



Implementing the Kansas Comprehensive Cancer Plan in the Community:

**Focus on Prevention, Survivorship and End of Life Care
for the Older Adult**

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Kansas Cancer Partnership



May 2 and 3, 2007
Capitol Plaza Hotel and Maner Conference Center
Topeka, Kansas

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What is the burden of cancer in Kansas?

- **12,000 new cancer cases each year**
- **5,000 deaths each year**
- **Medical costs**
- **Time lost**
- **Family burden**

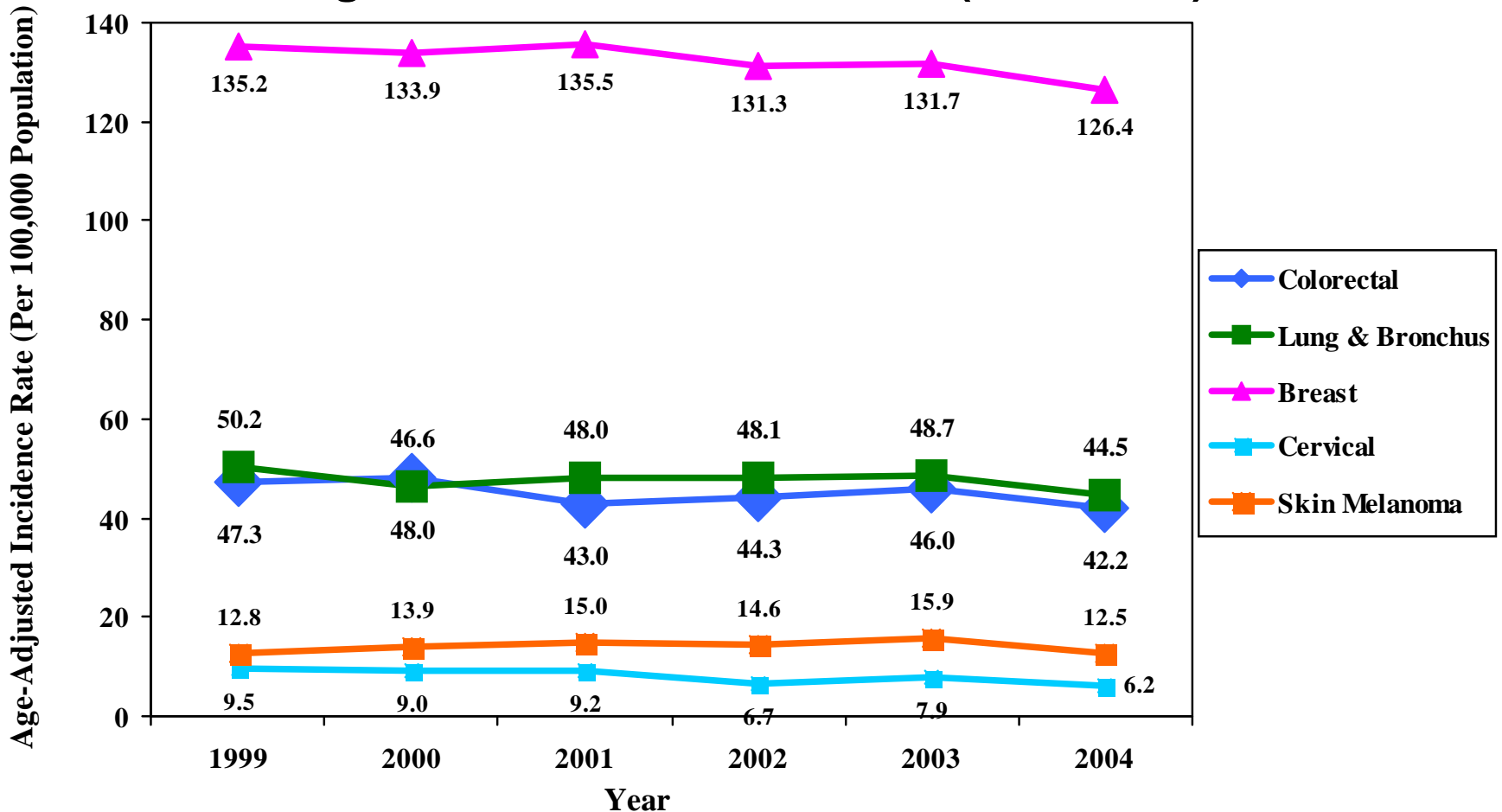


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Age-Adjusted Invasive Cancer Incidence Rates by Primary Site among Female Kansas Residents (1999-2004)



Rates are per 100,000 Female Population and age-adjusted to the 2000 U.S. Standard Population.

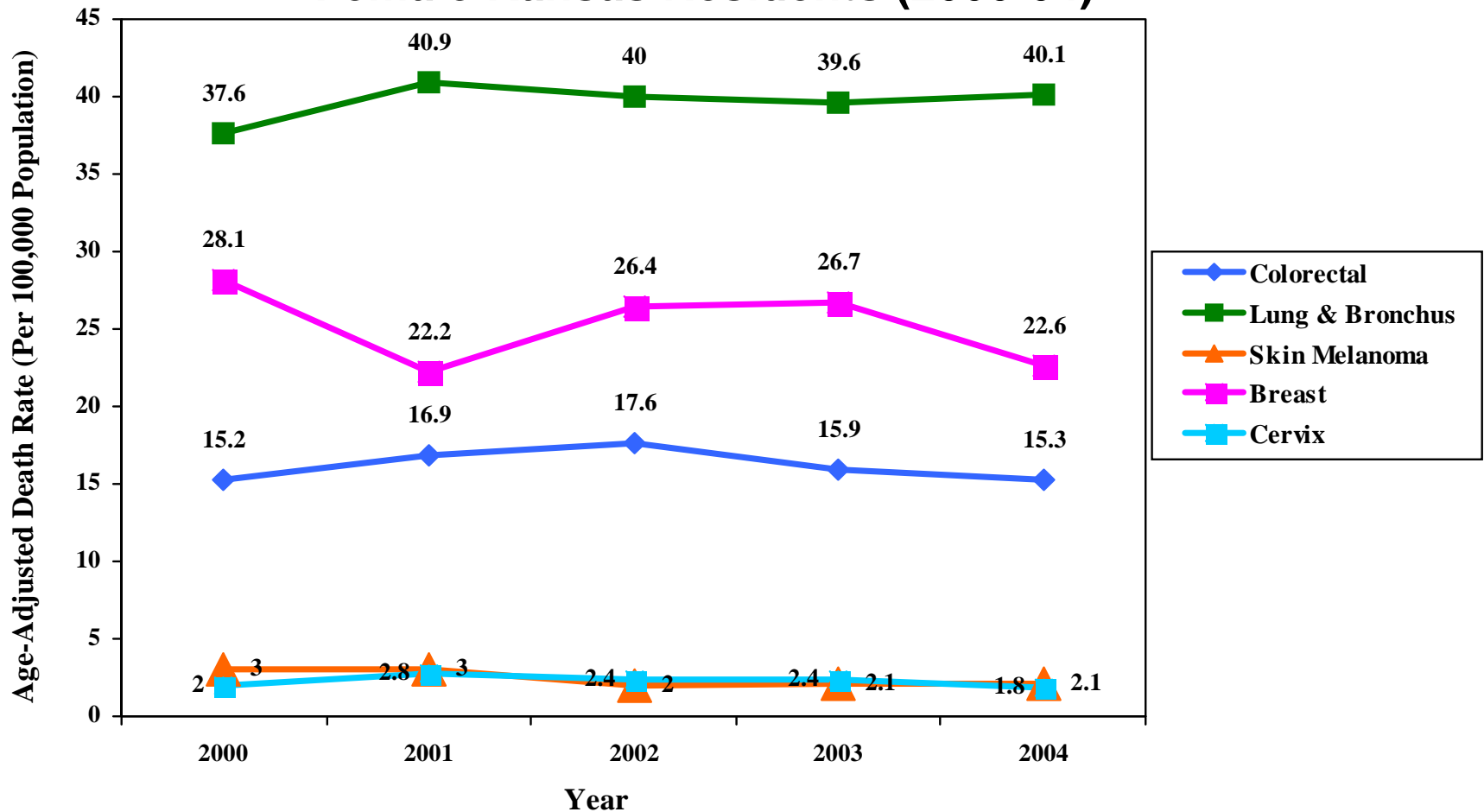
Data Source: Kansas Cancer Registry

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Age-Adjusted Cancer Death Rates by Site among Female Kansas Residents (2000-04)



Rates are per 100,000 Female Population and age-adjusted to the 2000 U.S. Standard Population.

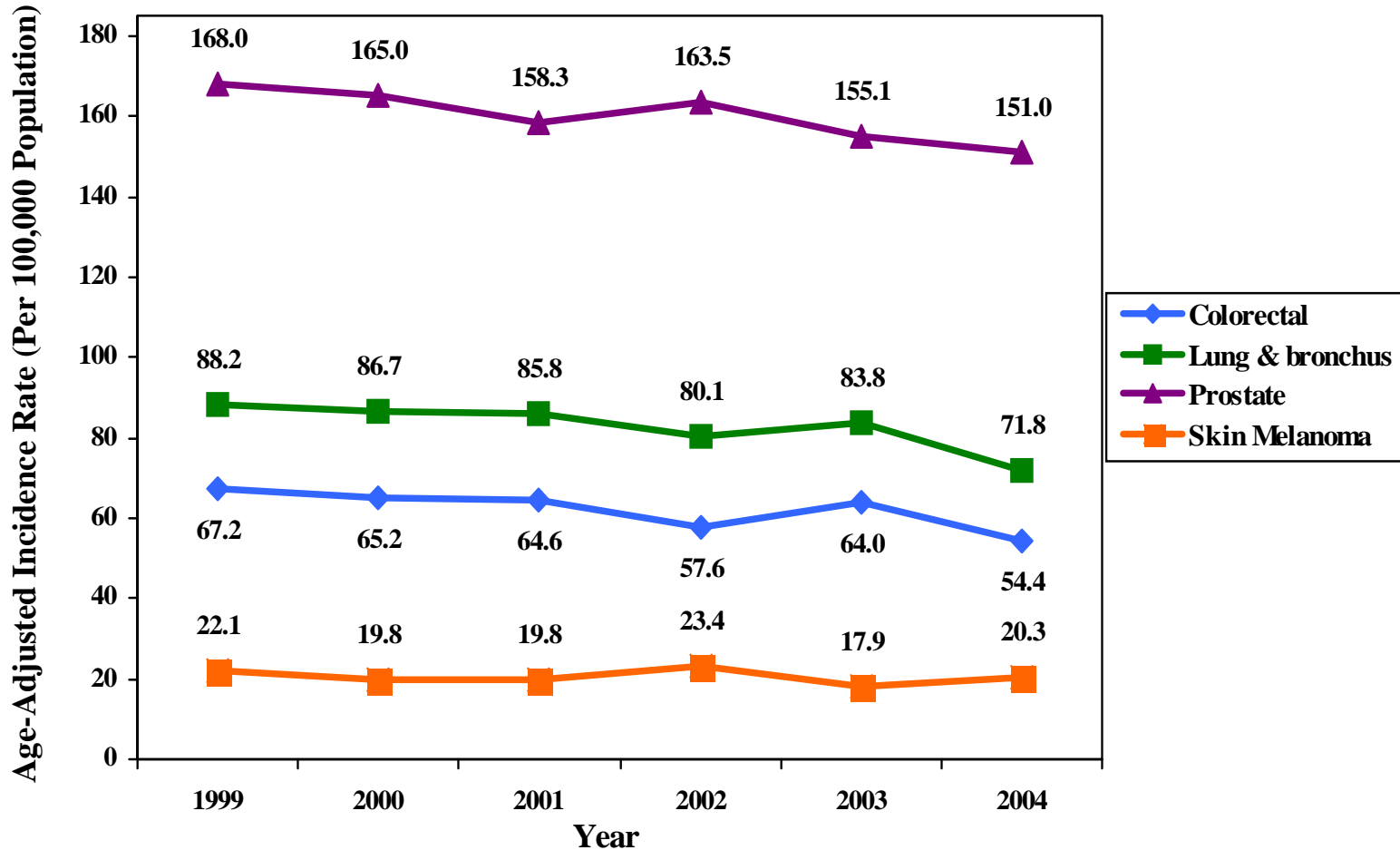
Data Source: Kansas Vital Statistics database, Center for Health and Environmental Statistics, Kansas Department of Health & Environment.

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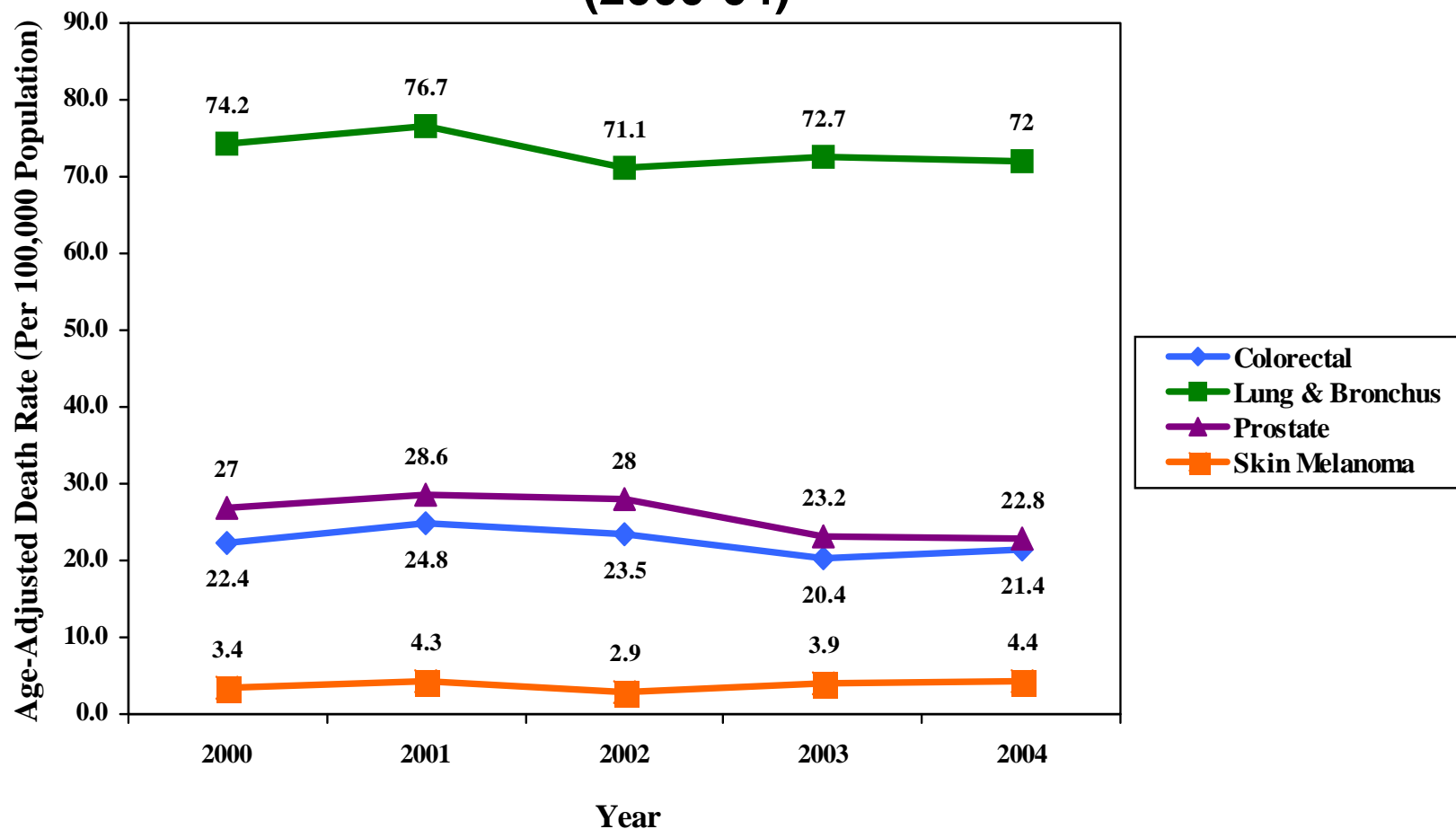
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Age-Adjusted Invasive Cancer Incidence Rates by Primary Site among Male Kansas Residents (1999-2004)



Rates are per 100,000 Male Population and age-adjusted to the 2000 U.S. Standard Population.
Data Source: Kansas Cancer Registry

Age-Adjusted Cancer Deaths by Site among Male Kansas Residents (2000-04)



Rates are per 100,000 Male Population and age-adjusted to the 2000 U.S. Standard Population.

