



National Institutes of Health  
National Cancer Institute  
Bethesda, Maryland 20892

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To: Office of Management and Budget (OMB)

Through: Seleda Perryman, DHHS Report Clearance Officer  
Marilyn Tuttleman, NIH Project Clearance Officer, OPERA  
Vivian Horovitch-Kelley, NCI OMB Project Clearance Liaison, OMAA

From: Nina Goodman, Project Officer  
Office of Communications and Education (OCE)  
National Cancer Institute/NIH

Subject: **Generic Sub-Study, “An Assessment of Rural and Uninsured Consumer Perspectives on Cancer and Related Communications: A Focus Group Study” (OMB No. 0925-0046-16), REVISED MEMO**

The National Cancer Institute (NCI) submits for OMB review the proposed NCI research project, “An Assessment of Rural and Uninsured Consumer Perspectives on Cancer and Related Communications: A Focus Group Study.” The NCI Office of Market Research and Evaluation has recently conducted a review of cancer-related communications research on what is known about six primary audiences served by the NCI: cancer patients, caregivers, and family members; cancer healthcare professionals; non-cancer healthcare professionals; researchers; general public and healthy people; and medically underserved audiences. As part of this review NCI has explored what is known about the key characteristics of each audience around cancer-related issues; which communication channels are currently relied on to reach each audience; how effectively each audience is being reached; and identifying future research needs to better understand each audience’s information needs and preferences. Gaps in the understanding of several medically underserved communities were identified: the working uninsured, rural populations, and African Americans. NCI proposes conducting a series of focus groups to help fill these gaps.

The sub-study described below seeks to address the information gaps within these underserved audiences and help NCI identify opportunities for improving NCI information materials and education resources and services for these medically underserved audiences. Addressing the cancer-related information needs of these medically underserved populations is consistent with the cancer priorities outlined in the Obama-Biden Plan to Combat Cancer<sup>1</sup>.

The research objectives guiding this sub-study are to:

1. Fill gaps in NCI's in-depth understanding of public perceptions, awareness, beliefs, attitudes, and experiences related to cancer prevention, screening, diagnosis, and treatment by focusing the sub-study on several underserved groups within the U.S.
2. Explore the communications preferences and cancer information needs; key intermediaries and preferred channels; barriers limiting access to health information and resources; and reactions to existing NCI materials and services among three medically underserved adult audiences – the uninsured (working and unemployed), rural populations, and African Americans.
3. Inform future development of communications strategies, educational tools, and other materials and resources to reach consumers with needed information about cancer; and specifically to inform potential NCI communication activities to reach the three underserved audiences (e.g., through tailoring materials and possible online content, utilizing dissemination channels and intermediaries, and responding to specific unmet and unidentified needs).

### Background on Project

The NCI Office of Communications and Education believes in the importance of understanding its primary audiences and using this knowledge, as well as audience segmentation strategies, to effectively reach and meet the cancer-related information needs of NCI's audiences. A review of communications research conducted by NCI identified gaps in the understanding of several medically underserved populations: the working uninsured, rural populations, and African Americans. Research scans were conducted to assess the widely available cancer-related bodies of literature as they related to these underserved audiences. These research scans revealed that there are substantial gaps in this literature on working uninsured and rural populations within the United States, and some research gaps with regard to African American audiences as well.

*The Working Uninsured.* According to the U.S. Census, 2007 Current Population Survey, this population is quite large – approximately 15 million uninsured adults (age 18 to 64) in the U.S. work full-time and an additional 4 million work part-time. With the current economic downturn, this population is likely to have grown in number. Working uninsured adults have limited access to and low utilization of preventive health care services compared to adults with health insurance, demonstrated by differences in cancer screening rates. The research suggests that uninsured adults are more likely to be diagnosed with later stage disease and have higher cancer mortality rates, largely because of their inability to afford routine and preventive care. In addition to the problem of cost, the literature suggested that uninsured adults may experience other barriers to accessing cancer screening, treatment, and related information (e.g., limited literacy levels). Despite rising concerns about the health status of the uninsured, the research scan revealed a dearth of literature on the health information needs and communications preferences and behaviors of this audience, particularly as they related to cancer.

