate.

What specific techniques are helpful?

Plan the content

- Plan content to meet your users' needs. What information do they want and need to know? What do they need to do? What questions do they ask?

- Plan to make the content interactive with question and answer format, or a quiz. Interaction increases active information processing, which helps people learn and recall information. Engaging users increases their interest and satisfaction.

- Consider narrating text to reduce literacy demands.

- Consider video to demonstrate skills.

Write simply and be succinct

- "Less is more". Think 'bullet points' not long paragraphs. Usability experts recommend using half the word count of conventional writing. Limit pages to 4 paragraphs, less than 4 lines per paragraph, and no more than 600 words.

- Use meaningful headings. Users with low literacy may only read the headings on a page, so make sure each heading sends a complete message that can be understood out of context.

Minimize scrolling

- Keep content "above the fold", meaning it is visible without scrolling.

- Have contact information visible on all webpages.

- Write a series of short pages instead of one long page that requires scrolling.

Be consistent

- Use the same design and navigation for all pages. Consistency means less time is needed to figure out the navigation on each page.

- Use conventional locations for navigation tools (top and left), where users expect buttons and links to be.

Put the most important information first

- First impressions matter. Users may only read the first few words on a page.

- Put the most important information first on a page, in a paragraph or in a list.

- Use 'inverted pyramid' writing: start with crucial information, then helpful information, then "nice-to-know" information.

Format for online reading

- Focus on the centre of the screen. Users with limited literacy have a narrow field of view.

- Preface content with links to headings.

- Put content in a single, main column. Don't put content or links in margins.

- Help users find their way. Use a 'breadcrumb' trail, or large previous/back and next buttons.

- PDF format is for printing, not reading online. PDF files have no navigation or have their own navigation, which is confusing. Users get lost and can't find their way back to the main site.

How can we tell if our website is useful?

1. Conduct usability tests:

- Ask users to complete a task and "think aloud" during the process.

- Ask content questions: Where would you click to get more information? Would you like to print any of the pages? Are any of the words unclear?

> **Usability is the ease with which a person can use a website to achieve a specific goal.**
>
> **Usability can predict user satisfaction.**

2. Use what you learn to improve your website.

3. Your website is a success when users say it is:

- ✓ Easy to navigate.
- ✓ Easy to read.
- ✓ Easy to use the information.

Resources: Writing for the web

- U.S. Department of Health and Human Services. (2006). Research-based web design and usability guidelines. Washington, DC: U.S. General Services Administration. www.usability.gov/pdfs/guidelines.html

- U.S. Department of Health and Human Services. (2010a). Health literacy online: A guide to writing and designing easy-to-use health web sites. Washington, DC: Office for Disease Prevention and Health Promotion. http://www.health.gov/healthliteracyonline/Web_Guide_Health_Lit_Online.pdf

- National Institute on Aging and the National Library of Medicine. (2009). Making your website senior friendly. www.nia.nih.gov/health/publication/making-your-website-senior-friendly

- Nielson Norman Group (2014). Lower literacy users: Writing for a broad consumer audience. www.nngroup.com/articles/writing-for-lower-literacy-users/

What is important to consider when presenting numerical information?

Numerical information is used to help people understand their health risks, compare treatment options, make decisions regarding their care, and manage their care.

Understanding numerical information can be challenging for many people because:

- Almost half (48%) of Canadian adults have difficulty with reading and understanding information in formats such as charts (Statistics Canada, 2005a).

- Over half (55%) of Canadian adults have below-proficiency numeracy skills. (Statistics Canada, 2005a). Low numeracy is predictive of poor performance in processing the numerical information needed to support medical decision making (Zikmund-Fisher, Smith, Ubel & Fagerlin, 2007).

We can help people understand numerical information by presenting it in ways that require less cognitive effort.

This means:

- ✓ Using plain language in spoken and written communication.

- ✓ Focusing on the key pieces of information that patients need and prefer for decision-making, rather than trying to be comprehensive.

- ✓ Doing mathematical calculations for patients or providing an example to follow and providing conversions (for example, ½ cup = 125 ml).

- ✓ Explaining what numbers mean (for example, clarifying whether a 9% risk is high or low in the context of a treatment decision, or describing a 3 to 4 oz serving of meat as the size of a deck of cards).

- ✓ Presenting information in helpful formats.

(Institute of Medicine, 2014; Fagerlin, Zikmund-Fisher & Ubel, 2011; Peters, Hibbard, Slovic & Dieckman, 2007)

A full discussion of risk communication is beyond the scope of this book.
For more information refer to these references:

- Zikmund-Fisher (2013)
- Riva, Monti, Iannello & Antonietti (2012)
- Fischhoff, Brewer & Downs (2011)
- Woloshin & Schwartz (2011)
- Peters, Hibbard, Slovic & Dieckmann (2007)

Numerical format

When the probability of an outcome is known, you can present this information using frequency (1 out of 10) or percentages (10%). Natural frequencies are recommended, although not strongly (Trevena et al, 2013; Fagerlin, Zikmund-Fisher & Ubel, 2011). Frequencies may also be easier to understand, because they require less cognitive effort and are perceived as more "people-oriented".

When you present more than one option, keep the denominator constant to make comparison easier (Trevena et al, 2013).

> **Instead of writing**: 1 out of 20 with Treatment A, and 1 out of 4 with Treatment B.
>
> **Write**: 1 out of 20 with Treatment A, and 5 out of 20 with Treatment B.

Use decimals with caution (U.S. Department of Health and Human Services, 2011). When possible, round numbers up or down to whole numbers. Use decimals when precision is needed (for example, a blood glucose of 6.4). Avoid using higher-level statistical concepts such as confidence intervals as they are unfamiliar to most people.

Word format

Everyday language may be used to describe risks. For example, 'a slight chance', 'extremely low', 'much higher' or 'most of the time'. A potential problem with this approach is that people may misinterpret the meaning of these phrases (U.S. Department of Health and Human Services, 2011).

Visual formats

There are many ways to present numerical data: scales, bar graphs, pie charts, flow diagrams, pictographs or icon arrays, and tables.

Research shows that using visual formats can increase people's understanding and may affect their decision-making (Trevena et al., 2013; Fagerlin, Zikmund-Fisher & Ubel, 2011; Tait, Voepel-Lewis, Zikmund-Fisher & Fagerlin, 2010; Zikmund-Fisher, Smith, Ubel & Fagerlin, 2007). International standards for patient decision aids recommend presenting numerical information in tables and/or pictographs, rather than in text only (Trevena et al, 2013).

Pictographs are diagrams that use dots or icons to represent people. They visually represent a risk as a frequency, showing the numerator and denominator at the same time. They are helpful at conveying the 'gist' of the message, getting the main point of the message without having to interpret all the details (Fagerlin, Zikmund-Fisher & Ubel, 2011; Tait, Voepel-Lewis, Zikmund-Fisher & Fagerlin, 2010).

This pictograph represents the risk of blood transfusion in cardiac surgery.

65 out of 100 people will not need a transfusion →

35 out of 100 people will need a transfusion →
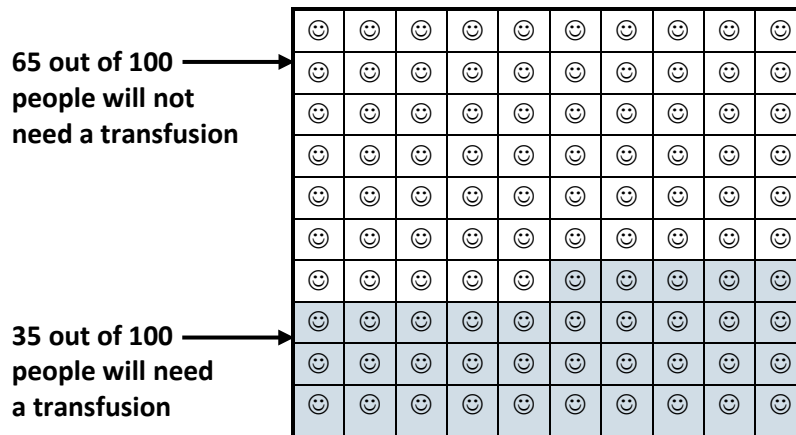
Line graphs are good for showing trends over time (U.S. Department of Health and Human Services, 2011). This line graph shows that with the blood disorder Factor V Leiden, the risk of a blood clot increases with age.

Risk of blood clot per 100,000 people

Writing health information for patients and families
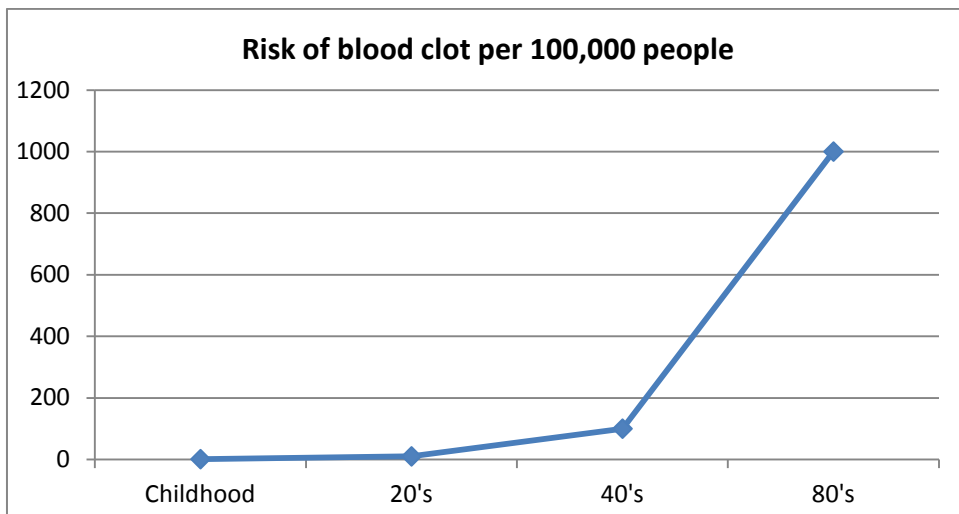
Bar graphs are helpful for comparisons, showing relative differences or patterns. This bar graph shows the number of calories in 1 gram of carbohydrate, protein, alcohol, and fat. The horizontal position puts text labels in an easy-to-read position (U.S. Department of Health and Human Services, 2011).

