

# Access to Care in Cancer 2016: Barriers and Challenges



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COMMUNITY**

*A Global Network of Education and Hope*



OPENING REMARKS

# Kim Thiboldeaux

CEO, Cancer Support Community



KEYNOTE

# Greg Simon

Executive Director White House Cancer  
Task Force

# Questions?



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COMMUNITY**

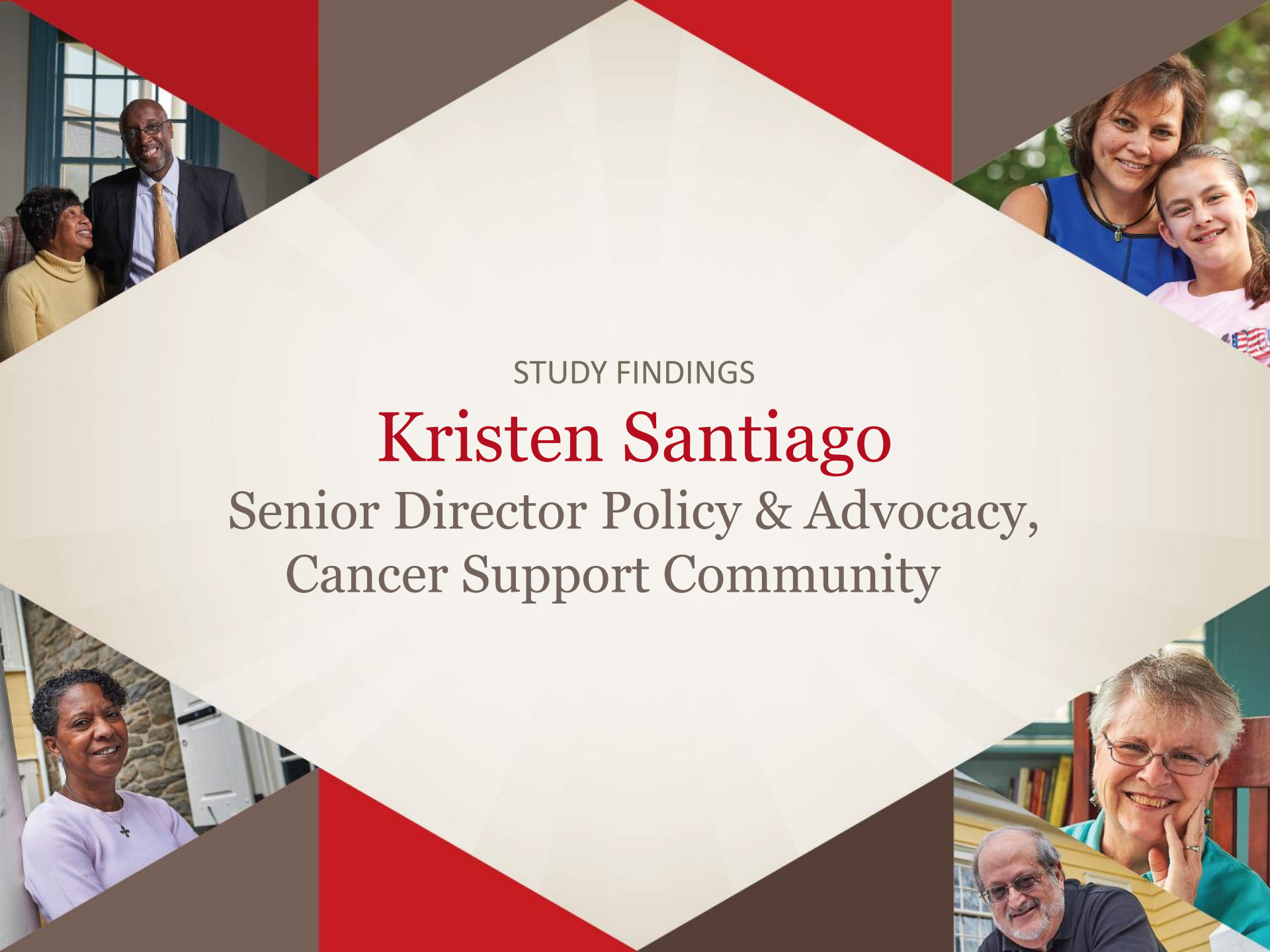
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PATIENT PERSPECTIVE

