Cancer 101 Adaptation Guidelines

Note: *The Cancer 101 Adaptation Guidelines were originally developed in March 2008 and were updated in October 2011.*

Purpose: The purpose of these guidelines is two-fold: 1) to provide background information and guidance on the future adaptation of the *Cancer 101* curriculum for cultural and/or linguistic appropriateness, and 2) to create uniformity of practice in the adaptation process.

Key points to consider when adapting the *Cancer 101* curriculum[1]:

1. Determine the needs of the target audience regarding communicating health information about cancer contained within the *Cancer 101* curriculum. Needs assessment should include primary (i.e. in-depth interviews with community leaders, focus groups, surveys, direct observation) and secondary (health status data, literature search) data collection.

2. Determine the extent of modifications necessary to address these needs (i.e. language, culture, literacy, age, social context, etc.).

3. Engage members of the target audience in the adaptation process to ensure the adaptation's appropriateness to the audience.

4. Employ measures to ensure that the adapted materials maintain the accuracy of the original *Cancer 101* content.

5. Pilot test the adaptation with representatives from the target audience to ensure adaptation is culturally relevant and meets intended program goals and objectives.

6. Make modifications based on feedback from pilot testing.

7. Evaluate the effectiveness of the adaptation.

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[1] *Based on NCI's Research-tested Intervention Programs (RTIPS)*

STEP ONE: Define the rationale for adapting the materials. Rationale for adaptation of the materials may include one or more of the following considerations listed below. (See last two pages of Section 1 for additional resources.)

1. **Language[2]:** Use of materials with non-English or limited English proficiency populations requires translation of content. Key considerations for translation include identification of qualified translator, definition of translator role, and verification of translation.

   Suggested guidelines for translation may include the following:
   - **Key characteristics of an appropriate translator:**
     - Proficient in reading in the source language
     - Native speaker of the target language
     - Demonstrated strong writing skills in the target language
     - Work experience in the target language in healthcare education settings

   - **Translator should be asked to do the following:**
     - Identify cultural differences
     - Find equivalent word and phrases
     - Ensure essential meaning does not change

   - **Method(s) used to verify the translation:**
     - Multiple forward translations
     - Back-translation
     - Translation review by bilingual experts
     - Pilot test

2. **Culture:** Information within modules can be tailored to address the cultural context of the target audience. This information may include knowledge, attitudes, beliefs, customs, and practices surrounding health, illness, and disease (cancer).

3. **Literacy:** Most of the *Cancer 101* content is written at about an 8th grade reading level. Therefore, content may require modification for those individuals with reading levels that fall below this level.

   In addition to general literacy, it will be important to assess the "health" literacy of the target audience. Health literacy refers to the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions[3].

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[2] Maxwell, B. (1996) "Translation and Cultural Adaptation of the Survey Instruments" in M.O. Martin and D.L. Kelly (eds.), *Third International Mathematics and Science Study (TIMSS) Technical Report, Volume I: Design and Development.* Chestnut Hill, MA: Boston College.
[3] Institute of Medicine, 2004.

Lastly, patterns of communication vary from one population to another. Assessment of these patterns and how to address them must be included in the adaptation process.

4. **Age and Gender:** What is the generational mix of the target audience? For example, content may need to be modified to adjust for learning style (e.g. youth vs. elder). Is it a single sex or mixed group? If so, consider any issues or concerns related to modesty and comfort level with the topics to be discussed.

5. **Social context:** It is important to integrate relevant information about factors related to the physical environment (community setting), geographical location, and available health resources for a particular community.

6. **Type and length of training:** *Cancer 101* content can tailored based on the goals and objectives of a particular training providing "general" information about cancer basics or "site specific" information. Learning modules are designed to be presented in 30- to 40- minute education sessions or the entire curriculum can be presented as a one or two-day workshop on cancer education.

STEP TWO: Identify content that requires modification (modules, PowerPoints, pre/post self assessment, etc.) and define approach that will be utilized to adapt content. Content and format may be adapted to reflect issues, concerns, and realities of target audience.

1. **Module One – Cancer Among American Indians and Alaska Natives:** This module can be tailored to reflect the rationale for why cancer has become a health concern for the target population. Information pertaining to the history of cancer in the population along with a brief description of factors that may have impacted cancer incidence rates expands the understanding of the problem. Representation of data should be population specific (if known) along with a listing and discussion of any relevant data issues and concerns (e.g. racial misclassification, undercounting, etc.). Consider tailoring the representation of data to reflect any issues related to numeracy, the ability of your target audience to reason with numbers and other mathematical concepts.

2. **Module Two – What is Cancer?:** Describing the disease cancer can be particularly challenging due to cultural variations surrounding language and lack of existing words for this disease among populations. Consider tailoring information within this module to reflect the *meaning* of the word "cancer" to the target population. Including information about relevant cultural beliefs and perceptions may be helpful in expanding the definition/terminology about cancer.

