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Standardizing Measurement of Social and Behavioral Dimensions of Cancer Prevention and Control to Enhance Outreach and Engagement in NCI-Designated Cancer Centers

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Introduction

In recent years, the NCI has focused on the impact that NCI-Designated Cancer Centers have in reducing the cancer burden in their defined catchment areas (1). NCI requires that Designated Cancer Centers define and describe their catchment areas, highlight community outreach and engagement activities within their catchment areas, and identify how research conducted at Designated Cancer Centers has relevance to local catchment areas (1). However, to conduct outreach and research that truly reduces cancer burden in their defined catchment area, each cancer center must have a mechanism to assess cancer-relevant factors, needs, and opportunities in the populations they serve. While data on cancer incidence, mortality, and clinical trial enrollments at the local level are readily available, data on cancer-relevant social and behavioral factors are less routinely collected in a standardized way. In 2016, NCI funded 15 cancer center support grant supplements to support cancer centers' abilities to better define and describe their catchment areas and needs to enhance cancer prevention and control. As part of this initiative, a working group developed standardized measures to capture demographic, social, knowledge, attitude, and behavioral factors to be included in the surveys fielded by all 15 cancer centers. In this commentary, we describe the process of selecting domains for measurement, the core measures used, and advantages of standardizing how social and behavioral factors are assessed. The survey items were streamlined enough to be incorporated into existing data collection efforts at Designated Cancer Centers and in other cancer care delivery contexts, and results can be used to inform community engagement, outreach activities, and research development.

Tool Development

A measurement working group of 15 researchers (Table 1) was convened to identify core measures to be fielded among all 15 sites that received P30 administrative supplements to define and describe NCI-Designated Cancer Center catchment areas. Working group members identified standard demographics, as well as key domains related to cancer prevention and control, and

through an iterative process narrowed the domains to be measured to: information seeking and information access, cancer screening behaviors, cancer screening knowledge, tobacco use, cancer beliefs, awareness of cancer risk, health care access, and financial barriers to health care. The final domains were determined in an effort to balance needs of core measure brevity and inclusion of key domains of broad relevance to cancer prevention and control. All 15 funded cancer centers included additional site-specific items to capture additional domains of relevance to their defined catchment area and research priorities.

Teams of working group members with expertise in each domain reviewed national surveys to identify and nominate candidate items for inclusion in the core measures to capture each respective domain. All core measures were selected from the Health Information National Trends Survey (HINTS), the Behavioral Risk Factors Surveillance System (BRFSS), the National Health Interview Study (NHIS), or Gallop surveys. The measures working group decided to rely on these national surveys to ensure use of measures with established psychometrics, as well as to permit comparison of catchment area data to national data. As shown in Table 2, the measurement working group identified 21 measures to capture the eight cancer-relevant knowledge, attitude, and behavioral domains. The final core measures also included 13 items assessing sociodemographic characteristics (Table 3).

Table 1. Measures development working group members

Working group member	Affiliation
Susan Rawl	Indiana University, Simon Cancer Center
Elizabeth Gage-Bouchard	Roswell Park Comprehensive Cancer Center
Heather Aker	Ohio State University, Comprehensive Cancer Center
Nadine Barrett	Duke Cancer Center
Kelly Blake	NCI
Rachel Faulkenberry McCloud	Dana-Farber/Harvard Comprehensive Cancer Center
Laura Fish	Duke Cancer Institute
Karen Glanz	Abramson Cancer Center, University of Pennsylvania
Gem Le	UCSF Helen Diller Family Comprehensive Cancer Center
Shannon Lynch	Fox Chase Cancer Center
Tracy Onega	Dartmouth-Hitchcock Norris Cotton Cancer Center
Electra D. Paskett	Ohio State University, Comprehensive Cancer Center
Bruce Rapkin	Albert Einstein Cancer Center
Linda Robertson	University of Pittsburgh Cancer Institute
K. Vish Viswanath	Dana-Farber/Harvard Comprehensive Cancer Center

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Table 2. Knowledge, attitude, and behavioral measures