Data Source: Kansas Vital Statistics database, Center for Health and Environmental Statistics, Kansas Department of Health & Environment.

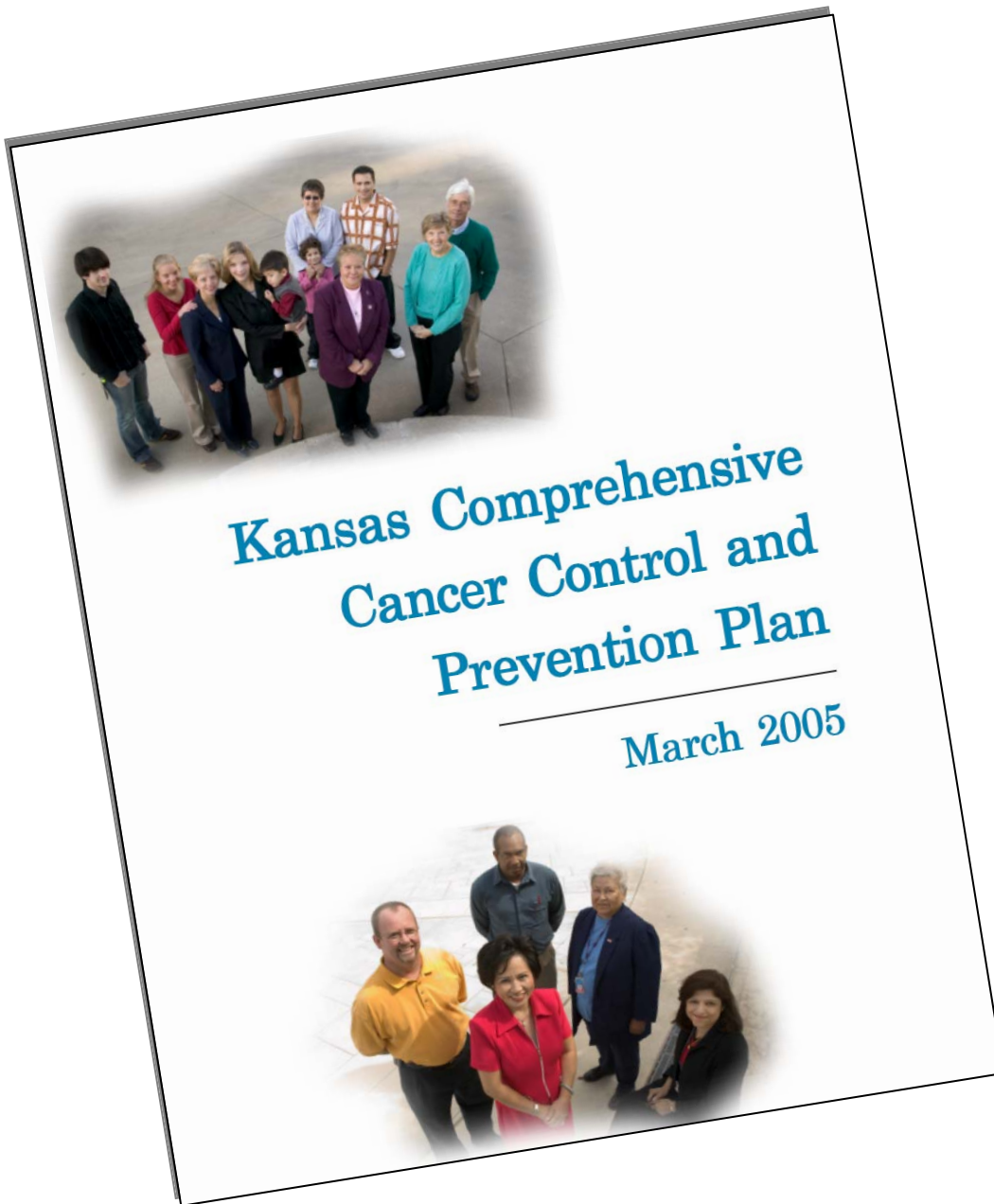
Cost of Cancer....

- **In the U.S. \$189.5 billion dollars**
 - \$64.2 billion for direct medical expenses
 - \$16.2 billion in indirect morbidity costs
 - \$109 billion in lost worker productivity
- **In KANSAS the cancer cost is estimated at \$1.6 billion annually including direct medical costs, cost of lost productivity due to illness and cost due to premature death.**

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The Updated KCCP Plan

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What is Comprehensive Cancer Control (CCC)?

... an integrated approach to reducing cancer incidence, morbidity and mortality through prevention, early detection, treatment, rehabilitation and palliation

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What informed development of the plan?

- **Community Listening Sessions**
- **Kansas Cancer Partnership expertise**

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Community Listening Sessions

Winter 2003 - 2004

- **8 sessions**
 - Garden City
 - Parsons
 - Wichita
 - Kansas City Area
- **Who participated?**
 - Cancer Survivors
 - Family members & friends of survivors
 - Family members & friends of victims
 - Health Care Professionals
 - Others:
 - community volunteers
 - outreach & planning workers
 - cancer advocates
 - outreach workers
 - ACS staff/volunteers
 - promoters of cancer research

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Community Listening Sessions

Participant Priorities

- **Universal access to screening, diagnosis and care**
- **Cancer education for all:**
 - **lifestyle & risk factor education for kids through schools;**
 - **physician skill development to counsel patients about lifestyle issues;**
 - **parent education on lifestyle and risk factors; and**
 - **social marketing for all**
- **All people will access preventive services that are available and follow through with any care necessary. We want to make Kansas 100% healthy!**

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Community Listening Sessions Priorities

- **Health insurance includes preventive coverage with incentives for healthy lifestyle**
- **Universal health coverage that makes cancer services available for everyone:**
 - education,
 - prevention measures,
 - early detection
 - treatment options,
 - recovery resources

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Kansas Cancer Partnership

140 individuals from a network of public and private organizations who provide leadership in the development and implementation of the Cancer Plan

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Their Mission...



- **Prevent cancer**
- **Screen for the disease**
- **Provide prompt and thorough treatment**
- **Ensure survivors lead productive and healthy lives**
- **Provide compassionate care and pain management for those at the end of life**

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Plan Developed by Partnership Based on Listening Sessions

- **Focus on six cancers:**
 - Breast
 - Cervical
 - Colorectal
 - Lung
 - Prostate
 - Skin

- **Focus in 5 areas:**
 - Prevention
 - Screening & Early Detection
 - Diagnosis & Treatment
 - End of Life
 - Survivorship

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The KCCCPP approach...

- **Six groups working on implementation**
 - **Patient Advocacy/Access to Care**
 - **Policy Issues**
 - **Professional Education**
 - **Public Education**
 - **Research and Data**
 - **Survivorship/End of Life**

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Diet, Physical Activity, Obesity & Cancer Prevention: What do we know?

“Evidence suggests that one-third of the 550,000 cancer deaths that occur in the United States each year are due to unhealthy diet and insufficient physical activity.”

Tim Byers, MD, MPH &
Colleen Doyle, MS, RD
American Cancer Society

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Diet, Physical Activity, Obesity & Cancer Prevention

- **Lack of physical activity is strongly associated with overweight & obesity**
- **Regular physical activity lowers the risk of colon & breast cancers**
- **A diet high in calories and/or fat appears to be an important risk factor for obesity**

New Cancer Diagnoses in 2002

- Of all new cancer cases in US 41,000 were estimated to be due to obesity.
- That means 3.2% of all new cancers are linked to obesity

A.P. Polednak
*Cancer Detection &
Prevention, 2003*

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Diet, Physical Activity, Obesity & Cancer Prevention

- **Obesity and physical inactivity may account for 25-30% of post-menopausal breast cancers**
- **Avoiding weight gain can lower risk of post-menopausal breast cancer**

Research on Body Weight & Breast Cancer

- **Being overweight or obese increases risk in women over 50 years old**
- **Overweight women 60% more likely to die from breast cancer compared to normal weight women**
- **Women, not currently overweight, who experienced an intentional weight loss of ≥ 20 lbs. or more had cancer rates of healthy women**

Diet-Related Prevention

- **Limited Alcohol Use (\leq 1 drink/day)**
- **Regular Physical Activity**
- **Healthy Balanced Diet**
 - **Fruits & Vegetables**
 - **Type of fat**

Research on Physical Activity (PA) & Cancer

- **Moderate PA reduced colon cancer risk by 50% across all BMI levels**
- **Postmenopausal women who walked 30 min./day had a 20% reduced risk of breast cancer**
- **For women of normal weight who walked 30 min./day , breast cancer risk was reduced 37%**

Diet & Cancer Risk

- **Fat Intake**

- **Diets high in fat linked to increased cancer risks**

- **Breast**
 - **Colon**
 - **Prostate**
 - **Possibly pancreas, ovary, and endometrium**

(USDHHS, 1988; National Research Council, 1989)

- **Saturated fats and trans-fatty acids associated with increased risk**

- **Monounsaturated fats and omega-3 fatty acids are associated with reduced risk**

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Diet & Cancer Risk

- **Fruit & Vegetable Consumption**
 - **Persons with low fruit and vegetable intake had about twice the risk of most cancers as those with high intake (Block et al., 1992).**
 - **Evidence of a protective effect for:**
 - Lung
 - Colon
 - Rectum
 - Breast
 - Oral cavity
 - Esophagus
 - Stomach
 - Pancreas
 - Uterus
 - Cervix
 - Ovary

Current Screening Guidelines

www.cancerkansas.org

The screenshot shows a Microsoft Internet Explorer browser window displaying the Kansas Cancer Partnership website. The browser's address bar shows the URL <http://www.cancerkansas.org>. The website header features the text "KANSAS comprehensive cancer control & prevention" and "Kansas Cancer Information". A navigation menu includes links for "Public/Community", "Home", "About the Partnership", "Partnership Meeting Minutes", "Research & Clinical Trials", "Screening & Tests", "News & Reports", "Cancer Information Links", "What Can Kansans Do About Cancer?", "Kansas Cancer Plan", "Kansas Resources", and "Contact Us". The main content area contains a paragraph: "Cancer in Kansas causes a heavy toll in both lives lost and the burden of the disease for patients and their families. Kansas has a long and rich history of taking a proactive approach to public health. Cancer prevention and control is a logical and important step in achieving the goal of Healthy Kansans by 2010." Below this is another paragraph: "This site is dedicated to bringing Kansans knowledgeable, quality cancer information to simplify your search for information, treatments and resources in our state. Click here to view a copy of the [Kansas Cancer Control and Prevention Plan](#)". A small advertisement for the "Are you the picture of health?" campaign is also visible, featuring a woman and logos for the CDC and the Kansas Department of Health.

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Kansas Cancer Partnership

Cancer Screening Patient Tool

The purpose of this patient tool is to educate and inform participants about cancer screening recommendations. It should not be used for diagnostic purposes. Please discuss only health concerns with your physician. The survey will take 10-15 minutes to complete and printout in one sitting as the information will not be saved.

Please answer the following questions:

1. Your present age is

2. Your current height in inches is

3. Your current weight in pounds is

This is your Body Mass Index calculated from the above information. 30.13

4. Your gender is Female Male

5. Race is

- White American Indian and Alaska Native Native Hawaiian and Other Pacific Islander
 Black or African American Asian Some other race

6. Your ethnicity is

7. Do you drink alcohol more than 3 times per week? Yes No

8. Are you a smoker or have you ever smoked in the past? Yes No

Lung Cancer:

1. Do you use tobacco products? Yes No

Current Screening Guidelines

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Advances in Geriatric Assessment for Cancer Treatment

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Benefits of Comprehensive Geriatric Assessment (CGA)

- **Recognize potentially treatable or reversible conditions that may reduce tolerance to treatment**
 - Depression and/or Malnutrition
- **Assess individual functional reserve**
- **Provide gross assessment of life expectancy**
- **Adopt a common language to classify the older cancer patient**

Source: Lodovico Balducci, Martine Extermann, *The Oncologist* 2000;5:224-237

CGA Recognizes Three Stages of Aging

- **Functionally independent without co-morbidities**
 - Candidate for any standard cancer treatment
 - Possibly not a bone marrow transplant candidate
- **Frail, dependent in ≥ 1 ADLs; ≥ 3 co-morbidities; ≥ 1 geriatric syndromes**
 - Candidate for palliative care only
- **People in between**
 - Reduced dose of chemotherapeutic agents
 - Gradually increasing doses to tolerance

Access to Quality Cancer Care Close to Home



**March 2006 self-report
survey by CCC
Partnership**

www.cancerkansas.org



57 Centers Providing Cancer Services Surveyed

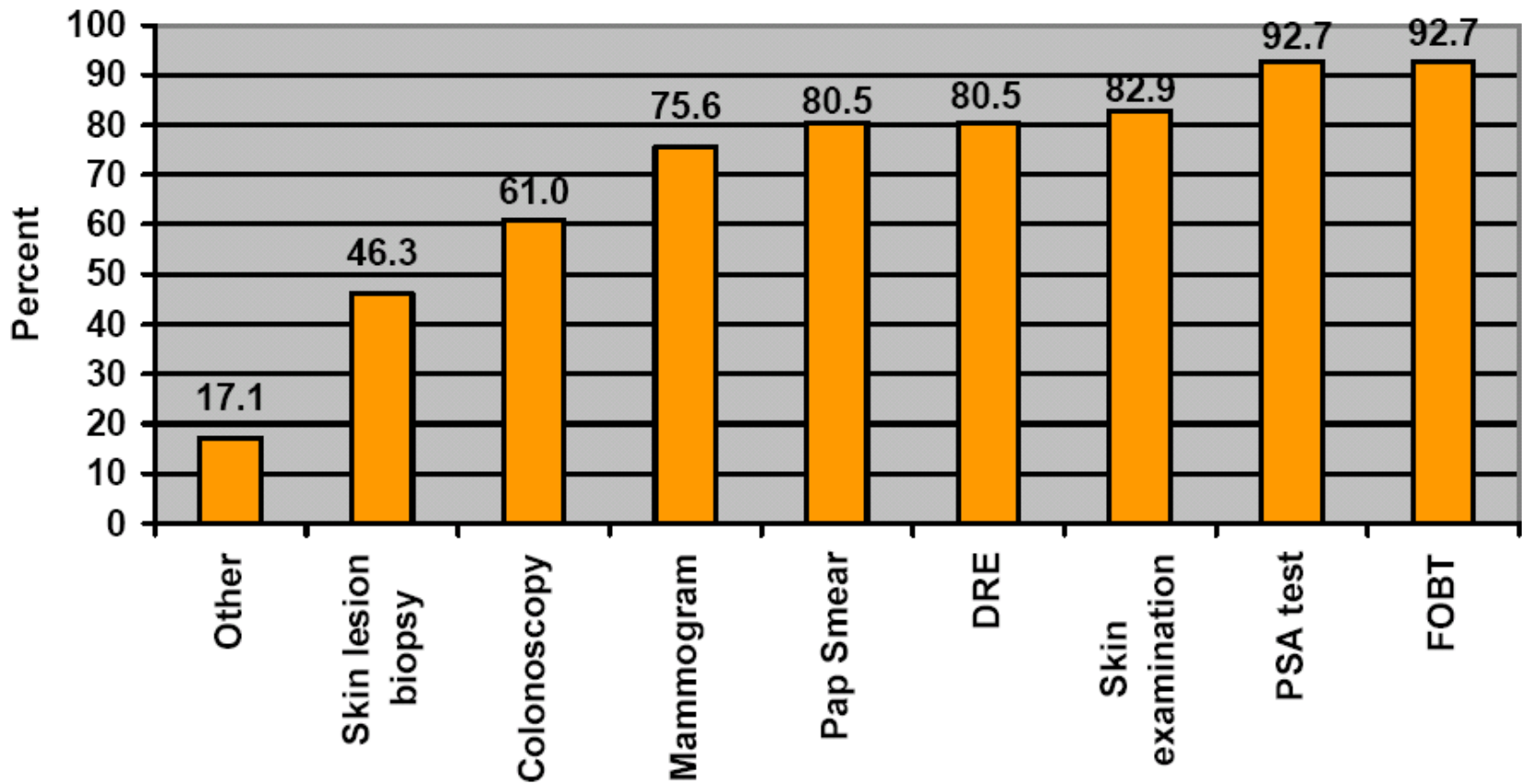
- **Identify statewide levels of coverage for cancer diagnosis and treatment services**
- **Identify strengths and weaknesses of current cancer care delivery system**
- **Inform cancer centers about existing services**
- **Generate pertinent information for future development of a Patient Navigator System in Kansas**

