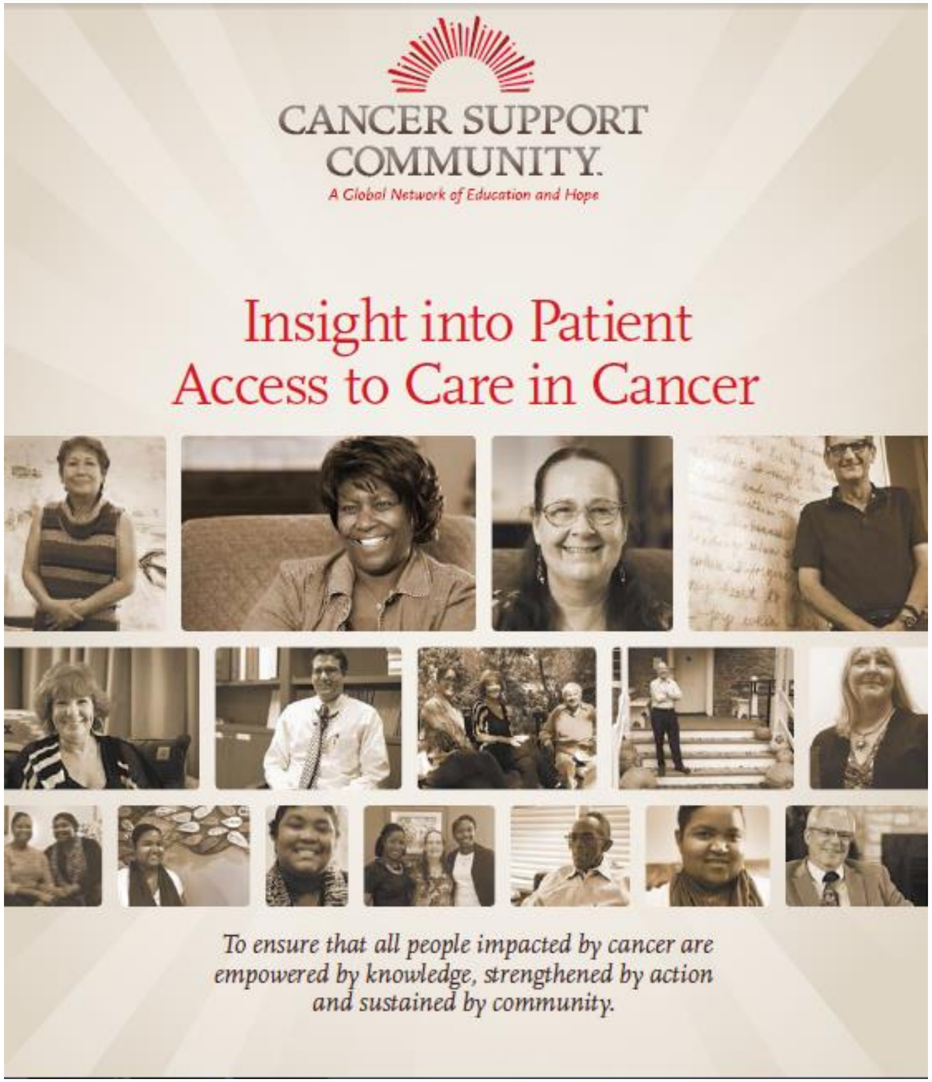
Welcome!



CANCER SUPPORT COMMUNITY.

A Global Network of Education and Hope

Insight into Patient Access to Care in Cancer

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Insight into Patient Access to Care in Cancer

In Memory
Regina Richardson

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Kim Thiboldeaux
Chief Executive Officer

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Mark McClellan, MD, PhD
Sr. Fellow and Director, Health Care Innovation and Value Initiative, Brookings Institution

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

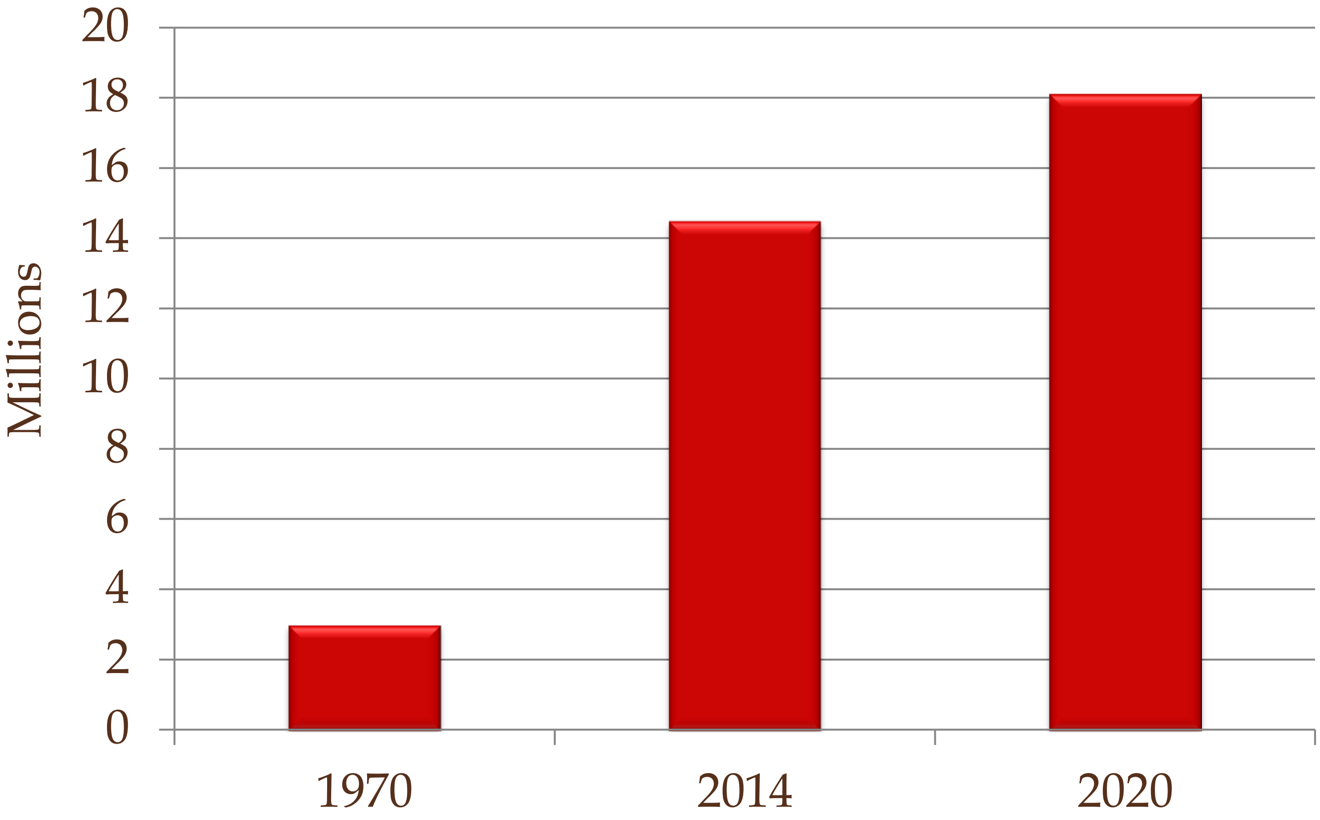
Questions?

