Guidelines for the Development of Patient/Family Education Resources for Adult Cancer Patients
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The best form of health education is always a purposeful conversation between the Patient and the Health Professional. Print and multimedia resources are tools to support this education. When used effectively, print/multimedia resources can assist health care professionals to maximize limited teaching time and enable patients to better manage their health. The provision of educational information is considered to be a fundamental prerequisite of consumer participation in health care.\textsuperscript{1,2,3}

The Guidelines for the Development of Patient/Family Education Resources for Adult Cancer Patients were created to support the selection and development of effective, evidence based, culturally sensitive patient/family education resources. Cancer Care Nova Scotia’s Education Standards for Adults Affected by Cancer\textsuperscript{2} form the foundation of these guidelines.

If you have suggestions to improve these guidelines or have questions, please contact Brian Taylor, Project Officer - Education, Cancer Care Nova Scotia.

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**Adapted from:** Patient/Family Education Print Material Guidelines. (2007). Queen Elizabeth II Health Sciences Centre, Capital District Health Authority, Halifax, Nova Scotia.\textsuperscript{1}

**Developers:** Meg McCallum, Provincial Manager, Education & Patient Navigation, Cancer Care Nova Scotia
Penny Logan, Manager, Library Services, Capital District Health Authority
Donna Smith, Diverse Communities Cancer Coordinator, Cancer Care Nova Scotia

**Contact Person:** Brian Taylor, Project Officer - Education, Cancer Care Nova Scotia
Phone: (902) 473-5106; Fax: (902) 473-6412
Email: BrianX.Taylor@ccns.nshealth.ca

**Approved by:** Nova Scotia Cancer Patient Education Committee, May 15, 2012

**Review date:** This document will be re-evaluated and revised in September 2014.

**Recommended Citation:**

May be reprinted with permission from Cancer Care Nova Scotia.
Introduction

Cancer is a leading cause of morbidity and mortality in Canada. Nova Scotia has high cancer incidence and mortality rates amongst both males and females compared to the national rates. Given the complex nature of the disease, the cancer care system and treatment modalities, those diagnosed with cancer and their family members will experience a variety of informational/educational needs throughout their cancer journey.

The Nova Scotia Cancer Patient Education Committee (NSCPEC) is a collaborative effort of Cancer Care Nova Scotia (CCNS), the Capital Health Cancer Care Program, the Cape Breton Cancer Centre and the province’s District Health Authorities (DHAs). Membership is multidisciplinary; inclusive of experts in oncology practice and patients and family members. The mandate of the committee is to ensure every adult cancer patient receives excellent, evidence-based, consistent and timely education in an appropriate format and setting. This mandate is achieved by establishing and maintaining processes related to patient education. Patient education is provided to cancer patients and families by health professionals throughout Nova Scotia.

Several qualitative studies commissioned by CCNS highlight the variety of information needs and preferences amongst people affected by cancer as well as the inconsistent, incomplete and, on occasion, insensitive approaches of health professionals attempting to address these needs. The 2007 Ambulatory Oncology Patient Satisfaction Survey identified specific education, information and communication needs as “top priority” because improvements in these areas would have the greatest impact on overall patient satisfaction.

Scope and Purpose

CCNS envisions a system where cancer patients throughout Nova Scotia receive excellent, evidence-based, consistent and timely education concerning their cancer journey in an appropriate format and setting. These guidelines have been written to assist health professionals and DHAs in achieving this vision.
The scope and purpose of this document is to:

- Establish guidelines for health professionals to support professional practice as it relates to the development of information materials for adults affected by cancer.
- Establish guidelines which improve and maintain high quality education for adults affected by cancer.
- Ensure educational resources are available to meet the needs of a diverse population, reflecting language, literacy, culture and ethnicity, gender, sexual orientation, age/stage of life, and physical or intellectual abilities.

**Assumptions**

These guidelines were written with the following assumptions:

- The [CCNS Education Standards for Adults Affected by Cancer](#) ground the selection/development of educational materials.
- The guidelines apply to all channels of information: print, web-based, videotape, audiotape and slide/multimedia presentations.
- Person affected by cancer is inclusive of the person with cancer and their family.
- Person refers to an adult.
- Family is defined by the person with cancer.
Selecting/Creating Quality Patient/Family Education

The need for quality patient/family education has become greater due to the acuity of the patient population, increasing complexity of care, shorter hospital stays and a shift towards outpatient care. Resource materials can be valuable tools for patient education but they are only supplements and never a substitute for verbal communication. Resource materials can convey basic repetitive information freeing the Health Care Professional to concentrate on individualized follow-up instruction. They can also enable consistency in teaching by a diverse group of health professionals.¹ ² ³ ⁴ ⁵ ⁶ ⁷

Health Literacy

Health literacy is the ability to obtain, process, and understand health information to make informed decisions about health care.

Limited literacy is a widespread but often hidden problem. The ABC Canada Literacy Foundation Report Summary notes that 48% of Canadian adults age 16 and over have low literacy. This has not changed since 1994. More than 80% of Canadians over 65, the biggest users of health care, have low literacy. Those with the lowest literacy are more likely to have the poorest health status.¹⁴ ¹⁵ These facts must be given consideration when we evaluate and prepare print material for our patients and their families. It should be noted that most people read at least two grade levels below their last school grade completed, so relying on the length of formal education as an assessment parameter is a serious limitation.¹⁵ ¹⁶ ¹⁷ ¹⁸ A great deal of available patient/family education material is highly technical, is written at the high school or university level, and as a result often fails to accomplish the goal of providing understandable material.¹⁴ ¹⁵ ¹⁶ ¹⁷ ¹⁸

A readability formula should be used to predict the level of reading skills needed to read the resource. The target grade level of our patient/family education print material at grade six or below.¹⁸ Computer software programs are available to assist us but they also give only an estimate of readability.¹
A low reading level is only one of many elements that make a piece of material easy to understand. If patients are to benefit from printed health information, the materials must be written clearly and concisely. Clear writing includes logical organization and familiar language, which sounds like every-day speech. Other topics to be considered when preparing and evaluating the readability of material is the overall appearance, sentence length and tone.  