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Percentage of Cancer Centers Offering Screening Services



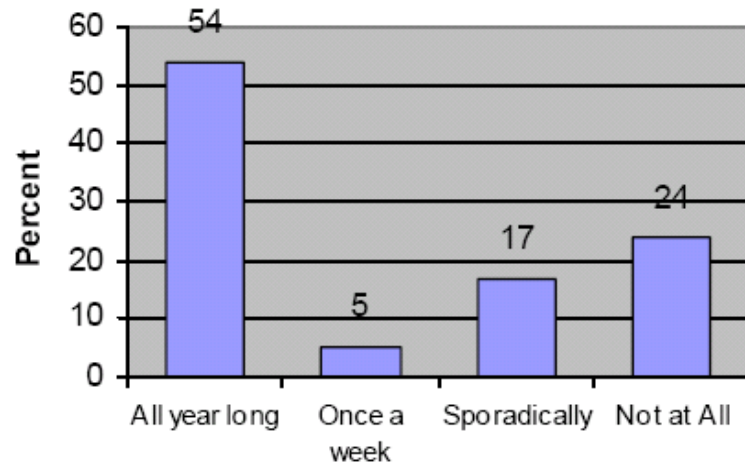
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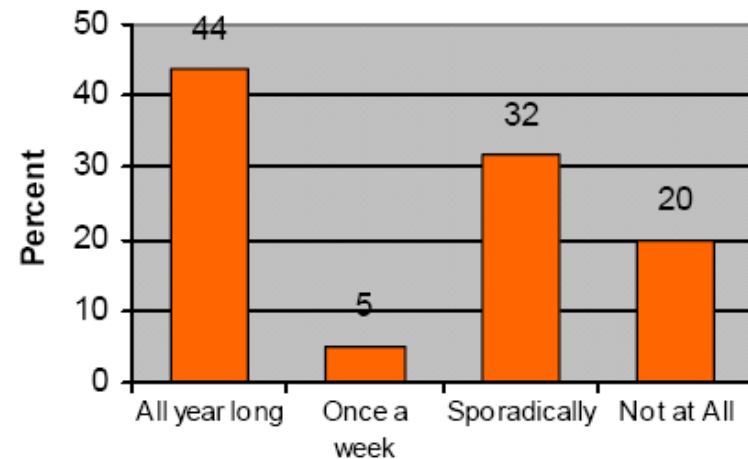
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Availability of Mammography & Pap Smears

Availability of Mammogram, According to The Respondents



Availability of Pap Smear, According to The Respondents



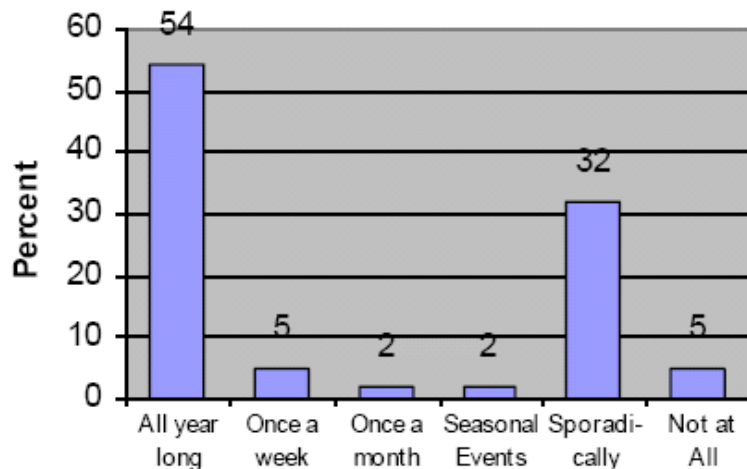
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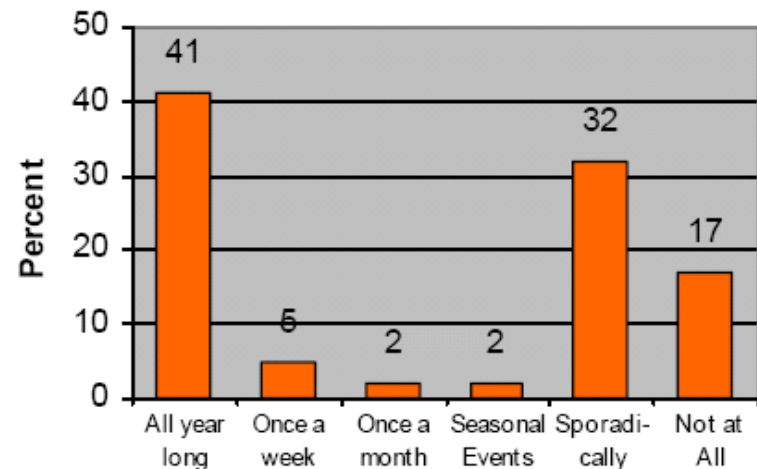
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Availability of Prostate Specific Antigen (PSA) & Digital Rectal Exam (DRE)

Availability of PSA, According to The Respondents

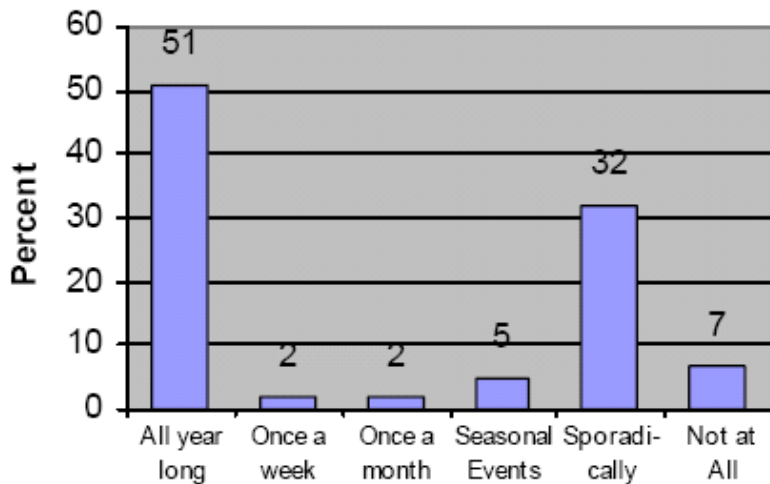


Availability of DRE, According to The Respondents

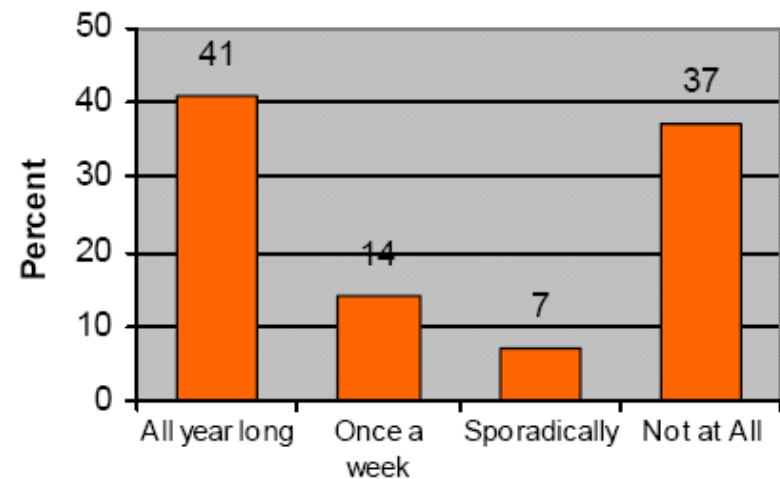


Availability of Fecal Occult Blood Test (FOBT) and Colonoscopy

Availability of FOBT, According to The Respondents



Availability of Colonoscopy, According to The Respondents



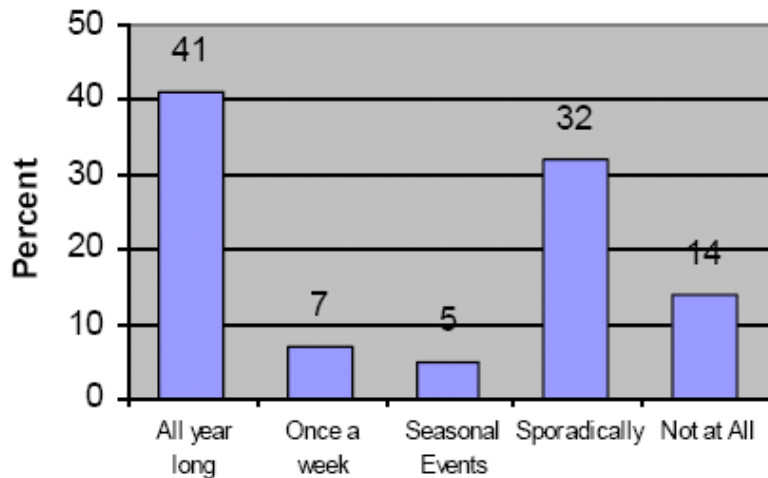
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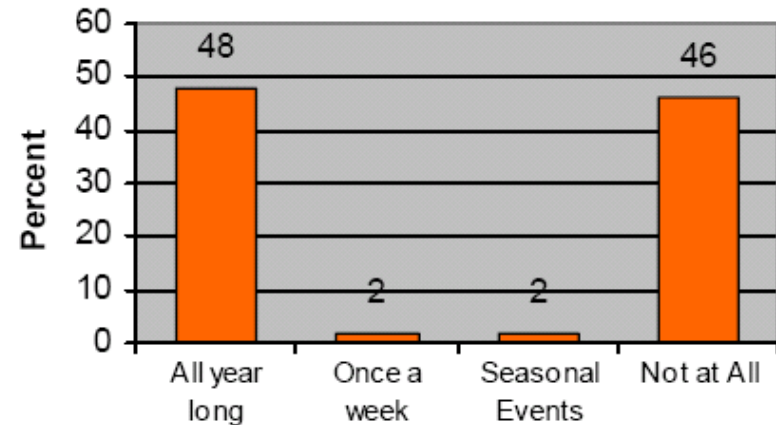
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Availability of Skin Cancer Testing

Availability of Skin Examination, According to The Respondents



Availability of Skin Lesion Biopsy, According to The Respondents



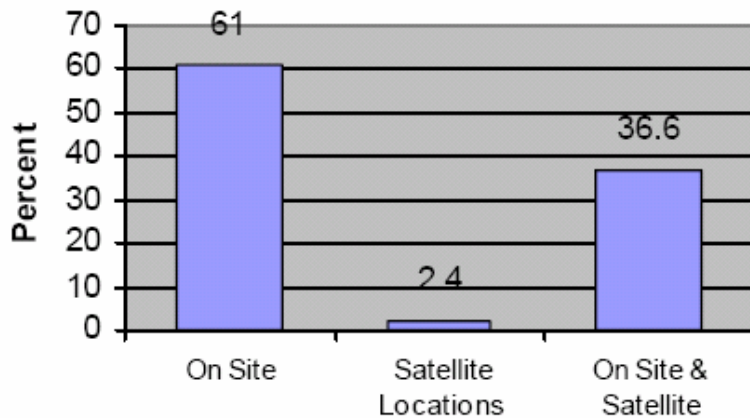
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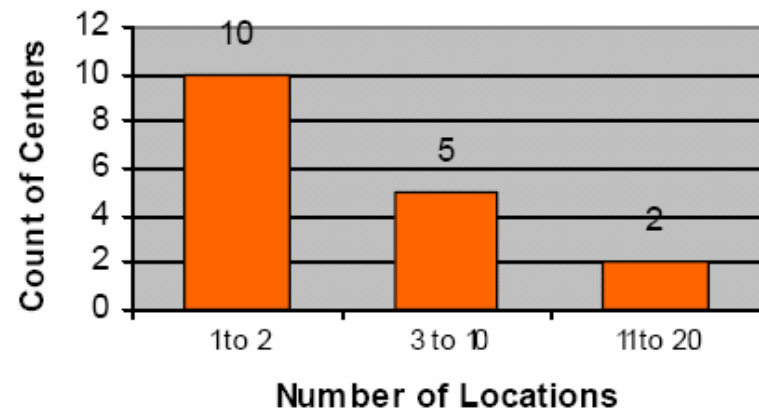
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Location of Screening Services

Locations Where Screening Services Are Provided, According to The Respondents



Distribution of Centers by the Number of Screening Satellite Locations Reported



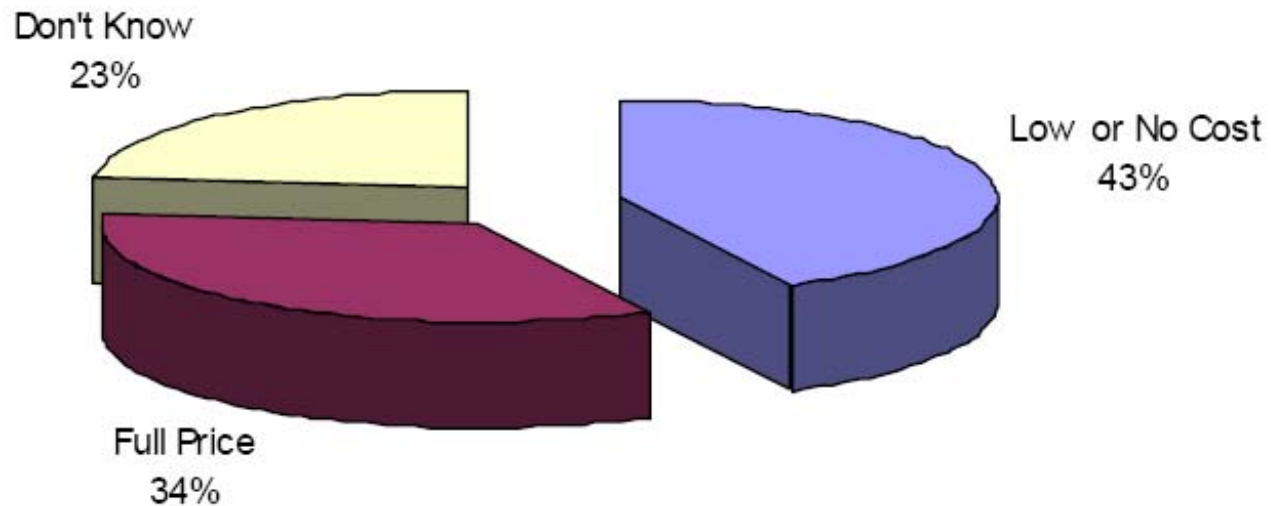
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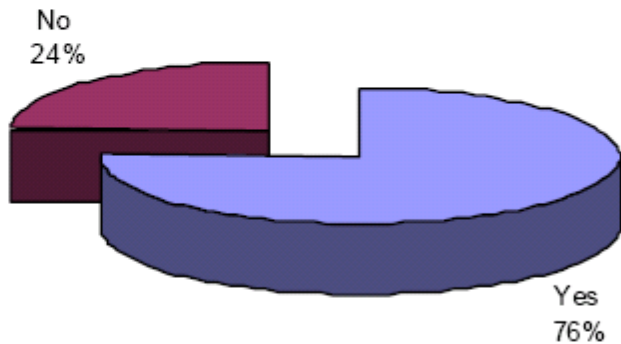
Cost of Services