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

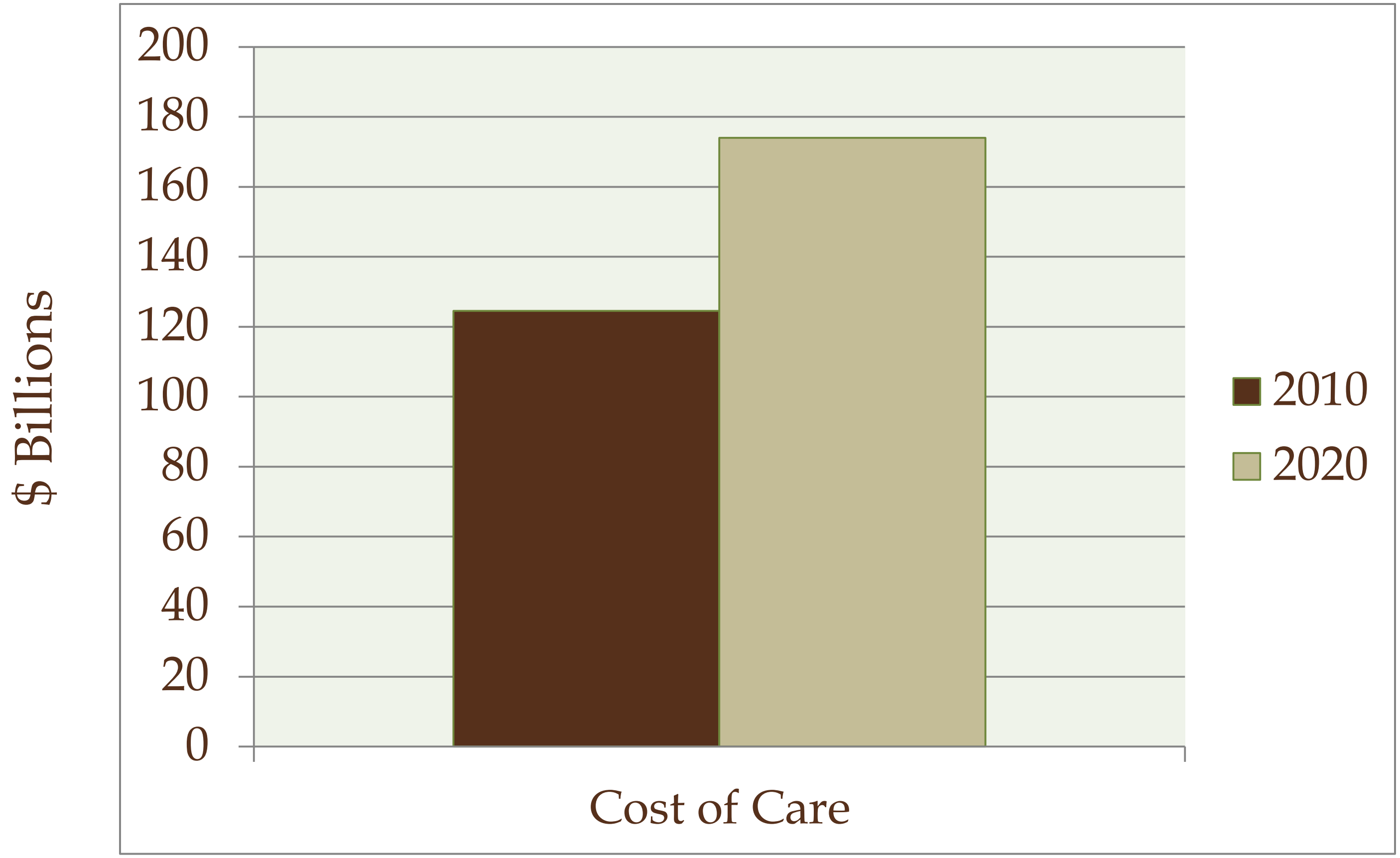
Joanne Buzaglo, PhD
Sr. Vice President, Research and Training

Number of Survivors



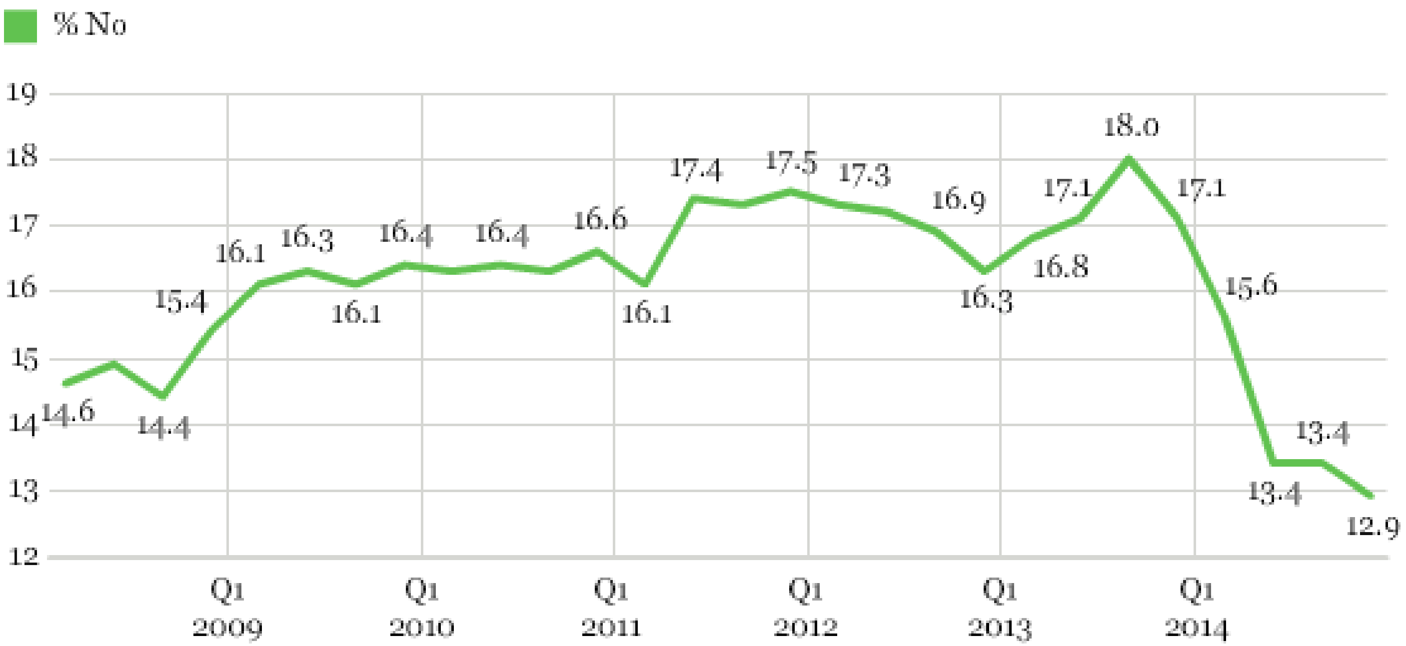
National Cancer Institute

Rising Cost of Cancer Care



Mariotto et al, JNCI, 2011

Uninsured in the U.S. Today



Percentage of U.S. Adults Without Health Insurance, by Quarter

Do you have health insurance coverage?