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. Plain language enables them to quickly read and immediately put to use essential health information. Even highly educated adults are not insulted by health material written in plain language.

The Canadian Health Literacy Study asked patients who were identified as being “hard-to-reach”, by virtue of language or anxiety, about their preferred ways to learn (patients could chose more than one option thus the total in Table 1 exceeds 100%).

Table 1. Learning Preferences

<table>
<thead>
<tr>
<th>Learning Preference</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning in a group with other patients</td>
<td>65%</td>
</tr>
<tr>
<td>Reading</td>
<td>66%</td>
</tr>
<tr>
<td>Watching videos</td>
<td>70%</td>
</tr>
<tr>
<td>Learning one-to-one with a health professional</td>
<td>85%</td>
</tr>
<tr>
<td>Verbal explanations from a healthcare professional</td>
<td>94%</td>
</tr>
</tbody>
</table>

According to the Canadian Council on Learning, the populations most likely to have low literacy levels are those being asked to manage their conditions - older adults, ethnic
minorities, people with low education and income levels, those who do not have English as their first language and those with a compromised health status. By exploring the use of group teaching sessions, with powerpoint presentations and demonstrations, and multimedia tools like video and the internet, we may be able to reach those who cannot or prefer not to use traditional print material.

The Selection/Development Process

- Identify and confirm the need for a patient education resource.
- Develop a work-group and appoint a leader.
- Contact the individual responsible for patient education in your District, if applicable. Request assistance, if available.
- Familiarize your group with the CCNS Education Standards for Adults Affected by Cancer and these guidelines.
- Develop a plan following the process (pages 8-11), criteria (pages 14-20) and checklist (Appendix IV) outlined in these guidelines.
- Before you begin to develop a new resource, do some research, find out what other organizations have created, assess if they are current and evidence based. Determine if any of these resources are suitable (refer to process, page 8).
  - All resources developed by the Canadian Partnership Against Cancer (CPAC), Canadian Cancer Society (CCS), Canadian Association of Nurses in Oncology (CANO) and Canadian Association of Psychosocial Oncology (CAPO) are automatically approved for use in Nova Scotia. Begin the process at step ** (page 11).
  - Resources developed by all other groups are to be reviewed by an Oncology Site team and the Nova Scotia Cancer Patient Education Committee Materials Working Group. Begin the process at step * (page 10).
The Selection/Development Process, continued

- A critical step in the process is field testing the resource with patients from your target audience.25, 33
  - Testing with five patients is considered sufficient.34
  - Use the form in Appendix V to capture patients’ feedback; first tailor the form to the nature of your resource.
  - You can conduct a focus group, interview patients individually or have them complete the form themselves.
  - Some researchers believe it is best to conduct the field test in the same type of environment in which the patient will be using the resource.33 For example, if a patient will be reading a factsheet in a noisy, busy clinic, be sure that test readers have the same distractions.
  - The goal of the field test is to determine if your patients can:
    - Understand the information, the words and the concepts.
      - Do readers understand the term “safe handling”? Or, do they understand a concept like “dressing check”, ask who checks and what are they looking for? The words may be easy but the concept may not be clear.
    - Find the information they need.
      - Ask your patients questions from the resource. Have them search the resource; they should be easily able to find the answers to your questions. For example, when can you lift heavy objects after your surgery? When can you drive your car?
    - Act on instructions.
      - If the resource says “If you have a fever, call your doctor.” Ask the patients what is considered a fever? Which doctor should they call? Do they have the phone numbers they need?
The Selection/Development Process, continued

- The goal of the field test is to determine if your patients can:
  - Understand the graphics.
    - Ask the patients to describe the images and ask them if they find them helpful. Pretesting visuals with your target audience ensures your message is clear and culturally acceptable.\(^{25, 33}\)
  - Follow the sequence of the information.
    - A great strategy to determine if you have sequenced the information properly is to cut up your document into sections and ask your patients to put it together like a puzzle. This reveals how they believe the information should flow. \(^{25}\)
**Figure 1 Patient Education Resource Development Process Flowchart**

**Development, Revision and Approval Procedure**

- Need for Patient Education resources identified
  - Locate existing material
  - Critique material using Check List for Developer (App IV)
    - Go to step of process
      - Pamphlet Meets Criteria
        - Yes
          - Minor Revision
          - Go to step of process
        - No
          - Major Revision
            - Establish work-group
              - Familiarize work group with Patient/Family Education Print Material Guidelines and Patient Education Standards
                - Contact, the Project Officer, Education (CCNS) to avoid duplication of efforts and increase awareness of resources.

**Who is Responsible?**

- Developer
- Developer
- Developer
- Developer
- Developer
- Developer
- Developer
- Developer
Development, Revision and Approval Procedure, cont

Consult with the appropriate resource people (including other disciplines) throughout the development process as required.

Prepare electronic draft of text, using checklist for developer (App IV)

Obtain and document clinical approval from appropriate stakeholders

Obtain feedback from someone who is unfamiliar with content area and adjust if needed.

Rewrite and reevaluate

No

Pamphlet Satisfactory

Yes

Field test the draft to ensure the product works using Field Test Evaluation of Patient Education Resources form (App V)

Rewrite and reevaluate

No

Pamphlet Satisfactory

Yes

Who is Responsible?

Developer

Developer

Developer

Developer

Developer

Developer
Development, Revision and Approval Procedure, cont

Submit final electronic draft to CCNS Project Officer - Education (CCNS) for consideration of NSCPEC and relevant site teams

NSCPEC Materials Working Group evaluates resources as a teaching tool

Site Team evaluates resource for clinical accuracy

Recommend adjustments to developer

Resource Meets Criteria

No

Yes

Is this an existing resource?