*Rural Populations.* About 17% of the U.S. population (50 million people) lives in rural regions. Lack of health insurance coverage is also common in rural areas, which are home

to 8.5 million uninsured Americans<sup>2</sup>. The literature highlighted that rural adults often need to travel considerable distances to access health care services and make treatment decisions based on their proximity to care. Rural adults are less likely than their non-rural counterparts to be screened and receive timely treatment for a variety of cancers, which is in part due to reduced access to services in their locality. Other barriers to screening and treatment that may be associated with the rural setting include religious beliefs and fatalism. The Internet and other new technologies offer an opportunity for reaching the rural audience, but limited access to these technologies among rural Americans may be an issue. While there is some literature on the cancer-related information needs of rural adults, much is unknown about their health information seeking behaviors and preferences for communications channels, particularly as they relate to cancer.

*African Americans.* Literature searches conducted to identify related literature on the working uninsured and rural adults in the U.S. revealed differences within these populations based on race/ethnicity and other sociodemographic indicators. National data show that the cancer mortality rates among African Americans are substantially higher than rates among other racial groups<sup>3</sup>. Underlying African Americans' higher cancer mortality rates is more limited access to health information and cancer services. African Americans are also less likely to receive recommended screening and are more likely to be diagnosed with cancer in later disease stages. Furthermore, African Americans are less likely to have Internet access at home or use it to find health information. Fear, limited disease knowledge, and low awareness of screening tests were identified as barriers to accessing preventive health services for working uninsured and rural populations, including African Americans. Unique barriers to receiving cancer screening tests (e.g., fear of injury from medical equipment and an association of cancer with sexual behavior) were also mentioned by African American segments. While a substantial amount of cancer and communications research has been conducted with African American audiences generally, little is known about working uninsured and rural African Americans' knowledge, attitudes, behaviors related to cancer or their personal experiences with cancer. Also, less NCI OMRE formative communications research has been conducted with this audience.

The research objectives and design of the proposed focus group sub-study have been informed by these findings from the current literature on communications and cancer and seek to address the gaps in understanding of these medically underserved audiences.

### Background Information on Focus Groups

During early stages of developing communications, such as the formative stage in which NCI is currently engaged, focus groups are commonly used to obtain insights into target audiences' perceptions, beliefs, and attitudes.<sup>4</sup> Focus groups are valuable in exploring consumer reactions to concepts, messages, and materials before additional resources are put into their development, and for learning audiences' preferred communication channels and intermediaries. Focus groups are usually composed of eight to ten people who have characteristics similar to the target audience or subgroups of the target audience. The groups are conducted by a professional moderator who keeps the session on track while allowing respondents to talk openly and spontaneously. The moderator uses a loosely

structured discussion outline, which allows him/her to change direction as the discussion unfolds and new topics emerge.

Focus group methodology results in the generation of qualitative data that can be analyzed to identify overarching themes and patterns as well as to understand the broader, socio-cultural context for future communications and marketing efforts. The proposed qualitative methodology does not afford the ability to generalize sub-study findings to the larger population or draw conclusions about the differences between sub-study groups. Qualitative methods typically produce a wealth of detailed information about a much smaller number of people and cases. This increases the depth of understanding of the cases and situations studied, but reduces generalizability.<sup>5</sup> NCI hopes to gather rich, in-depth qualitative data from small samples of respondents in each segment, but the research will not produce results that are representative, generalizable, or conclusive. At this time, this research is more explorative. Depending on the findings, this formative research may inform a future population-based, quantitative research study on similar topics (though there is no plan to do so at this time).

The proposed sub-study design involves a total of 24 focus groups with six to eight participants in each group and between four and twelve focus groups per segment, which is a sufficient number of groups and participants to support thematic data analysis using qualitative techniques. The major themes that are identified within segments, and patterns across audience segments, will be explored and explicated. Analysis of and observations made between sub-segments will be undertaken cautiously with the limitations of small sample size explicitly noted.