Among adults aged 18 and older

Quater 1 2008-Quarter 4 2014
Gallup-Healthways Well-Being Index

GALLUP

Headlines


PLAN 1
PLAN 2
PLAN 3


ATTENTION OFFICE STAFF:
CO-PAY
$
Collect at time of visit

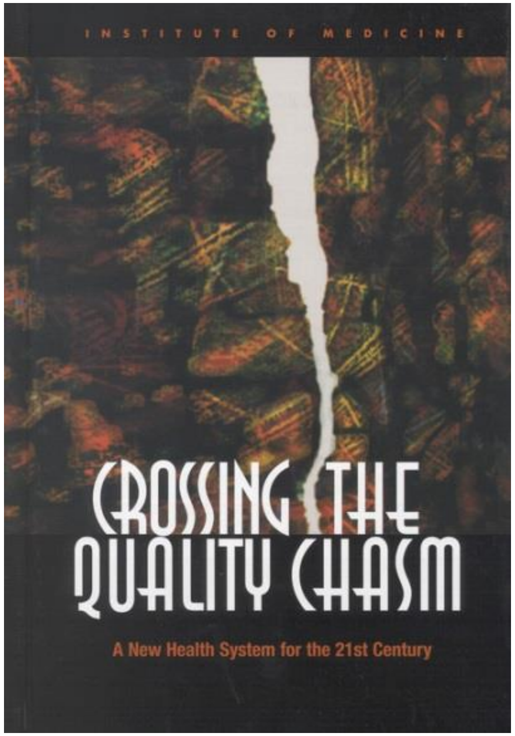

Rx
Problems with....
Copays &
Deductibles?


Hospitals/Doctors
Narrow Ahead


12
1
2
3
4
5
6
7
8
9
10
11


INSURANC
PREMIUM

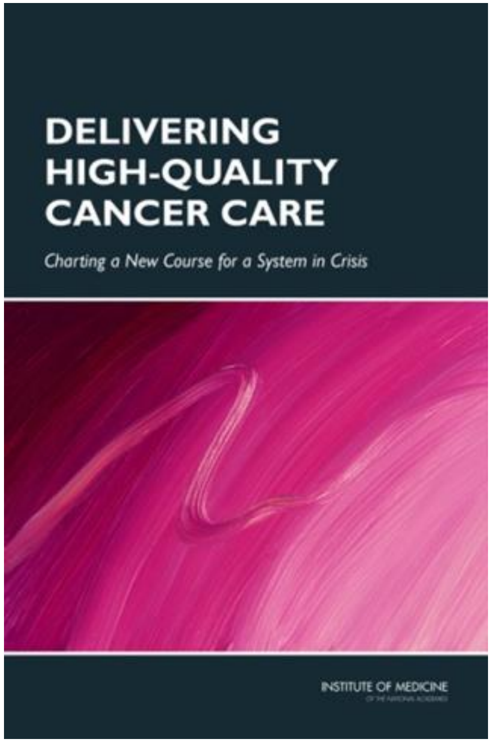
High Quality and Comprehensive Cancer Care



INSTITUTE OF MEDICINE

CROSSING THE QUALITY CHASM

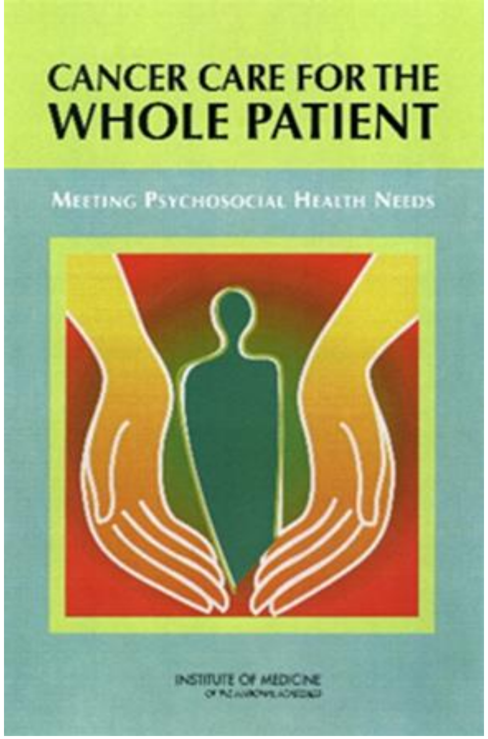
A New Health System for the 21st Century