Yes

Move to step**

No

Alert developer of NSCPEC and site team recommendation

Consult with Graphic Designer if illustrations are needed

Collaborate with the graphic designer

CCNS Project Officer

CCNS Project Officer

CCNS Project Officer

CCNS Project Officer

Step*

CCNS project officer emails the Capital Health Librarian Educator to request changes

Librarian Educator updates the pamphlet content and sends approved pamphlet in print layout to Dalhousie PrintShop, plus layout for online reading to CCNS Project Officer

If CCNS pamphlet then publish to CCNS web page. If CDHA pamphlet then submit to Librarian Educator who will send to Web Team to update posting.

Who is responsible

Developer

CCNS Project Officer

CCNS Project Officer

CCNS Project Officer

Librarian Educator/Project Officer/Web Team
Who is Responsible?

Notify NSCPEC when the resource is available.

Send samples of pamphlet and order instructions to the Manager of Satellite clinics, Directors of Cancer Centers, Capital Health Patient Education Coordinator and Patient Navigators

Maintain a record: resource title number, development or revision date and owner (unit or department)

Ensure pamphlet is placed on CCNS website

Review and ensure resource is updated every 3 years, or more frequently if necessary.

Print shop adds, exchanges or deletes proof as appropriate

Proof resources to Project Officer

Final approval following consultation with developer

Step **

Notify NSCPEC when the resource is available.

Send samples of pamphlet and order instructions to the Manager of Satellite clinics, Directors of Cancer Centers, Capital Health Patient Education Coordinator and Patient Navigators

Maintain a record: resource title number, development or revision date and owner (unit or department)

Ensure pamphlet is placed on CCNS website

Review and ensure resource is updated every 3 years, or more frequently if necessary.

Who is Responsible?

CCNS Project Officer

CCNS Project Officer

Chair, NSCPEC

CCNS Project Officer

CCNS - Communications Assistant

CCNS Project Officer
Updating Resources

- All patient/family education resources are to be reviewed every 3 years.
  - For web-based information, changes in clinical practice or contact numbers need not wait for the regular review cycle, these updates should be made by the developer as soon as possible.

- The CCNS Project Officer will notify the developer when a pamphlet needs to be evaluated, in January of the year it is to be reviewed.

- A second notice will be sent in April if the Developer has not responded.

- On December 31st of that year, the CCNS Project Officer will remove the resource from circulation if there has not been any response from the Developer.

The clinical department/group which developed the resource will review and update the resource considering:

- Changes in evidence/clinical practice.
- Changes in contact numbers/persons.
- Changes in pre or post instructions.
- Changes in drugs or dosages.
- Changes in equipment the patient uses.
- Feedback regarding the effectiveness of the resource:
  - Do patients appear to be confused by the information?
  - Are they using the resource?
  - Are patients following the instructions provided?
  - Is there a change in the number of cancellations or complications?

Implementing New Resources
When developing or revising resources, it is critical to consider an implementation plan. Patient Education resources are effective only when used as a part of an overall patient education strategy. Simply handing your patient a pamphlet or a DVD or directing them to an online resource is not enough to promote understanding or behaviour change.  

**Questions to consider when developing your implementation plan:**

- How does this resource fit into the overall patient education approaches for this patient population?
- Will Health Professionals require additional training to use the resource?
- How will you communicate the availability of the resource to health professionals, patients and families?
- If the new resource replaces another resource currently in use, how will you get the outdated resources out of the system?
- How will you evaluate if the resource is effective?

For additional implementation considerations, refer to the Guidelines for Health Care Professionals using the Resource on pages 24-28.

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*For further information about comprehensive approaches to patient education, refer to Education Standards for Adults Affected by Cancer and Patient Education Fundamentals © Crown copyright, Province of Nova Scotia, 2011, available via Cancer Care Nova Scotia or visit [http://www.nchealthliteracy.org](http://www.nchealthliteracy.org) or access the American Medical Association Health literacy and patient safety, Manual for clinicians.*
Organization

- Title reflects content.
- The opening paragraph states the purpose of the pamphlet.
- Question & Answer format is useful.
- Headings and subheadings are required.
- A glossary is important and should be placed at the beginning rather than at the end of a pamphlet so the reader is more likely to find and use it.
- A table of contents is not necessary if the pamphlet is less than 8 pages in length.

Style & Language

- Use a friendly tone. A conversational style has a more natural tone and is easier to read and understand. Read your material aloud to see how it sounds.
- Write in an active voice. For example, take your medication after meals rather than, your medication should be taken after meals.
- Promote the patient taking an active role in their health.
- Talk directly to the reader. Use the words: you, I, we, us and our to make the material more personal. Do not refer to your readers as clients or patients.
- Include quotes from patients/family members that reflect their experience.
- Use gender free language.
- Be sensitive to the cultural values and beliefs of diverse communities.
- Place the subject and verb close to the beginning of the sentence.
- Eliminate all unnecessary words.
- Use 1 or 2 syllable words as much as possible.

Style & Language, continued
• Maintain average sentence length of 10 words or less.
• Limit paragraphs to 4 or 5 sentences.
• List information whenever possible, focus on the “need to know” rather than the “nice to know” information.
• Emphasize important information.
• When using abbreviations and acronyms give them first and spell the word in parentheses; e.g., after your surgery you may stay in ICU (Intensive Care Unit).
• Be consistent with word use. Choose the most familiar words and use them throughout. For example, Vincristine and Oncovin may be the same thing to you, but your reader may think they are two different drugs.
• Use analogies familiar to your audience. Say: Feel for lumps the size of a pea. Instead of: Feel for lumps about 5 to 6 mm in diameter.
• Instead of using statistics, use general words like most, many, or half. If you must use statistics, try putting them in parentheses.

Illustrations
• Consult with the graphic designer in the Audio Visual Department regarding illustrations. Limited clip art is available from the designer.
• Use illustrations that are copyright free or obtain written permission to use from owner. Submit copyright permission with draft of text to CCNS.
• Use simple line drawings.
• Use adult rather than child-like images.
• When using line drawings of anatomy, include body landmarks.
• Ensure that illustrations are up-to-date.