#### Proposed Focus Group Research Study Design, Methodology, and Limitations

Through its contractor, the Academy for Educational Development (AED), NCI proposes using focus groups to conduct qualitative research with African American adults, rural adults, and uninsured adults. NCI proposes convening 24 consumer focus groups using standard focus group methodologies to elicit formative information and gain an understanding of their perceptions, awareness, beliefs, attitudes, and behaviors related to cancer prevention, screening, diagnosis, and treatment. The focus groups will also assess respondents' access to and use of cancer-related information, and their preferences for health communication channels and intermediaries. How participants' perceptions and preferences are influenced by their insurance status and geographic location will also be explored. Existing NCI materials will be used in the discussions simply to further elicit thoughts, perceptions, understanding, challenges, and unmet needs relating to cancer communications and resources. The purpose of the sub-study is not to test existing materials, but to conduct formative research that can be used to inform the development and dissemination of future NCI communications strategies and activities.

The proposed focus group sub-study will address the following key research topics:

- Beliefs about and attitudes towards cancer prevention, screening, diagnosis, and treatment; as well as how respondents have been shaped by personal experiences and how they influence related behaviors.
- Perceived facilitators and barriers to receiving cancer prevention, screening, diagnosis, and treatment information and services, particularly those related to insurance status and rural residential location.
- Insights into the cancer information-seeking practices and preferences for communications channels and intermediaries from whom to receive cancer information.
- Perceived need for information on cancer prevention, screening, diagnosis, and treatment, including awareness of and information needs related to cancer clinical trials.
- Perceptions of existing NCI informational materials, educational resources, and services; and suggestions for improving them and modes of disseminating them.

Based on the previously described background findings, three primary audiences – African American, rural, and uninsured adults – will be investigated in a single qualitative sub-study. Because of the emphasis on cancer-related topics, separate focus groups will be conducted with participants who have had personal experience (either themselves or a close friend or family member) with cancer and those who have not. The focus groups will take place in three to four U.S. locations, with six to eight groups convened at each. The following table presents the number and distribution of focus groups according to the 2 (rural status) x 3 (employment/insurance status) x 2 (personal experience with cancer) design of the proposed research project. Note that half of the focus groups will be exclusively with participants who identify as African American. Within each cell in the below table, one group will consist of African American respondents and one group will include participants representing other ethnic/racial groups. For the latter twelve groups, potential participants may identify as one or more races (including White/Caucasian, Native American/American Indian, and Asian/Pacific Islander) and ethnically as Hispanic/Latino or not.

	Rural			Not Rural		
	Working – Insured	Working – Uninsured	Not Working – Uninsured	Working – Insured	Working – Uninsured	Not Working – Uninsured
Personal experience with cancer	[A] 2	[B] 2	[C] 2	[G] 2	[H] 2	[I] 2
No personal experience with cancer	[D] 2	[E] 2	[F] 2	[J] 2	[K] 2	[L] 2

Focus groups participants will be screened and segmented on these key dimensions:

- 1) *Rural status (rural / non-rural)*
  - Resident in a zip code classified as rural (Rural-Urban Commuting Areas, classification 10) or resident in a zip code not classified as rural (Rural-Urban Commuting Areas, 1-9)<sup>6</sup>.
- 2) *Employment / insurance status (working insured/working uninsured/not working uninsured)*
  - The presence / absence of health insurance coverage of any kind over the past 6 months.
  - Employed and working at least 20 hours per week / unemployed and looking for work.
- 3) *Personal experience with cancer (personal experience / no personal experience)*
  - The incidence or absence of lifetime history of cancer diagnosis/treatment of self, immediate family member, or close friend.
- 4) *Race / Ethnicity*
  - African American (including multi-racial) / general population (not African American)

In addition, the sub-study focuses on a low to moderate income population, recruiting respondents who have an annual household income of \$50,000 or less, approximately the national median household income<sup>7</sup>. And because of the subject matter and current cancer screening recommendations, participants in these consumer focus groups will be restricted to consumers between the ages of 40 and 64. Potential participants will include both men and women. All groups will be recruited to attempt to include a mix of sexes, education levels, and job types; and in insured groups, a mix of respondents with private employer-based, and other forms of health insurance coverage (including public).