DELIVERING HIGH-QUALITY CANCER CARE

Charting a New Course for a System in Crisis

INSTITUTE OF MEDICINE

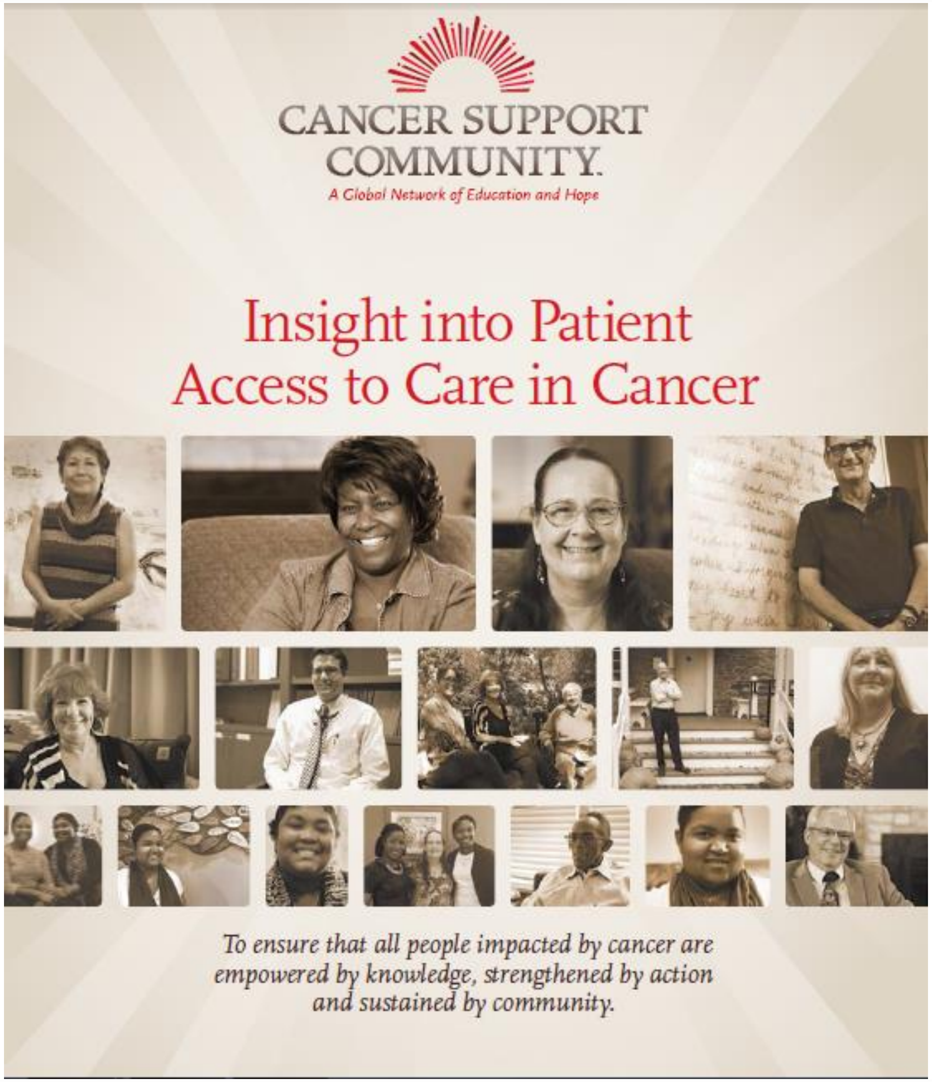


CANCER CARE FOR THE WHOLE PATIENT

MEETING PSYCHOSOCIAL HEALTH NEEDS

INSTITUTE OF MEDICINE

Purpose



CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

Insight into Patient Access to Care in Cancer

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

- Better understand the challenges patients face in accessing care:
  - Access to and satisfaction with insurance
  - Access to providers including availability, time and discussions with providers
  - Access to services including psychosocial care
  - Concern about direct costs of cancer and care
- Direct future research efforts
- Inform policy discussions

Study Methods

- Cross-sectional survey of adults (18 years and older) affected by cancer
- Administered online through Survey Monkey during October 2014
- Outreach through CSC's online network, Cancer Experience Registry, advocacy partners and social and traditional media outlets

692 individuals initiated the survey

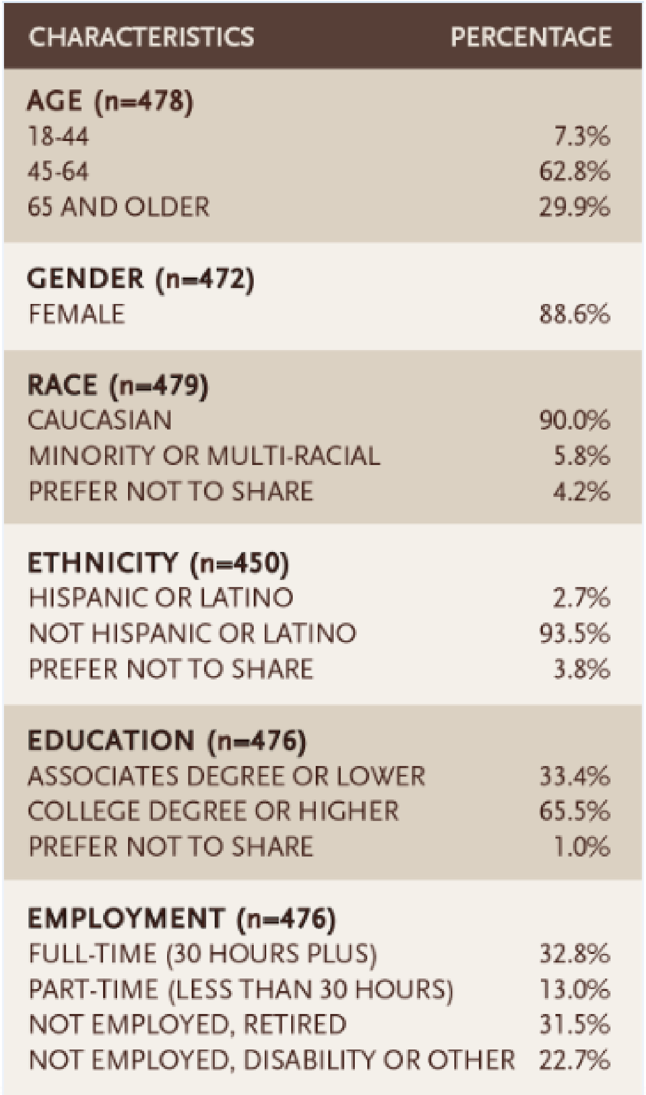
511 complete respondents

31 lived outside of the United States or did not report residence

480 adults living in the U.S. who had been diagnosed with cancer

Participants

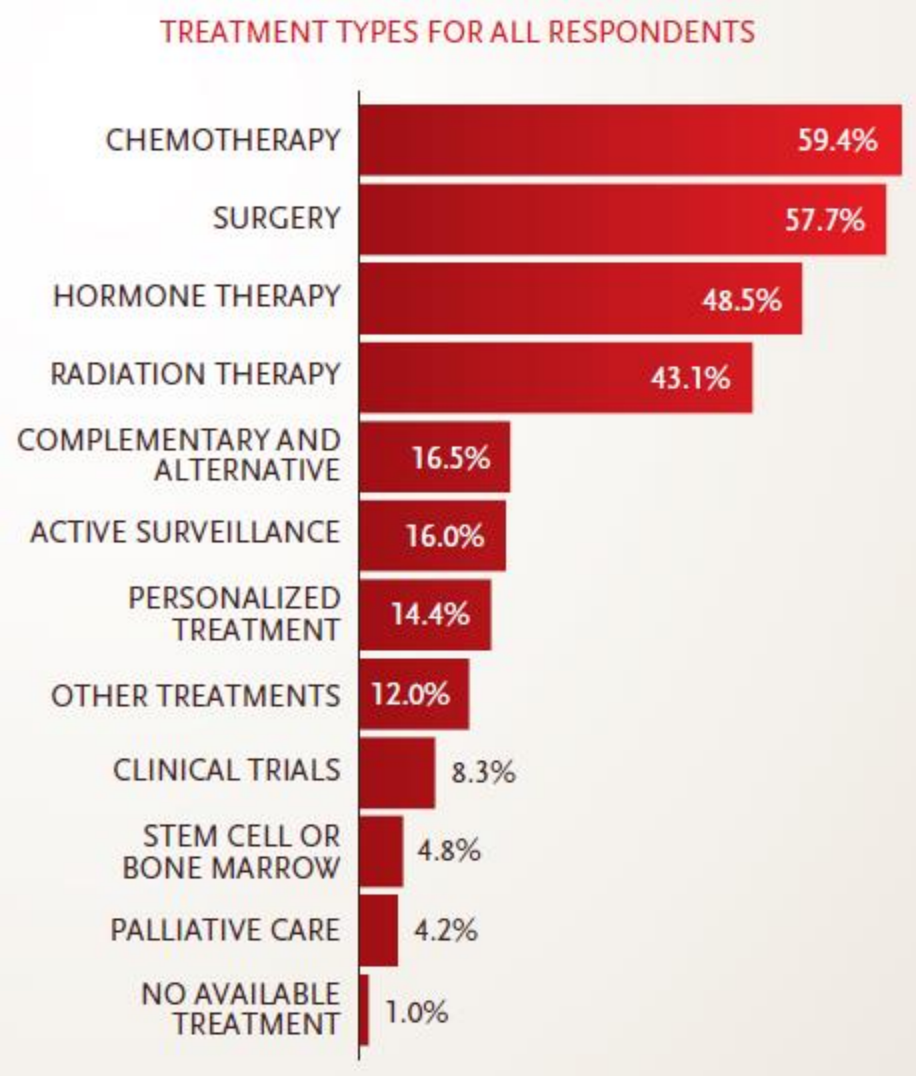
- Predominately non-Hispanic, white and female
- Cancer types:
    - Breast cancer – 41%
    - Other - 39.4%
    - Metastatic breast cancer – 19.6%