Illustrations, continued
• Label diagrams with familiar words.
• If using colours, be aware that some people cannot tell red from green and printing in colour increases your cost. Resources don’t have to be in colour to be effective.
• Use pictures and photos with concise captions; keep captions close to graphics.
• Present one message per visual.
• Create visuals that help to emphasize or explain the text. Avoid visuals that decorate your materials or are very abstract. Note: not all audiences understand cartoons or take them seriously.
• When showing internal body parts, include the outside of the body to aid viewer understanding. Avoid cutting off body parts.
• Use images showing actions you want readers to take. Avoid images that show what the reader should not do.
• To prevent patients from mistaking a "Do Not" drawing for a "Do", use the familiar heavy slash through the diagram.
• Avoid graphs/charts unless they really help readers to understand the material.
• Try to include pictures that represent various ethnic groups, both men and women equally and avoid stereotypical occupational roles.
• Balance the use of text, graphics, and clear “white” space. In general: leave at least 0.5 to 1 inch of white around the margins of the page and between columns.
• If medication information is included, consider adding pictograms.
  o The USP Pictograms are standardized graphic images that help convey medication instructions, precautions, and/or warnings to patients and consumers. You can download the pictogram library from www.usp.org/audiences/consumers/pictograms.  

Readability
• Target the reading level to grade six or below.
  o Use a readability formula - SMOG\textsuperscript{36} and Flesch – Kincaid\textsuperscript{37} are good choices (refer to Appendix I & II for more detail).
  o A variety of readability scores can be compared at a glance by pasting text from a WORD document into the readability calculator found at: http://www.wordscount.info/index.html

• Unless it is necessary for the reader to learn medical words, always use plain language (refer to Appendix III).

• When used, define medical terms.

• Use dark type (navy or black) on white or cream background.

• Avoid glossy paper.

• Do not use Roman numerals.

• Do not use abbreviations.

• Do not hyphenate words over two lines.

• Focus on “need to know” information. Limit number of messages; present readers with no more than three or four main ideas per document or document section.

• Clearly state the actions readers are to take.

• Don’t include details that are irrelevant to the reader’s healthcare needs. For example, if you are writing about how to prevent Skin Cancer, you don’t need to tell readers how and when skin cancer was first discovered.

• Stick to one idea at a time; skipping back and forth between topics can be confusing.

• Avoid lengthy lists. Limit lists to five or six items. If some items are more important than others, list them in order of priority.

**Visual Appearance**
• Do not use all upper case letters.
• Limit the use of italics.
• Do not use different type faces on the same page.
• Use a font between 11 - 14 point sizes in the body text.
• Use Adobe Georgia or Arial font.
• Use a justified left margin and a ragged right margin.
• Use generous amounts of white space (areas without print).
• Use wide margins and borders.
• Use bullets.
• Skip at least one line between paragraphs and sections.

Translation
• Depending on the diversity of your patient population, you may wish to consider arranging translation to target patients/families who do not speak English.
• Do not use online translation tools and/or computer software. A professional, certified translator must be used.
• Within CDHA, translation will be initiated by the CDHA Patient Education Coordinator. Other Districts should connect with their Communications Department to explore translation options.
• Rather than translating your resource you may wish to note organizations and websites where similar information can be found in languages other than English. A list of such resources can be found at www.cancercare.ns.ca.

General Hints
• Be prepared to go through several drafts.
• Remember your readers' cultural, ethnic, economic and educational backgrounds.

• If you are adapting an existing resource, cite the approval to adapt (e.g. Adapted, with permission, from Nausea, X Cancer Agency, 2010).

• Develop and maintain a bibliography of sources used in the development of the pamphlet. Do not include these in the pamphlet.

• If there are websites or other resources patients may find helpful, list them at the end of your resource,

Additional Information regarding Video/Multimedia Resources

In addition to the guidelines noted in previous sections, when selecting/creating video/multimedia resources, the following guidelines apply.

• **Content:** must be current and consistent with best practice.
  - Language used should be simple, everyday conversation with medical jargon kept to a minimum.
  - The title used should reflect the content.
  - The key take-home message should stand out.
  - Choose 2-3 main concepts, goals or messages to focus on.
  - All information should be essential, immediately applicable and actionable.
  - Offer positive examples of practical behavior changes the learner can engage in right away, e.g. starting a walking program or eliminating sugary pop from their diet.
  - Different cultures should be portrayed wherever possible.

Additional Information regarding Video/Multimedia Resources

- Patient participation in video development, either directly or indirectly, is highly recommended.
- Hearing from patients in similar situations tends to be reassuring to many patients and connects them with the video content.

- **Length**: Shorter videos are more appealing to those feeling ill or under stress.
  - Recommended: TV - 10 minutes or less; Web - 5 minutes or less.
  - If the information cannot be delivered in 5-10 minutes, break it into two or more parts (eg. Managing Pain – Part 1, Managing Pain, Part 2).

- If you are planning to post the video on a hospital TV system, please check with your District regarding District specific content and placement processes.

- For additional helpful hints, review the “Death by PowerPoint” article noted in the reference list.38
Visual Appearance

- Do not use all upper case letters.
- Limit the use of italics.
- Do not use different type faces on the same page.
- Use a font between 11 - 14 point sizes in the body text.
- Use Adobe Georgia or Arial font.
- Use a justified left margin and a ragged right margin.
- Use generous amounts of white space (areas without print).
- Use wide margins and borders.
- Use bullets.
- Skip at least one line between paragraphs and sections.
- Ensure copyright approval is secured for all illustrations.
- Use one of the standard covers.

General

- Include the name of the developer with credentials and unit or department (on the back cover, if in pamphlet format).
- The year that the resource is developed / revised is to be placed on the front.
- Only the developer can revise / replace a resource. Anyone who identifies that a resource requires updating is to contact the developer.
- Pamphlet size will be 8½ x 11 inch or 8½ x 5½ inch or 8½ x 11 tri-fold.
- Page numbers are to be included if it is more than one folded page.
General, continued

- Include the CCNS and District Health Authority logo on each pamphlet.