# VJ Sleight

Tobacco Treatment Specialist

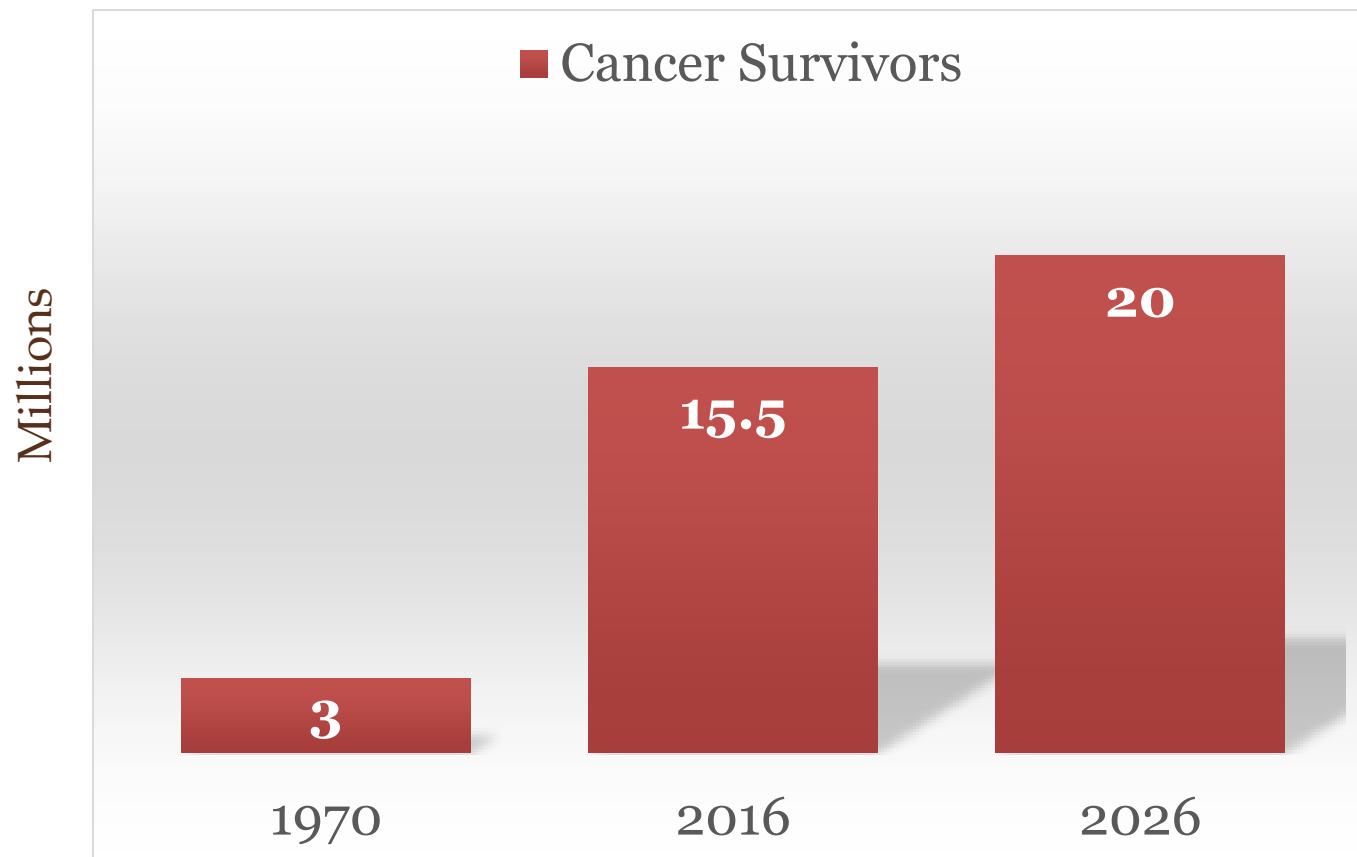


STUDY FINDINGS

# Kristen Santiago

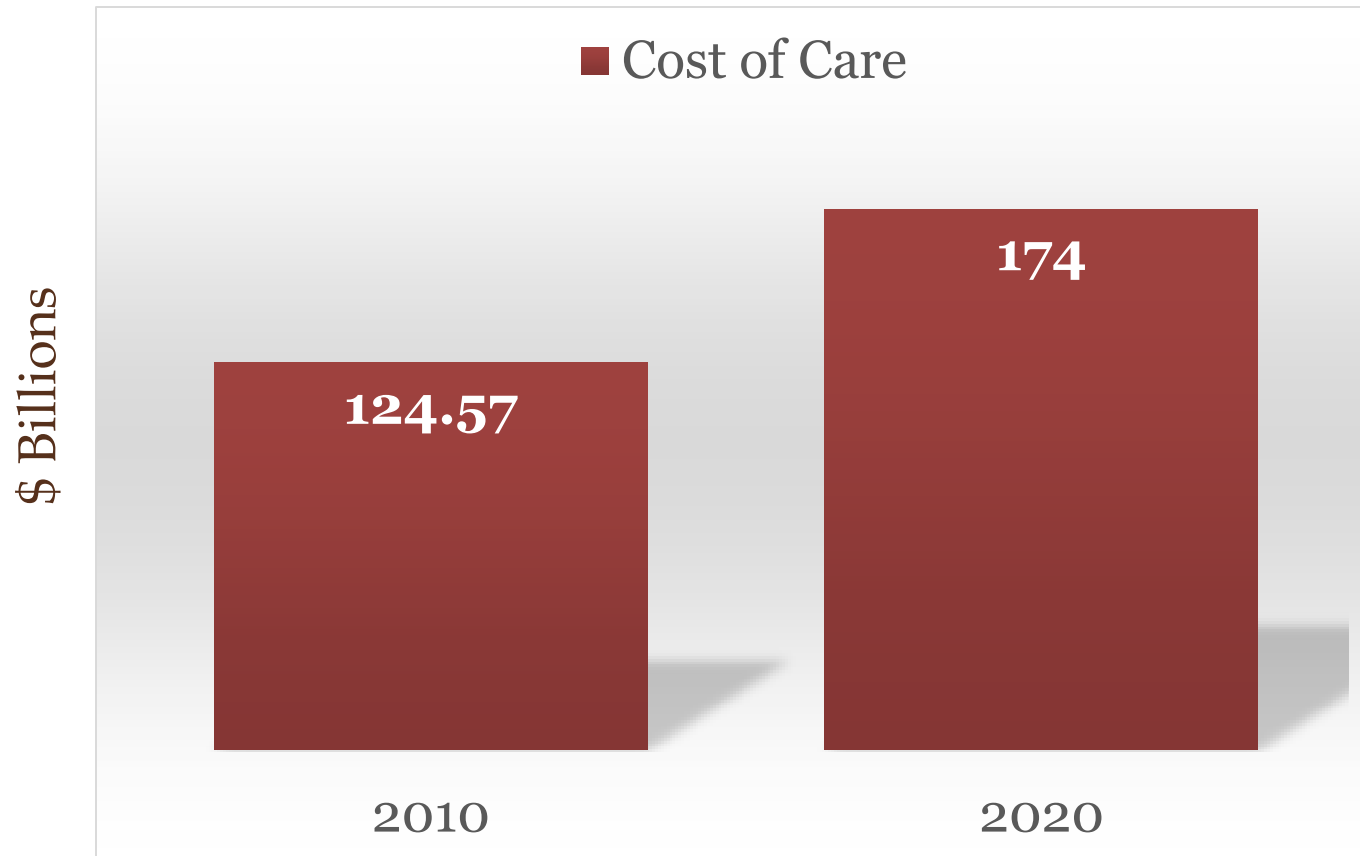
Senior Director Policy & Advocacy,  
Cancer Support Community

# NUMBER OF SURVIVORS



Source: American Cancer Society, Cancer Facts, 2016

# RISING COST OF CARE



Source: Mariotto et al, JNCI, 2011



# UNINSURED IN THE U.S.



## Percentage Uninsured in the U.S., by Quarter

Do you have health insurance coverage? Among adults aged 18 and older

■ % Uninsured



Quarter 1, 2008 – Quarter 1, 2016

Source: Gallup Healthways Well-Being Index



# Study Findings

# ACCESS TO CANCER CARE 2016

## Purpose



- Identify patients' issues, concerns and barriers regarding:
  - Access to health insurance
  - Access to services
  - Treatment decision making
  - Cost of care
  - Cost containment strategies
- Communicate the learnings to the broader cancer community, including health care providers, advocates and policymakers

# ACCESS TO CANCER CARE 2016

## Overview of Findings



The findings in the report highlight that despite progress being made expanding access to health care, many patients still experience numerous barriers and challenges. In particular:

- Increased cost
- Significant levels of uncertainty
- Delays
- Trade off decisions

# ACCESS TO CANCER CARE 2016

## Methodology



- Approved by the Independent Review Board
- Based on a cross-sectional survey of adults 18 years old and older affected by cancer
- Conducted online between June and August of 2016
- Recruitment through CSC's online network, affiliate network, Cancer Experience Registry<sup>®</sup>, advocacy partners and social and traditional media outlets
- Analysis based on 1,046 respondents who reported living in the United States and receiving a cancer diagnosis

# ACCESS TO CANCER CARE 2016

## Demographics



CHARACTERISTICS	PERCENTAGE
<b>AGE (n=982)</b>	
18-44	8.8%
45-64	54.9%
65 AND OLDER	36.3%
<b>GENDER (n=982)</b>	
FEMALE	78.6%
MALE	21.4%
<b>RACE (n=976)</b>	
WHITE OR CAUCASIAN	86.5%
BLACK OR AFRICAN AMERICAN	6.4%
ASIAN OR PACIFIC ISLANDER	2.3%
MINORITY OR MULTIRACIAL	1.5%
AMERICAN INDIAN OR ALASKAN NATIVE	1.0%
PREFER NOT TO SHARE	2.3%
<b>ETHNICITY (n=859)</b>	
HISPANIC OR LATINO	6.4%
NOT HISPANIC OR LATINO	84.4%
PREFER NOT TO SHARE	9.2%
<b>EDUCATION (n=980)</b>	
ASSOCIATE DEGREE OR LOWER	36.3%
BACHELOR'S DEGREE OR HIGHER	63.7%
<b>EMPLOYMENT (n=982)</b>	
RETIRED	35.1%
NOT EMPLOYED, DISABILITY OR OTHER	26.9%
EMPLOYED FULL-TIME	26.4%
EMPLOYED PART-TIME	11.6%