Percentage of Centers Offering Screening Services at Low or Full Cost

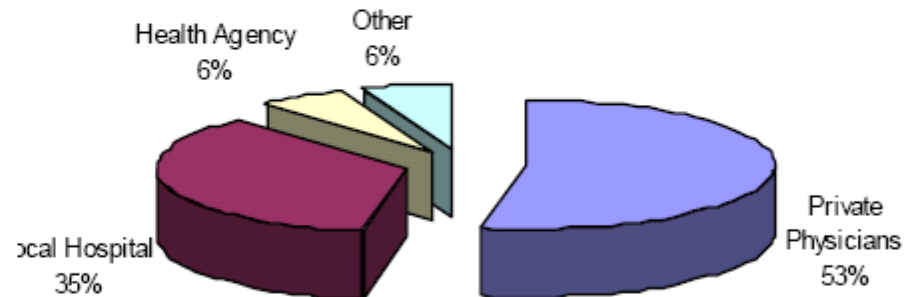


Cancer Diagnosis Services

Percentage of Centers Offering Diagnosis Services in their Facility



Places of Referral for Centers that Do Not Offer Diagnosis Services On Site



Access to Specialists for Cancer Diagnosis & Treatment

Table 1 Level of access to specialists as reported by survey respondents

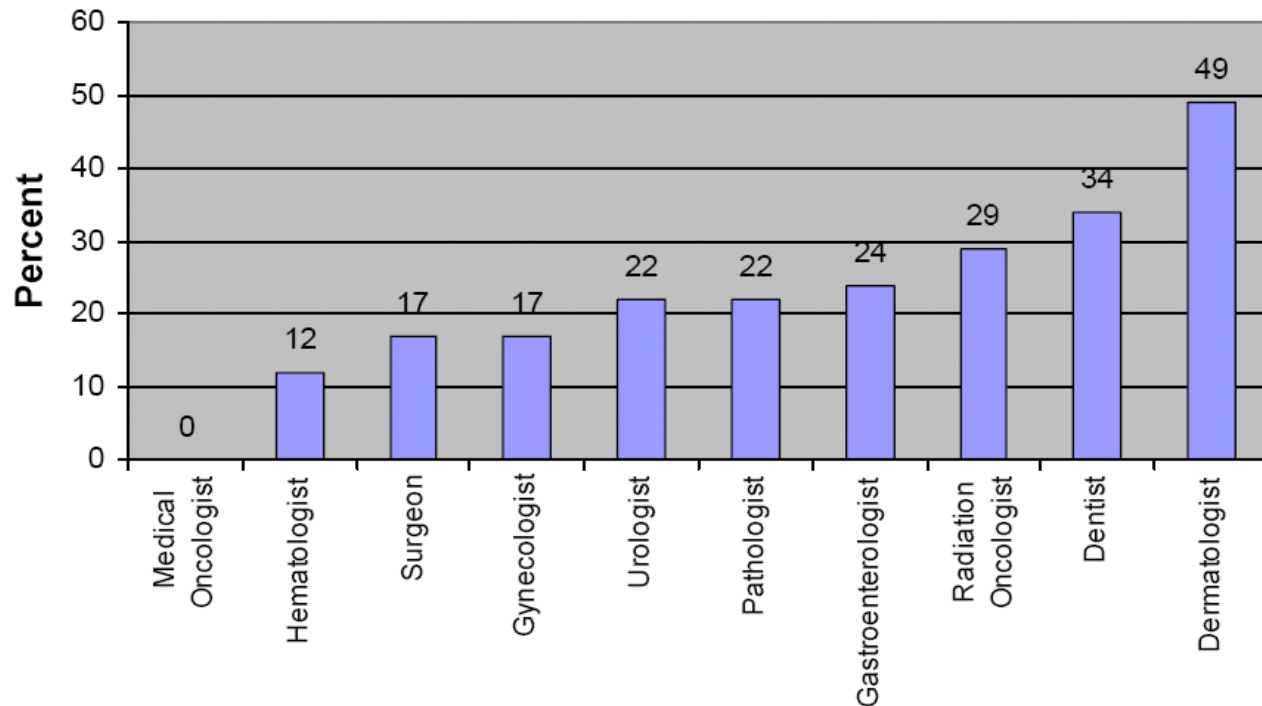
	On Staff	Visiting	No Access
Hematologist	59%	29%	12%
Urologist	54%	24%	22%
Surgeon	71%	12%	17%
Medical Oncologist	76%	24%	0%
Radiation Oncologist	56%	15%	29%
Dermatologist	29%	22%	49%
Gynecologist	61%	22%	17%
Pathologist	51%	37%	22%
Dentist	46%	20%	34%
Gastroenterologist	49%	27%	24%

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Percentage of Respondents Reporting No Access to Specialists, by Category of Specialist

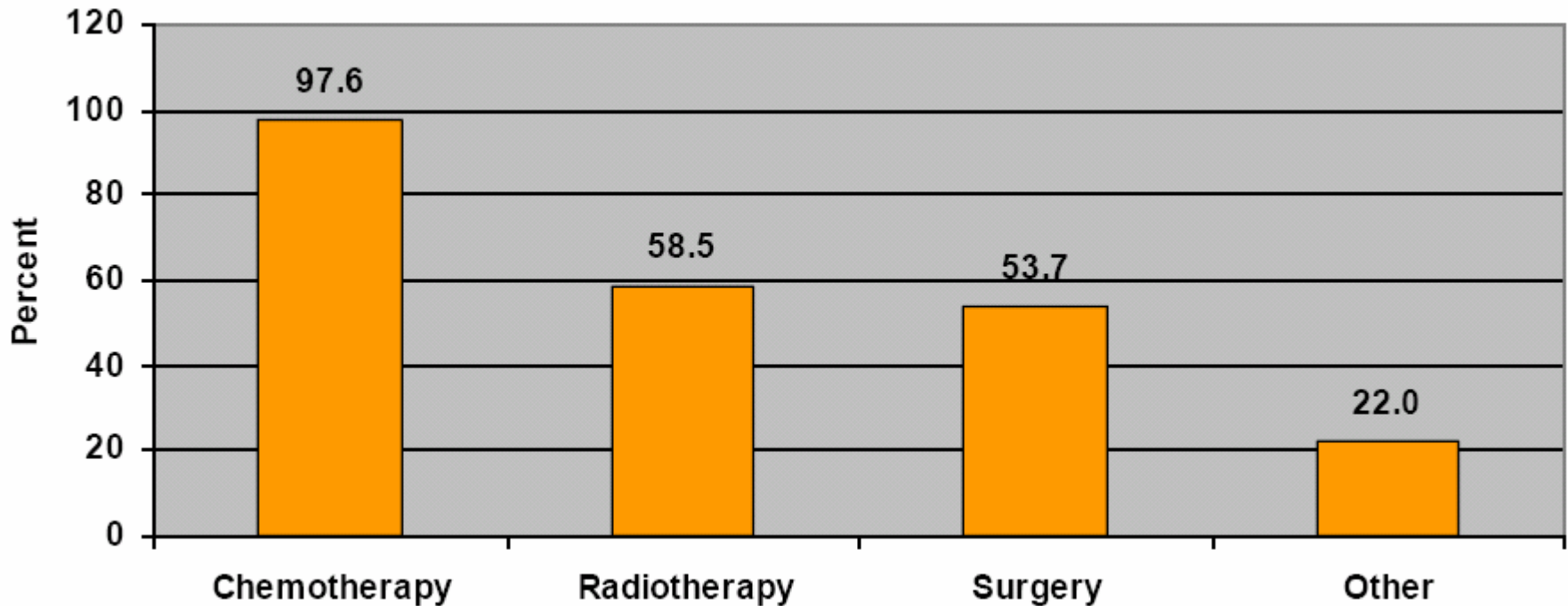


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Percentage of Centers Offering Specific Cancer Treatments

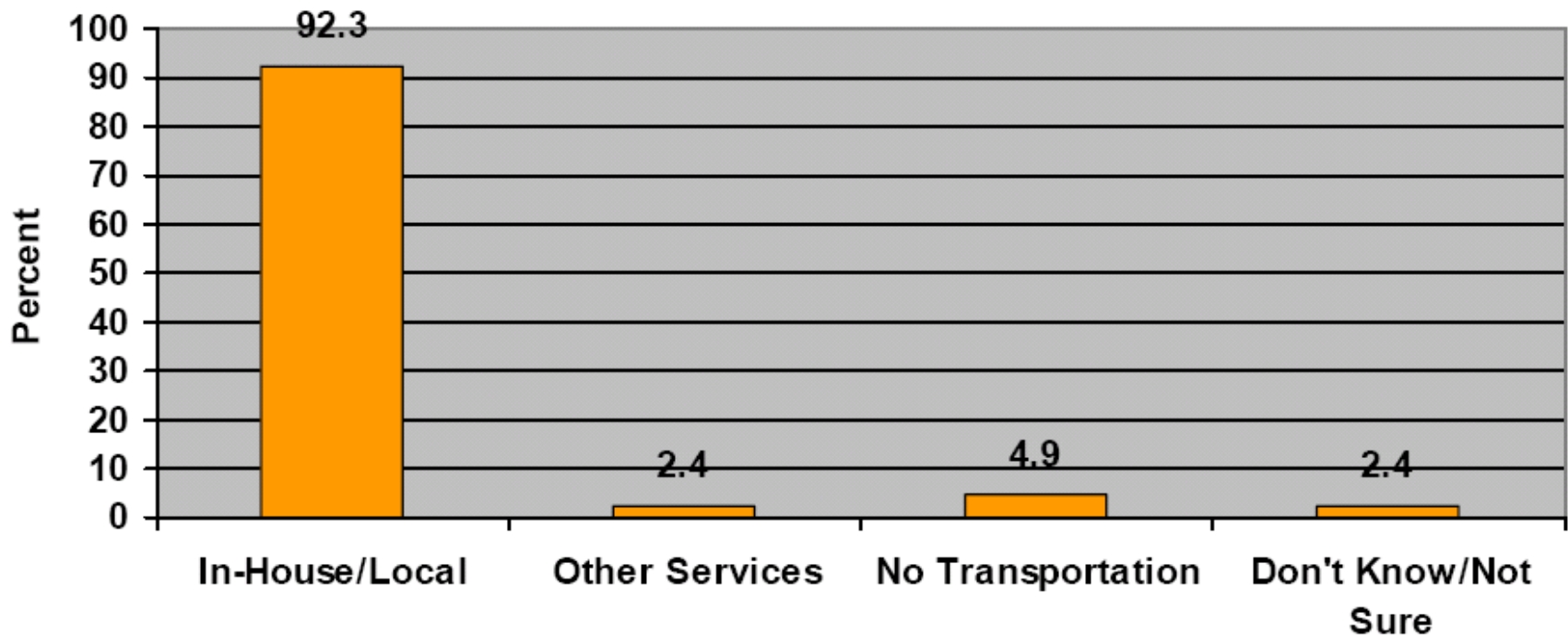


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Other Resources: Types of Transportation Services Available to Patients at Cancer Center



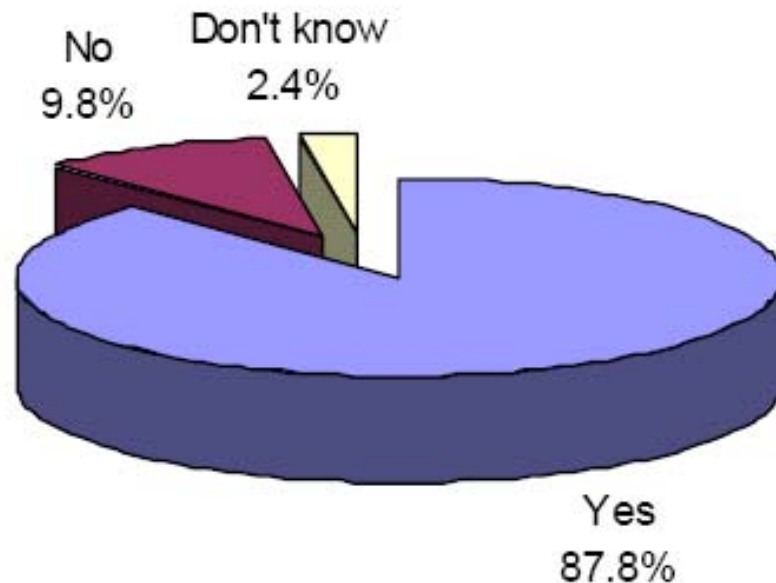
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Facility Sponsored Translation Services

Do patients receiving care at your facility use translation services that you have available?