- Place a Print Shop order number on each pamphlet and ensure that this is entered into the catalogue.
  - If this version replaces another resource, alert the Print Shop so they discontinue printing of the previous version.

- Include the hospital smoking and scent policy on the pamphlet.

- Place this disclaimer on the back cover of each resource:

  This information is provided for educational purposes only and is not intended to replace medical advice, the instruction of a healthcare provider, or to substitute for medical care. If you have any questions about your health and/or your treatment, please ask your healthcare provider.

- Promote the CCS website and HRM Library Services on the back cover of each pamphlet with the following statements:

  Looking for more information?
  Visit [www.cancer.ca](http://www.cancer.ca) or call 1-888-939-3333
  Contact your local public library for books, videos and online health information.
  For a list of public libraries in Nova Scotia go to [www.library.ns.ca](http://www.library.ns.ca)
Patient Education Approaches

Patient education plays a major role in empowering patients and families with cancer. Educating patients about their disease, treatment, side effect management and quality of life can reduce patient anxiety, enhance coping mechanisms, reduce decisional conflicts, promote patient autonomy and improve the experience for patients and families. Patients who understand their disease and treatment have greater compliance with therapy, which translates into better outcomes.³

Education is an ongoing process and should be provided in a variety of ways to meet the individual needs of patients. Formal or informal approaches using individual or group teaching supported by various teaching strategies such as print material, computer based education programs, interactive multimedia technology, audiovisual programs and support groups are widely used. Regardless of the approach used, health professionals must continuously reinforce learning throughout the provision of care.⁴³⁴¹⁴²

Patient Education resources are effective only when used as a part of an overall patient education strategy. Simply handing your patient a pamphlet or a DVD or directing them to an online resource is not enough to promote understanding or behaviour change.

Patient Education resources should be used to facilitate discussion, not replace it. Review the material with the patient. Make note of important information by circling or highlighting it, and discuss how it relates to the patient’s care. Consider personalizing the materials by adding the patient’s name, medications, or specific care instructions.

Researchers estimate that 40-80% of the medical information patients receive is forgotten immediately and nearly half of the information retained is incorrect.⁴⁰⁴¹

* For further information about comprehensive approaches to patient education, refer to Education Standards for Adults Affected by Cancer and Patient Education Fundamentals © Crown copyright, Province of Nova Scotia, 2011, available via Cancer Care Nova Scotia or visit http://www.nchealthliteracy.org or access the American Medical Association Health literacy and patient safety. Manual for clinicians.
Patient Education Approaches, continued

One of the easiest ways to close the communication gap between the health care professional and the patient is to use the “teach-back” method, also known as the “show-me” method. Teach-back enables you to confirm that you have explained to the patient what they need to know in a manner that the patient understands. Patient understanding is confirmed when they explain it back to you. 42, 43, 45

**Figure 2 Teach Back Method** 42

![Teach Back Method Diagram]

Step 1: Using plain language, explain the concept/instruction or demonstrate the process to the patient.

Step 2: Ask the patient to describe the concept/instruction or demonstrate the process.

Step 3: Identify and correct misunderstandings of or incorrect procedures by the patient.

Step 4: Ask the patient to explain the concept/instruction again or demonstrate the process to ensure the above-noted misunderstandings are now corrected.

Step 5: Repeat Steps 4 and 5 until you are convinced the patient understands the concept or has the ability to perform the procedure accurately and safely.
Patient Education Approaches, continued

When using "teach-back," health professionals ask patients to state in their own words key concepts, decisions, or instructions just discussed:

- You could begin with statements such as, "I want to make sure I explained this clearly. When you go home today, what will you tell your [friend or family member] about [key point just discussed]?" or “Please explain to me how and when you will take your medications, so I can be sure I explained everything correctly.” Or “What is your understanding of your treatment plan?”

- If patients cannot restate/demonstrate the instructions correctly, then you explain it again by drawing pictures or using simpler words.

- Then the teach-back method is used again and repeated until you confirm that the key message is correctly understood. If you know you explained this well but after two or three tries the patient still does not "get it," then look for other explanations (beyond your teaching) about why the message was not understood. 42,43,45

When summarizing and restating key aspects of what patients are sharing, you might say, "I just want to make sure that I heard you correctly. When you said [key point], I understood that to mean [x]…. Is that correct? Is there something I missed?" By doing this, you not only confirm (or not) that messages are correctly understood but also demonstrate your commitment to helping patients feel that they've been heard. In addition, this line of questioning models the teach-back technique so that patients are not surprised when you ask them to repeat back what you just said. 42,43,45

When using the teach-back technique, health professionals take responsibility for adequate teaching. If patients cannot explain or demonstrate what they should do, the health professional must assume that they did not provide an adequate explanation or understandable instructions and that they must try another approach to ensure that patients learn what they need to know. 42,43,45
Patient Education Approaches, continued

The “teach-back” technique is intended to replace the more common practice of simply asking a patient, “Do you understand what I have told you?” More often than not patients will answer “yes” to this question, even when they understand nothing. 42,43,45

The same is true for another question commonly asked by health professionals “Do you have any questions?” When asked this question, patients are likely to respond “no” even when they have questions or don’t know where to start with their numerous questions. A more appropriate approach is offer a statement like – “Most of my patients usually have questions about [key point just discussed]” and follow by offering the answers to the most frequently asked questions. 42, 43, 45

Research indicates that the teach-back technique is effective, not just for improving patients’ understanding, but also for improving outcomes. For example, patients with diabetes whose physicians assess patient’s comprehension and recall with the teach-back technique have significantly better diabetes control than patients whose physicians do not use the technique. 42,43,45

Ordering Print Resources

- Use the pamphlet number noted in the CDHA catalogue, do not use the number on the pamphlet itself – if you do, you risk ordering outdated resources.

- Use pamphlets printed from a master in the Print Shop. Do not photocopy.

- Order limited numbers from the Print Shop. An order can be as small as only 15 copies. This may help to prevent waste as materials are updated regularly.