Calories in 1 gram

Food	Calories
Carbohydrate	4
Protein	4
Alcohol	7
Fat	9
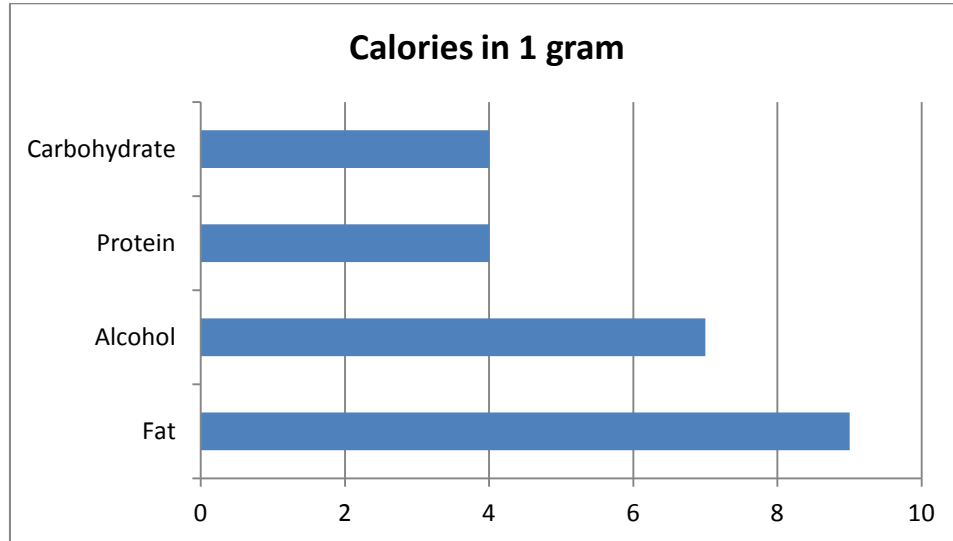
Pie charts depict proportions or percentages of 100%. They are helpful to show how smaller parts relate to each other and the 'whole' (U.S. Department of Health and Human Services, 2011).

Where does sodium come from?

- Added during cooking or at the table 11%
- Occurs naturally in foods 12%
- Added during processing, 77%
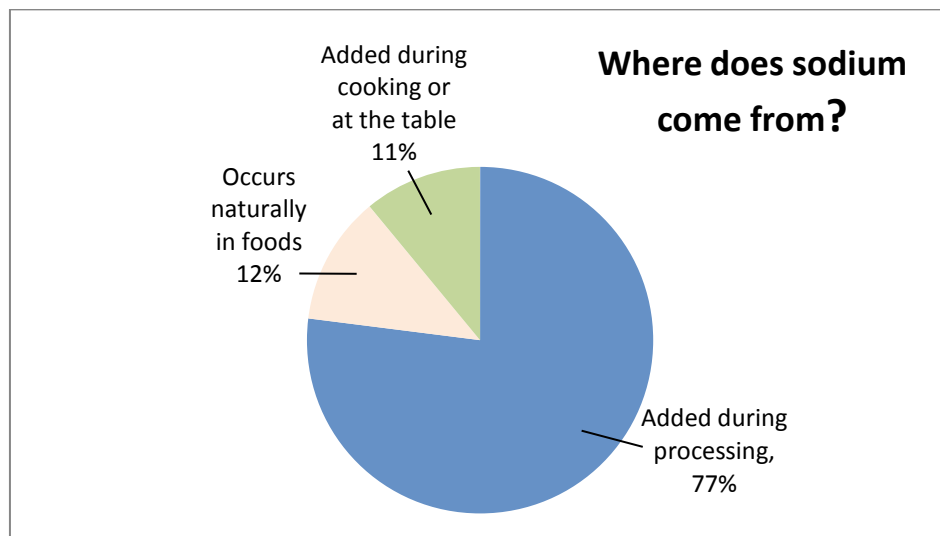
For more information about the visual presentation of risk

- U.S. Department of Health and human Services. National Cancer Institute (2011). Making Data Talk: A Workbook.
www.cancer.gov/cancertopics/cancerlibrary/MDT-Workbook.pdf

- United Nations Economic Commission for Europe. (2009). Making Data Meaningful.

  Part 1: A guide to writing stories about numbers.
www.unece.org/fileadmin/DAM/stats/documents/writing/MDM_Part1_English.pdf

  Part 2: A guide to presenting statistics
www.unece.org/fileadmin/DAM/stats/documents/writing/MDM_Part2_English.pdf

Is it helpful to include references in patient education materials?

There is limited evidence available to answer this question.

In a small qualitative study of the information needs and preferences of consumers regarding colorectal cancer screening (Smith, Trevena, Nutbeam, Barratt & McCaffery, 2008), participants responded to the inclusion of scientific references:

- Participants with higher literacy welcomed references as 'extra' information, that reassured them that the content had been well-researched.

- Participants with limited literacy referred to references as 'meaningless', 'irrelevant', and exclusively for academics.

- Both groups expressed concerns about the perceived barriers to accessing and understanding scientific information.

Our experience matches these findings. We do not include references in our patient education materials, for these reasons:

- References are not useful to most patients and families. This is not 'need-to-know' information and few people can access medical literature or judge the quality of evidence.

- Reference lists are often lengthy and it is not feasible to include them in most materials.

As some patients and families may want to read more detailed information or evidence from the literature, consider developing a reading list or learning pathway. Make sure the articles and other resources are accessible to patients and families.

> For example: The Juravinski Cancer Centre has developed a series of 'Pathfinders' - lists of books and websites that guide people to find information about cancer. They are available in the Patient and Family Resource Centre and online at http://jcc.hhsc.ca/body.cfm?id=173

How is the quality of patient education materials assessed?

There are many ways to assess the quality of patient education materials, including:

- involving people from the intended audience

- using a checklist to see if the material meets recommended criteria

- using a readability formula to assess the difficulty of words and sentences

Involving patients and families

Involve patients and families who represent your intended audience in planning, developing, and evaluating educational materials (Mitic & Rootman, 2012).

> **Patients and families are the experts. Only they can determine if your material is easy to read and understand, and meets their needs.**

At any time during development, ask a small sample of patients and families to review your ideas or material and provide feedback. At our hospital, we use a simple survey called **Tell us what you think** (page 108) for formative evaluation. We describe our process in more detail on page 94.

Using a checklist

Checklists enable you to compare your materials with the criteria recommended for health education materials.

Our **Checklist for Patient Education Materials** (page 106) includes criteria for:

- content
- writing style
- design
- illustrations
- process of development

The "process of development" criteria ensure that materials are:

- **Accurate** - reviewed by clinical experts from all relevant disciplines

- **Accessible** - reviewed by a Patient Education Specialist (or a person with expertise in plain language writing) to make sure they are patient-centred, based on sound educational theory, and follow principles of plain language and clear design.

- **Actionable** - tested with patients and families to make sure the materials meet their needs and are easy to read, understand, and use.

Other checklists:

- **SAM - Suitability Assessment of Materials** (Doak, Doak and Root, 1996)

- **Health Literacy INDEX** (Kaphingst et al. 2012)

- **PEMAT - Patient Education Materials Assessment Tool** (Shoemaker, Wolf & Brach, 2013)

- **CDC Clear Communication Index** (Centers for Disease Control and Prevention, 2013)

Using a readability formula

There are many readability formulas, but they all measure the same two factors: the number of syllables in the words and the number of words in the sentences. Most formulas result in a grade level. This is a rough estimate of the number of years of schooling required to understand the material.

Some commonly used readability formulas are:

- Flesch-Kincaid Readability Index. Available in Microsoft® Word products.

- Gunning Fog Index (Gunning, 1952). This formula is calculated 'by hand'. See instructions on page 105.

- SMOG: Simple Measure of Gobbledygook (McLaughlin, 1969).

- Fry Readability Formula (Fry, 1977)

> **Try calculating readability 'by hand'. By working with the text, you can gain valuable insights into your writing.**

Some online readability calculators let you enter text and get results from several formulas:

- Online-Utility.org
  www.online-utility.org/english/readability_test_and_improve.jsp

- Readability-Score.org   www.readability-score.com/

- Readability Test Tool (tests the readability of webpages) www.read-able.com

Grade level scores for the same text will vary, depending on the formula.

Readability formulas: cautions and recommendations

Readability formulas estimate grade level by measuring the structure of words and sentences. Short words and sentences result in lower grade level scores.

> We do not recommend setting a grade level requirement. Shortening words and sentences to achieve a low grade level can lead to oversimplification and choppy writing that sounds childish.

All words with 3 syllables or more are considered difficult, including familiar words such as 'family' and 'hospital'. All 1 or 2 syllable words are considered easy, even though patients find words such as 'per', 'oral', 'prior' or 'avoid' hard to understand.

> It is more important to use familiar words, than short words.

Patient education materials often include difficult words that all patients and families need to know. These words will increase the grade level of the material.

> Patients need to learn the meaning of medical words such as chemotherapy and cholesterol. They cannot be replaced by simper words.

Readability formulas focus on text, not the reader. They measure the length of words and sentences, not whether readers can understand or use the information. They do not take into account the reader's characteristics, such as motivation and experience.

> Feedback from readers is the best way to determine if material is clear and effective.

Readability formulas can only be applied to text in full sentences. They do not take into account design features that can affect readability.

> Clear design techniques such as font size, bulleted lists, short chunks of text and white space make information easier to read.

Writing health information for patients and families

When to use a readability formula

The process of using a readability formula can help you decide if the structure of the language (length of words and sentences) may be too difficult for readers.