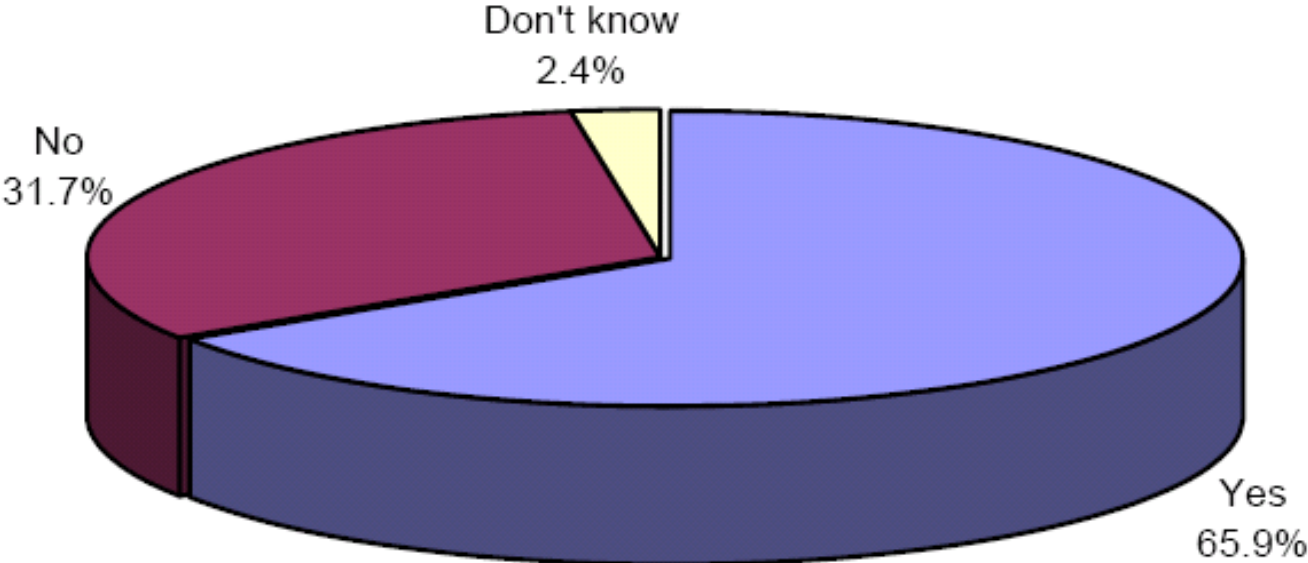
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In-House Resource Center

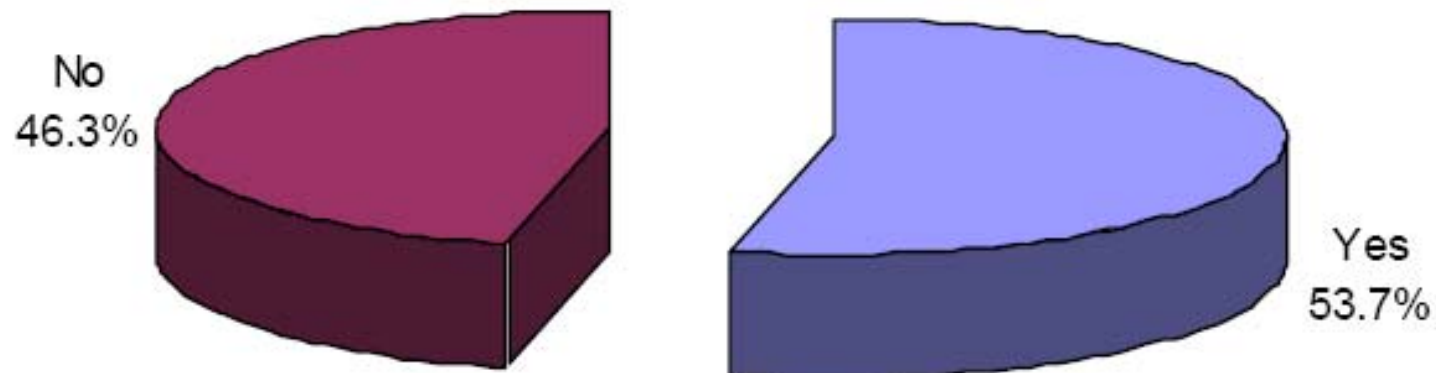
Do you have an in-house library or resource center where cancer patients can come to access information?



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Facility sponsored web access for patients

Do you have on-line access and computers for cancer patients to use?



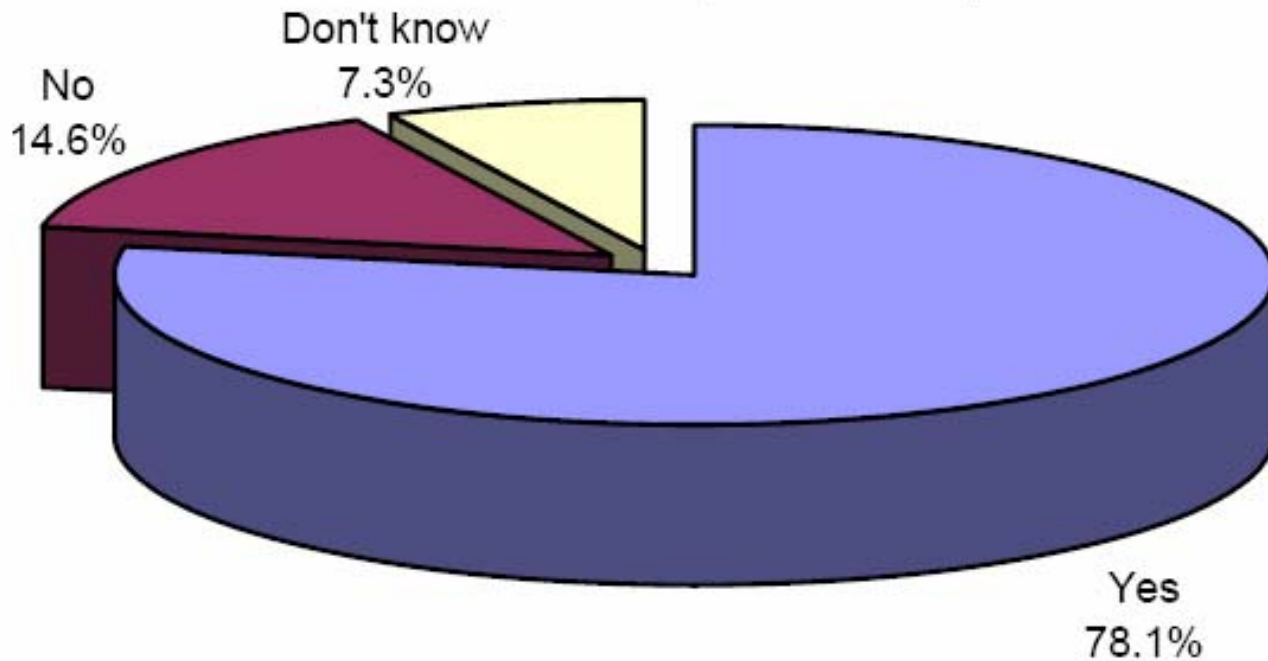
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Availability for Clinical Trial Enrollment

Do cancer patients have an opportunity to enroll in cancer-related clinical trials at your facility?



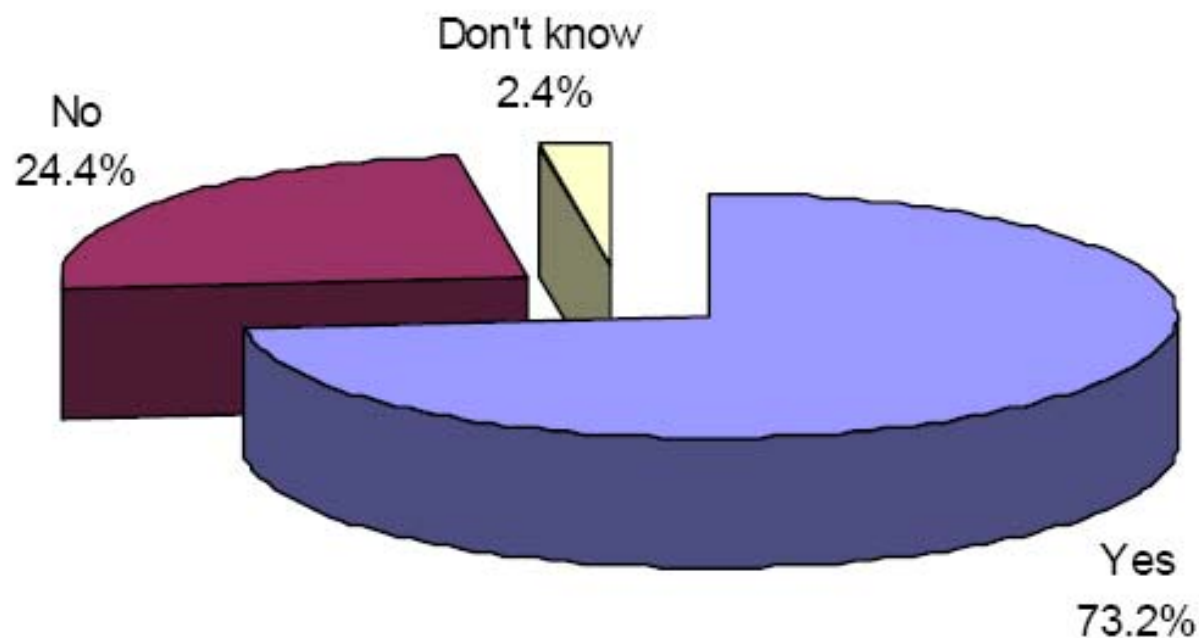
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Clinical Trial Management

Does your facility manage cancer-related clinical trials?



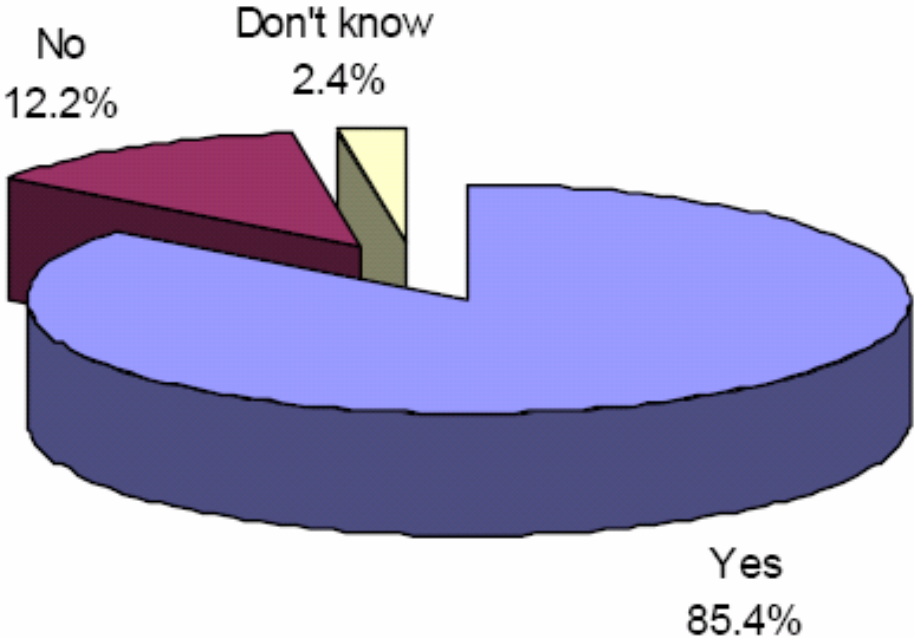
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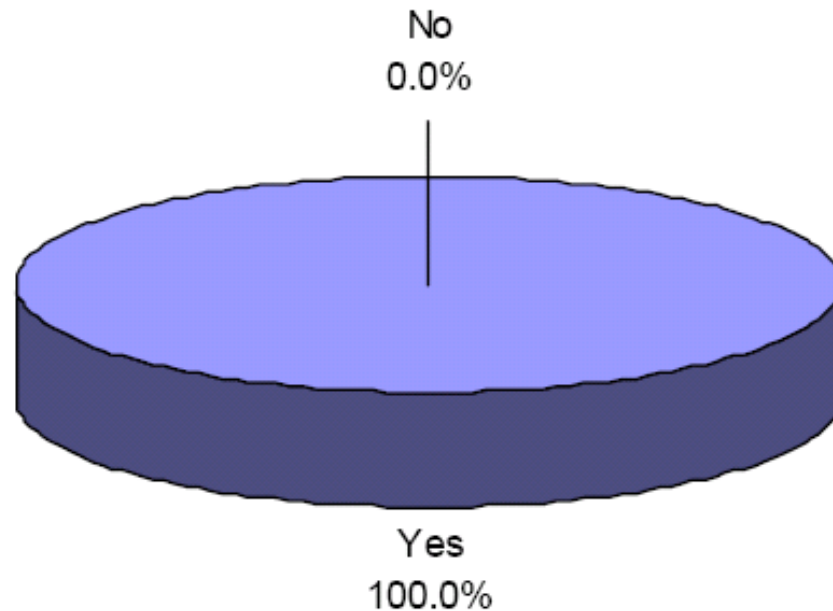
Facility Sponsored Palliative Care Program

Does your facility have a program for palliative care for cancer patients?



Hospice Referral

Does your facility refer terminally ill patients to hospice services?



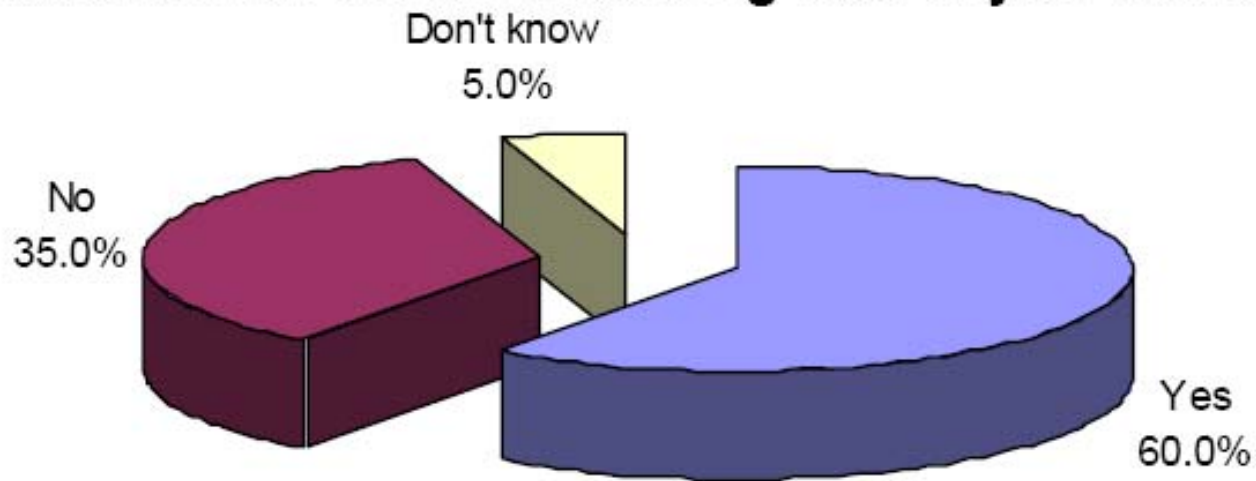
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Sponsored Professionally Facilitated Support Groups

Do you provide support groups led by health professionals for patients with cancer receiving care at your facility?

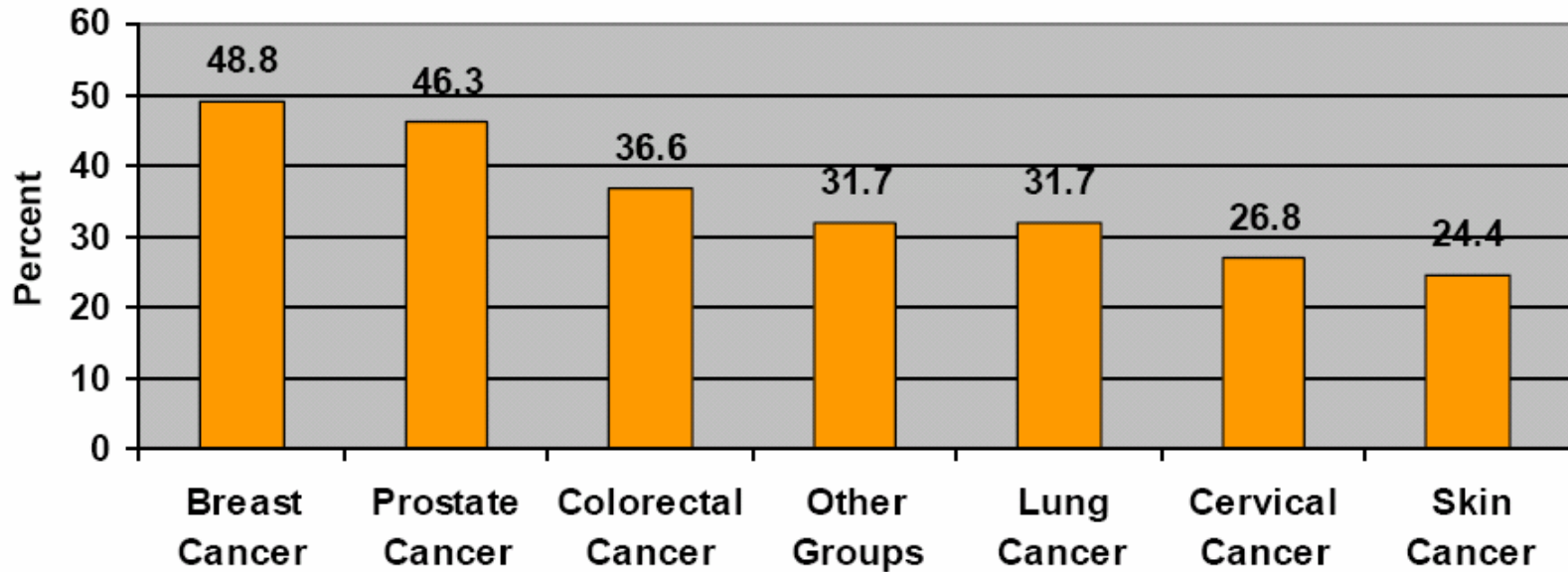


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Availability of Support Groups Reported by Cancer Centers



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Listen and Learn with Cancer Patients and Families

- **Review Process and Demographics**
- **Present Participant Feedback**
- **Identify Key Findings**
- **Propose Potential Action Steps**
- **Formulate Key Recommendations**

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Survivorship and End of Life

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More people survive cancer

- Prevention, earlier detection, and improved treatment exhibit profound effects on survival rates.
- In the 70s, about 50 percent of cancer patients survived five years or longer.
- By the late 1990s, rates had increased to 65 percent.
- First ever cancer death decline reported in 2006

Is Cancer becoming a Chronic Disease?