- When a particular topic is rarely addressed, print the relevant resources from the District, CCNS or another recommended website.
Displaying Resources

- Assign one staff person to order the pamphlets and maintain the pamphlet racks.
  - This person should regularly scan the resources; discarding outdated materials and replacing them with the most current.

- Placing patient information resources in high-traffic areas gives patients and families ready access to information that is relevant to them.

- Display resources in an organized manner so it is easy for the patient to find the information they need.
Appendix I  SMOG Readability Formula

Patients and their families must be able to read, understand and act upon our instructions. We must remember that many individuals read at least two grade levels below their last school grade completed.\textsuperscript{17}

\textit{Target the reading level for grade six or below.}

A readability formula enables us to take a rough measure of the reading level of material. But, it is not a substitute for common sense, as there are other considerations when preparing material. The fact that an item is written at a low reading level does not mean that it is clear and well written.

\textbf{SMOG for Text Containing More Than 30 Sentences:}

1. Choose 10 consecutive sentences from near the beginning, middle and end of your text. Skip titles and headings.
   a. If a sentence contains a colon, avoid using that sentence in your count, OR count it as two sentences.

2. In the sample of 30 sentences, count all words that have 3 or more syllables
   a. Verbs ending in "ed" or "es" that give the word a third syllable are not counted.
   b. Include repetitions of the same word, no matter how often it is used.
   c. Hyphenated words are considered one word.
   d. Numbers should be pronounced to determine the number of syllables.
   e. Abbreviations should be read as unabbreviated to determine the number of syllables.

3. Find the nearest square root of this total.

4. Add 3 to the square root to find the reading level.

\textbf{SMOG Readability Calculator}

The SMOG Calculator assesses an entire text, not just a sample. To use the Calculator, go to: \url{http://www.harrymclaughlin.com/SMOG.htm}. 
In Microsoft Office Word 2003 and earlier, go to Tools Options Spelling & Grammar; in Word 2007, go to Office button Word Options Proofing. In either case, check the box for "Show readability statistics".

When you check spelling manually by pressing F7, after the check is complete you'll see a dialog box with statistics, one of which is the Flesch-Kincaid Grade Level.

The Flesch-Kincaid tool rates text on a U.S. school grade level. For example, a score of 8.0 means that a person who has completed grade eight can understand the document.

The formula for the Flesch-Kincaid Grade Level score is:

\[
(.39 \times \text{ASL}) + (11.8 \times \text{ASW}) - 15.59
\]

\[
\text{ASL} = \quad \text{average sentence length (the number of words divided by the number of sentences)}.
\]