This is helpful when:

- you are learning to use plain language
- you want to show others where plain language revisions are needed
- you want to compare 'before' and 'after' versions of text to show how plain language has simplified the text

Example: Checking readability in Microsoft® Word 2010

1. Enable the 'readability statistics' option:
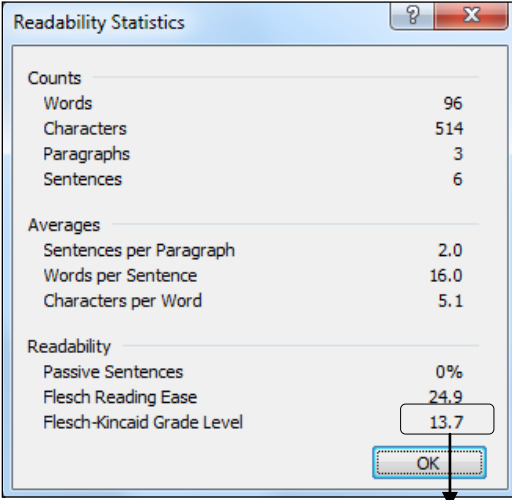
- Select **Office button**, then **Word Options**
- Select **Proofing**
- Under **When correcting spelling and grammar in Word**, check the box **Show readability statistics**

2. Prepare the text:

- Remove titles, headings and bulleted lists. Readability formulas can only be applied to text written in full sentences.
- Remove periods from abbreviations and numbers. Some readability formulas count every period as the end of a sentence. For example, the periods in Dr., E.N.T. or 38.5°C signal the end of sentences. This makes the sentence count inaccurate.

3. Check the readability:

- Open document. From the tool bar across the top, select **Review**.
- Select **Spelling and grammar**.
- When the spelling and grammar check is completed, a dialogue window will open and display the readability statistics.

Sample text from: www.fightflu.ca	Readability statistics
What is the flu? Seasonal influenza (flu) is a common infection of the airways and lungs that can spread easily among humans. In Canada, flu season usually runs from November to April. Most people recover from the flu in about a week. However, influenza may be associated with serious complications such as pneumonia, especially in infants, the elderly and those with underlying medical conditions like diabetes, anemia, cancer, immune suppression, HIV and kidney disease. On average, the flu and its complications send about 20,000 Canadians to hospital every year, and between 2,000 and 8,000 Canadians die.	Readability Statistics Counts Words — 96 Characters — 514 Paragraphs — 3 Sentences — 6 Averages Sentences per Paragraph — 2.0 Words per Sentence — 16.0 Characters per Word — 5.1 Readability Passive Sentences — 0% Flesch Reading Ease — 24.9 Flesch-Kincaid Grade Level — 13.7 Flesch-Kincaid Grade Level = 13.7

4. Interpret the results

- A Flesch-Kincaid Grade Level of 13.7 suggests that readers need some post-secondary education to understand the words and sentences.

- If the public is the intended audience, you may need to revise the information to make it easier to understand.

Difficult	Average	Easy
Grade 10 and over	Grade 7 to 9	Grade 4 to 6
Seasonal influenza (flu) is a common infection of the airways and lungs that can spread easily among humans. In Canada, flu season usually runs from November to April. Most people recover from the flu in about a week. However, influenza may be associated with serious complications such as pneumonia, especially in infants, the elderly and those with underlying medical conditions like diabetes, anemia, cancer, immune suppression, HIV and kidney disease.	The flu (influenza) is an infection of the lungs and airways. It spreads easily from person to person. Flu season is usually from November to April. Most people recover from the flu in about a week. Some people develop serious complications such as pneumonia. Complications are more likely in babies, older adults and people with certain medical conditions.	The flu is an infection of the nose, throat and lungs. It is also called influenza. Flu spreads easily from person to person. Flu season is usually from fall to spring. Most people get better in about a week. Some people with flu develop serious health problems. This is more likely to happen in babies, older adults and those with medical conditions.

How can health professionals provide information to patients with limited English proficiency?

You can meet the information needs of patients and families who are not fluent in English by (Nova Scotia Department of Health, 2010):

1. Providing multi-lingual health information from other sources.

2. Translating English materials.

3. Developing materials with the intended audience.

Regardless of the method, make sure the health information patients receive is written in plain language.

Why is plain language important?

- We cannot assume that people are literate in their spoken languages. Low literacy is a common experience around the world (Statistics Canada 2005b; Downing and Bogoslaw, 2003; Bowen, 2001).

- Materials must be simply written to reach the widest possible audience (Andrulis & Brach, 2007). This is true for all languages.

What websites provide multilingual health information?

Multilingual health information is available online. We have listed some sources of multi-lingual health information on the next two pages.

To decide which materials are suitable:

1. Review the English versions to determine if the content is accurate, relevant to patients and families, and written in plain language.

2. Test the materials with patients and families to determine if the material is easy to read, culturally acceptable, and meets their needs.

Canadian sources of multi-lingual health information

BC Health Guide: www.bchealthguide.org/healthfiles/bilingua/index.stm

Canadian Association of Family Resource Programs:
www.welcomehere.ca/index.cfm?fuseaction=Page.ViewPage&pageId=1113

Canadian Breast Cancer Foundation:
www.cbcf.org/ontario/YourDollarAtWork/EducationAwareness/Resources/Pages/Multilingual-Brochure.aspx

Canadian Cancer Society: www.cancer.ca Publications in French, Chinese and Punjabi are found under: Supports and Services > Resources > Publications

Canadian Mental Health Association: http://edmonton.cmha.ca/mental-health/multi-language-brochures/

Hamilton Health Sciences: www.hhsc.ca/body.cfm?id=1786

Health Canada: Canada's Food Guide: www.hc-sc.gc.ca/fn-an/food-guide-aliment/order-commander/guide_trans-trad-eng.php

Heart and Stroke Foundation of Canada:
www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3479037/

Hospital for Sick Children:
www.aboutkidshealth.ca/En/HealthAZ/Multilingual/Pages/home.aspx

MultiLingual-Health-Education.net: www.multilingual-health-education.net/faq.asp

Settlement.org (for newcomers to Canada): www.settlement.org/translatedinfo/

University Health Network:
www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Pages/multilingual_resources.aspx

International sources of multi-lingual health information

Health Information Translations www.healthinfotranslations.com/

US Department of Health and Human Services - National Library of Medicine
http://sis.nlm.nih.gov/outreach/multicultural.html

MedLine Plus www.nlm.nih.gov/medlineplus/languages/languages.html

EthnoMed http://ethnomed.org/patient-education

Healthy Roads Media   www.healthyroadsmedia.org/index.htm

The Stanford Health Library
http://healthlibrary.stanford.edu/resources/foreign/_intro.html

National Network of Libraries of Medicine
http://nnlm.gov/outreach/consumer/multi.html

NSW Multicultural Health Communication Service (Australia)
www.mhcs.health.nsw.gov.au/

We do not know whether providing translated materials overcomes language barriers and improves outcomes. More research is needed.

(Garcia-Castillo & Fetters, 2007)

What is the process for translating English materials?

1. Begin by reviewing the source material

- Ensure the source material is written in plain English. Clear and simple language is easier to translate.

- Remove colloquial expressions that have no meaning when translated literally into other languages. Examples: picture of health, clean bill of health, feeling blue, in bad shape, pins and needles, under the weather, out of sorts, back on your feet, and new lease on life.

- Ensure references to food, clothing and behaviours are familiar to and culturally appropriate for the intended audience.

- Ensure visual images are familiar to and culturally appropriate for the intended audience.

2. Determine the target language(s)

To determine the priority of languages for translation:

- Review your use of interpretation services. Each clinical area serves a unique patient population with different language needs.

- Review the demographics of the city or region you serve. You can check the **Census Profile** for your community at Statistics Canada's website: www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/index.cfm?Lang=E

- Consider language variations. In some countries, many languages are spoken. For example, in India people speak Hindi, English, Punjabi, Bengali and other languages. Even within a single language, there can be many dialects and variations. For example, different versions of Spanish are spoken in Spain, Mexico, and Columbia.

Writing health information for patients and families

3. Choose a translation service provider

French Language Services

Ontario's **French Language Services Act** guarantees French-speaking residents the right to communicate with the government and receive services in French.

The Ministry of Health and Long-Term Care and the Local Health Integration Networks (LHIN) are required to provide French-speaking residents with reasonable access to health services in their own language.

Planning and promoting French Language Services (FLS) occurs at the LHIN level. There is government support available for translation services, which are provided through a regional network. There is no charge for this service.

> **For more information, go to the Ontario Ministry of Health and Long-Term Care website and contact the French Language Services Coordinator for your LHIN.**
> www.health.gov.on.ca/en/public/programs/flhs/coordinator.aspx

Non-official languages

Criteria checklist for a Translation Service Provider
❑ A professional translator, accredited or certified by an industry association such as the Association of Translators and Interpreters of Ontario (ATIO).
❑ A native speaker of the target language who understands the culture of the intended audience.
❑ Experienced in translating health or medical information.
❑ Experienced in translating into plain language.
❑ Provides checking and proofreading by a second translator.
❑ Provides graphic design services to match the source material.

Bilingual staff members are not recommended as translators as they may lack:

- the required level of language proficiency
- skills in translating medical and technical language
- an understanding of ethics
- cultural sensitivity

4. Get a quote

For translation other than French, provide the source material to the translation service provider and ask for a written quote. The cost is based upon the word count in the source material and the languages chosen. There may be additional charges for graphic design services.

For example: The cost to translate a 3-page handout with 677 words was:

- $0.26 a word for French and Spanish

- $0.29 a word for Arabic

- $0.35 a word for Albanian and Mandarin

In our hospital, cost is a significant issue. Patient Education Services reviews each request for translation and provides this service when a specific need is identified and funding is available.

5. Check the quality of the translation

Testing the translated materials with patients, families and community members is the best way to make sure:

- the language is easy to read and understand

- the meaning of your messages has been clearly conveyed

- they are comfortable with the way the information is expressed

Testing can be done with individuals or in a focus group. A local community organization that serves the intended population may be able to help you get this feedback.

Questions to ask the intended audience include:

- Does the material sound natural?

- Does the material reflect the cultural norms of the people?
  For example, health beliefs, foods, and social activities.

- Are the words and images familiar and not offensive?

- Does reading the material convey an appropriate level of respect?