Domain	Item	Response options		Item source
Information seeking and information access	Have you ever looked for information about health or medical topics from any source?	• Yes • No		HINTS
	The most recent time you looked for information about health or medical topics, where did you go first?	• Books • Brochures, pamphlets, etc. • Cancer organization • Family • Friend/coworker • Doctor or health care provider • Internet • Library • Magazines	• Newspapers • Telephone information number • Complementary, alternative, or unconventional practitioner • Social media site, such as Facebook, Patients Like Me, Caring Bridge • Other _____	HINTS
	Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?	• Completely confident • Very confident • Somewhat confident	• A little confident • Not confident at all	HINTS
Cancer screening behaviors	A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood. Have you ever had this test using a home kit?[a]	• Yes • No		BRFSS
	How long has it been since you had your last blood stool test using a home kit?[a]	• Within the past year (anytime less than 12 months ago) • Within the past 2 years (1 year but less than 2 years ago) • Within the past 3 years (2 years but less than 3 years ago) • Within the past 5 years (3 years but less than 5 years ago) • 5 or more years ago		BRFSS
	Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems. Have you ever had either of these exams?[a]	• Yes • No		BRFSS
	For a SIGMOIDOSCOPY, a flexible tube is inserted into the rectum to look for problems. A COLONOSCOPY is similar, but uses a longer tube, and you are usually given medication through a needle in your arm to make you sleepy and told to have someone else drive you home after the test. Was your MOST RECENT exam a sigmoidoscopy or a colonoscopy?[a]	• Sigmoidoscopy • Colonoscopy		BRFSS
	How long has it been since you had your last sigmoidoscopy or colonoscopy? Mark only one.[a]	• Within the past year (anytime less than 12 months ago) • Within the past 2 years (1 year but less than 2 years ago) • Within the past 3 years (2 years but less than 3 years ago) • Within the past 5 years (3 years but less than 5 years ago) • Within the past 10 years (5 years but less than 10 years ago) • 10 or more years ago		BRFSS
	A mammogram is an X-ray of each breast to look for breast cancer. Have you ever had a mammogram?[b]	• Yes • No		BRFSS
	How long has it been since you had your last mammogram?[b]	• Within the past year (anytime less than 12 months ago) • Within the past 2 years (1 year but less than 2 years ago) • Within the past 3 years (2 years but less than 3 years ago) • Within the past 5 years (3 years but less than 5 years ago) • 5 or more years ago		BRFSS
Cancer screening knowledge	At what age are most women supposed to start having mammograms?	____ Years old		HINTS
	At what age are most people supposed to start doing home blood stool tests, having a sigmoidoscopy or having a colonoscopy?	____ Years old		HINTS
Tobacco use	Have you ever smoked at least 100 cigarettes in your entire life?	• Yes • No		HINTS
	Do you now smoke cigarettes . . .	• Every day • Some days • Not at all		HINTS
Cancer beliefs	How much do you agree or disagree with each of the following statements? 1. It seems like everything causes cancer. 2. There's not much you can do to lower your chances of getting cancer. 3. There are so many different recommendations about preventing cancer, it's hard to know which ones to follow.	• Strongly agree • Somewhat agree • Somewhat disagree • Strongly disagree		HINTS

(Continued on the following page)

Table 2. Knowledge, attitude, and behavioral measures (Cont'd)

Domain	Item	Response options		Item source
Awareness of cancer risk	Compared to other people your age, how likely are you to get cancer in your lifetime?	• Much less likely • Less likely • About the same	• More likely • Much more likely	HINTS
Health care access	Is there a place that you USUALLY go to when you are sick or need advice about your health?	• Yes • There is NO place • There is MORE THAN ONE place		NHIS
	What kind of place do you go most often?	• Clinic or health center • Doctor's office or HMO • Hospital emergency room • Hospital outpatient department • Some other place		NHIS
Financial barriers to health care	In the past 12 months was there a time when you needed to see a doctor, but could not because of cost?	• Yes • No		BRFSS

NOTE: Question wording was provided for both self-administered and interviewer-administered surveys. The question wording was adapted for mode without fundamental or consequential changes to the stem or response options.
[a]This item was only asked if respondent was 50 years old or older.
[b]This item was only asked if respondent was female.