CHARACTERISTICS	PERCENTAGE
AGE (n=478)	
18-44	7.3%
45-64	62.8%
65 AND OLDER	29.9%
GENDER (n=472)	
FEMALE	88.6%
RACE (n=479)	
CAUCASIAN	90.0%
MINORITY OR MULTI-RACIAL	5.8%
PREFER NOT TO SHARE	4.2%
ETHNICITY (n=450)	
HISPANIC OR LATINO	2.7%
NOT HISPANIC OR LATINO	93.5%
PREFER NOT TO SHARE	3.8%
EDUCATION (n=476)	
ASSOCIATES DEGREE OR LOWER	33.4%
COLLEGE DEGREE OR HIGHER	65.5%
PREFER NOT TO SHARE	1.0%
EMPLOYMENT (n=476)	
FULL-TIME (30 HOURS PLUS)	32.8%
PART-TIME (LESS THAN 30 HOURS)	13.0%
NOT EMPLOYED, RETIRED	31.5%
NOT EMPLOYED, DISABILITY OR OTHER	22.7%

Cancer-Related Treatment

- Types of treatment included
  - Chemotherapy
  - Surgery
  - Hormone therapy
  - Radiation therapy
- Route of administration
  - Oral (51%)
  - IV infusion (13.3%)
  - Injection (12.3%)



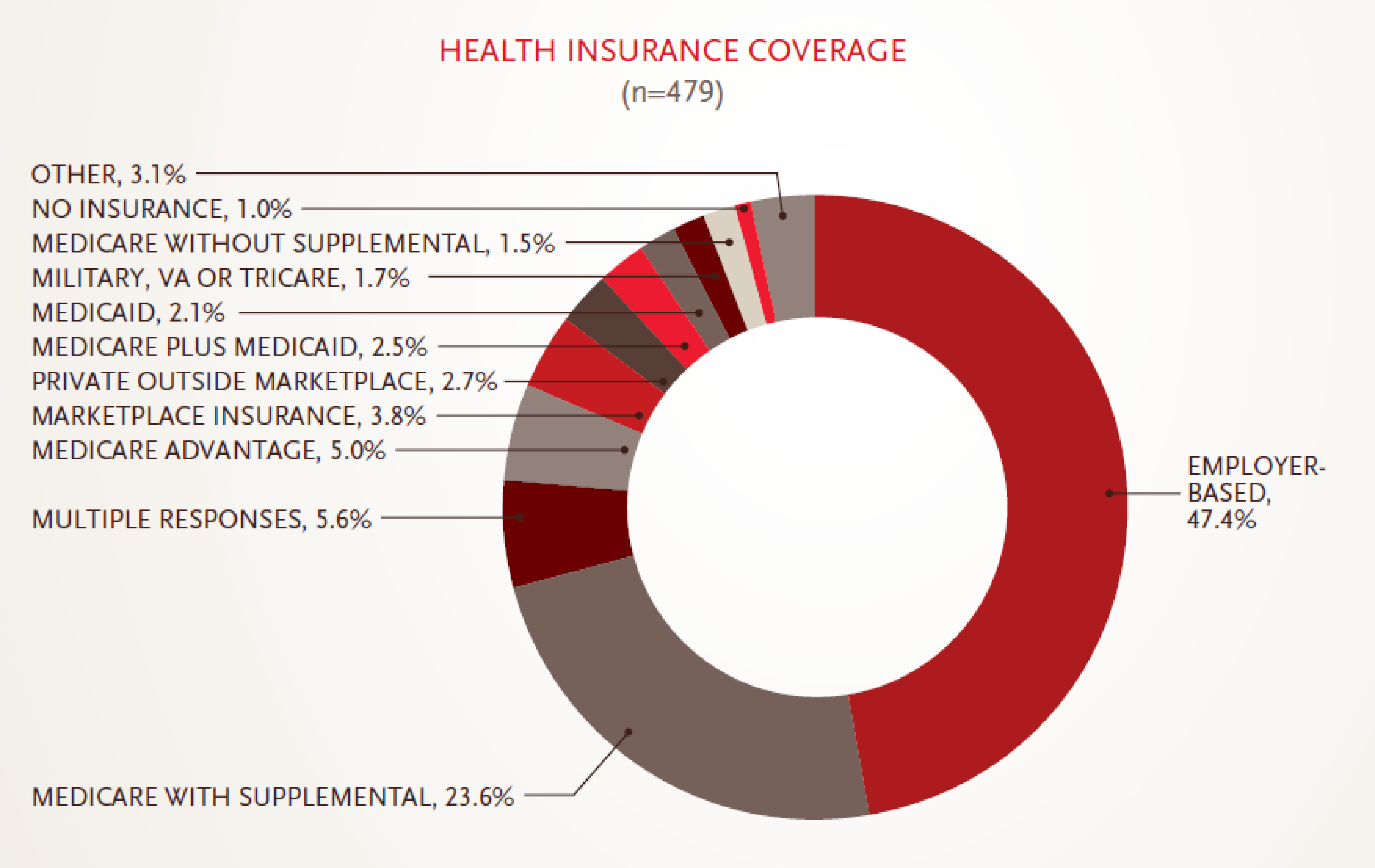
Current Engagement

- Over half of the participants were in treatment at the time of the survey
- 93.2% not in treatment 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
  - other services

"I am in complete remission. Last chemo was in 1998. I do have severe neuropathy from the chemo though…so I am unfortunately disabled."