\[
\text{ASW} = \quad \text{average number of syllables per word (the number of syllables divided by the number of words)}.
\]
<table>
<thead>
<tr>
<th>Complex</th>
<th>Simple</th>
<th>Complex</th>
<th>Simple</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdomen</td>
<td>Stomach area</td>
<td>Decrease</td>
<td>Lessen, reduce</td>
</tr>
<tr>
<td>Ability</td>
<td>Skill</td>
<td>Demonstrate</td>
<td>Show, explain</td>
</tr>
<tr>
<td>Accompany</td>
<td>Go with</td>
<td>Detect</td>
<td>Find, notice</td>
</tr>
<tr>
<td>Accomplish</td>
<td>Do, carry out</td>
<td>Determine</td>
<td>Find out</td>
</tr>
<tr>
<td>Acetaminophen</td>
<td>e.g., Tylenol®/Tempra®</td>
<td>Difficulty</td>
<td>Problem, trouble</td>
</tr>
<tr>
<td>Achilles tendon</td>
<td>Heel cord</td>
<td>Discolouration</td>
<td>Change in colour</td>
</tr>
<tr>
<td>Acidosis</td>
<td>Too much blood acid</td>
<td>Discontinue</td>
<td>Stop</td>
</tr>
<tr>
<td>Acne</td>
<td>Red pimples</td>
<td>Discover</td>
<td>Learn, find out, see</td>
</tr>
<tr>
<td>Acquire</td>
<td>Gain, get</td>
<td>Discuss</td>
<td>Talk about, speak with</td>
</tr>
<tr>
<td>Adequate</td>
<td>Enough</td>
<td>Dressing</td>
<td>Bandage, covering</td>
</tr>
<tr>
<td>Administer</td>
<td>Give</td>
<td>Due to the fact that</td>
<td>Because</td>
</tr>
<tr>
<td>Advise</td>
<td>Tell, recommend</td>
<td>Effect</td>
<td>Result, bring about</td>
</tr>
<tr>
<td>Aggravate</td>
<td>Make worse, worsen</td>
<td>Elevate</td>
<td>Raise, lift (up)</td>
</tr>
<tr>
<td>Alternative</td>
<td>Choice</td>
<td>Eliminate</td>
<td>Reduce, remove, cut out</td>
</tr>
<tr>
<td>Ambulate</td>
<td>Walk</td>
<td>Endeavor</td>
<td>Try, attempt</td>
</tr>
<tr>
<td>Analgesic</td>
<td>Pain reliever</td>
<td>Ensure</td>
<td>Make sure</td>
</tr>
<tr>
<td>Annually</td>
<td>Yearly</td>
<td>Epidermis</td>
<td>Skin</td>
</tr>
<tr>
<td>Anticipate</td>
<td>Expect</td>
<td>Excessive</td>
<td>Too much</td>
</tr>
<tr>
<td>Appears</td>
<td>Seems</td>
<td>Experience</td>
<td>Feel, have</td>
</tr>
<tr>
<td>Complex</td>
<td>Simple</td>
<td>Complex</td>
<td>Simple</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------</td>
<td>--------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Apply</td>
<td>Put on, use</td>
<td>Facilitate</td>
<td>Help, aid, assist</td>
</tr>
<tr>
<td>Approximately</td>
<td>About</td>
<td>Failed to</td>
<td>Did not</td>
</tr>
<tr>
<td>Ascertain</td>
<td>Find out</td>
<td>Frequently</td>
<td>Often</td>
</tr>
<tr>
<td>Assist</td>
<td>Help</td>
<td>Fundamental</td>
<td>Basic, important</td>
</tr>
<tr>
<td>At the present time</td>
<td>Now</td>
<td>Furthermore</td>
<td>Also</td>
</tr>
<tr>
<td>Attempt</td>
<td>Try</td>
<td>Hazardous</td>
<td>Unsafe, harmful, risky</td>
</tr>
<tr>
<td>Available</td>
<td>Ready</td>
<td>Hematoma</td>
<td>Bruise</td>
</tr>
<tr>
<td>Bacteria</td>
<td>Germs</td>
<td>However</td>
<td>But, yet, still</td>
</tr>
<tr>
<td>Benefit</td>
<td>Help</td>
<td>Ibuprofen</td>
<td>e.g. Advil®, Motrin®</td>
</tr>
<tr>
<td>Cessation</td>
<td>Stop, pause</td>
<td>Identical</td>
<td>Same, alike, equal</td>
</tr>
<tr>
<td>Choose</td>
<td>Pick</td>
<td>Indicate</td>
<td>Show</td>
</tr>
<tr>
<td>Close proximity</td>
<td>Near</td>
<td>Impair</td>
<td>Harm, make worse</td>
</tr>
<tr>
<td>Commence</td>
<td>Begin</td>
<td>Implement</td>
<td>Carry out</td>
</tr>
<tr>
<td>Complete</td>
<td>Finish, fill out</td>
<td>In addition</td>
<td>Also</td>
</tr>
<tr>
<td>Comply</td>
<td>Do, follow</td>
<td>In an effort to</td>
<td>To</td>
</tr>
<tr>
<td>Components</td>
<td>Parts</td>
<td>In the event that</td>
<td>If</td>
</tr>
<tr>
<td>Conclude</td>
<td>End, finish</td>
<td>In the near future</td>
<td>Soon</td>
</tr>
<tr>
<td>Consult</td>
<td>Ask</td>
<td>Inadvisable</td>
<td>Unwise</td>
</tr>
<tr>
<td>Contraceptive</td>
<td>Birth control</td>
<td>Incision</td>
<td>Cut, opening</td>
</tr>
<tr>
<td>Contact</td>
<td>Call</td>
<td>Incorrect</td>
<td>Wrong</td>
</tr>
<tr>
<td>Complex</td>
<td>Simple</td>
<td>Complex</td>
<td>Simple</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------</td>
<td>--------------</td>
<td>----------</td>
</tr>
<tr>
<td>Contains</td>
<td>Has</td>
<td>Indicate</td>
<td>Show</td>
</tr>
<tr>
<td>Contusion</td>
<td>Bruise</td>
<td>Indication</td>
<td>Sign</td>
</tr>
<tr>
<td>Inform</td>
<td>Tell</td>
<td>Presently</td>
<td>Now</td>
</tr>
<tr>
<td>Ingest</td>
<td>Eat</td>
<td>Provide</td>
<td>Give, offer</td>
</tr>
<tr>
<td>Initial</td>
<td>First</td>
<td>Provided that</td>
<td>If</td>
</tr>
<tr>
<td>Interrupt</td>
<td>Stop</td>
<td>Purchase</td>
<td>Buy</td>
</tr>
<tr>
<td>Injection</td>
<td>Shot, needle</td>
<td>Receive</td>
<td>Get</td>
</tr>
<tr>
<td>Insufficient</td>
<td>Not enough</td>
<td>Recuperate</td>
<td>Get better, get well</td>
</tr>
<tr>
<td>Intention</td>
<td>Aim</td>
<td>Regarding</td>
<td>About</td>
</tr>
<tr>
<td>Laceration</td>
<td>Cut, tear</td>
<td>Rehabilitate</td>
<td>Recover, restore</td>
</tr>
<tr>
<td>Locate</td>
<td>Find</td>
<td>Relating to</td>
<td>About, on</td>
</tr>
<tr>
<td>Location</td>
<td>Place</td>
<td>Remainder</td>
<td>Rest of</td>
</tr>
<tr>
<td>Maintain</td>
<td>Keep, support</td>
<td>Remove</td>
<td>Take out</td>
</tr>
<tr>
<td>Medication</td>
<td>Medicine, pills</td>
<td>Request</td>
<td>Ask</td>
</tr>
<tr>
<td>Minimal</td>
<td>Least</td>
<td>Require</td>
<td>Need</td>
</tr>
<tr>
<td>Modify</td>
<td>Change, revise, adjust</td>
<td>Requires</td>
<td>Asks, calls for, needs</td>
</tr>
<tr>
<td>Monitor</td>
<td>Check, watch</td>
<td>Retain</td>
<td>Keep</td>
</tr>
<tr>
<td>Negative</td>
<td>No, harmful</td>
<td>Reveal</td>
<td>Show</td>
</tr>
<tr>
<td>Notify</td>
<td>Tell</td>
<td>Review</td>
<td>Check, go over</td>
</tr>
<tr>
<td>Observe</td>
<td>Watch, see, note</td>
<td>Ruptured</td>
<td>Burst</td>
</tr>
<tr>
<td>Obtain</td>
<td>Get, find</td>
<td>Sensation</td>
<td>Feeling</td>
</tr>
<tr>
<td>Optimum</td>
<td>Best</td>
<td>Similar</td>
<td>Like</td>
</tr>
<tr>
<td>Complex</td>
<td>Simple</td>
<td>Complex</td>
<td>Simple</td>
</tr>
<tr>
<td>---------------</td>
<td>------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Option</td>
<td>Choice</td>
<td>Sufficient</td>
<td>Enough</td>
</tr>
<tr>
<td>Permit</td>
<td>Allow, let</td>
<td>Sutures</td>
<td>Stitches</td>
</tr>
<tr>
<td>Persuade</td>
<td>Convince</td>
<td>Therapy</td>
<td>Treatment</td>
</tr>
<tr>
<td>Physician</td>
<td>Doctor</td>
<td>Torn ligament</td>
<td>Sprain</td>
</tr>
<tr>
<td>Place</td>
<td>Put, rest, lay</td>
<td>Unnecessary</td>
<td>Needless, not needed</td>
</tr>
<tr>
<td>Prior (to)</td>
<td>Before, earlier</td>
<td>Utilize</td>
<td>Use</td>
</tr>
<tr>
<td>Present</td>
<td>Give</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Adapted, with permission, from Guidelines for Developing Printed Health Material, Calgary Health Region, 2005.*
# Appendix IV  Check List for Developer