- Respondents were predominantly non-Hispanic, white and female
- The majority were between the ages of 45 and 64 years old
- And 38% were either working full or part time
- Most were diagnosed with breast cancer – with 25% having non-MBC and 11% having MBC
- 44% of the sample received a cancer diagnosis less than 3 years ago

# ACCESS TO CANCER CARE 2016

## Current Status



- Over 70% of the participants were in treatment at the time of the survey
- Of those not in treatment, 67% were in remission and continued to receive the following care:
  - follow-up visits with the doctor
  - follow-up tests
  - reconstructive surgery
  - services with other specialists
  - rehabilitation or physical therapy
  - fertility treatments

# ACCESS TO CANCER CARE 2016

## Type of Cancer-Related Treatment



### Types of treatment included:

- Chemotherapy\* (61%)
- Surgery (59%)
- Radiation therapy (48%)
- Hormone therapy (31%)

\* includes immunotherapy

### Route of administration:

- Oral (40%)
- IV infusion (25%)
- Injection (10%)





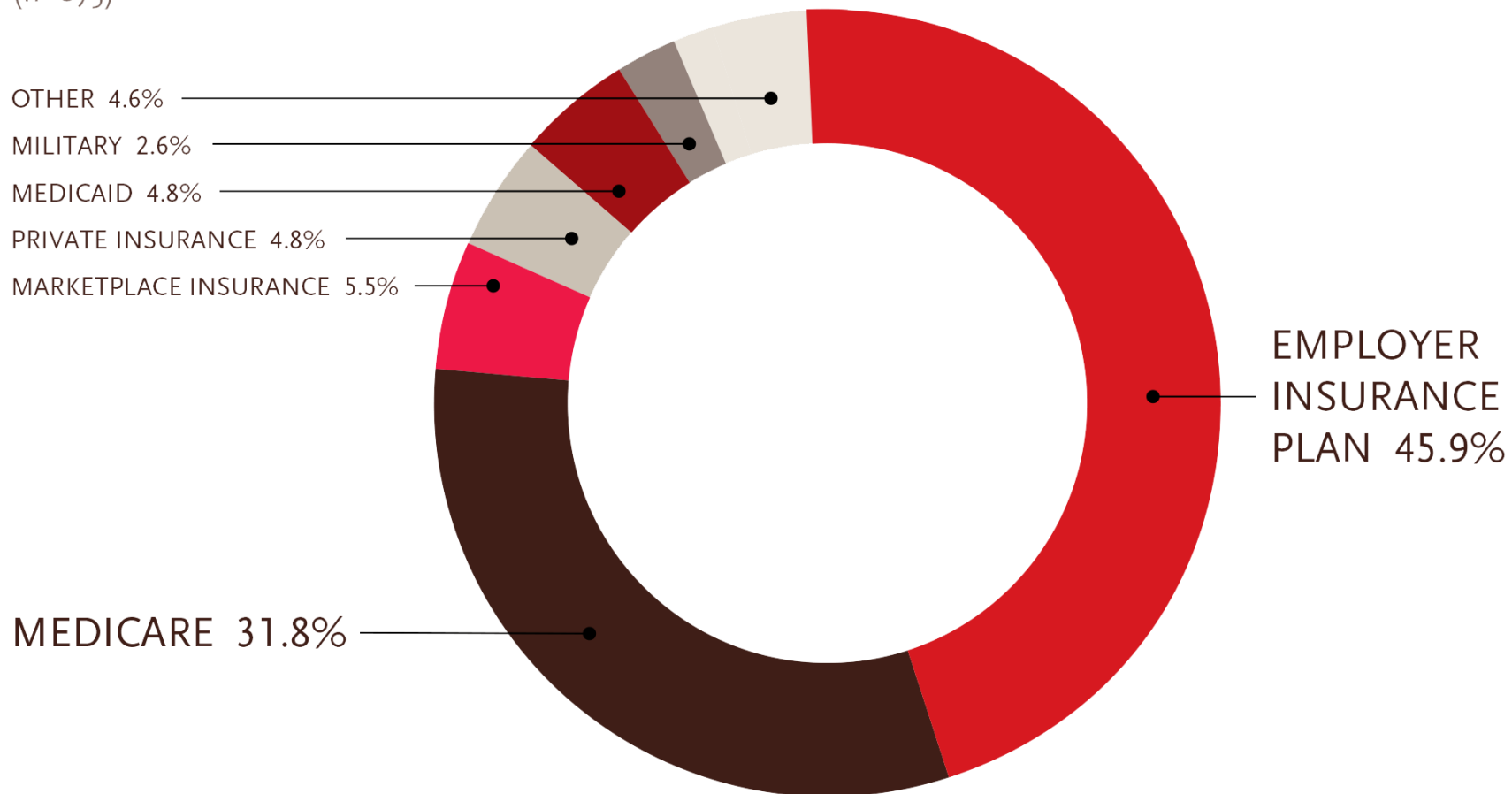
# Access to Health Insurance

# ACCESS TO HEALTH INSURANCE

## Types of Health Insurance

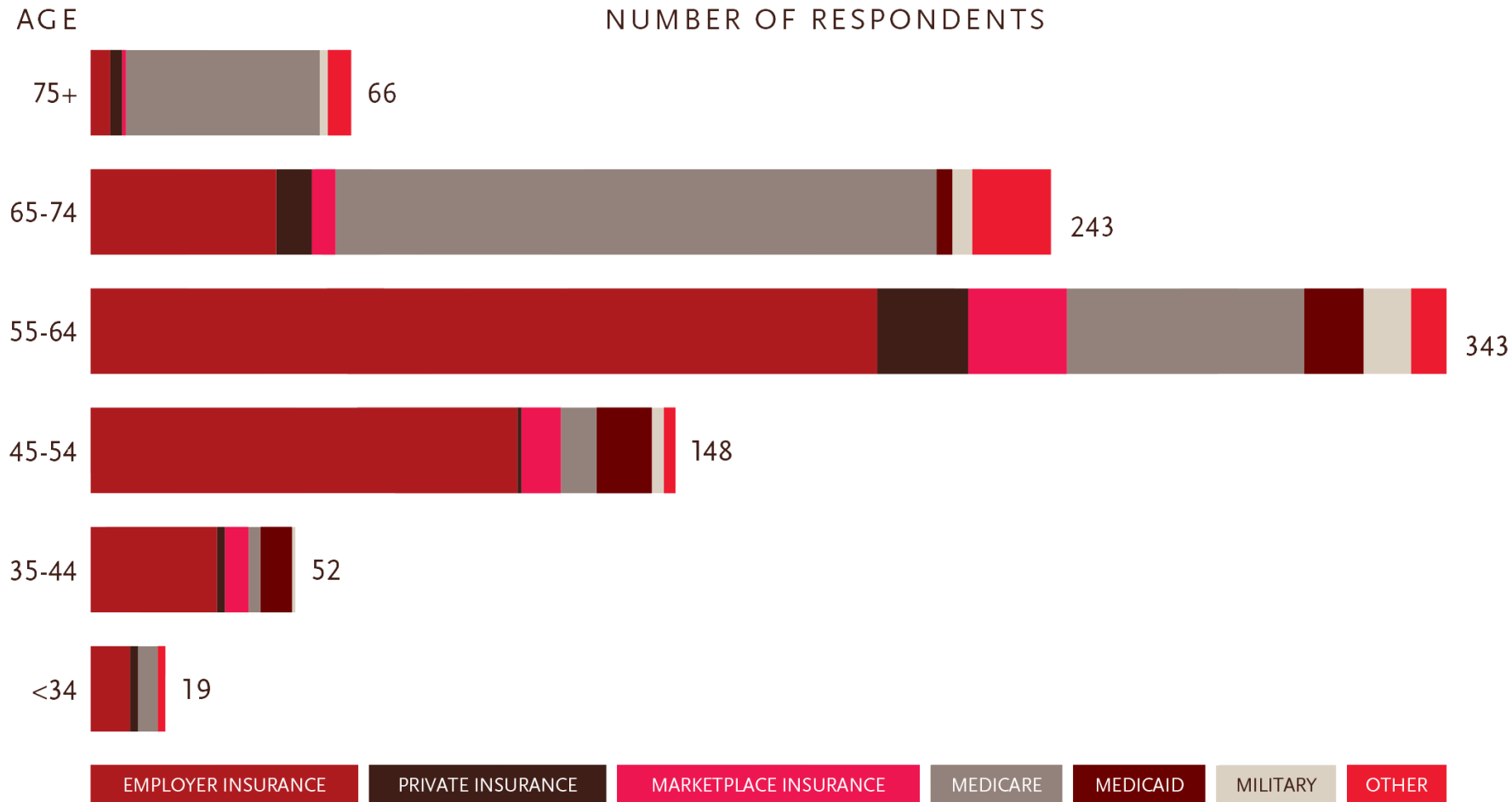


(n=875)