Access to Care Participant

Access to and Satisfaction with Insurance – Types of Insurance

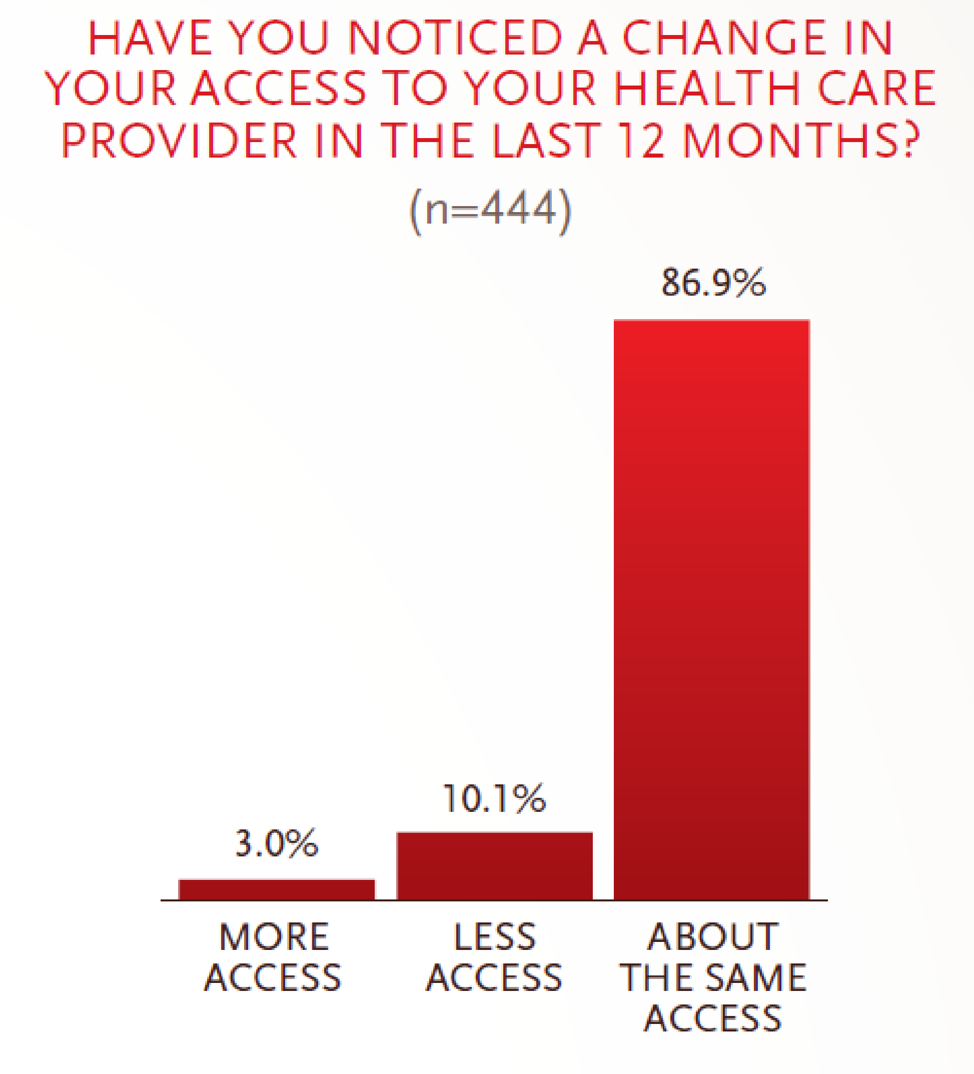


Access to and Satisfaction with Insurance – Concerns about Cost

CONCERNS WITH THEIR HEALTH INSURANCE (MULTIPLE RESPONSES ALLOWED)	% AMONG THOSE WHO DO NOT LIKE THEIR COVERAGE (n=81)	% AMONG THOSE WHO LIKE THEIR COVERAGE (n=391)
HIGH OUT-OF-POCKET COSTS FOR CO-INSURANCE TO COVER SERVICES OR PROCEDURES	66.7%	37.6%
HIGH OUT-OF-POCKET COSTS TO PAY INSURANCE PREMIUMS	58.0%	40.7%
HIGH CO-PAY COSTS FOR MEDICATIONS	54.3%	37.6%
I HAVE LIMITED OR NO ACCESS TO MY HEALTH CARE TEAM OF CHOICE	23.5%	6.6%
I HAVE LIMITED OR NO ACCESS TO MY HOSPITAL OF CHOICE	17.3%	3.3%
I HAVE TO DRIVE A LONG DISTANCE TO RECEIVE CARE	8.6%	7.4%
I DON'T HAVE ENOUGH INFORMATION TO MAKE DECISIONS ABOUT INSURANCE	8.6%	4.6%
OTHER	22.2%	18.7%

Top three concerns consistent regardless of respondents liking or disliking health insurance coverage

Access to Providers



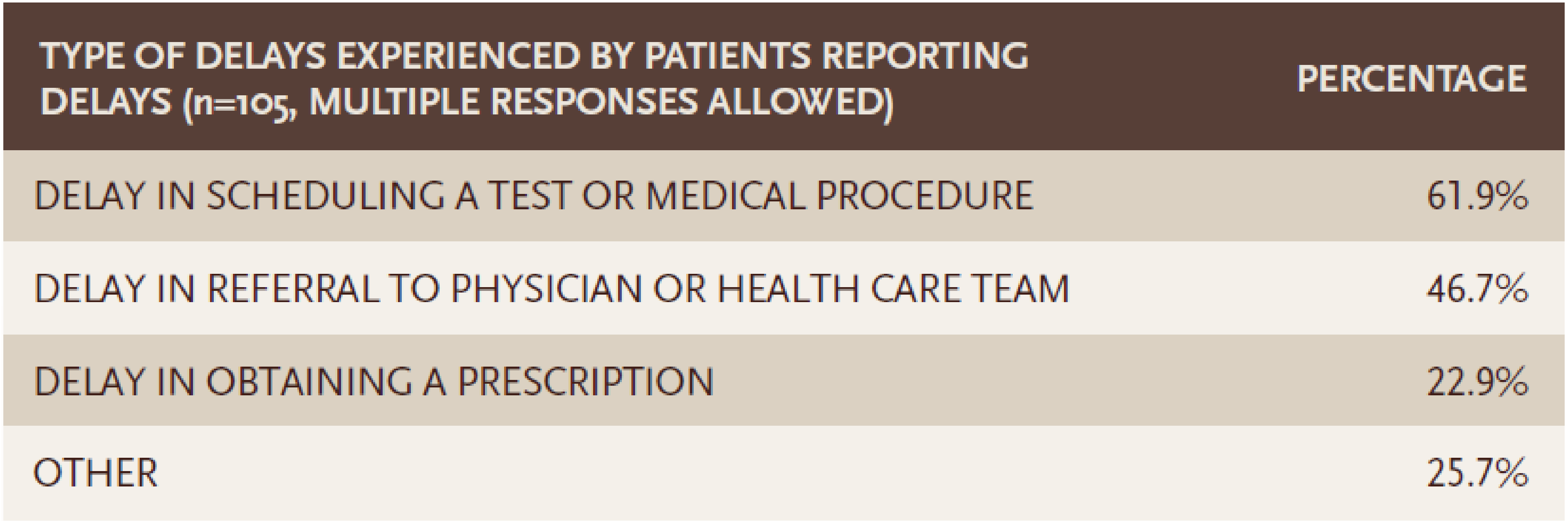
Access to Providers
Provider - Patient Communication

19.5% did not have enough time with the health care team (n=476)

PERCENT TALKING WITH THEIR HEALTH CARE TEAM ABOUT THE FOLLOWING WHEN MAKING THEIR CARE DECISIONS	PERCENTAGE
YOUR GOALS OF THERAPY, FOR EXAMPLE: CURE, QUALITY OF LIFE, ETC. (n=473)	79.5%
THE RISKS AND BENEFITS OF EACH TREATMENT OPTION (n=471)	78.8%
MORE THAN ONE TREATMENT (n=472)	78.2%
WHAT YOU VALUE ABOUT YOUR TREATMENT (n=464)	62.3%
PALLIATIVE CARE, SUCH AS TREATING SIDE EFFECTS, MANAGING PAIN (n=468)	62.2%
IMPACT ON WORK (n=467)	51.8%
CLINICAL TRIALS AS A TREATMENT OPTION (n=471)	48.8%
THE FINANCIAL COST OF TREATMENT (n=468)	34.4%
NON-TREATMENT RELATED COSTS SUCH AS TRANSPORTATION, CHILD OR ELDER CARE (n=465)	14.0%