Depending on the results of testing, you may need to revise the material.

6. Format to match the source material

The layout of the translated material should match the English version. As many languages use more words than English, the text may expand up to 30%. Try to accommodate the text without reducing the size of the font.

Help English staff identify and use the material correctly. Put the English title and the name of the target language on each page.

How helpful are online translation tools?

Online translation tools use technology to translate text. The software applies linguistic rules, generated from a statistical analysis of vast amounts of text. The goal is to 'understand' language and imitate the actions of a translator. This process, called machine translation, is being studied as an alternative to human translations (Kirchhoff, Turner, Axlerod & Saavedra, 2011).

In our experience, we used machine translation (Google Translate) as a first step towards translating handouts into Spanish. After translation, a bilingual health professional reviewed and edited the documents. Combining machine translation with human post-editing was necessary to improve the quality of the translation.

The quality of machine translation will improve with rapid changes in technology, making it a promising strategy within the process of translating health information.

When is it better to develop materials with the intended audience rather than provide materials translated from English?

Direct translation of English materials into other languages may not be enough to make the information culturally appropriate to the intended audience (Arora, A., Liu, MN., Chan, R. & Schwarz, E., 2012; Shaw, Huebner, Armin, Orzech & Vivian, 2009). There are times when it is preferable to create new materials in partnership with the audience.

This process creates materials that meet the health literacy, informational, language and cultural needs of a specific group.

A bilingual author works with health professionals and members of the intended audience to:

- Identify the main health messages to be included.

- Identify the best way to communicate the messages using language and visuals that reflect the audience's cultural beliefs, values and traditions.

- Evaluate the finished material (assess the audience's comprehension and cultural acceptance of the information and its presentation).

This partnership ensures that the information will be easy to understand and culturally acceptable.

This process is essential when the purpose of patient education materials is to change health behaviours.

Some examples in the literature:

Authors	Project
Jones et al, 2011	Creating education materials related to cardiovascular risks for Indo-Asian Canadians.
Simmons, Cruz, Brandon & Quinn, 2011	Developing smoking relapse-prevention booklets for Hispanic populations.
Song et al, 2010	Developing a tailored nutrition education program for Korean-American immigrants.
Tu et al, 2008	Developing a video and pamphlet about colorectal cancer screening for Chinese Americans.

Part Three

Developing quality health information requires commitment and investment.

The process of developing patient education materials has 12 steps.

Doing this well takes teamwork.

Involving patients and families ensures your material will meet their needs.

Developing patient education materials requires commitment and investment

Providing health information is an intervention

It impacts patients' health and contributes to all aspects of quality healthcare:

- clinical effectiveness
- safety
- patient experience

Health information must adhere to quality standards

Patient education materials are:

- designed to meet patients' needs
- created using principles of plain language and design
- tested with patients and families when possible

Developing health information is a highly skilled activity

Staff who produce patient education materials need infrastructure, support and learning opportunities.

Developing effective patient education materials requires:
✓ An organization-wide commitment to provide quality health information to patients and families.
✓ Staff education to increase awareness of health literacy and build skills in plain language and clear design.
✓ Designated staff to produce patient education materials and manage the collection. This includes clinical, technical, support and design experts.
✓ Funding for the production and evaluation of resources.

(Patient Information Forum, 2013)

The process of developing patient education materials

Whether you are writing a pamphlet for patients attending a clinic or a resource book to be used by hospitals and public health services, certain steps are common to most projects. Although we list them as twelve steps, they do not have to be completed in order. For example: feedback from patients, families, health care providers, administrators and other stakeholders is helpful at any time during the process.

This work occurs in complex organizations where challenges and changes abound.
It helps to be flexible, as the scope of the project or the resources (available funds, staff and time) may change.

Developing patient education materials	
1	Establish a planning group
2	Identify your purpose and the intended audience
3	Assess available materials
4	Decide on the content
5	Write the information in plain language
6	Apply a clear design
7	Get feedback from the clinical team
8	Get feedback from patients and families
9	Get approval
10	Produce the material
11	Distribute and use the material
12	Evaluate the material

1. Establish a planning group

Developing patient education materials is a collaborative process that takes teamwork.

Start by establishing a small working group that will be responsible for developing the material.
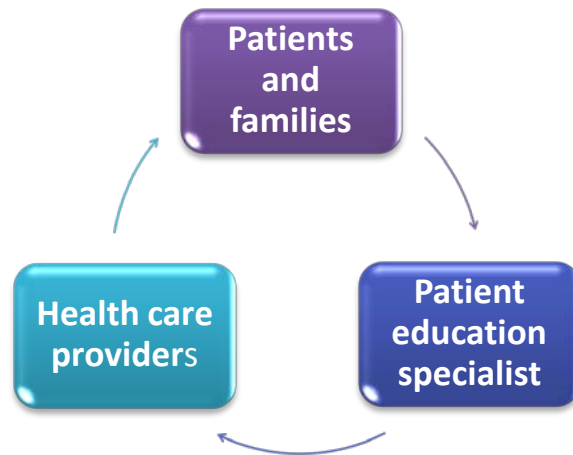
An interprofessional approach is needed. Identify the health care providers and administrators who will provide input or review the material during development. Involve a representative from each of the health disciplines that works with the intended audience.

At our hospital, working groups partner with a Patient Education Specialist who contributes expertise related to:

- plain language and clear design
- health education and adult learning theories
- patient-centred education
- production of patient education materials

2. Identify the purpose and the intended audience

Determine the purpose of the material you wish to develop and describe the intended audience (specific patient population).

The purpose of your material

The value of patient education materials depends on how well they meet their purpose.

Questions to help you define your purpose:

Do you want to help patients:

- increase awareness or knowledge?
- develop or improve skills (self-care, problem-solving)?
- change a specific health behaviour?
- increase their self-confidence or decrease their anxiety?

Do you want the material to be used:

- as an interactive tool during health teaching with a health care provider?
- daily, at home, to monitor progress towards a goal?
- occasionally, as reference material?
- as a guide, before making a decision regarding a treatment?
- before admission, to learn what to expect before, during and after surgery?

The intended audience

Try to create a portrait of the group of patients you want to reach with your health information. The more you know about your patients, the better.

> **Your knowledge of the audience will guide all decisions about the vocabulary, writing style, content, and format needed for your material.**

Questions to help you describe your intended audience:

Who are the patients and family members that will be using this material?

- age

- gender

- health status – including knowledge and concerns about their health condition, and past experience with this condition

- lifestyle, health-related attitudes and behaviours

- language and education background

- occupation and socioeconomic background

- ethnic and cultural background

- readiness and motivation to learn

Do the patients have any limitations that could influence learning?

- vision problems

- cognitive impairment

- mental health issues

- pain, fatigue or anxiety

3. Assess available materials

Before you develop new materials, check to see what is already out there!

Check to see what materials are available internally. At our hospital, staff check the online Patient Education Library at www.hhsc.ca/pedl

Check with your colleagues at other hospitals or health care organizations to see what they use and recommend.

Check other sources of health information, such as:

- reputable health information websites
- community or hospital resource centres
- health associations
- commercial producers

Look for materials that are:

Accurate	• Reflect current practice and what is taught by the interprofessional team
Accessible	• Easy to read and understand
Actionable	• Focus on what patients need to know and do, with clear action steps.

The **Checklist for patient education materials** on page 106 can help you assess the quality of patient education materials. To confirm that materials are suitable for patient education, test them with patients and families. Step 8 on page 94 describes patient testing.

At this point, you have to decide whether to purchase the material, adapt it to meet your needs or develop your own patient education materials.

Purchase or use	- If you find suitable material, your group may decide to use or purchase it. Consider adding an endorsement. - For example: applying a sticker printed with "This information has been approved for patient and family education at _____ [your organization]". - If the material is general in nature, you may wish to develop additional materials to provide patients with hospital-specific instructions and local resources. - Plan to periodically evaluate the material. See step 12 on page 100.
Adapt	- If the materials don't exactly suit your purpose or intended audience, you may decide to ask for permission to adapt the material to your needs. - With the author's or producer's permission, follow Steps 4 to 12 to revise the patient education material. Include an acknowledgement of the original source of the information in your material.
Develop	If you don't find suitable materials, proceed with developing your own materials. Reviewing other materials can give you good ideas about content, artwork, and design.

Writing health information for patients and families

4. Decide on the content

To decide on the content for your material, you will need to:

- find out what patients want to know

- identify the best clinical practice from health care providers and the literature

- identify the relevant learning theories

What do patients want to know?
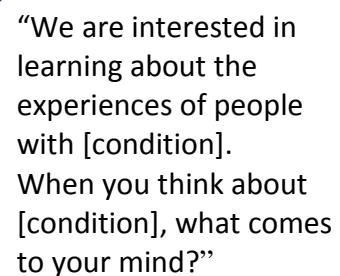
The content of your material should:

- include what patients and families want to know

- address their major areas of interest and concern

- reflect the way they think about their health conditions

You may think that you know what patients need to know, but it is better if patients and family members identify their needs. Ask them open-ended questions, develop a survey or conduct a focus group. You will always gain new insights from listening to patients.

**Questions to help you determine
what patients want to know:**

- What do you already know about…?

- What concerns do you have about…?

- What do you need to learn about…?

- How would you like to learn about…?

- What have you found helpful in dealing with…?

"We are interested in learning about the experiences of people with [condition].
When you think about [condition], what comes to your mind?"

Patients usually want to know what will happen to them. Present enough realistic detail that patients will know what to expect and do when they experience the situation.

Patients may want to know how they can take an active role in their health care and what options they have. Your material should invite them to talk with and ask questions of the health care team. If there is a contact person, give his or her name and telephone number.

Patients may be interested in learning how to manage their health condition, such as self-care and how to cope with emotions. They may be less interested in learning about anatomy or pathophysiology. Provide practical information for real-life situations.

> For example: When patients are learning about a low salt diet, help them practice what to do at a restaurant by writing – "When you go out to eat, ask how the food is prepared. Let the server know you need to limit salt". This helps patients apply the content to their daily lives.

Prepare a list of other resources that are accessible to patients and families who would like more information.