3. **Module Three – Cancer Risk Factors and Risk Reduction:** Population specific risk factor data varies or may be unknown. Consider addition of relevant information about how cancer risk has evolved over time for the target population. For example,

how have changes in lifestyle and the environment influenced cancer risk? Are there certain forms of cancer that have a disproportionate effect on the target population?

4. **Module 4 – Role of Genes in Cancer:** Consider adding a story about someone from the target population/community with a strong family history of breast or colorectal cancer. For example, develop a scenario that describes someone's experience learning about their family history and exploring the option of genetic testing to learn more about their own risk.

5. **Module 5 - Cancer Screening and Early Detection:** Consider adding relevant information about barriers to participating in early detection and screening practices specific to the target population. For example, what are the health seeking behaviors or illness belief systems that influence timely participation in cancer screening?

6. **Module 6 – Cancer Diagnosis and Staging:** Consider adding information that provides a description of the diagnosis and staging process that someone from the target population/community would be subject to based on healthcare facility access, etc. For example, develop a scenario that is cancer site specific and describes someone's experience from first sign/symptom through diagnosis and staging process.

7. **Module 7 – Basics of Cancer Treatment:** In addition to the various conventional (Western, mainstream) methods used to treat cancer described within this module, consider adding descriptions, as appropriate, of any alternative and/or traditional pathways for healing utilized by the target population. Because beliefs surrounding illness, wellness, and healing vary greatly among populations, alternative and/or complementary forms of medicine may be considered as part of getting well again.

8. **Module 8 – Biospecimens and Biobanking:** Discussing biospecimens and biobanking can be particularly challenging in some communities due to past cases such as Henrietta Lacks and the Havasupai Indian case. Consider tailoring information within this module to reflect history (or lack thereof) around biospecimens within the target population as well as potential benefits in advancing cancer detection and treatment. Including information about relevant cultural beliefs and perceptions may be helpful in generating discussion around this topic.

9. **Module 9 – Chronic Conditions and Cancer:** Population specific data around chronic conditions may vary or may be unknown. Consider addition of relevant information about how chronic conditions and cancer have evolved over time for the target population. For example, how have changes in lifestyle and the environment influenced chronic condition risk? Are there certain forms of chronic conditions that have a disproportionate effect on the target population?

10. **Module 10 – Support for Patients and Caregivers:** Cultural variations may also have an influence of the recovery or healing pathway following cancer treatment. Add information, as appropriate, that describes cultural considerations in addressing the psychological, emotional, spiritual impact and healing related to cancer.

STEP THREE: Employ methods to ensure the adaptation is relevant to the target population and the content is accurate.

1. **Determine the type of evaluation needed according to the type of objectives (process, educational/learning, behavioral and environmental, and program). Although it may be time-intensive to develop four types of objectives, it is important for getting a complete picture of what is happening and why. Much of the literature recommends developing objectives that are specific, measurable, achievable, realistic, and time-framed (SMART)[4].**

   a. **Process Objectives:** The process objectives are what you do to accomplish all other levels of objectives. Think of them as inputs and process components needed to carry out the program. For a very comprehensive process evaluation, you may choose to create specific objectives that will track all possible components, which could include:
      - Program resources (materials, funds, space)
      - Type and appropriateness of activities
      - Target audience exposure and attendance

   b. **Educational/Learning Objectives:** The educational/learning objectives follow a hierarchy. If the intent is for the target audience to adopt and maintain a behavior, participants must 1) be aware of the need or value, 2) expand their knowledge of available and appropriate resources, 3) adopt and maintain beliefs in the effectiveness of these resources and their own ability to use them, and 4) possess the actual skills to obtain information efficiently.
      - The results may be change in awareness, knowledge, attitudes, beliefs, skills, and practices.
      - Evaluation of educational/learning objectives helps determine if the desired change in awareness, knowledge, attitudes, beliefs, skills, and practices has occurred.

   c. **Behavioral and Environmental Objectives:** The behavioral and environmental objectives
      - The results from behavioral objectives may be to seek changes in behavior that resolve health information needs - such as becoming information seekers.

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[4] Burroughs CM, *Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach.* National Network of Libraries of Medicine Pacific Northwest Region, 2000.

- Environmental objectives can be loosely defined as those that remove physical and social barriers to enacting behavioral changes.

  d. **Program Objectives:** Program objectives are the ultimate objectives of a program, expressed as the outcomes of individual and community change in using or providing health information.

2. **Pilot Test**
   - You may want to do a pilot test in order to evaluate the effect of your program. Do a practice run using a small group that is similar to your target audience[5]. This allows you to[6]:
     1. Assess comprehensibility (does the target audience understand the content?)
     2. Identify strong and weak points (what parts of the adaptation are and aren't doing their job?)
     3. Determine personal relevance (does the target audience identify with the adaptation?)
     4. Gauge confusing, sensitive, or controversial elements (do particular topics make the target audience uncomfortable?)
        - Provides an opportunity to see if there are any major problems.
        - Gives an idea of possible evaluation results.
        - Can use pilot test results/feedback to fine-tune the adaptation.