Access to Providers
Delays

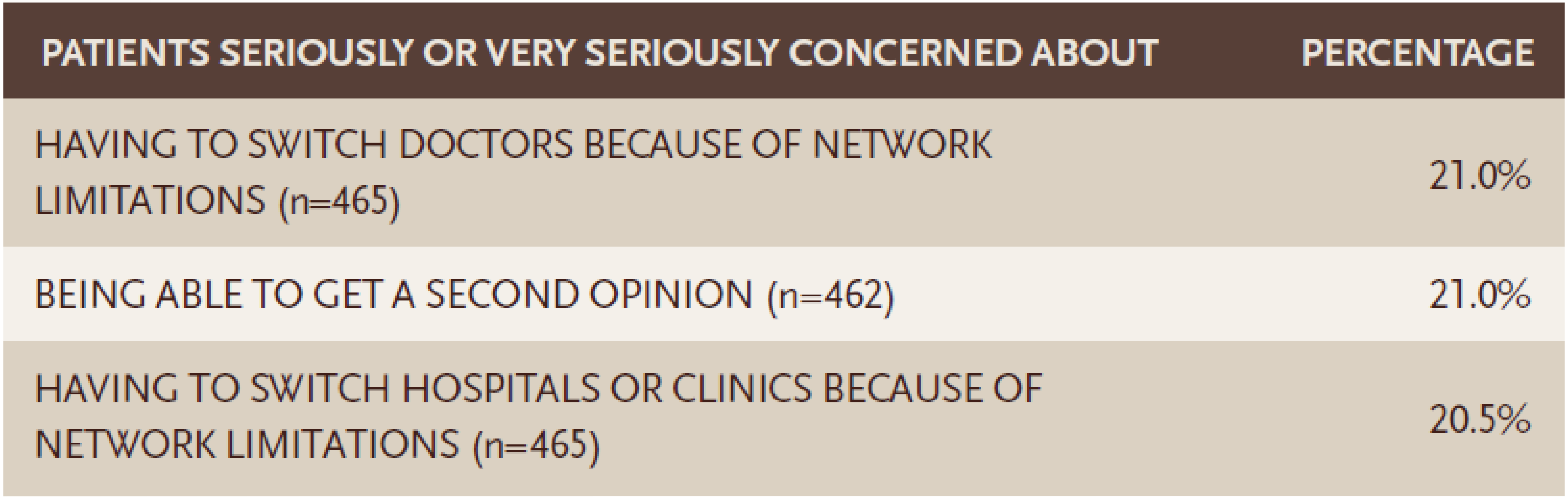
20% experienced delays in getting access to care (n=475)



TYPE OF DELAYS EXPERIENCED BY PATIENTS REPORTING DELAYS (n=105, MULTIPLE RESPONSES ALLOWED)	PERCENTAGE
DELAY IN SCHEDULING A TEST OR MEDICAL PROCEDURE	61.9%
DELAY IN REFERRAL TO PHYSICIAN OR HEALTH CARE TEAM	46.7%
DELAY IN OBTAINING A PRESCRIPTION	22.9%
OTHER	25.7%

Access to Providers
Access Concerns

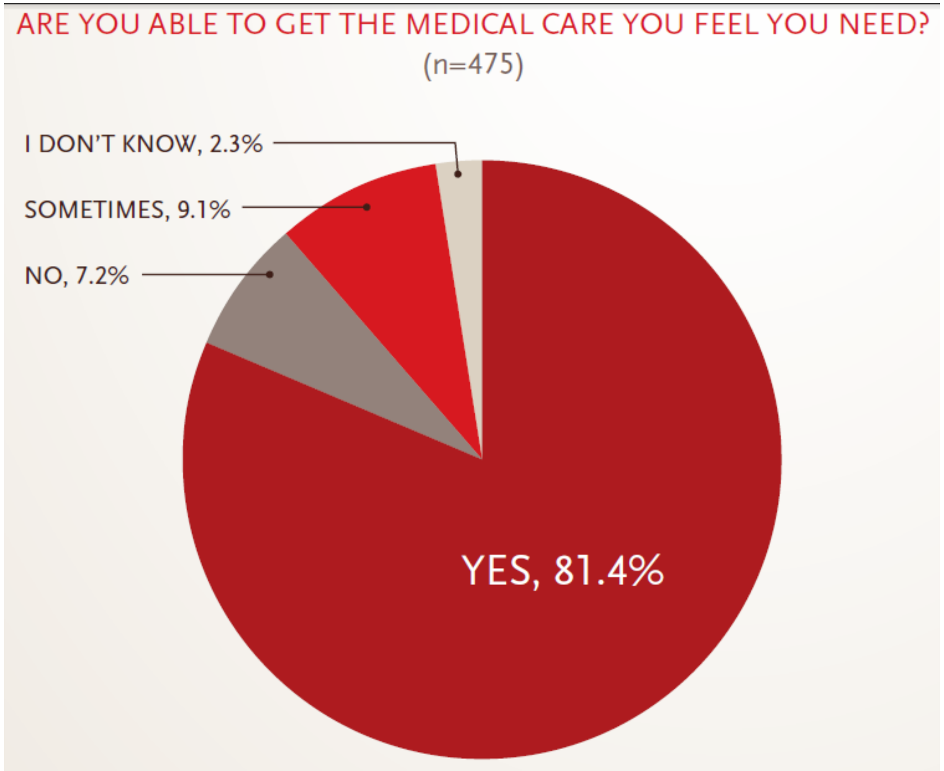
Patient concerns about network adequacy:



PATIENTS SERIOUSLY OR VERY SERIOUSLY CONCERNED ABOUT	PERCENTAGE
HAVING TO SWITCH DOCTORS BECAUSE OF NETWORK LIMITATIONS (n=465)	21.0%
BEING ABLE TO GET A SECOND OPINION (n=462)	21.0%
HAVING TO SWITCH HOSPITALS OR CLINICS BECAUSE OF NETWORK LIMITATIONS (n=465)	20.5%