- **Earlier Detection**
- **Prevention works**
- **Longer Survival rates**
- **Improved treatment effectiveness**
 - **Prevention through vaccines (HPV, Hepatitis B)**
 - **Certain cancers more responsive to treatment**
 - **Co-morbidities affected by earlier detection**
 - **Late effects can sometimes be less burdensome**

2006 Listening Process

LIFE Project responsibilities:

- ***Develop “Listen and Learn” inquiry***
 - ***Open ended questions***
 - ***Consistent format and uniformity***
- ***Administer individual patient/caregiver surveys***
- ***Identify and convene groups across state in separate locales***

Focus Group Limitation:

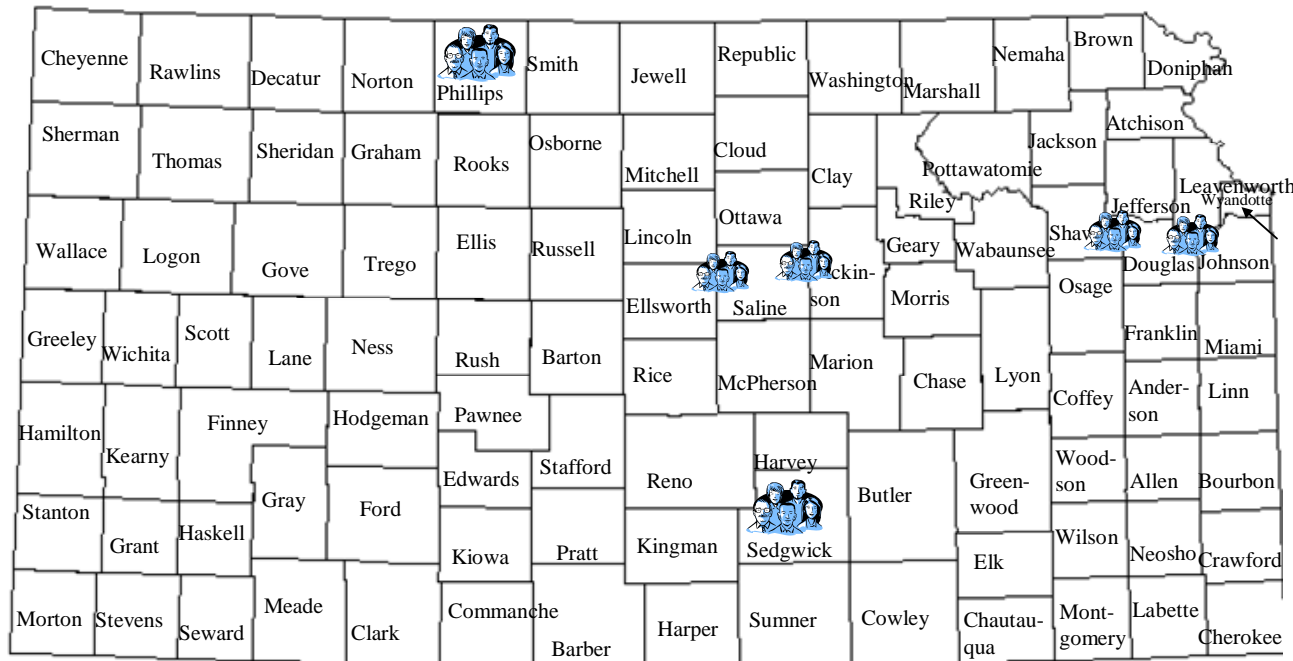
Demographic bias – insured, educated, female and white

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Listening Process Locations



- ❑ 52 Cancer survivors & Caregivers
- ❑ 6 groups, 4 communities
- ❑ Spring of 2006

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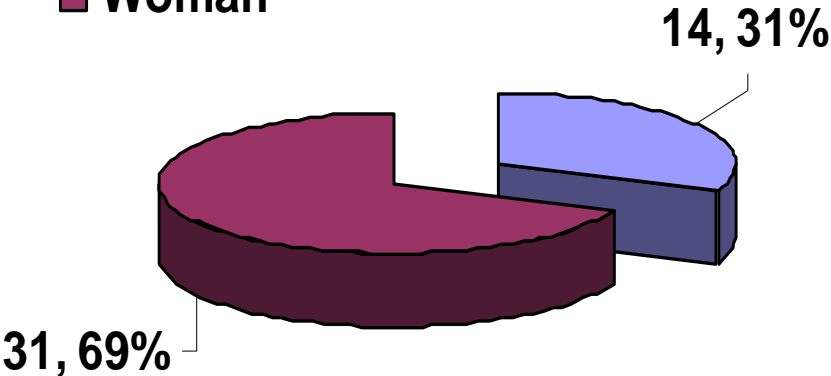
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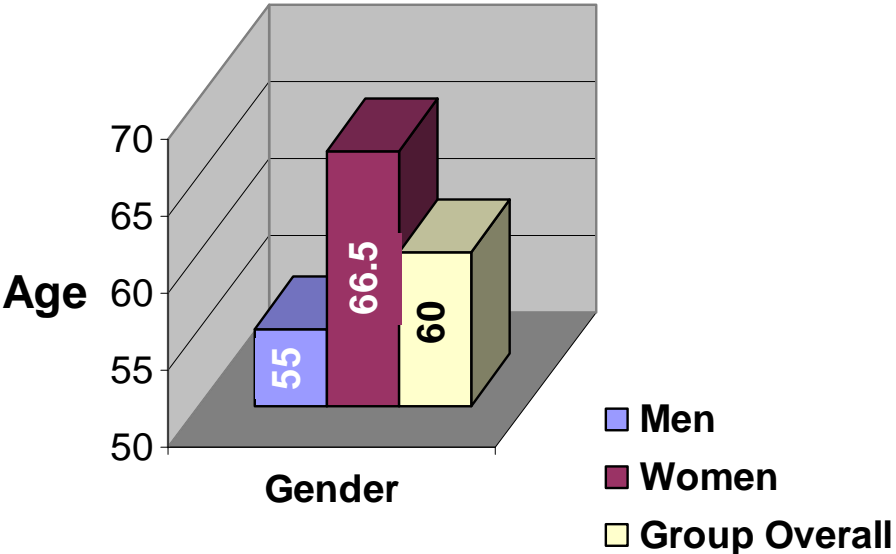
Listening Group Participant Profile

Participants by Gender

- Men
- Woman



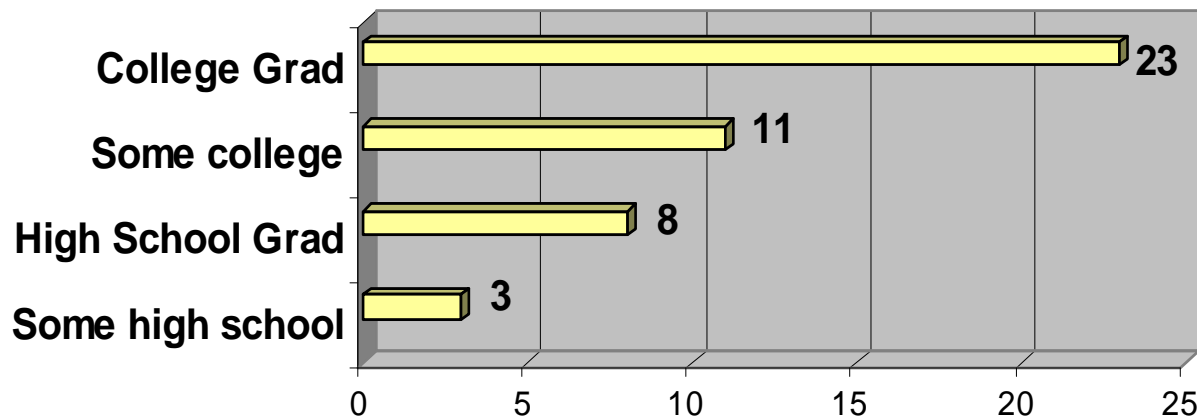
Median Age



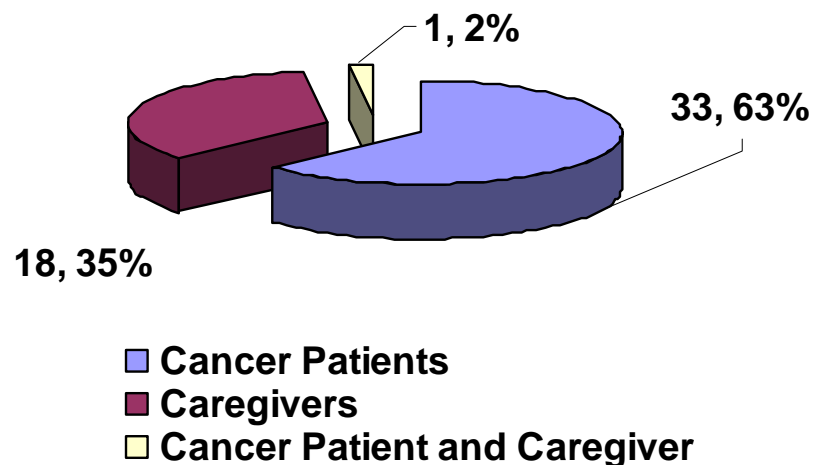
Predominantly Female
Mature

Listening Group Participant Profile

Level of Education



Experience with Disease Process



Educated
Experienced

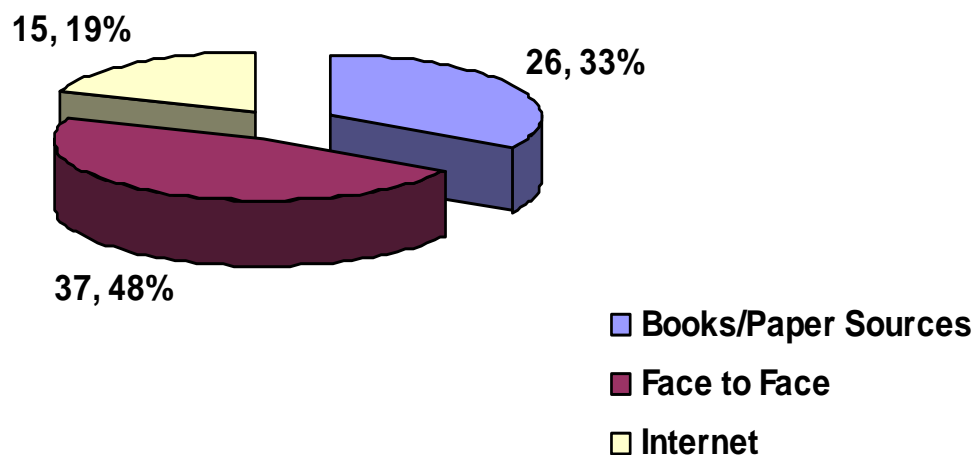
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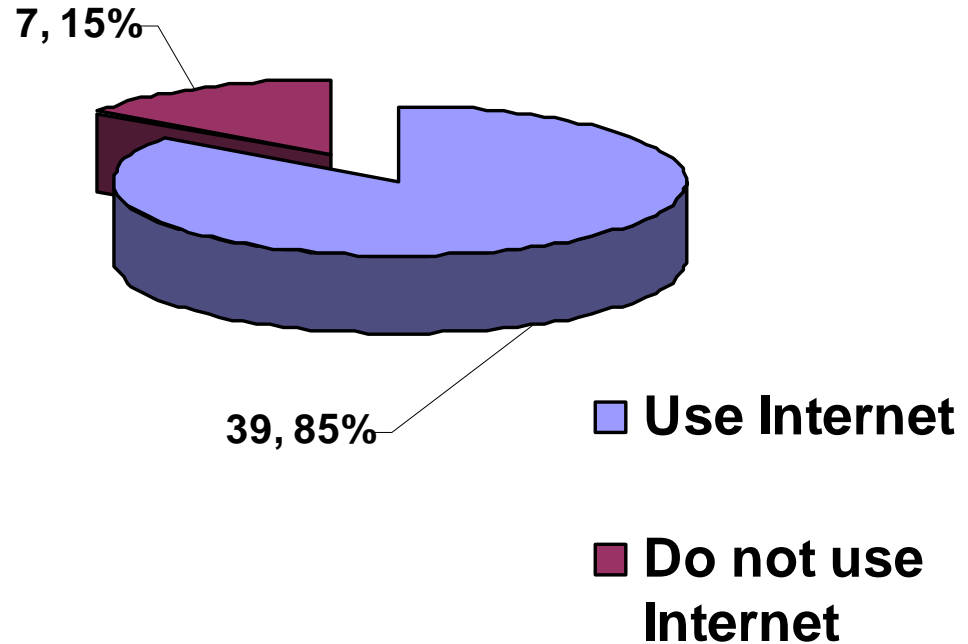
Listening Group Participant Profile