What is best practice?

The content of your material should reflect current standards of practice and be consistent with the information provided by the health care team.

To determine content from the perspective of health care providers:

- ask members of the health care team to describe current practice

- complete an online search and a review of the literature

- review clinical practice guidelines

It may not be possible or desirable to develop a comprehensive resource. Patients' working memory, required for processing information, is limited. By minimizing unnecessary text, we reduce the cognitive demands upon patients, allowing them to focus their attention on relevant information (Wilson & Wolf, 2009).

Filter the content to focus on what is most important to patients and families at that point in their care.

The critical content may be:

- What do patients need to **know**?

- What do patients need to **do**?

In a study evaluating education materials used in a rehabilitation hospital, clients clearly stated that the information that was of most value to them is what they need to do.

(Hunter, Dignan & Shalash, 2012)

Getting a diverse group of health care providers to reach consensus on the content can take lots of time and effort, but it's worth it! This step ensures all patients will receive accurate and consistent information, wherever the material is used.

What theories and models can guide us?

Theories help us understand and influence health behaviour. Use a health education theory to guide your project. A theoretical framework is most helpful when you are developing materials to help people change health behaviours. Applying a health education theory can help your material be more effective with your intended audience.

Some helpful theories are:

- Social Constructivism
- Social Cognitive Theory
- Health Belief Model
- Transtheoretical Model (Stages of Change)

- Patient Activation
- Theory of Planned Behavior
- Chronic Care Model (Self management)

Examples of theory-informed patient education materials:

Holly, J., Hale, E., Bennett, P., Treharne, G., Carroll, D. & Kitas, G. (2011). Translating patient education theory into practice: Developing material to address the cardiovascular education needs of people with rheumatoid arthritis. Patient Education and Counseling. 84(1-2): 123-127.

Knowing your purpose and the intended audience can help you pick the most relevant theory. If you need more information, talk with an education specialist (Patient Education Specialist, Advanced Practice Nurse, Clinical Specialist or Professional Practice Leader) or refer to the references below.

A full discussion of health education theories is beyond the scope of this book. For more information refer to these references:

- Hibbard & Greene, 2013
- Registered Nurses Association of Ontario, 2012
- World Health Organization, 2012
- Tomaszewski & O'Callaghan, 2009
- U.S. Department of Health and Human Services, 2005

5. Write the information in plain language

Write the content in your own words, as if you are speaking with a patient. Use familiar words in a conversational style.

If there is more than one author contributing to the material, be explicit that all work must be original. You must have permission to use or adapt information from other sources. This includes photos and visuals from websites.

When writing material, use these techniques to promote learning:

- Use a question and answer format. This is helpful to patients who are scanning material, looking for answers to their questions.

- Use repetition to help patients remember important information. Highlight and/or summarize the main points in your material.

- Encourage patients to interact with the material, by including questions or sample problems to solve. As patients interact with the material, it becomes more personal and relevant. Interaction also helps patients retain information and apply what they are learning.

- Provide concrete, real-life suggestions. If you intend to communicate the results of current research to patients (knowledge transfer) include practical ways that patients can apply the findings.

- Stay focused on patients' needs. The purpose of your material is patient education, not public relations or marketing.

Review your draft

Have we used plain language?	• Read your material aloud, pretending that you are talking with a patient. Ask yourself, "Is that the way I would explain this to a patient?" • Ask someone who does not have a background in health care to read your material and let you know if it makes sense. • Use the **Checklist for patient education materials** on page 106 to compare your material with the content and writing style criteria.
Is it free from bias?	Read the information looking for any bias with respect to: • gender and sexual orientation • ethnicity, culture or socioeconomic status • disability • product or commercial endorsement
Is the writing style consistent?	When many people contribute to the writing, have one person review the material to make sure it has a cohesive "voice".

Plain language takes time and practice

Many health care providers and students say that writing in plain language is much harder than they thought it would be. It involves much more than simplifying words. Communicating health and medical information in a way that is easy to understand requires specific knowledge, attitudes and skills. It takes time and practice to master these skills.

Don't worry if your first draft isn't perfect. It will change as you get feedback from clinicians, patients, and families. Plain language is an iterative process.

6. Apply a clear design

Once you have written the information in plain language, the next step is to choose a format and apply clear design techniques. With experience, steps 5 and 6 will blend together. You will naturally start to integrate clear design techniques into your writing.

Choose a format

Knowing how patients will use the material helps you decide on the format.
You can develop material in print and/or electronic formats. The format of printed material refers to the type of paper, page size, and binding.

Here are examples of how the patients' use can affect format:

- If patients need to carry around the material and use it every day,
  it needs to be pocket or purse size and durable.

- If the material will be displayed in a rack, it needs to be sized for the display rack
  so that the title is easily seen.

- If the material guides patients when they are practicing a skill, it needs
  to lie flat when open.

- If the content will change frequently, it needs a format that can be
  easily updated.

- If the material is on a website, write short webpages so that users do not have to
  scroll down long pages of text.

- If the material will be printed from a PDF file on a webpage, format
  so that it will print on letter-size paper, which most people have in
  their printers.

Apply clear design techniques

Microsoft Word and other word processing software have all the features that you need to create the simple design recommended for patient education. Follow the guidelines for clear design on page 42. Just remember to keep things simple.

If you use a graphic designer, be explicit that your goal is to make information easy to read. Ask the designer to use accessible design standards (Russell-Minda, 2006).

In our experience

At our hospital, we create documents in Microsoft Word®. All staff use this program, which makes it easy to share and edit documents via e-mail.

The Document Production Specialist has created standard formats for many types of patient education materials, such as cards, information sheets, and booklets. Each format uses clear design techniques.
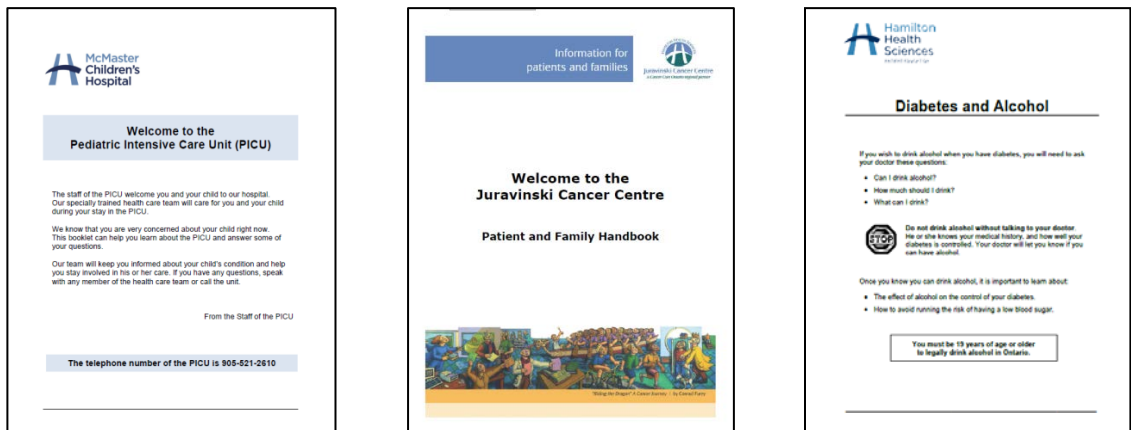
At the end of each document, we include:

- the hospital name
- a printing order (PD) number
- an identification code for document management
- the dates the document was developed and last updated

© Hamilton Health Science, 2013
PD 8375 – 01/2014
WPC\PtEd\CH\Pyeloplasty-lw.doc
dt/January 22, 2014

Staff use the PD number to order patient education materials from the hospital's Printing Services.

7. Get feedback from the clinical team

Your material is ready to be reviewed and edited by health care providers, patients and families. Usually the clinical team completes their review before getting feedback from patients and families.

Ask health care providers from your hospital or health care organization and the community to review the material. You will need their feedback to answer these questions:

- Is the information accurate and relevant to the intended audience?

- Does the information support what is taught by the health care team?

- Does this material duplicate or contradict other materials given to patients?

- Does the material help patients make a smooth transition to the next phase of care - to home or community services?

- Does this material fit with your organization's mission, vision and values?

> **Make sure that each health discipline involved with the intended audience has the opportunity to review the material.**

Strategies for getting feedback from the members of the clinical team include:

- facilitating a meeting of health care providers to review the material as a group

- emailing the material to health care providers to review

If you send the material to reviewers include this information in your message:

- the purpose of the material and the patient population

- what they are to assess, such as accuracy and consistency with their practice

- how to return their feedback

- the deadline for responses

Health care providers work under extreme time pressures:

- If you do not get a response, send them a reminder. Emphasize how important their input is to the development of this material.

- Consider adding a default option for not responding. That is, if you do not receive a response by the deadline, you will assume that the reviewer approves of the material.

> **Carefully consider the feedback you receive from the clinical team and other stakeholders and make any necessary changes.**

Although this sounds easy, in today's health care environment this can be challenging:

- You may receive little feedback. Health care providers have limited time to assist with developing patient education materials.

- You may receive multiple inputs and conflicting demands. Not all of the feedback you receive will be appropriate to use. You won't be able to create a document that completely satisfies everyone.

- Some members of the clinical team may have more knowledge (of clinical evidence or health literacy) than others.

- Some disciplines may have more influence or power than others to direct patient education.

- Some projects involve collaboration across many programs or organizations. The content and methodologies for patient education will vary. Relationships may be less than collegial.

If reviewers want to add unnecessary or complex information, remind them of the impact this would have on readability and clarity. Stay focused on your purpose and the intended audience, and use your judgment. There will be times when you need to make less-than-optimal choices in order to move the project forward. Gal and Prigat (2005) provide a good description of the complex organizational processes that can lead to these informed compromises.

8. Get feedback from patients and families

Patients and families are experts in their own care. Their input is invaluable in the development of patient education materials. This is how you can determine if your material meets patients' needs.