All data will be collected by AED, and all personal identifiers will be excluded from the data records. Any necessary identifying or potentially identifying information (e.g., signed consent agreements) will be secured and kept separate from the data records. All information provided by respondents will be maintained in a confidential manner, unless compelled by law. The focus group data files that are delivered to NCI will be analyzed in the aggregate and no identifiable individual respondents will be provided. NCI and AED's Institutional Review Board (IRB) Research Integrity Officers will review the research instruments and ensure that all necessary human subject protection procedures are in place.

Participants for the consumer focus groups will be recruited using standard focus group recruitment methods; by calling their households and administering a brief screening questionnaire to pre-qualify them. Most participants will be drawn from an existing database (or list) of potential participants which is maintained by each focus group facility. Others will come from referrals (from health clinics, unemployment offices, adult learning centers, and other community resources), and some may be solicited through advertisements or fliers in local media or online to let potential participants know about the opportunity to participate in the focus groups.

Recruiters will use a screening questionnaire (“screener”) to identify eligible respondents. The screener has been carefully thought out so that the questioning process is short, easy to-understand, friendly, and efficient. In addition, the moderator’s guide for the focus groups has been developed specifically to ensure that the questions are easy to understand and answer, well-organized, and flow well. The moderators will be instructed to restrict focus group discussions to 2 hours to limit respondent burden with respect to their time. Participation will be strictly voluntary and respondents will be asked to participate in a focus group only once. Respondents’ comments will not have any effect on their eligibility for, or receipt of, medical services.

Analysis of the focus group data will employ a notes-based approach that relies primarily on observation notes, debriefing session notes, and summary comments made after the conclusion of each focus group. The focus groups will be audio taped, but the recording will be used primarily to verify specific quotes. Names and images will not be recorded, nor will personal identifying data be maintained. The primary analysis documents are the detailed observation notes. If more rigorous analysis is later needed, the tapes are available for transcription. Analysis will include the identification of key findings and overarching themes which will be presented in a report to NCI.

To avert the misinterpretation of the data, particularly the perception that the results are generalizable, NCI will take steps to ensure that the research findings are not taken out of context, misrepresented, or misused. NCI will include the purpose and formative nature of the sub-study, as well as the qualitative research methodology along with its limitations, in any presentation of data and results generated from this sub-study.

#### Participant Burden and Participation

Research on participation in focus groups indicates that, without providing minimal levels of monetary compensation, insufficient numbers of participants will attend the group and results will not be useful. Notably, participants for some of the proposed focus groups may be harder to recruit (i.e., hard to reach populations and those living in less densely populated areas). Focus group facilities indicate that without a sufficient incentive, recruiting fees are higher because the refusal rate is higher. Recommendations for incentive amounts have been collected from eight focus group facilities located in the states/areas where these focus groups will potentially take place. Most of these facilities recommended incentive amounts within the \$65 to \$75 range, but acknowledged that rural participants will have higher transportation costs. Based on the market-specific information gathered for this proposed research sub-study, respondents in the focus groups will receive \$75 as modest remuneration for participating in a 2-hour focus group. This remuneration will be provided in order to defray the cost of participation in the focus groups (parking, transportation, child care, etc.) and to provide participants with a nominal compensation. Light refreshments will also be provided to participants.

There will be *a maximum of 192 respondents (24 groups with 8 or fewer respondents/group)*. For each group, up to 10 individuals will be recruited and, based on prior focus group experience, we realistically expect 6-8 to show for the group. However,

to ensure we accurately reflect a maximum burden potential, we are estimating the burden total on the assumption that 8 will attend each group. An average total participation time of 2.5 hours for each participant includes 10 minutes responding to the screener questionnaire, 20 minutes for having the respondents read and sign consent forms, complete name tags, enjoy refreshments, and 120 minutes to participate in the focus group. This culminates in a maximum total annual hour burden of 480 hours.