Participant Preference in Obtaining Medical Information

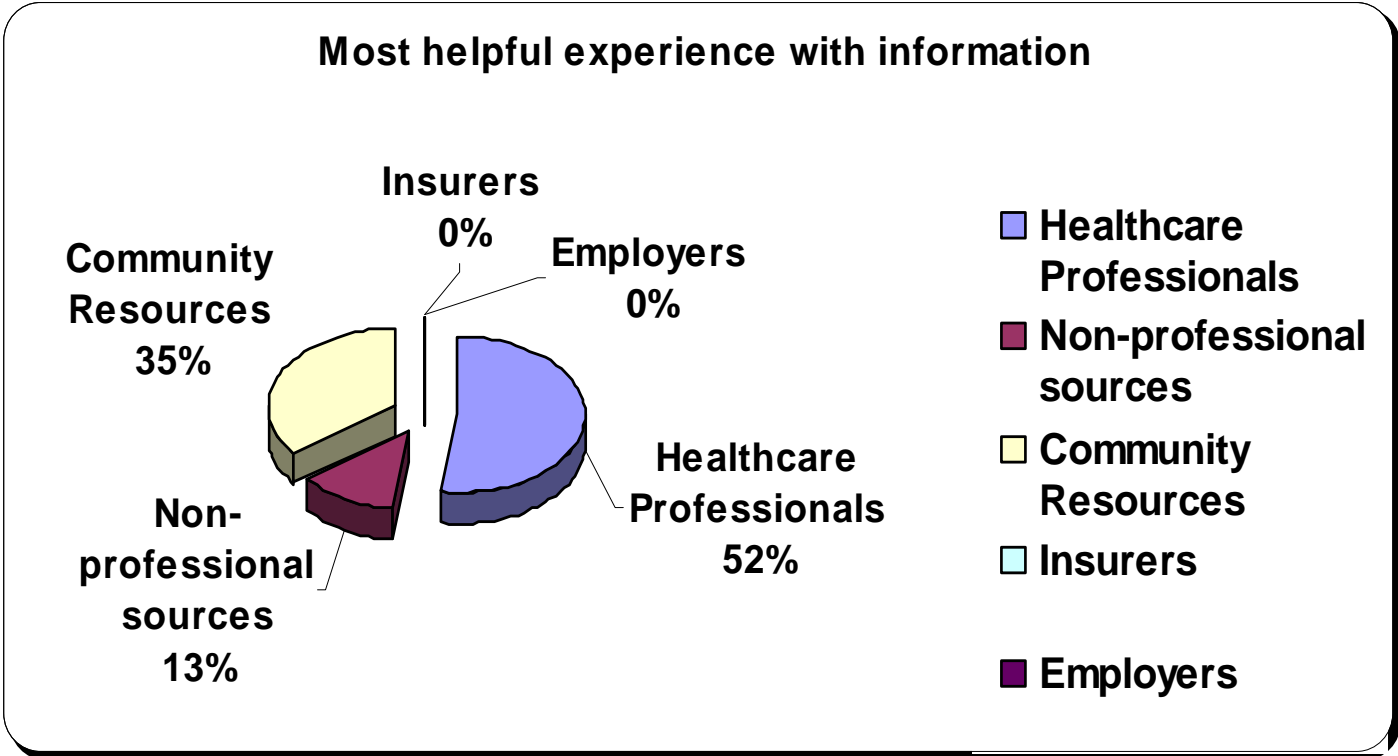


Listening Group Participant Profile

Participant Utilization of Internet for
Information

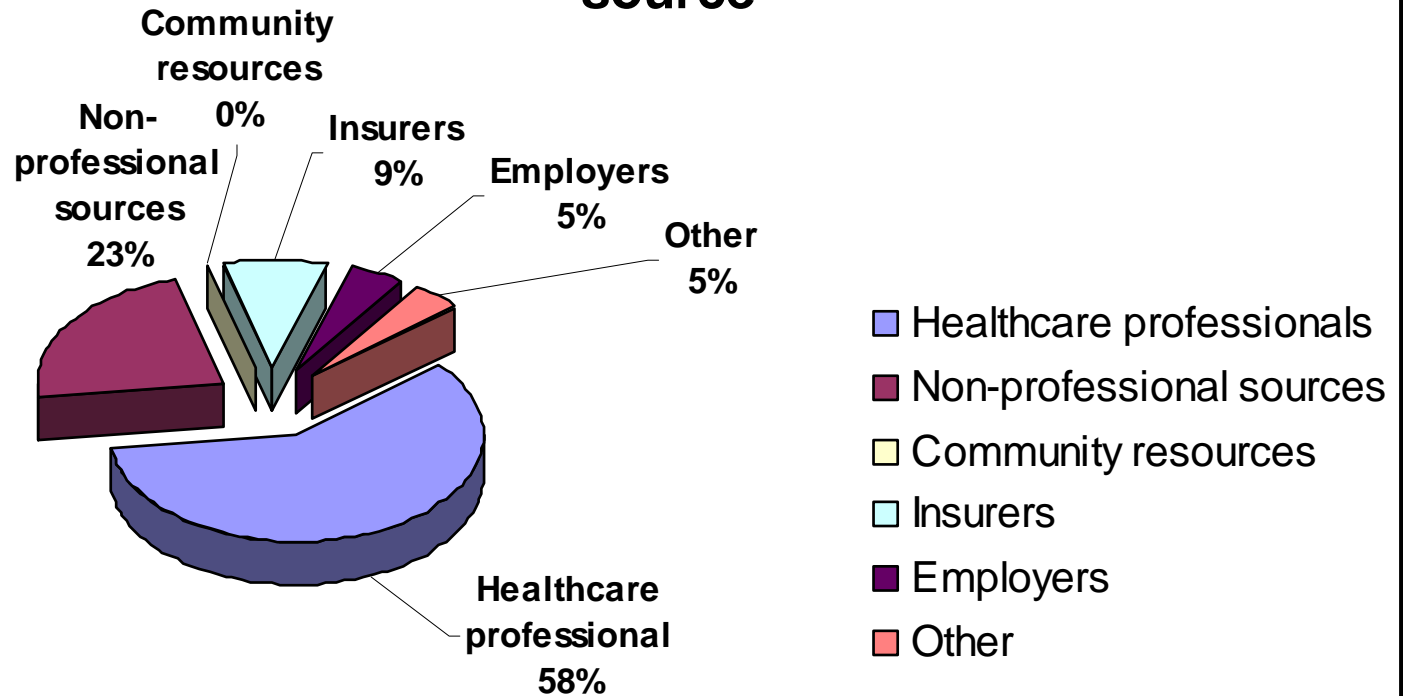


Listening Group Participant Feedback



Listening Group Participant Feedback

Least helpful experience with information source



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“My employer was not supportive and made me feel guilty about taking time off to get treatments.”

“No one was able to show me a picture of how this (mastectomy) would look and that would have been a great help.”

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“I became dependent on my role as cancer patient. It is what defined me.”

“The doctor gave me a 15% chance of living– I thought, well somebody’s got to do it. It might as well be me.”

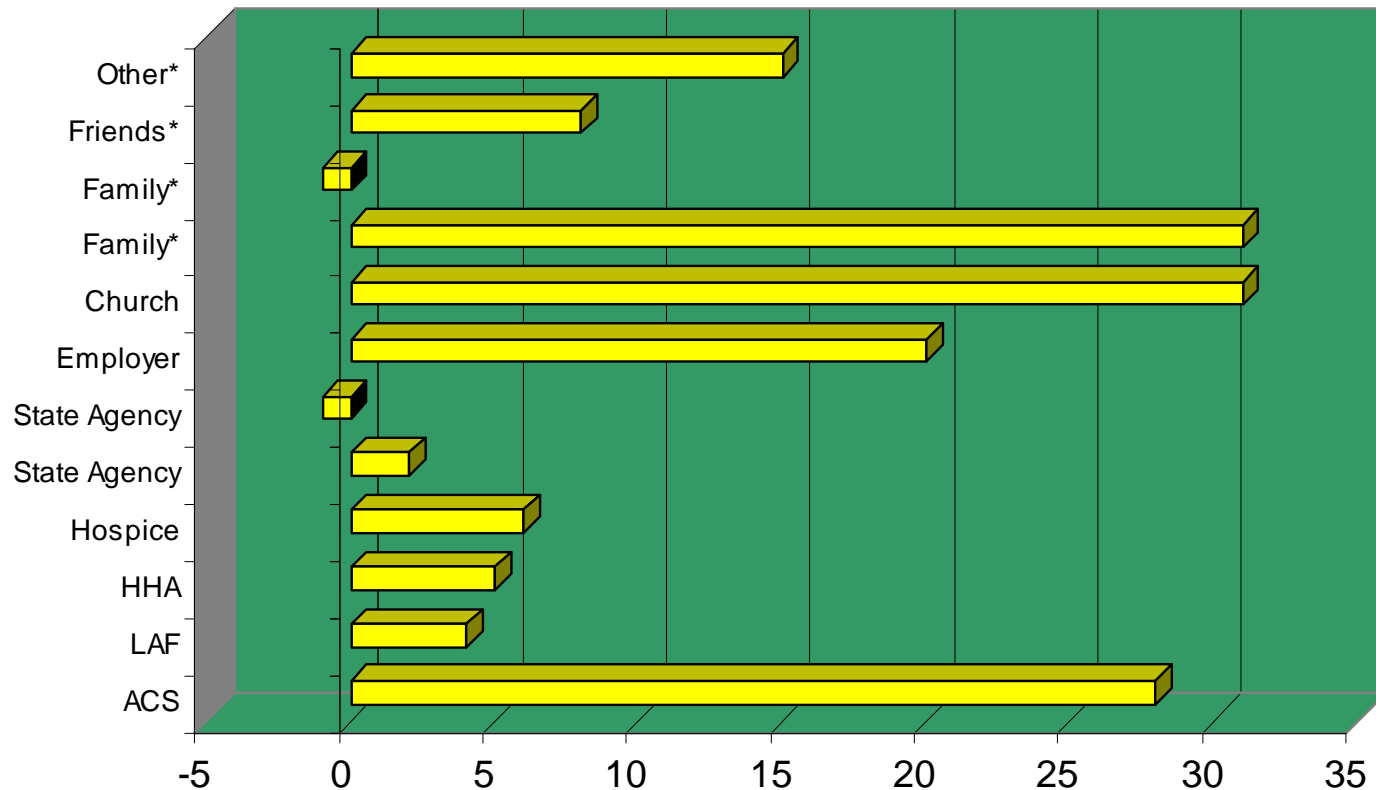
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Listening Group Participant Feedback

Ratings of Services Received from Key Sources

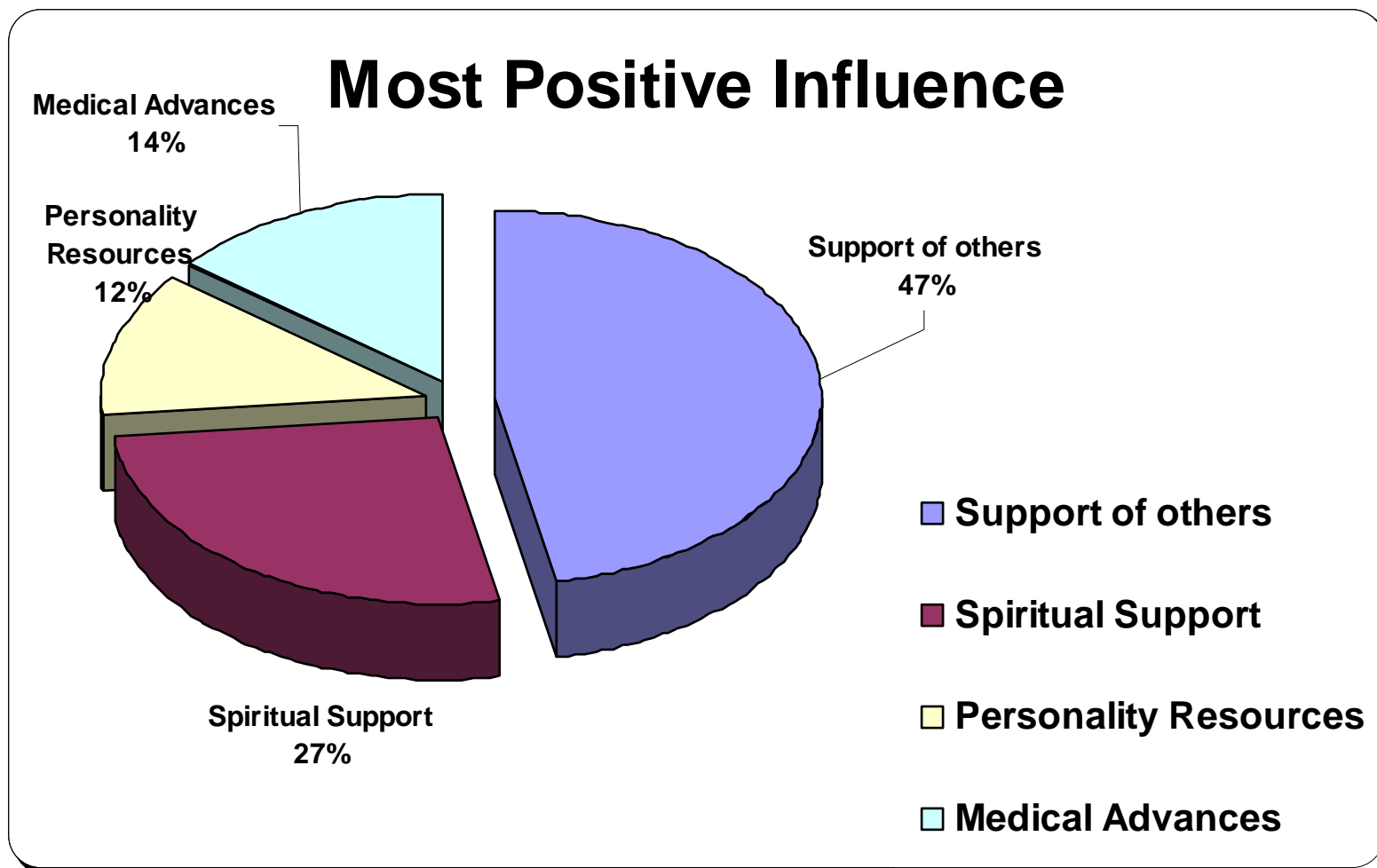


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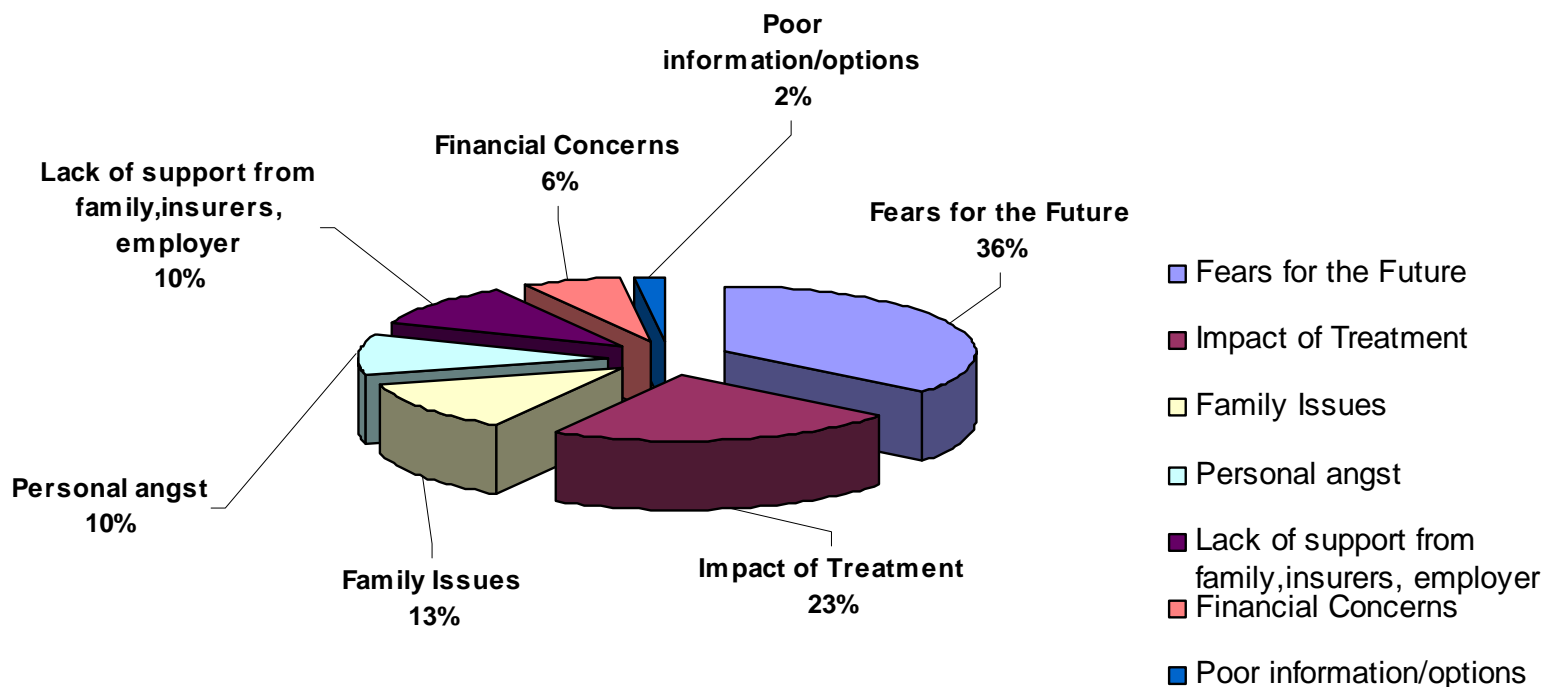
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Most Difficult Issues Faced



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“The whole world stops.”