3. **Evaluation: The evaluation process should be sensitive to the history of research-related issues and concerns with diverse populations. For example, members of diverse communities may be skeptical or mistrustful of the evaluation process because their experience has been that scientists enter their communities and collect data, but frequently fail to share their findings or take visible and beneficial action.**

   a. It is important to build confidence in the purpose and benefits of evaluation results for the community[7]:
      - Try to involve respected community members and leaders in evaluation planning (e.g. to review a questionnaire and data collection strategy).
      - Ask their cooperation in helping you to recruit participation.
      - Directly involve members of the community in data collection efforts.
      - Be sure to share your findings, if possible as early as the draft state, for their review and comment.

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[5] Using What Works: Adapting Evidence-Based Programs to Fit Your Needs. U.S. Department of Health & Human Services, 2006.
[6] Making Health Communications Works, U.S. Department of Health & Human Services, 2004.
[7] Burroughs CM, *Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach.* National Network of Libraries of Medicine Pacific Northwest Region, 2000.

b. When trying to measure effectiveness to determine if the objectives were achieved, you may consider using one or more of the following methods. Keep in mind that each one has advantages and disadvantages[8,9,10]:

- Questionnaires (pre-test/assessment, post test/assessment, surveys, oral test)
- Interviews
- Observation (skills test, vignettes)
- Records (activity logs, attendance sheets, diaries, medical/social service records)
- Focus groups (meetings, talking circles, etc.)
- Case study

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[8] Using What Works: Adapting Evidence-Based Programs to Fit Your Needs. U.S. Department of Health & Human Services, 2006.

[9] Burroughs CM. *Measuring the Difference: Guide to Planning and Evaluating Health Information Outreach.* National Network of Libraries of Medicine Pacific Northwest Region, 2000.

[10] Mantell JE, DiVittis AT, Auerbach MI. *Evaluating HIV Prevention Interventions.* Plennum Press, New York, NY, 1997.

ADDITIONAL RESOURCES *(Disclaimer: Links to non-Federal organizations are provided solely as a resource. These links do not constitute an endorsement of these organizations or their programs by the NCI or the Federal Government, and none should be inferred. The NCI is not responsible for the content of the individual organization Web pages found at these links.)*

1. **Culture**
   a. **Cancer Disparities**, *National Cancer Institute* http://www.cancer.gov/health-disparities
   b. **Cancer Fact Sheets**, *Intercultural Cancer Council* http://iccnetwork.org/cancerfacts/
   c. **Cultural Competence in Cancer Care: A Health Professional's Passport**, *Intercultural Cancer Council* http://iccnetwork.org/pocketguide/
   d. **Curricula Enhancement Module Series**, *National Center for Cultural Competence* www.nccccurricula.info
   e. **Developing Culturally and Linguistically Competent Health Education Materials: A Guide for the State of New Jersey**, *Healthy Systems Research* http://www.state.nj.us/health/fhs/asthma/documents/pacnj_guide.pdf
   f. **Diversity Rx**, *Resources for Cross Cultural Health Care and Drexel University School of Public Health's Center for Healthy Equality* http://www.diversityrx.org/
   g. **Ethnomed**, *University of Washington – Harborview Medical Center* http://ethnomed.org/
   h. **Practicing Cross-Cultural Communication**, *New York New Jersey Public Health Training Center*, http://www.nynj-phtc.org/pccc.cfm
   i. **The Community Toolbox**, *Work Group for Community Health & Development at the University of Kansas* http://ctb.ku.edu/
   j. **The Provider's Guide to Quality & Culture**, *Management Sciences for Health* http://erc.msh.org/mainpage.cfm?file=1.0.htm&module=provider&language=English

2. **Health Literacy**
   a. **Clear & Simple**, *National Cancer Institute* http://www.cancer.gov/cancertopics/cancerlibrary/clear-and-simple
   b. **Clear Health Communication Initiative**, *Pfizer* http://www.pfizerhealthliteracy.com/
   c. **Guide to Health Education Materials for Adults with Limited English Literacy Skills**, *Authored by Julie McKinney & Sabrina Kurtz-Rossi* http://lincs.worlded.org/docs/culture/index.html

   d. **Healthy Literacy Improvement**, *U.S. Department of Health & Human Services – Office of Disease Prevention & Health Promotion* http://www.health.gov/communication/literacy/default.htm

e. **Health Literacy Style Manual,** *Covering Kids & Families*
      http://coveringkidsandfamilies.org/resources/docs/stylemanual.pdf
   f. **Teaching Patients with Low Literacy Skills, Second Edition**
      Authored by: Cecelia C. Doak, Leonard G. Doak, & Jane H. Root
      http://www.hsph.harvard.edu/healthliteracy/resources/doak-book/

3. **Materials/Curriculum Review and Analysis**
   a. **Health Education Curriculum Analysis Tool (HECAT)**, *Centers for Disease Control and Prevention*, http://www.cdc.gov/healthyyouth/HECAT/index.htm
   b. **Materials Health Literacy Scoring Sheet (SAM + Comprehensibility)**
      UNM Health Evaluation & Research Office - Jane Cotner

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