Table 3. Sociodemographic measures

Item	Response options		Item source
What is your age?	_____ Years old (18–130)		HINTS
Are you male or female?	• Male • Female		HINTS
What is your race? One or more categories may be selected. Mark all that apply.	• White • Black or African American • American Indian or Alaska Native • Asian Indian • Chinese • Filipino • Japanese	• Korean • Vietnamese • Other Asian • Native Hawaiian • Guamanian or Chamorro • Samoan • Other Pacific Islander	HINTS
Are you Hispanic, Latino/a, or Spanish origin? Mark all that apply.	• Mexican, Mexican American, Chicano/a • Puerto Rican • Cuban • Another Hispanic, Latino/a, or Spanish origin • None of these		BRFSS
Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre tax income from all sources earned in the past year?	• $0 to $9,999 • $10,000 to $14,999 • $15,000 to $19,999 • $20,000 to $34,999 • $35,000 to $49,999 • $50,000 to $74,999 • $75,000 to $99,999 • $100,000 to $199,999 • $200,000 or more		HINTS
Do you currently rent or own your home?	• Own • Rent • Occupied without paying monetary rent		HINTS
Which one of these comes closest to your own feelings about your household's income these days?	• Living comfortably on present income. • Getting by on present income. • Finding it difficult on present income. • Finding it very difficult on present income		Gallup
Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare, or Indian Health Service?	• Yes • No		BRFSS
What is the primary source of your health care coverage?	• A plan purchased through an employer or union (including plans purchased through another person's employer) • A plan that you or another family member buys on your own • Medicare	• Medicaid or other state program • TRICARE (formerly CHAMPUS), VA, or Military • Alaska Native, Indian Health Service, Tribal Health Services • Some other source	BRFSS

Table 3. Sociodemographic measures (Cont'd)

Item	Response options		Item source
What is the highest grade or level of schooling you completed?	• Less than 8 years • 8 through 11 years • 12 years or completed high school • Post high school training other than college (vocational or technical) • Some college • College graduate • Postgraduate		HINTS
What is your marital status? Mark only one.	• Married • Living as married • Divorced	• Widowed • Separated • Single, never been married	HINTS
What is your current occupational status? Mark only one.	• Employed • Unemployed • Homemaker • Student	• Retired • Disabled • Other (Specify)_____	HINTS
Were you born in the United States?	• Yes • No		HINTS

NOTE: Question wording was provided for both self-administered and interviewer-administered surveys. The question wording was adapted for mode without fundamental or consequential changes to the stem or response options.

Conclusion

Understanding the needs and opportunities related to cancer prevention and control in a Designated Cancer Center's defined catchment area is critical to reduce the burden of cancer among the populations served by each cancer center. A foundational step in this process is conducting population health assessments to identify the cancer-relevant demographic, social, knowledge, attitude, and behavior factors most critical to target. Understanding more about the unique opportunities and barriers in a cancer center's catchment area can enhance the impact of research that is directly relevant to the catchment area and enhance participation in research. Measurement of demographic, social, knowledge, attitude, and behavior factors can also guide community outreach and engagement activities, and permit tailoring of such activities to meet the needs of a cancer center's defined catchment area. Within health care delivery, there is a growing focus on standardizing assessment of the social determinants of health and other factors that shape health and health care experiences (2, 3). In the context of Designated Cancer Centers, standardized measurement of factors related to cancer prevention and control has several important advantages. First, use of measures replicated from national surveys ensures that assessments are psychometrically sound and permits comparison with national datasets. Second, using uniform measures affords the opportunity for analysis of data across cancer centers and the merging of data from multiple catchment areas into a larger, comprehensive national dataset. Third, standardization of the demographic, social, knowledge, attitude, and behavior domains included in catchment area assessments can contribute to harmonization of benchmarks for such domains among cancer centers. Finally, these measures and benchmarks will allow consistent data to be collected repeatedly over time to monitor changes/improvements in catchment areas that may directly result from cancer prevention and control efforts. Ongoing evaluation of progress is essential to reducing the burden of cancer and improving population health.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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