<table>
<thead>
<tr>
<th>Clinical Assessment</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information is current, accurate and evidence based.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information is aligned with clinical practice guidelines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information is sufficient for purpose.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational Assessment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintains interest and attention.</td>
<td></td>
</tr>
<tr>
<td>Organization of information is logical.</td>
<td></td>
</tr>
<tr>
<td>Technical terms or acronyms are identified.</td>
<td></td>
</tr>
<tr>
<td>Reading level is grade 6 or below. If not, note the grade level</td>
<td></td>
</tr>
<tr>
<td>Focuses on “need to know” information</td>
<td></td>
</tr>
<tr>
<td>Key messages are clear</td>
<td></td>
</tr>
<tr>
<td>Adheres to the <em>Cancer Care Nova Scotia’s Education Standards for Adults Affected by Cancer</em> (available via <a href="http://www.cancercare.ns.ca">www.cancercare.ns.ca</a>).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Technical Assessment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Adheres to the <em>Cancer Care Nova Scotia’s Education Standards for Adults Affected by Cancer</em> (available via <a href="http://www.cancercare.ns.ca">www.cancercare.ns.ca</a>).</td>
<td></td>
</tr>
<tr>
<td>Headings are used.</td>
<td></td>
</tr>
<tr>
<td>Illustrations are simple and easy to understand.</td>
<td></td>
</tr>
<tr>
<td>Illustrations promote the text.</td>
<td></td>
</tr>
<tr>
<td>Illustrations are copyright free or permission has been granted</td>
<td></td>
</tr>
<tr>
<td>Main points stand out clearly.</td>
<td></td>
</tr>
<tr>
<td>Sentences are 10 words or less.</td>
<td></td>
</tr>
<tr>
<td>Paragraphs are short and simple (4-5 sentences).</td>
<td></td>
</tr>
<tr>
<td>Information is listed when possible.</td>
<td></td>
</tr>
<tr>
<td><strong>Technical Assessment</strong></td>
<td><strong>Yes</strong></td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Text font is 11 point or greater.</td>
<td></td>
</tr>
<tr>
<td>All upper case letters are not used.</td>
<td></td>
</tr>
<tr>
<td>White space used to minimize concentration of text.</td>
<td></td>
</tr>
<tr>
<td>Dark type is used on white or light background.</td>
<td></td>
</tr>
<tr>
<td>Lists are limited to 4-6 items</td>
<td></td>
</tr>
<tr>
<td>If video/powerpoint, visual and sound technical quality is satisfactory</td>
<td></td>
</tr>
<tr>
<td>If video/powerpoint, program is less than 10 minutes</td>
<td></td>
</tr>
<tr>
<td>If video/powerpoint, program pace is acceptable</td>
<td></td>
</tr>
<tr>
<td>Has the bibliography been developed?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Affective Assessment</strong></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall appearance is appealing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Written in a friendly, conversational tone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Content/presentation does not create fear or stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stereotyping is avoided.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender free language is used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commercial product promotion is not used.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural values/beliefs are respected</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Various cultures are represented</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Reviewers</strong></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the draft evaluated by patients?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were the issues raised by patients incorporated into the next draft of the document?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the draft evaluated by content experts?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were the issues raised by content experts incorporated into the next draft of the document?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix V  Field Test Evaluation of a Patient Education Resource

Note to developer: please contact CCNS for an electronic version of this evaluation form which you can tailor to the nature of your resource and the type of evaluation you are conducting (eg. 1:1, group, self directed)

Title: Note to developer: insert title here ____________________________

1. Please review the resource and circle any words or ideas that are hard to understand.

If this is a video or web based resource, write the words or ideas that are hard to understand on a separate sheet of paper.

2. Refer to the resource and tell us how easy it is to find this information:
   (Note to developer: remove lines and insert topic headings, add or delete space as needed)

<table>
<thead>
<tr>
<th></th>
<th>Easy to find</th>
<th>Hard to Find</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

3. Refer to the resource and tell us how what you would do in each situation:
   (Note to developer: remove lines and insert situations (eg fever, pain), add or delete space as needed)

<table>
<thead>
<tr>
<th>Situation</th>
<th>What I would do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

36
4. How easy was it to read the resource?  
   Easy  1 2 3 4 5  
   Hard

5. How easy is it to follow any instructions in the resource?  
   Easy  1 2 3 4 5  
   Hard

6. Was there any unnecessary information included?  Yes □ No □  
   Please list the information you believe is unnecessary:  
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

7. Do you have any questions that we did not answer in the resource?  
   ___________________________________________________________________
   ___________________________________________________________________

8. Is there other information that you think is important that we have not included?  
   ___________________________________________________________________
   ___________________________________________________________________

9. Would you make any changes to how the information is organized?  
   ___________________________________________________________________
   ___________________________________________________________________

10. How helpful are the pictures in the resource?  
    Very Helpful  1 2 3  
    Not Helpful  4 5
11. What other pictures would be helpful?

____________________________________________________________________

____________________________________________________________________

12. How do you think you would use this resource: (check all that apply)

☐ Read it once and throw it away
☐ Take it home to read again
☐ Share it with my family
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____________________________________________________________________

13. How would you change the resource to make it better?

____________________________________________________________________

____________________________________________________________________

14. Please give the resource your overall rating:

       Poor 1  2  3  Excellent 4  5

Thank you for helping us to improve this patient education resource.