Getting feedback from patients and families is the best way to validate that your material:

- is readable

- is presented clearly

- is understood

- contains the right information – what patients want to know

- is practical – shows patients what they need to do

- is culturally acceptable

- achieves its purpose

Involve a small number of patients that represent your intended audience. With individual patients, use a survey or conduct informal interviews. Another option is conducting focus groups with patients and families.

Designate a health care provider who will approach patients or family members and ask if they wish to take part in providing feedback. The health care provider shows the material to the patients and family members and then asks them questions.

If possible, review the material line-by-line to:

- learn what is important and appealing to patients

- discover the affective impact (decreased anxiety, increased confidence)

- find any words, concepts or instructions that are confusing

If the purpose of your material is to increase knowledge or skills, ask patients:

- What would you do if…?

- How would you tell if…?

- What are the steps in doing…?

- When would you call…?

If the purpose of your material is to influence a specific health behaviour, ask patients:

- After reading this material, what will you do? How will you use this information?
- How confident are you that you will be able to do this at home, by yourself?

At our hospital, we use the survey method most often for patient testing. The health care provider gives the patient or family member a copy of the material along with an evaluation form, or patients are asked to complete an online version of the survey.

> **Testing is more successful when the health care provider emphasizes the importance and value of the patient's and family's input.**

Tell us what you think! (on page 108) is our template for a patient and family evaluation form. The survey combines closed and open-ended questions and invites comments. It addresses these basic questions:

> **Tailor this survey to suit your project.**

- Are the words easy to read?
- Is the information easy to understand?
- Is the material helpful?
- Did reading the information help you learn about your condition and how to care for yourself?
- Does the material answer your questions?
- Would you recommend the material to other patients?
- Would you like more or less information?
- What other suggestions do you have to improve the material?

If testing cannot be completed during the patient's hospital stay, provide a self-addressed, stamped envelope.

Keep all the feedback that you receive from patients and families. This documentation can be helpful during accreditation to demonstrate how you seek input from patients and families to evaluate services.

Summarize the patient and family feedback and share it with your planning group.

> **Carefully consider the feedback you receive from patients and families and make any necessary changes.**

9. Get approval

Once the material has been reviewed and modified based on the feedback from the clinical team, patients and families, it is ready to be approved for use in patient and family education. You will need to get approval from the health care providers who are involved with the project.

Proofread your final copy carefully. Check all phone numbers and hyperlinks.
Ask someone who is unfamiliar with the project to review the material, as he or she will be more likely to identify text that is unclear and spot the inevitable typos.

At our hospital, documented verbal approval or an e-mail confirmation is sufficient.
If you need to get key stakeholders to "sign off", circulate the final copy of your material with an approval form. A sample form, **Approval of patient education materials**, is shown on page 110. Give a reasonable deadline for returning the approval form.

The approval process ensures that all relevant disciplines have reviewed and approved the material. This can be helpful during accreditation, as a way of demonstrating an interdisciplinary approach in patient education.

10. Produce the material

At our hospital, the Patient Education Specialist and the Document Production Specialist coordinate the production of patient education materials.

The Document Production Specialist maintains a central catalogue of patient education materials that are available in print and electronic formats:

- Staff members can order printed materials from our in-house Printing Services. The printing costs are charged to their clinical program.

- Staff can access electronic files using the hospital's internal website (intranet).

- Most materials are available to the public in our online Patient Education Library at www.hhsc.ca/pedl.

A central database of all approved materials helps to keep the quality consistent.

To produce patient education materials, you will need to decide:

- where the documents will be stored (electronic and paper copies)

- how documents will be ordered and printed

- who will coordinate the production process

- what sources of funding are available for production costs

- who will maintain the inventory of patient education materials

Before printing materials, you will need to determine the printing specifications, such as:

- type and colour of paper

- type and colour of paper for cover pages, if needed

- if folding, stapling, 3-hole punching or binding are needed

- number of copies

If you are printing on both sides of the paper, choose a heavier weight of paper (60 lb) instead of bond paper (20 lb). If a single page is printed on both sides, make sure to direct the reader to turn the page over.

If your material is divided into sections, consider using dividers with tabs or print each section on a different colour of paper. This will make it easier for patients to locate information.

Cover pages are usually made of heavier paper (120 lb) or card stock.

Many patient education materials are produced as information sheets on 8.5 x 11 pages, which are standard for any printer. When there are several pages, you can staple them together or put 4 pages on 11 x 17 paper (this may require a special printer) and have it folded to letter size. If you use several sheets of 11 x 17 paper, they can be "saddle stitched", which puts staples at the fold.

Materials such as books may require binding. There are two main types of binding; coiled wire binding and plastic binding (Cerlox®). Wire binding costs more, but is more durable. To choose the binding, consider how often patients will use the book.

When deciding on the number of copies to print, consider how often the content is likely to need updating. If the information is likely to change, you may decide to print only enough materials for a few months. If the information is not expected to change, print enough copies for a year. Printing a larger number of copies will reduce the cost per copy (especially for larger materials or books).

11. Distribute and use the material

The effectiveness of your patient education materials will depend on how easily they can be accessed and used. Your planning group should decide:

- How will the material be introduced to staff?

- Where will the material (printed copies or electronic files) be stored so that staff can easily access it?

- Will printed copies be given to patients following discussion with their health care provider (mediated distribution)? Or available in print or website for patients to access (direct distribution)?

- Who will keep track of the supply of printed materials and reorder as needed?

- How often should the content be reviewed?

- Who will be responsible for updating the material?

- Who will remove old stock or re-post the material on the website when it has been updated?

> **Patient education materials are more effective when they are used as teaching tools to support face-to-face interaction with patients.**
>
> (Weiss, 2003)

12. Evaluate the material

Over time, expect to see changes in patients' needs, clinical practice, and delivery of patient care. Periodic evaluation and revisions can make sure your material continues to meet patients' needs and reflects current clinical practice.

Questions to ask:

- Is the content relevant to patients' and families' needs?

- Is the content accurate (based on best practices, clinical guidelines)?

- Does the content support the verbal teaching?

- Are staff aware of the material and how to access it (print on demand or stored on the unit)?

The results of evaluation will support your decision to:

- continue using the material, as is

- revise the material

- change how the material is distributed or used

- discontinue using the material

Part Four

The tools and forms you can use to develop patient education materials.

References and resources for more information.

Appendix A: Literacy

Appendix B: Health literacy assessment tools

Tell us what you think!

Steps to developing patient education materials

1	Establish a planning group
2	Identify the purpose and the intended audience
3	Assess available materials
4	Decide on the content
5	Write the information in plain language
6	Apply a clear design
7	Get feedback from the clinical team
8	Get feedback from patients and families
9	Get approval
10	Produce the material
11	Distribute and use the material
12	Evaluate the material

**The process is flexible and dynamic, not linear.
You may not always complete the 12 steps in order.**

Planning guide

Use these questions to help you plan a patient education project.

Purpose	• What knowledge do you want patients to learn? • What specific attitudes or behaviour(s) are the materials designed to support or change? • How is this material different from existing materials? • How will this material benefit your practice or program?
Patient population	• Who is the intended audience? • What characteristics are common to these patients? • Have patients identified this as a learning need? • What do these patients already know? • When and how will they receive the material? • Are patients and families available to evaluate materials?
Content	• Have patients described what they want to learn? • What are the most important messages you want to convey? • Have you considered all health literacy activities? • Do you need to complete a literature search for current evidence and practice guidelines? • What theoretical framework will guide the knowledge, attitude or behaviour change? • Have members of the interprofessional clinical team reviewed the information for accuracy? Does it reflect what they teach? • Is the information written in plain language and presented with a clear design? • Does the information support the mission, vision and values of your hospital or organization?

Format	• Will the format of printed material be easy for patients to use? Does the format need to be durable?
	• How will the printed material be stored, displayed and distributed? Will it be easy for staff to access?
	• Does the information need to be available in print and electronic formats?
	• Does the electronic format need to be "text accessible" for people with disabilities?
Printing budget	• How many patients would need to use/have this material? What quantity is needed?
	• Have you identified the printing specifications? (# of pages, paper size, weight of paper, artwork, binding)
	• Do you have a quote for the printing costs?
	• Do you have approval for funding the initial and ongoing costs?
Support	• Do you have a working group to help develop the material?
	• How will members of the interprofessional clinical team give their input?
	• Do you have the support of the health care providers who will use this material?
	• Have you consulted a Patient Education Specialist or plain language expert?
	• Can you develop this material collaboratively with other organizations?

Gunning Fog Readability Index

The Fog Index is a manual tool for analyzing readability (Gunning, 1952). Applying the Fog Index results in a Grade level for the selected passage of text. This is the number of years of schooling required to understand the passage.

To analyze writing with the Fog Index:

1.	Choose a passage of text with at least 100 words. Count the total number of words.	**# words =**
2.	Count the number of sentences in the passage of text.	**# sentences =**
3.	Find the average sentence length [ASL]. number of words ÷ number of sentences = ASL	**ASL =**
4.	Count the number of 'hard' words with 3 or more syllables. Do not include: • words that are capitalized like proper names/nouns • compound words that are combinations of short, easy words (such as bookkeeper or butterfly), • verbs that have been made into three syllables by adding -ed or –es (such as created or trespasses)	**# HW =**
5.	Find the percentage of hard words [%HW]. (number of hard words x 100) ÷ number of words = %HW	**% HW =**
6.	Find the grade level of the passage. • Add the average sentence length and percentage of hard words. • Multiply this number by .4 to get the grade level of the passage. (average sentence length + % hard words) x .4 = Grade Level	**ASL + %HW =** **x .4 =** **GRADE LEVEL**

Checklist for patient education materials

Use these criteria to assess the suitability of material for patient and family education.