# ACCESS TO HEALTH INSURANCE

## Source of Health Insurance by Age



# ACCESS TO HEALTH INSURANCE

## Top Concerns about Insurance



- Overall cost remains the single most important factor in choosing a health insurance plan
- More than 85% of respondents reported that cost was very or moderately important in their decision
- Most participants experienced concerns with:
  - high out-of-pocket costs for services (48.7%)
  - high deductibles (47.7%)
  - high premiums (47.2%)
  - high copay costs for medications (41.7%)

# ACCESS TO HEALTH INSURANCE

## Understanding of Coverage



Patient understanding of health insurance plan structure and coverage is critical

- Ten percent of respondents reported poor understanding of their health insurance
- People with less understanding of their insurance more frequently reported that they were not able to receive the care that they felt they needed

*“After being diagnosed, the increased and confusing issues with health insurance coverage have caused me added expenses, diminished benefits and a great deal of financial stress.”*  
- Survey Participant



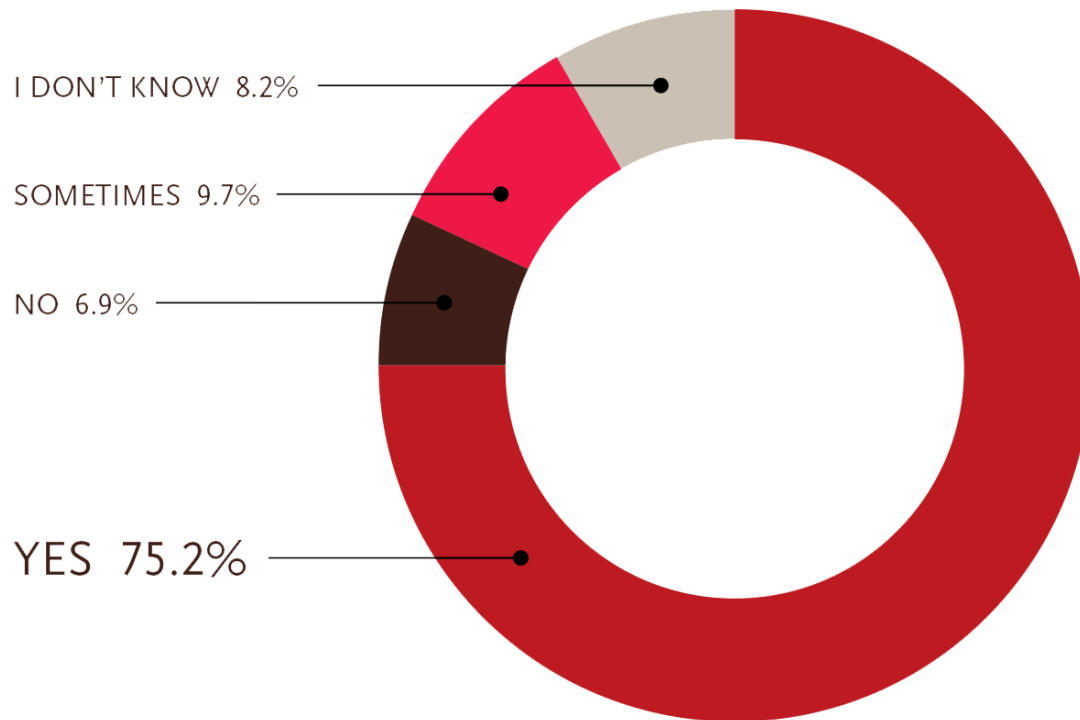
# Access to Services

# ACCESS TO SERVICES



## Are you able to get the care that you need?

(n=951)



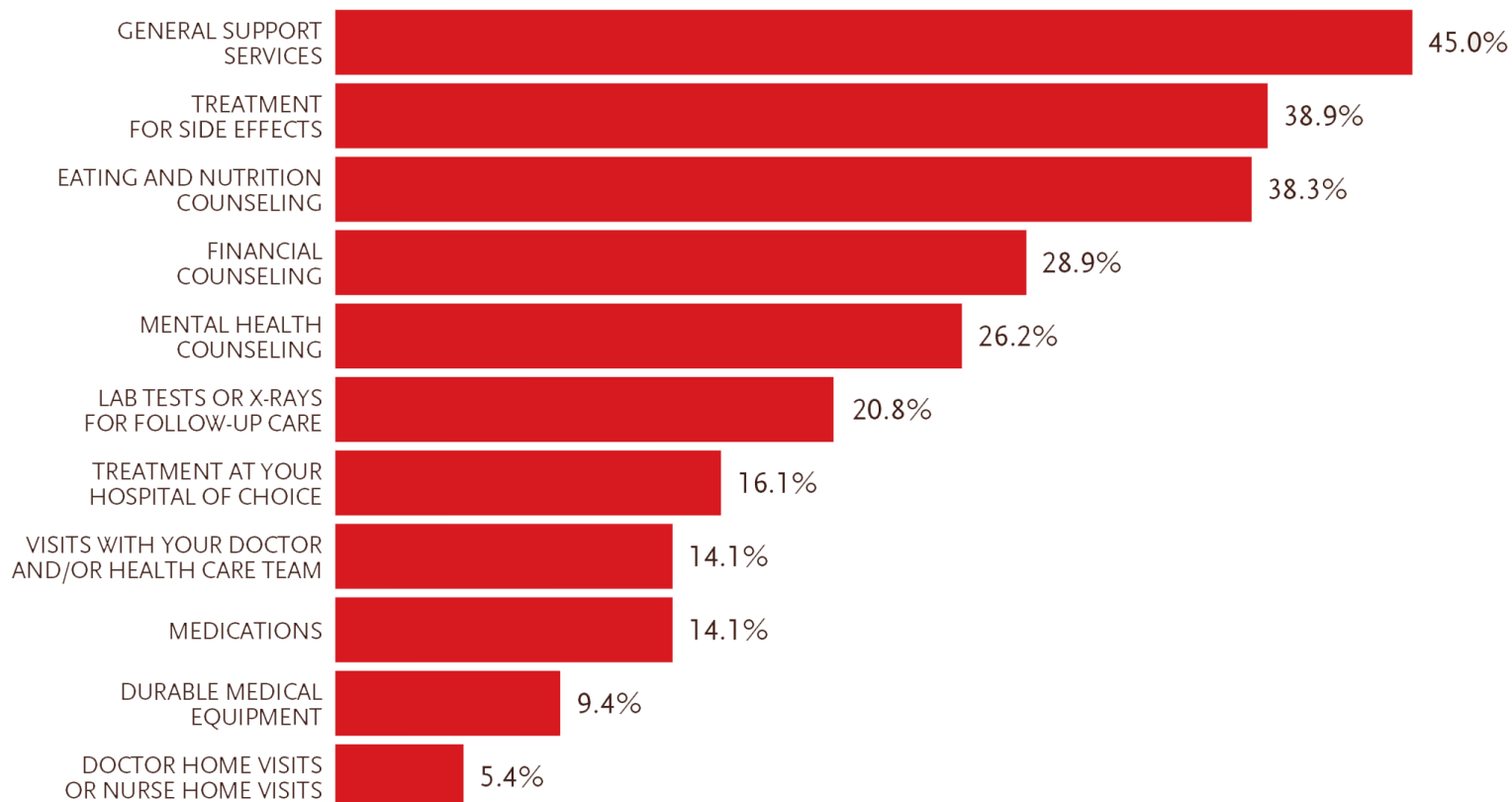
- Altogether, nearly a quarter of respondents did not feel confident that they received the care that they needed