“There is the issue of identity.... All a patient does is sit in the doctors' offices and schedule appointments. That becomes your life.”

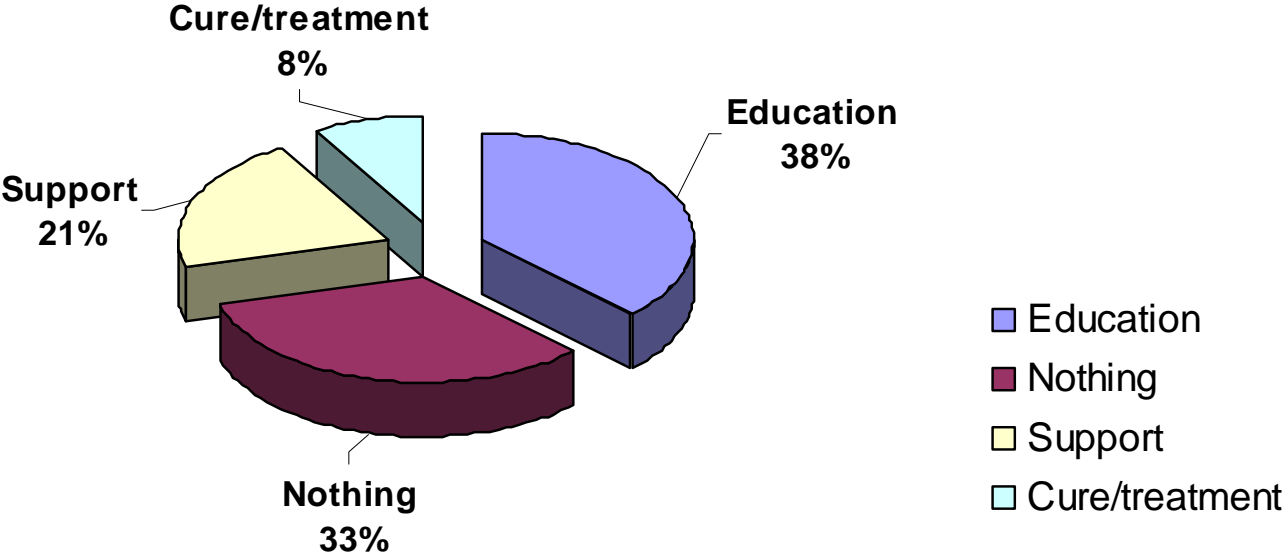
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Listening Group Participant Feedback

Wished for or needed and did not find



Listening Group Participant Feedback

“It is important to be in control of the situation; patient must be, first of all, in control – nothing goes to family without first going through patient.”

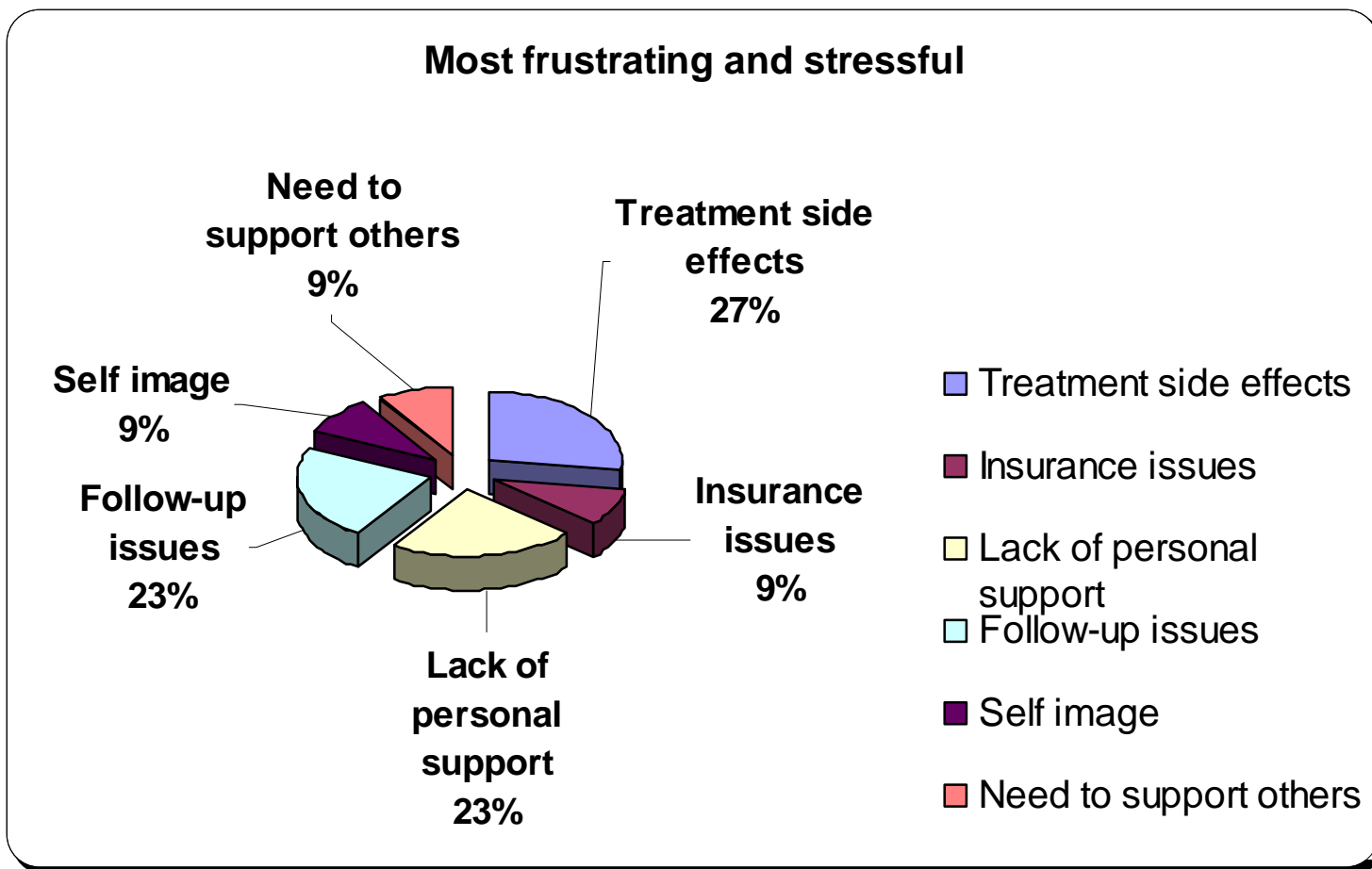
“I don’t know how to be my own advocate.”

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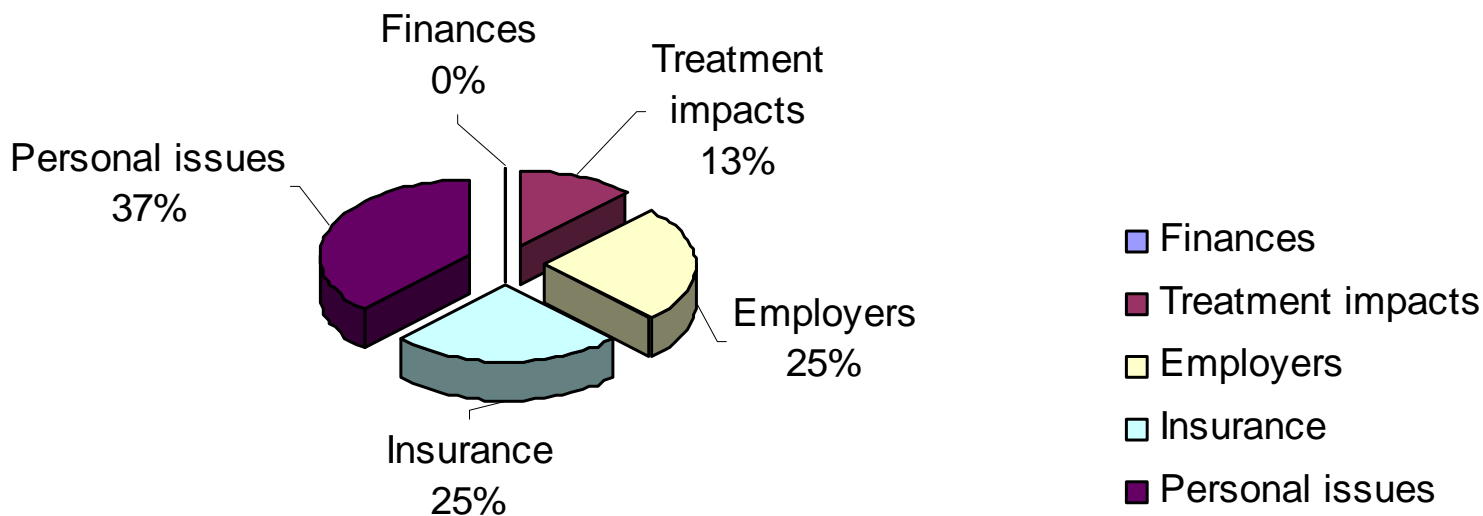
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Listening Group Participant Feedback

Least able to find support and information and resources to deal with

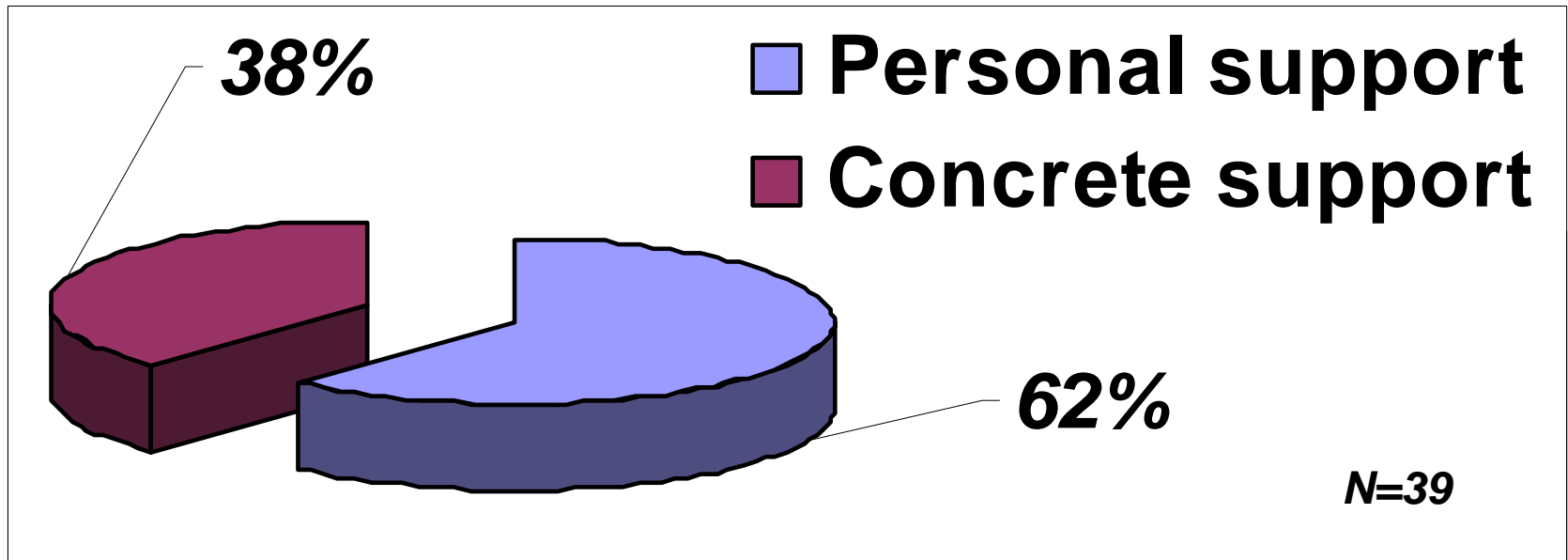


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Most needed...Didn't get



Concrete Support – items such as transportation, wigs, prostheses, concessions from employer, medical equipment

Personal Support – includes need for someone to talk with and/or listen

Key Findings

- ***Self-advocacy***
 - ***Throughout process of receiving care Kansas cancer patients and caregivers must serve as their own advocates.***

- ***Support groups***
 - ***critical sources of information***
 - ***coping for both patients and caregivers.***

Key Findings

- ***Importance in Overall QOC***
 - ***Healthcare providers who:***
 - ***talk openly with patients***
 - ***help them understand their choices***
 - ***honor their choices***
- ***Major source of anxiety***
 - ***Waiting for tests results***
- ***Great Importance to patients & families***
 - ***When and how patients are informed***

Potential Action Steps

- **Follow-up assessments to assure psycho-social needs being met.**
- **Educate Kansans to expect good pain management and how to serve as self advocates.**
- **Identify best practices in insurance**
 - **Review variances**
 - **Promote and recognize excellence through Kansas Insurance Commissioner**

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Potential Action Steps continued

- **Explore provider best practice in patient preferences**
 - **Consider variance in patient needs**
 - **Identify practitioner solicitation and response**
 - **Match need (gap) with resources**
 - **In faith communities**
 - **ACS and other support providers**
 - **Family support networks**

Potential Action Steps continued

- **Examine the interaction and collaboration between (among) groups**
 - **Assess resources and assets of each**
 - **Examine and identify ways for increased partnering.**

Potential Action Steps continued

- **Workplace - Employer Best Practice**
 - Identify and Recognize (Reward)
- **Provide support and resources to HR**
 - Develop demonstration project(s) with employer/s (e.g. State of Kansas) to showcase environmental (workplace) excellence for cancer survivors.

Potential Action Steps continued

- **Address healthcare policy deficits**
 - Relative to age and health status.
 - Rapidly changing demographics make this need more apparent.
- **Consider value and benefit of mentoring programs.**
- **Develop caregiver support measures as integral to patient care.**
- **Study efficacy of low cost awareness campaigns.**

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Potential Action Steps continued

- **Assure all cancer patients voluntary access to cancer support groups**
 - Develop measures and interventions.
- **Assess support group utilization factors**
 - Information and referral
 - Patient and Survivor self-determined “support” - *“What I need” not what’s offered.*
- **Educate providers in responsibility to help patients find meaningful support groups.**

L&L Group Participants

Key Recommendations

- ***Provide Kansas cancer patients survivors and caregivers with information and support to serve as self-advocates.***
 - Centralized
 - Easy to find
 - Easy to understand

Key recommendations continued

- ***Assure support groups are available and accessible to all Kansas cancer patients and families.***
 - Identify support groups in every Kansas County

Key recommendations continued

- ***Provide focused education to Kansas healthcare providers***
 - ***Stressing key components of good communication with patients,***
 - ***Breaking bad news, and***
 - ***Understanding issues and needs faced by cancer patients.***

Key recommendations continued

Raise the Bar

- ***Provide leadership in support of***
 - ***patient advocacy***
 - ***high expectations for care and quality of life***
 - ***provision of information and resources to patients.***
- ***Provide employer education and spur action to better meet needs***

Next Steps....

- **KCCCPP leaders**
 - Determine available resources (human and financial) volunteer, in-kind and paid
 - Prioritize Key Recommendations and Action Steps
 - Secure new partners & commitments like **YOU!**
 - To learn more go to www.cancerkansas.org



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