Content	Yes	No	N/A
Does the title clearly identify the topic or content?	○	○	○
Is the purpose of the material clearly stated at the beginning?	○	○	○
Is there a table of contents to show how the material is organized?	○	○	○
Is the content divided into short sections or 'chunks' of information?	○	○	○
Does each section have a meaningful heading (a question or key message) that helps the reader find information?	○	○	○
Is the content organized in way that makes sense to the reader and is easy to follow?	○	○	○
Does the content reflect current practice guidelines, research evidence and what is taught?	○	○	○
Is the content limited to the information of greatest interest to readers? (not medical facts or 'nice-to-know' information)	○	○	○
Does the content include action steps (what readers need to do)?	○	○	○
Are important points emphasized or summarized?	○	○	○
Does the material encourage interaction with the reader (Q&A, quiz, checklists, blanks for responses, stories, quotes)?	○	○	○
Does the material encourage readers to take an active role in their health care?	○	○	○
Does the material tell readers where to get help or more information?	○	○	○
Is the material free from bias and commercial endorsement?	○	○	○

Writing style	Yes	No	N/A
Is the material written in plain language - the familiar, everyday language of the readers?	○	○	○
Are medical and technical words, acronyms and abbreviations defined?	○	○	○
Is the material written mostly in the active voice?	○	○	○
Is the tone positive and encouraging (not formal or clinical)?	○	○	○
Is the writing style conversational, with personal pronouns (I, we, you)?	○	○	○
Is the average sentence length about 10 to 15 words?	○	○	○
Are numbers in the material clear and easy to understand?	○	○	○
Are there clear instructions or examples of numerical calculations?	○	○	○

Writing health information for patients and families

Clear design	Yes	No	N/A
Is the format (card, information sheet, pamphlet, booklet) suitable for the way readers will use the material?	O	O	O
Are there no more than 2 simple fonts?	O	O	O
Is the font for body text large enough for easy reading (12 to 14 pt)?	O	O	O
Do fonts get larger from body text, to subheadings and headings?	O	O	O
Are upper and lower case letters used (not all capitals)?	O	O	O
Is the line length comfortable? (70 characters, 10 to 14 words, 5")	O	O	O
Is the text left justified, without hyphens?	O	O	O
Is there enough white space around margins and between sections?	O	O	O
Are bullets used to present lists?	O	O	O
Are important points emphasized with bold or a box?	O	O	O
Is a dark font used on a light background or non-glare paper?	O	O	O
Does colour emphasize important information or guide the reader?	O	O	O
Is the design of each page consistent?	O	O	O

Visuals (Photos, line drawings, graphics, clipart, cartoons)	Yes	No	N/A
Do visuals help explain the text or reinforce key messages?	O	O	O
Do visuals have clear captions and labels?	O	O	O
Do visuals show people, activities and objects that are familiar, realistic, age-appropriate and positive to readers?	O	O	O
Do drawings have simple, clear lines without distracting details?	O	O	O
Are body parts shown within the context of the whole body?	O	O	O

Process of development	Yes	No	N/A
Has the content been reviewed by the relevant health professionals?	O	O	O
Has the material been tested with typical readers?	O	O	O
Has the material been reviewed by a patient education specialist or a person with experience in plain language writing?	O	O	O
Does the material identify the organization, logo and publication date?	O	O	O

For a percent score: Add number of 'Yes' responses, divide by (44 – number of 'N/A' responses), then multiply by 100. The higher the score, the more suitable the material is for patient and family education.

Template for a Patient/Family Evaluation Form
(adapt to meet your needs)

Tell us what you think!

After reading **[title]** please respond to the following statements. Your answers and comments will help us improve the information.

Circle one number for each statement:

	strongly disagree ☹		☺		strongly agree ☺
The words are easy to read. Comments	1	2	3	4	5
The information is easy to understand. Comments	1	2	3	4	5
Reading this information was helpful. Comments	1	2	3	4	5
The information helped me [understand, know…] Comments	1	2	3	4	5
The information helped me know how to [behaviour, skill]. Comments	1	2	3	4	5
The information answered my questions. Please list what other questions you have:	1	2	3	4	5
I would recommend this information to other [patients, people with…] Comments	1	2	3	4	5
The [drawings, photographs, charts…] helped me understand the information. Comments	1	2	3	4	5

Please turn over →

Writing health information for patients and families

I would have liked more information about:

_____

_____

_____

_____

_____

_____

I would have liked less information about:

_____

_____

_____

_____

_____

_____

Other comments and suggestions:

_____

_____

_____

_____

_____

_____

_____

Thank you!

Please return this form to:

Approval of patient education materials

Title of patient education material:

[Insert title]

Review this material from the perspective of your health discipline. Sign this form if you approve of using this material for patient and family education.

Printed name	Title	Date	Signature

Please return this form to:

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Appendix A: Literacy

The Canadian Public Health Association defines literacy as "the ability to understand and use reading, writing, speaking and other forms of communication as ways to participate in society and achieve one's goals and potential" (Rootman & Gordon-El-Bihbety, 2008, p. 10).

Literacy involves a set of skills	
Prose	The ability to read, understand and use information from texts.
Document	The ability to locate and use information contained in various formats such as forms, maps tables and charts.
Numeracy	The ability to effectively manage the mathematical demands of diverse situations.
Problem solving	The ability to use reasoning and goal-directed thinking in situations for which no routine solution procedure is available.

(OECD & Statistics Canada, 2011)

What do we know about literacy in Canada?

In 2003, the Adult Literacy and Life Skills Survey measured and compared the literacy skills of a representative sample of people from each of six participating countries. The International Adult Literacy and Skills Survey (IALSS), the Canadian component of the survey, measured the literacy skills of over 23,000 Canadians over the age of 16 (Statistics Canada, 2005a). Participants completed the survey in either English or French and there was a nationally representative sample of respondents for each language.

Each literacy skill was measured along a continuum from 1 (lowest) to 4/5 (highest). Level 3 is considered to be the minimum level of proficiency required to meet the demands of life in an industrialized nation. A significant proportion of the Canadian population has below proficiency literacy skills.
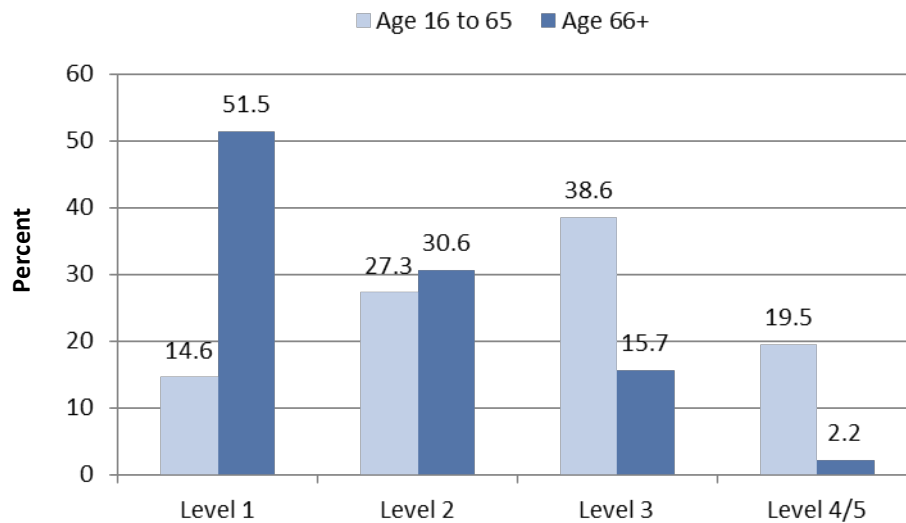
The extent of low literacy in Canada
Of Canadian adults over 16 years of age: 48% have low prose skills   48% have low document skills   55% have low numeracy skills   73% have low problem-solving skills   (Statistics Canada, 2005a)

How well do Canadians read?

A significant proportion of Canadian adults have difficulty with reading. This is much more of a problem for older Canadians. In the IALSS, age and literacy were inversely related, even after controlling for education (Statistics Canada, 2005a).

Prose literacy skills of Canadian adults, by age

Age 16 to 65   **Age 66+**

	Level 1	Level 2	Level 3	Level 4/5
Age 16 to 65	14.6	27.3	38.6	19.5
Age 66+	51.5	30.6	15.7	2.2

(Percent on vertical axis, scale 0 to 60)

Reading skills	
Level 1	People with Level 1 prose skills have a few, basic reading skills. They have difficulty dealing with printed materials.
Level 2	People with Level 2 prose skills can read simple, clear materials involving uncomplicated tasks.
Level 3	People at Level 3 have adequate prose skills. They can cope with the demands of everyday life and work.
Level 4/5	People at Levels 4 and 5 have strong prose literacy skills. They can read and process information very well, even when it is complex or abstract.

Almost half (42%) of working-age Canadians have difficulty with reading.

Most (82%) of Canadians over age 65 have difficulty with reading.

(Statistics Canada, 2005a)

Other key findings about literacy in Canada

Literacy and education

- There is a strong, positive association between education and literacy. However, educational attainment cannot predict an adult's literacy skills.

- Education and experience do not "fix" a person's skill level for life. Literacy skills can be acquired, developed or lost over a lifetime.

- Adults who engage in lifelong learning at home, work and in the community can compensate for low levels of schooling.

- Literacy skills will diminish if they are not used. The more time spent beyond the initial education system, the greater a person's skill sets diminish.

Literacy and immigration

- In 2011, 20.6% of Canadians were born outside of the country (Statistics Canada, 2011).

- IALSS data showed immigrants had lower literacy skills (in English and French) than the Canadian-born population. Sixty percent of immigrants, compared to 37 percent of the Canadian-born population, were at Levels 1 and 2 in prose literacy (Statistics Canada, 2005b).

- Duration of residence in Canada has some impact on literacy skills. Recent immigrants (those who have been in Canada for 5 years or less) outperform the established immigrants (those who have been in Canada for more than 5 years) in all skill domains.

- Immigrants whose mother tongue is English or French have significantly higher prose literacy scores than immigrants whose mother tongues are neither English nor French (Statistics Canada, 2005b).

Literacy and life experience

- Adults can improve their literacy skills by daily reading.

- Different life contexts (work, home and the community) impose different literacy demands on individuals.

- A person's literacy skills may be adequate in one situation, but insufficient in another. For example, a person with low literacy skills who copes well in daily life will face challenges as new situations, such as changing jobs or admission to hospital, present higher literacy demands.