# ACCESS TO SERVICES

*What are the services you feel you need but are not able to receive?*



(Multiple responses allowed, n=149)



*“Getting post-treatment information, like dealing with side effects, nutrition, emotional support is difficult. Some doctors don’t even seem to see any value in these services.” - Survey participant*



# ACCESS TO SERVICES

## Reasons for Services not Received



- Reasons for services not received:
  - availability
  - coverage
  - high cost
- Medicare recipients were more likely to report:
  - services were not offered
  - respondents didn't know they were available
- Marketplace covered respondents indicated:
  - services were not covered by their health insurance
  - they could not afford the high cost

# ACCESS TO SERVICES

## Psychosocial Support



### Receipt of Social and/or Emotional Support Services

(n=940)



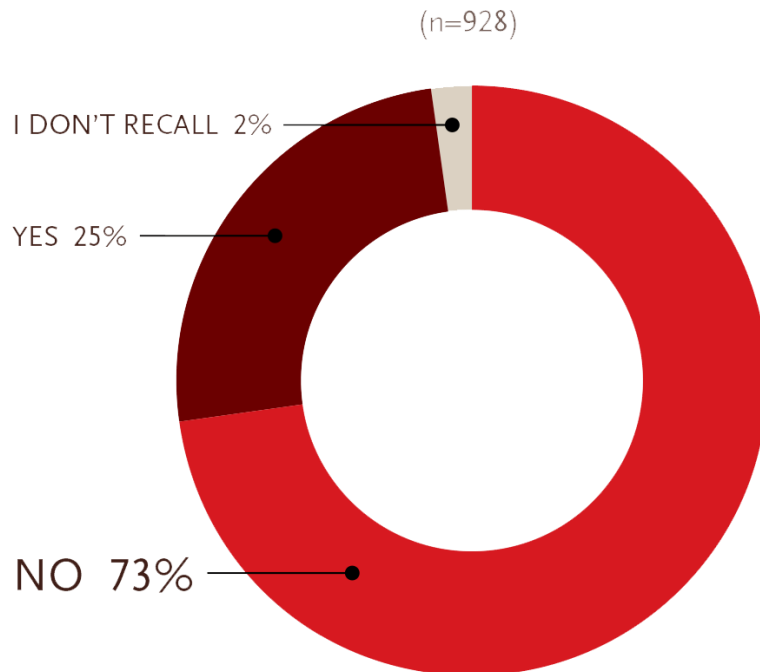
- Nearly 70% of those reported that they would have liked to receive social and emotional support services as a part of their cancer care
- 45% of those not receiving psychosocial support reported not filling a prescription or skipping appointments due to inability to pay copays

# ACCESS TO SERVICES

## Delays in Care



*Have you experienced any delays in getting access to cancer care?*



- 25% of respondents reported experiencing delays
- 38% of respondents with Medicaid coverage reported delays in gaining access to cancer care
- 19% of respondents with Medicare-covered experienced delays

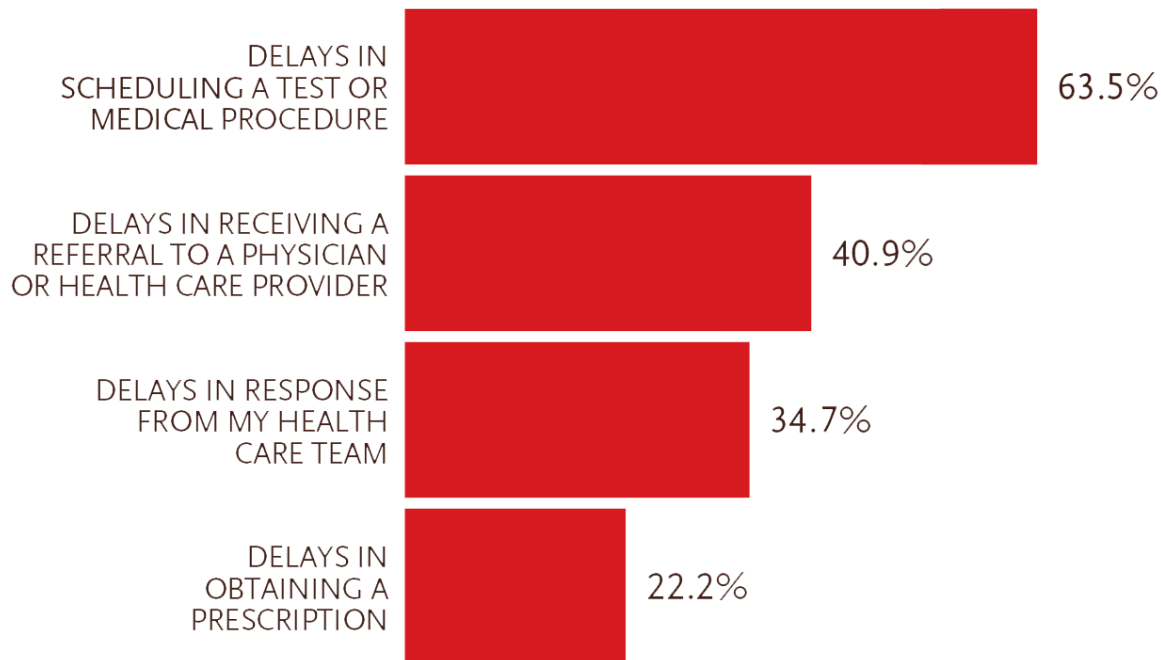
# ACCESS TO SERVICES

## Type of Delays



*What type of delays have you experienced?*

(Multiple responses allowed, n=255)