<b>Estimate of Burden</b>						
<b>Types of Respondents</b>	<b>Number of Respondents</b>	<b>Frequency of Response</b>	<b>Average Response Time (Hours)</b>	<b>Annual Hour Burden</b>	<b>Hourly Wage Rate</b>	<b>Annual Respondent Cost</b>
General Public	192	1	2.5	480	\$75.00	\$36,000

Assuming respondents are compensated by the proposed maximum remuneration amount of \$75.00/hour (depending on locality); the total annual respondent cost is estimated at \$36,000 for the proposed focus group sub-study.

- Attachments: A) Focus Group Recruitment Screener,  
 B) Moderator’s guide for Participants with No Cancer Experience  
 C) Moderator’s guide for Participants with Cancer Experience  
 D) Overall Research Design  
 E) Recruitment Charts  
 F) Informed Consent Form

The full generic study, approved on January 26, 2007, requested a total of 2010 burden hours. There have been 15 previous sub-studies approved by OMB under this umbrella submission, totaling 1208 burden hours requested to date. Approval by OMB of this sub-study would bring the total burden hour requested to date for 0925-0046 to 1688; well below the original request of 2010 hours.

Thank you for your consideration of this proposed sub-study #0925-0046-16.



## Endnotes

<sup>1</sup> [http://www.barackobama.com/pdf/issues/healthcare/Fact\\_Sheet\\_Cancer\\_FINAL.pdf](http://www.barackobama.com/pdf/issues/healthcare/Fact_Sheet_Cancer_FINAL.pdf) (accessed May 20, 2009).

<sup>2</sup> This statistic comes from the *Hard Times in the Heartland: Health Care in Rural America* report produced by the DHHS and available on the [www.healthreform.gov](http://www.healthreform.gov) Web site (accessed June 10, 2009), which offers this and other timely and relevant information on the uninsured and rural populations within the U.S.

<sup>3</sup> According to NCI Surveillance Epidemiology and End Results data from 2001-2005, the age-adjusted cancer death for all Americans is 634.4 deaths per 100,000; African Americans have an age-adjusted cancer death rate of 773.1 deaths per 100,000 (accessed at <http://seer.cancer.gov/> on June 8, 2009).

<sup>4</sup> Krueger, R.A., (1994). *Focus groups: A practical guide for applied research*, (2nd ed.) Thousand Oaks, CA: Sage Publications.

<sup>5</sup> Patton, M.Q. (2002). *Qualitative Research & Evaluation Methods* (3<sup>rd</sup> edition). Thousand Oaks, Ca: Sage Publications.

<sup>6</sup> Based on 2000 Census data, all U.S. zip codes have been classified into one of ten Rural-Urban Commuting Areas (RUCAs) by the U.S. Department of Agriculture Economic Research Service with assistance from the University of Washington; accessed at: <http://www.ers.usda.gov/briefing/rurality/ruralurbancommutingareas/> (accessed June 4, 2009). RUCA codes are based on the same theoretical concepts used by the Office of Management and Budget (OMB) to define county-level metropolitan and micropolitan areas. Similar criteria are applied to measure population density, urbanization, and daily commuting to identify urban cores and adjacent territory that is economically integrated with those cores. The use of census tracts instead of counties as building blocks for RUCA codes provides a different and more detailed geographic pattern of settlement classification. A ZIP code approximation of the RUCA codes is available and based on an overlay of ZIP code areas on census tracts. Note: the NCI Health Information National Trends Survey (HINTS) uses a 9-point rural-urban classification system based on the RUCA codes; however, the public use data file does not include zip code information.

<sup>7</sup> The real median annual household income was \$50,233 in 2007 based on U.S. Census Bureau report: *Income, Poverty, and Health Insurance Coverage in the United States: 2007* - <http://www.census.gov/prod/2008pubs/p60-235.pdf> (accessed June 10, 2009).