Literacy and gender

- For adults aged 16 to 65, the greatest gender differences occur in numeracy skills, with men scoring higher than women. Women score slightly higher on the prose domain. (OECD & Statistics Canada, 2011)

Literacy and health

- Literacy is a determinant of health (Public Health Agency of Canada, 2013).

- Population sub-groups with low literacy skills are at risk of poor health (OECD & Statistics Canada, 2011)

- Poor numeracy in combination with either prose or document skills have a strong link to health status in Canada (OECD & Statistics Canada, 2011).

- Daily reading habits have the single strongest effect on health literacy proficiency (Canadian Council on Learning, 2008).

How can I identify which patients have trouble reading?

Almost half of Canadians over the age of 16 have some difficulty with reading (Statistics Canada, 2005a). Chances are you meet some of these people every day, but there is no way to know who has low literacy.

- You can't tell by looking. People of all ages, cultures and socioeconomic levels have low literacy.

- Most people with low literacy have developed coping strategies for daily life that compensate for poor reading skills (Schwartzberg, 2002). They may not consider reading to be a problem.

- People with low literacy may have feelings of shame, embarrassment, low self-esteem, fear, and inadequacy. They may not admit that they have trouble reading to anyone, including their children, spouse or doctor. (Parikh, Parker, Nurss, Baker & Williams, 1995). They may ask fewer questions of their health care providers (Weiss, 2003).

Writing health information for patients and families

What if patients would like help with reading?

Reassure them that they are not alone. Let them know there are many places to get support and help to improve their skills.

> **Become familiar with information and literacy resources
> in your community and refer patients to them.**
>
> (Mitic & Rootman, 2012)

Offer some ways to find the help they need:

- Encourage them to talk with staff at their local public library.

- Look for ABC Life Literacy Canada in the yellow pages of the phone book
  or visit at http://abclifeliteracy.ca/

- Give them the phone number or promotional literature from your local literacy council or adult learning centre.

Appendix B: Health literacy assessment tools

Here are details about specific tools for measuring health literacy. Some are in use, others are still being developed or tested. We have grouped them into 4 sections:

- Screening questions
- Self-assessments
- Direct tests of skills
- Tools for specific populations

Screening questions

The Single Item Literacy Screen (SILS)

- The SILS uses one question to identify patients who need help with reading health related information, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"

- The possible responses are Never (1), Rarely (2), Sometimes (3), Often(4) and Always (5). Scores greater than 2 are considered positive, indicating some difficulty with reading printed health related material (Brice et al., 2014; Morris, MacLean, Chew & Littenberg, 2006).

Brief Health Literacy Screen (BHLS)

- The BHLS consists of three items that are read aloud to participants:
  1. How confident are you filling out medical forms by yourself?
  2. How often do you have someone help you read hospital materials?
  3. How often do you have problems learning about your medical conditions because of difficulty understanding written information?

- Each item has a 5-point response scale.

- In testing, the BHLS demonstrated adequate reliability and validity when used as a health literacy measure in clinic and hospital settings (Wallston et al, 2014).

The 4-item BRIEF instrument

- This instrument includes the three questions in the Brief Health Literacy Screen and a fourth question addressing spoken information "How often do you have a problem understanding what is told to you about your medical condition?" (Haun, Luther, Dodd & Donaldson, 2012).

Self-assessments

Health Literacy Management Scale (HeLMS)

- HeLMS assesses an individual's ability to seek, understand and use health information within the healthcare setting and the broader social and environmental contexts (Jordan et al, 2013).

- HeLMS is based upon a conceptual framework of health literacy from the patient perspective (Buchbinder et al., 2011; Jordan, Buchbinder & Osborne, 2010). It measures these personal and system factors affecting health literacy.

Individual abilities	Broader factors
• understanding health information • accessing healthcare services • communicating with health professionals • being proactive • using health information	• patient attitudes towards health • social support • socioeconomic considerations

Health Literacy Questionnaire (HLQ)
(Osborne, Batterham, Elsworth, Hawkins & Buchbinder, 2013)

- HLQ asks individuals to rate their abilities in 9 domains:
  1. Feeling understood and supported by healthcare providers
  2. Having sufficient information to manage their health
  3. Actively managing their health
  4. Social support for health
  5. Appraisal of health information
  6. Ability to actively engage with healthcare providers
  7. Navigating the healthcare system
  8. Ability to find good health information
  9. Understanding health information well enough to know what to do

- HLQ is available in many languages. To apply for a license, go to: www.deakin.edu.au/health/research/phi/health-litracy-questionnaire.php

3-Level Health Literacy Scale

- The 3-level Health Literacy Scale measures a patient's self-reported skills in three types of health literacy (functional, communicative and critical) as defined by Nutbeam (2000).

- Developed in Japan, this scale was determined to be a valid and reliable measure of health literacy in patients with diabetes (Ishikawa, Takeuchi & Yano, 2008). Further validation was completed in The Netherlands (van der Vaart et al., 2012).

- The 3-level Health Literacy Scale can provide a better understanding of a patient's potential barriers to health promotion and self-management of disease.

Subjective Numeracy Scale (SNS)

- This 8-item scale is a self-assessment of ability to perform mathematical tasks and preference for numerical information (Zikmund-Fisher, Smith, Ubel & Fagerlin, 2007).

- Members of the public with higher SNS scores performed significantly better in numerical information-processing tasks related to medical decision making.

Direct tests of skills

Rapid Estimate of Adult Literacy in Medicine (REALM)
(Davis et al., 1993)

- REALM is a word-recognition tool. It does not measure comprehension.

- The patient is given a list of 66 health-related words, arranged in columns from the simplest (fat) to the most difficult (impetigo). He or she is asked to read each word aloud. The more words that are pronounced correctly, the higher the patient's reading level.

- Other versions include the 8-item REALM-R (Bass, Wilson & Griffith, 2003), the 7-item REALM-SF (Arozullah et al., 2007), the REALM-Teen for youth ages 10 to 19 (Davis et al., 2006a) and the Rapid Estimate of Adult Literacy in Dentistry (REALD-30) for oral health literacy (Hom, Lee, Divaris, Baker & Vann Jr., 2012).

Test of Functional Health Literacy in Adults (TOFHLA)
(Parker, Baker, Williams & Nurss, 1995)

- TOFHLA tests a patient's ability to use actual materials that he or she might encounter in the health care setting.

- The patient is asked to read and comprehend text, interpret documents and do basic calculations. This involves prose (reading), document and numeracy skills. The number of correct responses in this written test indicates the person's health literacy level.

- TOFHLA is also available in a shortened format (S-TOFHLA) that takes 8 to 12 minutes to administer (Baker, Williams, Parker, Gazmararian & Nurss, 1999).

The Newest Vital Sign (NVS)
(Osborn et al., 2007; Weiss et al., 2005)

- The NVS tests a patient's ability to read, understand and use information contained in a nutrition label from a container of ice cream.

- The patient is given a copy of the label in a large font, while the examiner asks six questions about the label. Answering the questions correctly requires prose (reading), document, numeracy and problem-solving skills. The number of correct responses indicates whether the person has adequate health literacy or if low health literacy is possible or likely.

- The NVS takes about 3 minutes to complete (Shah, West, Bremmeyr & Savoy-Moore, 2010; Johnson & Weiss, 2008).

- The Newest Vital Sign is available from Pfizer Clear Health Communication: www.pfizerhealthliteracy.com/public-policy-researchers/NewestVitalSign.aspx

Health Literacy Skills Instrument (HLSI)
(McCormack et al, 2010; Bann, McCormack, Berkman & Squiers, 2012)

- The HLSI is a 25-item computer administered tool that assesses five components of health literacy. HLSI measures the ability to:
    - read and understand text (prose skills)
    - locate and interpret information in documents (document skills)
    - use quantitative information (numeracy skills)
    - listen effectively (oral skills)
    - seek information through the Internet (navigation skills)

- The HLSI-SF is a shorter version with 10 items, found to be a valid and reliable measure of health literacy skills (Bann, McCormack, Berkman & Squiers, 2012).

Health Activities Literacy Tests

- The Health Activities Literacy Tests are based on the health-related tasks included in international surveys of literacy skills. They measure the prose, document and quantitative skills needed to perform health-related literacy tasks.

  – The Full-length Test provides a profile of an individual's skill at performing health-related literacy tasks. It takes about 1 hour to complete.

  – The Locator Test provides a general evaluation of an individual's skills at performing health-related literacy tasks. It takes about 30 to 40 minutes to complete.

- You can purchase these tests from ETC at www.ets.org/literacy/about/content/health_activities_content

Numeracy Understanding in Medicine Instrument (NUMi)
(Schapira et al., 2012)

- A 20 item test that assesses health numeracy. This is the first instrument to measure a comprehensive set of skills related to numeracy in the context of health (use of basic math skills, interpretations of tables and graphs, and understanding of probability and statistics).

- The authors propose that using NUMi in clinical settings could indicate the degree to which a patient has the skills to process and use numerical information, including understanding the probability of risks with treatment alternatives.

Tools for specific populations

Parental Health Literacy Activities Test (PHLAT)
(Kumar et al., 2010)

- Kumar et al. (2010) evaluated a 20-item Parental Health Literacy Activities Test (PHLAT) and a 10-item, shortened instrument PHLAT-10. These tools measure the health literacy and numeracy skills involved in caring for young children.

- After evaluating reliability and validity, the authors concluded that PHLAT may be a useful tool to identify parents who need better communication of health-related information.

HIV-Related Health Literacy Scale (HIV-HL)
(Ownby et al., 2013)

- The HIV-HL is a 20-question health literacy test that is computer administered and scored. The questions relate to actual tasks required of persons treated for HIV, and measure listening comprehension as well as reading.

- This tool has not been tested in a clinical setting.

Cancer Message Literacy Tests
(Mazor et al., 2012)

- The CMLT-Listening test assesses patients' comprehension of spoken health information on cancer prevention and screening. This test is self-administered via touchscreen laptop computer.

- The CMLT-Reading is a written test that assesses patients' comprehension of printed health messages related to cancer prevention and screening.

Tell us what you think!

We would like to hear from you. Please tell us what you think about this book.
All your comments and suggestions are welcome.

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