*“I experienced delays in getting a referral to an oncologist after being diagnosed with neuroendocrine cancer. By the time it was acknowledged, it was inoperable due to size and location.”*  
- Survey Participant



# Treatment Decisions

# TREATMENT DECISION MAKING



- Nearly 35% of patients indicated that they did not have a choice of treatment
- More than a third of respondents indicated that they would have liked to have been more involved in decisions about their care and treatment options

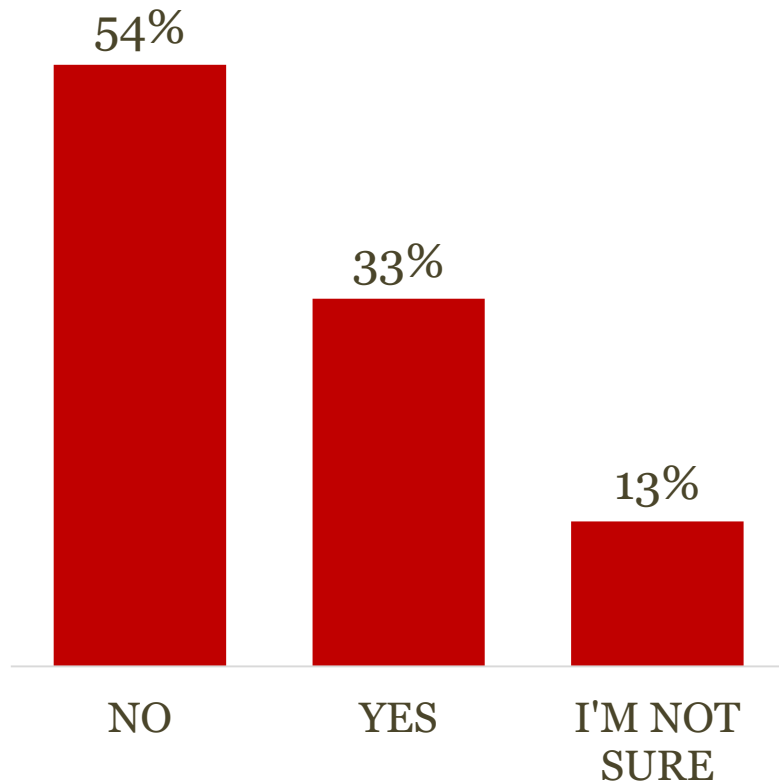
*“I would have preferred to be informed of ALL options, not just told what the treatment would be. I was led to believe that there was only one option if I was to live.” - Survey Participant*

# TREATMENT DECISION MAKING

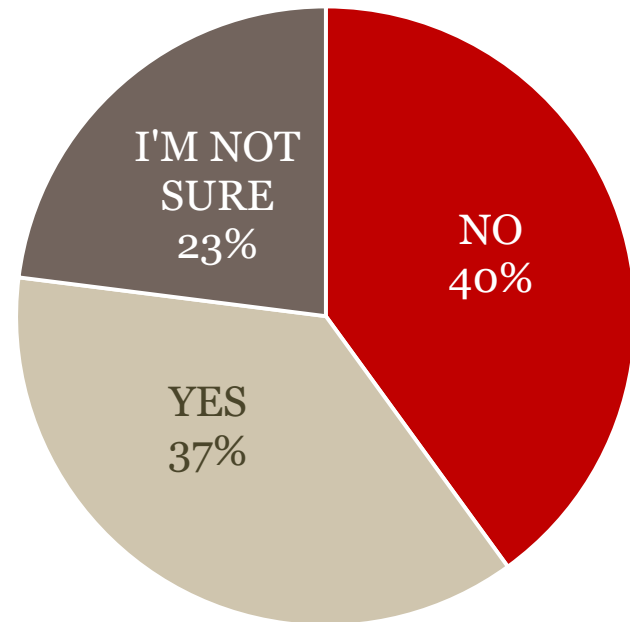
## Understanding of Clinical Guidelines



*Have you heard the term "Clinical Practice Guidelines"? (n=895)*



*Was the decision about your treatment made as a part of a clinical practice guideline? (n=895)*

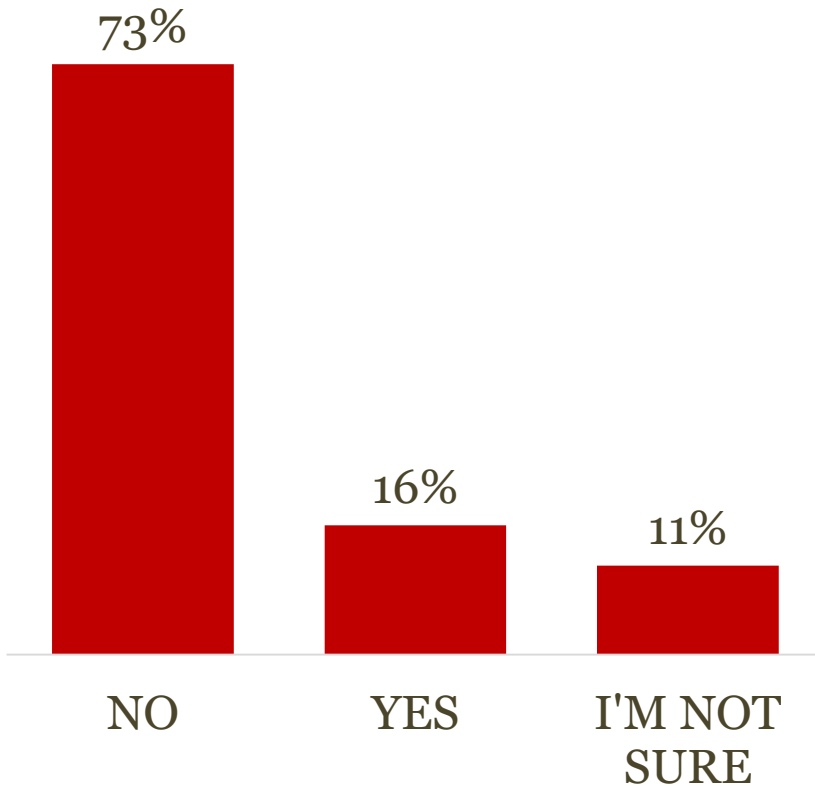


# TREATMENT DECISION MAKING

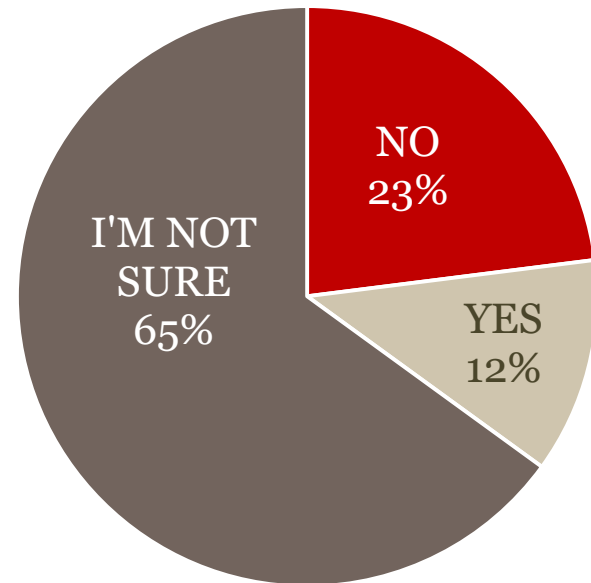
## Understanding of Clinical Pathways



*Have you heard the term "Clinical Pathways"?* (n=895)



