

Proposed Title: Cancer Related Information Needs: Hints from the Health Information National Trends Survey (HINTS)

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Research questions:

1. What cancer-relevant information is being sought by the public?
2. Are there differences in the types of information sought among various groups defined by sociodemographic, health care access and health status variables?

Study description/rationale: While considerable research has been conducted on the cancer-relevant information needs of cancer patients, very little is known about the cancer-relevant information needs of the general public (Buckland, 1994). Few studies of the information needs of the general public have been conducted. With increasing emphasis on cancer prevention and early detection, understanding the cancer-relevant information needs of the public is critical.

This study proposes to examine respondents' information needs and to determine whether such needs differ by sociodemographic, health care access, and health status subgroups. Ascertaining the cancer-relevant information needs of the public will provide insight into the types of information that need to be made readily available for public consumption. Furthermore, appreciation of differences in informational needs by subgroups will provide a basis for tailoring cancer-relevant information to the needs that are most salient to certain subgroups.

Descriptive piece looking at item HC-14, which asks "What type of information were you looking for in your most recent search". I would like to modify and apply a coding scheme (typology of cancer information needs) I developed in my literature review examining patients' information needs to the needs identified in response to this item.

Use the following typology of cancer information needs to categorize information sought:

Type of Need	Description
1=Cancer-specific information: 1=breast 2=lung 3=skin 4=prostate 5=colorectal 6=gynecological 7=leukemia 8=oral/throat/esophageal 9=lymphomas [(non)-Hodgkins] 10=other	<ul style="list-style-type: none">• information about a specific cancer (i.e. "information on breast cancer", or "prostate cancer", etc.).• Named body parts, e.g., kidneys, stomach, are included in this category.

<p><u>2=General cancer information:</u></p>	<ul style="list-style-type: none"> • general information about cancer; “general information”; “information about cancer”; “cancer”; “anything related to cancer”; “different types of cancer”. • responses referring to a specific cancer without actually naming it (i.e. “cancer that my wife had” or “cancer that my friend had”). • information on tumor growth or basic cellular processes involved in cancer • prevalence or “epi” topics (e.g. prevalence in certain groups like men, blacks, etc.) • “no specific topic” • information about health concerns relevant to cancer, e.g., hormone replacement therapy, menopause. • available research and scientific evidence, “new information” or “latest” information, • professional societies such as ACS.
<p><u>3=Causes/risks:</u></p>	<ul style="list-style-type: none"> • information about the causes of or risk factors associated with cancer, risk associated with exposures (i.e. radon, agent orange) • information about the role of hereditary, family history, or genetic factors in cancer • information about tobacco use or cessation, and cancer risks associated with tobacco, smoking, etc. • (potential) associates of cancer (i.e. syndromes/conditions like gastritis, COPD, polycystic ovary disease, Barrett’s, etc., autoimmune disorders, irritable bowel syndrome).
<p><u>4=Diagnosis/Symptoms/early detection/testing:</u></p>	<ul style="list-style-type: none"> • information about diagnostic procedures, cancer diagnoses, and cancer stages • symptoms of cancer (ie. Dysplasia, precancer, mole, lymphedema, cysts) • cancer screening or testing (ie. self exams, mammography, PSA testing, diagnostic tests)

<u>5=Treatment/Cures:</u>	<ul style="list-style-type: none"> • treatments and Tx options, cures, alternative/complimentary Tx, side effects of Tx (risks/benefits), reducing side effects of Tx, physical effects of Tx, how Tx works, • medications/drugs, therapies, and purpose of Tx. • information relevant to <i>identifying medical care</i> including locating cancer care centers and hospitals, clinical trials. • information about financial concerns such as treatment cost, insurance, Medicare, VA coverage. • palliative care - information about death and dying, pain, terminal cancer, end of life.
<u>6=Prognosis/Recovery/Post-Treatment:</u>	<ul style="list-style-type: none"> • information about prognosis such as: Life span/survival, spread of disease (metastasis), recurrence. • information about recovery such as: self care issues/home care, follow-up care and treatment, long-term side effects, recovery time. • information about coping such as “dealing with cancer”, hospice care, caring for cancer patients, community counseling or support, support groups, emotional reactions/support/coping. • post-treatment issues
<u>7=Prevention/nutrition/maintenance:</u>	<ul style="list-style-type: none"> • information about cancer prevention or maintaining health (i.e. nutrition/ vitamins, prevention, lifestyle, etc.).
<u>8=Other - unclear:</u>	<ul style="list-style-type: none"> • Anything that cannot be placed into one of the other categories (i.e. “can’t remember”, unrecognized terms, seemingly cancer-irrelevant health concerns, etc.).

Variable list:

spage First, what is your age?
 spgender Are you male or female?
 hc1usual Do you have a regular health care provider?
 hc14what What type of cancer information did you seek?
 ch1everh Ever been told you had cancer?
 hs5healt Do you have any kind of health coverage?
 dm1maina What is your employment status?
 dm2marit What is your marital status?
 dm4hispa Are you Hispanic or Latino?
 dm5race1 What is your race?(1)
 dm5race2 What is your race?(2)
 dm5race3 What is your race?(3)
 dm5race4 What is your race?(4)

dm5race5	What is your race?(5)
dm6educa	Highest grade/year of school completed?
dm7ainco	Is income less than 25K?
dm7binco	Is income less than 20K?
dm7cinco	Is income less than 15K?
dm7dinco	is income less than 10K?
dm7einco	Is income less than 35K?
dm7finco	Is income less than 50K?
dm7ginco	Is income less than 75K?
dm7hinco	Is income 75K or more?

Method of analysis

Each of the topics given by respondents in response to the question regarding what type of cancer information they sought will be coded according to the typology of cancer information needs.

Research Question 1. *What cancer-relevant information is being sought by the public?* The frequencies and weighted percentages falling into each category in the typology will be summarized.

Research Question 2. *Are there differences in the types of information sought among various groups defined by sociodemographic, health care access and health status variables?* The frequencies and weighted percentages falling into each category in the typology for subgroups defined by sociodemographic variables will be summarized.

References

Buckland S. Unmet needs for health information: a literature review. *Health Libraries Review* 1994, II, 82-85.

Rees A. Bull Communication in the physician-patient relationship. *Med Libr Assoc*, 1993;81(1):1-10.