*Was the decision about your treatment made as a part of a clinical pathway?* (n=895)





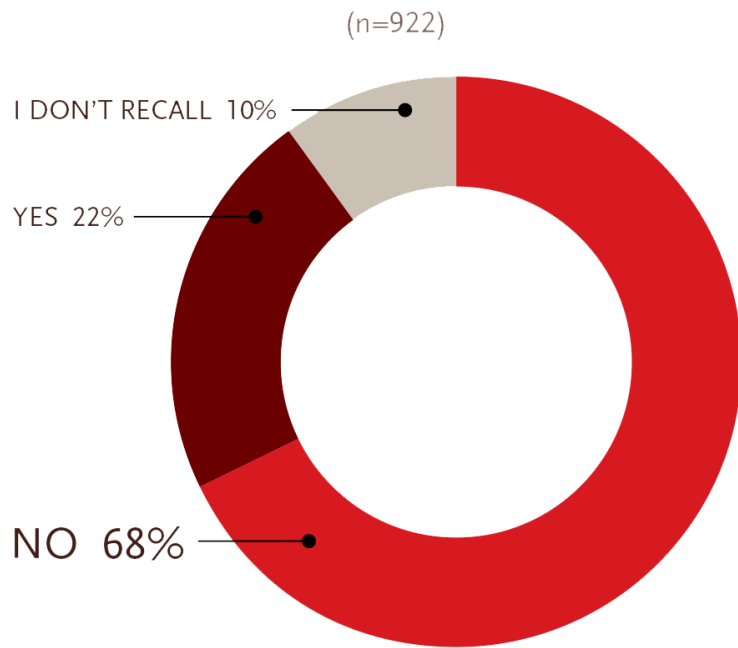


# Cost of Care

# CONCERNS ABOUT COST OF CARE



*Did you ever discuss with your doctor how much you would have to pay for your health care services before you received them?*



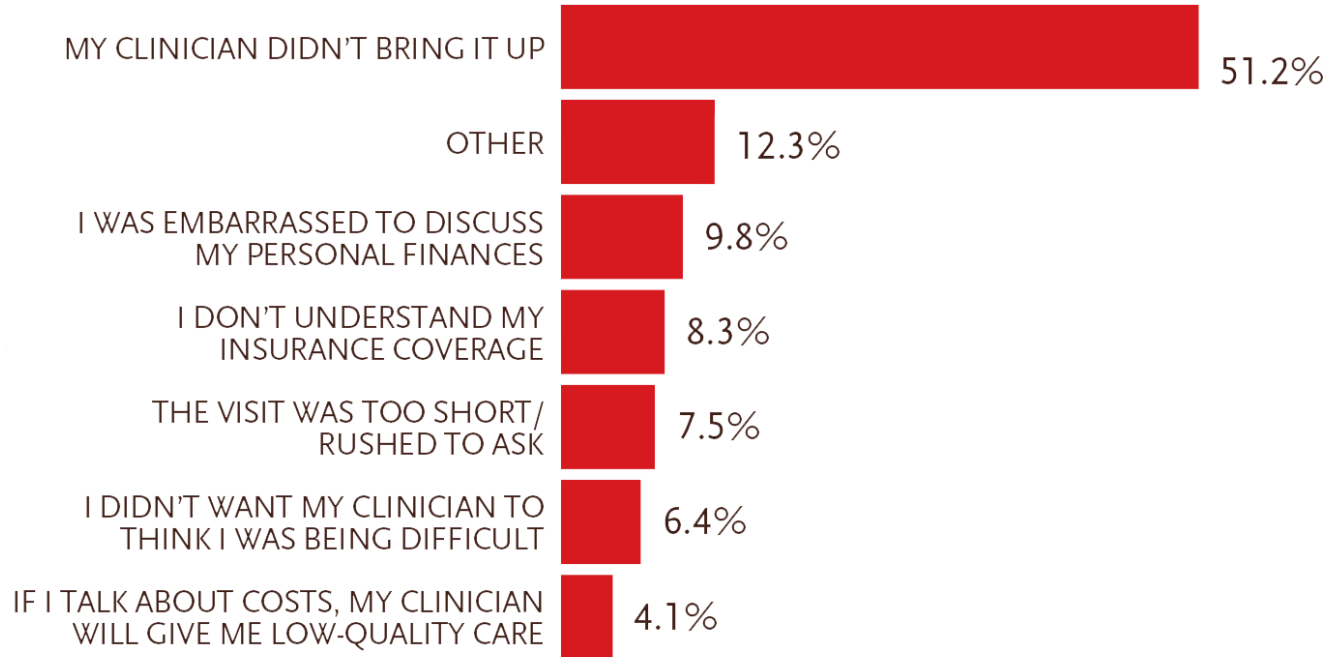
- 78% of respondents have not had or don't recall having cost conversations with their doctor prior to treatment
- 43% of participants reported that in the last 12 months their out-of-pocket costs have been larger than expected

# COST OF CARE CONVERSATIONS



*Why didn't you discuss how much you would have to pay for your health care services with your doctor?*

(Multiple responses allowed, n=622)



# COST OF CARE CONVERSATIONS

## Caregivers' Role



- Of the 22% of patients who discussed the cost of treatment, 68.1% of them reported having a family member or caregiver as a part of the discussion
- Caregivers not only provide physical and emotional support; they play an important role in the treatment decision-making process, especially for newly diagnosed patients who are asked to make decisions

# COST OF CARE CONVERSATIONS

## Decision Tools



- 77.5% of respondents who discussed cost with their doctor reported not using a guide or a decision tool during discussions
- Those who used a tool cited:
  - conversation guide (4.5%)
  - decision aid (2%)
  - an online tool designed to help calculate out-of-pocket costs (2%)
- Decision tools can be extremely helpful in facilitating cost conversations

# COST OF CARE

## Patient Impact



- Nearly 22% of patients surveyed chose not to get recommended health care services because of high out-of-pocket costs
- 18% of patients surveyed reported not filling medications prescribed due to cost
  - 50% sought financial assistance
  - 58% of patients received financial help when they sought out assistance
  - 44% of those not seeking assistance were unaware of the options

# COST OF CARE

## Other Reasons for not Getting Care



- Primary
  - Insurance company wouldn't pay for it (90.4%)
  - Doctor did not accept my insurance (72.2%)
  - Could not afford the care (71.8%)
- Secondary
  - Could not get time off work (71.4%)
  - Could not get child care/adult care (50%)
  - Have scheduled, but appointment is months away (47.3%)
  - Lack of transportation (46.1%)

# Cost Containment Strategies





# COST CONTAINMENT STRATEGIES

## Prior Authorization



- 45% of participants reported that, in the last 12 months, they were told that the treatment prescribed for them would require approval from their insurance company
  - Oral medications (35.4%)
  - IV infusion treatments (35.9%)
- Approximately 37% of respondents required prior authorization for diagnostic testing

# COST CONTAINMENT STRATEGIES

## Prior Authorization (cont'd)



- Prior authorization for treatment was most frequently reported by patients with:
  - Marketplace coverage (53.3%)
  - Medicare (51.2%)
- Prior authorization for diagnostic testing was most frequently reported by patients with:
  - Marketplace coverage (50%)
  - Private insurance (48.7%)

# COST CONTAINMENT STRATEGIES

## Prior Authorization (cont'd)



- Prior authorization for treatment was most frequently reported by patients in:
  - Iowa (66%)
  - Indiana (60%)
  - New Jersey (54%)
- Prior authorization for diagnostic testing was most frequently reported by patients in:
  - Florida (49%)
  - Maryland (48%)
  - Pennsylvania (46%)

# COST CONTAINMENT STRATEGIES

## Prior Authorization Impact



- Delays
  - 26% reported experiencing significant delays in starting physician-recommended treatment
  - 20% reported delays in receiving a cancer diagnosis
- Out-of-pocket costs
  - 22% of respondents reported unexpected out-of-pocket costs for diagnostic testing
- Changes to treatment
  - 17.3% experienced changes to their treatment decision

# COST CONTAINMENT STRATEGIES

## Step Therapy



- 14% of respondents were required by their insurance company to take another medication first before they could receive the medication originally prescribed by their doctor:
  - Oral medicines (75%)
  - IV infusion treatment (8.7%)
- Approximately 8% of respondents required step requirements for diagnostic testing

# COST CONTAINMENT STRATEGIES

## Step Therapy (cont'd)



- Step therapy requirements for treatment were most frequently reported by people with:
  - Private insurance coverage (25.6%)
  - Medicare coverage (15.2%)
- Step requirements for diagnostic testing was most frequently reported in people with:
  - Private insurance coverage (16.7%)

# COST CONTAINMENT STRATEGIES

## Step Therapy (cont'd)



- Step therapy for treatment was most frequently reported by patients in:
  - Indiana (24%)
  - New York (22%)
  - Ohio (19%)
- Step requirements for diagnostic testing was most frequently reported by patients in:
  - California (14%)
  - Illinois (9%)
  - Virginia (8%)

# COST CONTAINMENT STRATEGIES

## Step Therapy Impact



- Delays
  - 52.4% reported delaying treatment
- Out-of-pocket costs
  - 52.9% experienced unexpected out-of-pocket costs for treatment
  - 44% experienced unexpected out-of-pocket costs for diagnostic testing
- Changes to treatment
  - 32% reported switching to insurance mandated treatment
- No treatment
  - 8.5% decided not to start any medication





# COST CONTAINMENT STRATEGIES

## Narrow Networks



- Approximately 11% of respondents reported experiencing difficulties in the last 12 months finding an in-network specialist in their area:
  - Private insurance (28%)
  - Employer sponsored (9.2%)
  - Medicare (8.8%)
- “Top Concerns About Health Insurance”
  - Having to travel long distance (12.5%)
  - Limited or no access to health care team of choice (10.5%)
  - Limited or no access to hospital of choice (6.9%)

# Conclusions



# CONCLUSIONS



Findings in this report underscore the need to:

- Ensure that the patient voice is represented in every step of the decision making process and that patients are fully engaged
- Minimize access limitations and maximize patient adherence
- Partner to leverage and create resources

# Questions?



  
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PANEL DISCUSSION

**Jacquetta Brooks**, Manager of Mautner Project,  
Whitman-Walker Health

**Michael Kolodziej**, National Medical Director, Managed Care Strategy,  
Flatiron Health, Inc.

**VJ Sleight**, Tobacco Treatment Specialist

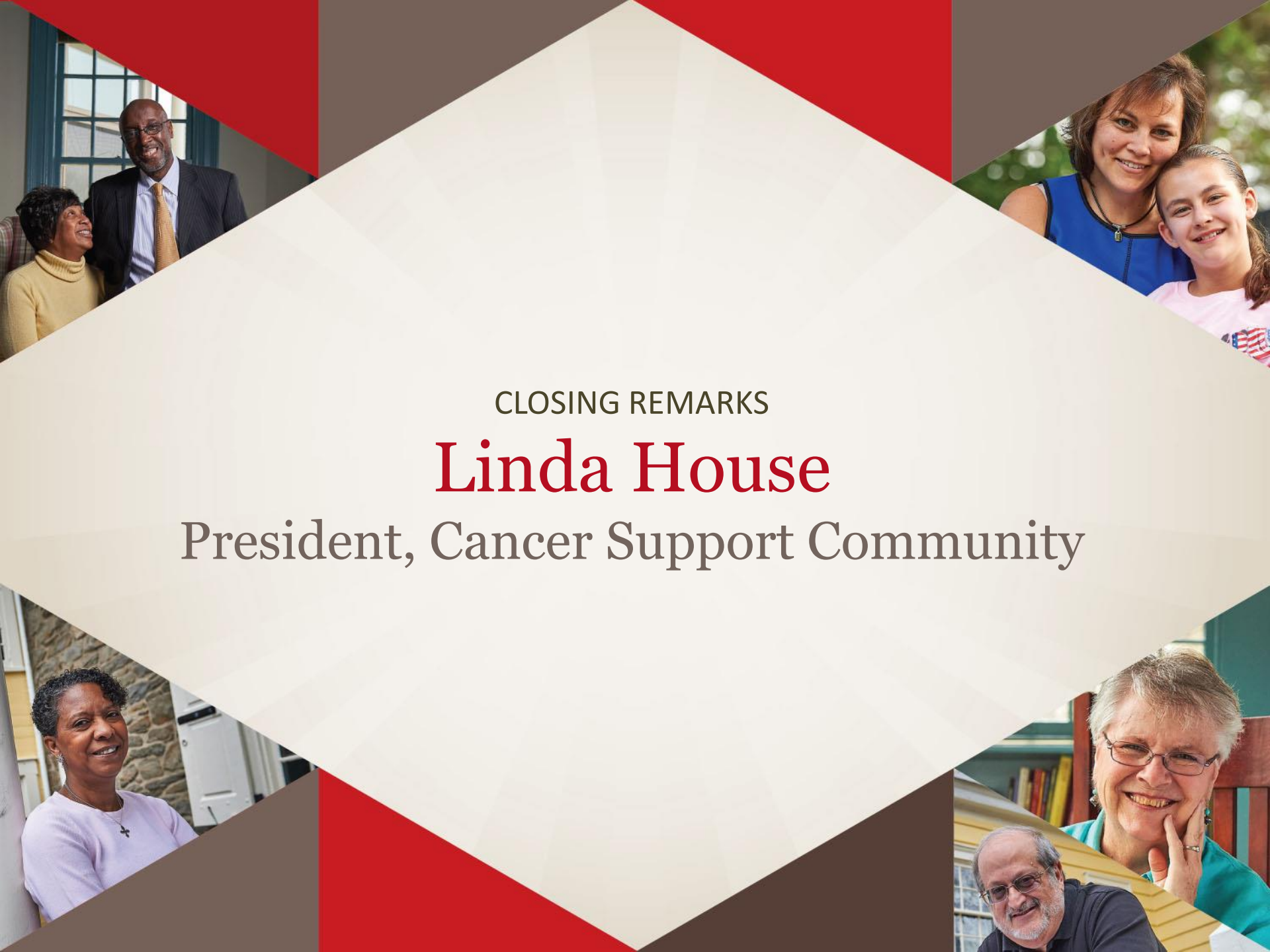
Moderated by:  
**Linda House**, President,  
Cancer Support Community

# Questions?



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CLOSING REMARKS

# Linda House

President, Cancer Support Community



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Amgen Oncology  
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