Access to Services
Medical Care

Nearly 20% reported not having access to needed medical care



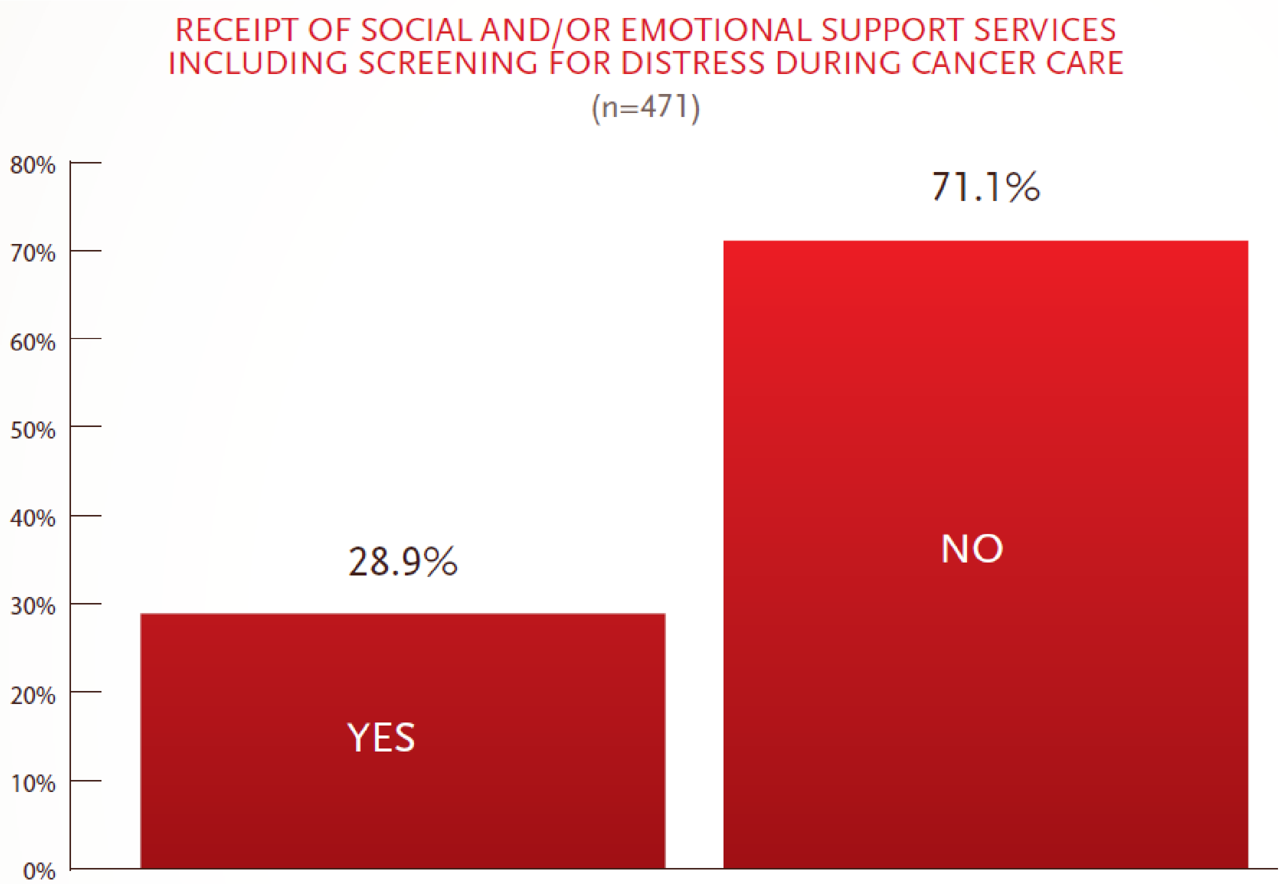
Patients with higher incomes were significantly more likely to report having access to needed medical care

Access to Services
Concerns about Having Access

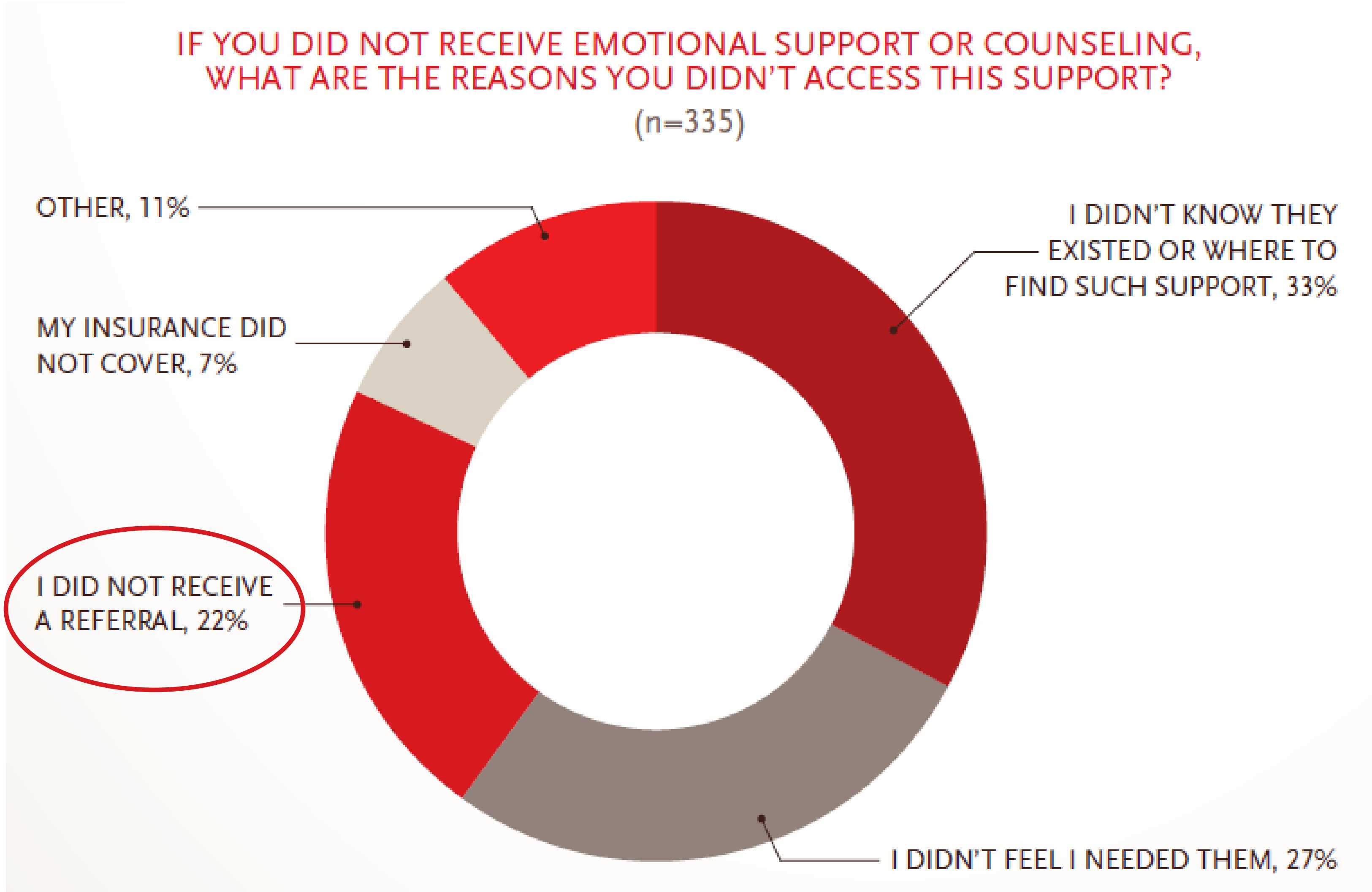
PATIENTS SERIOUSLY OR VERY SERIOUSLY CONCERNED ABOUT	PERCENTAGE
HAVING ACCESS TO GENETIC/BIOMARKER TESTING AND COUNSELING (n=466)	20.8%
HAVING ACCESS TO CLINICAL TRIALS (n=463)	20.3%
HAVING ACCESS TO EMOTIONAL SUPPORT SERVICES (n=471)	19.9%
HAVING ACCESS TO PHYSICAL THERAPY (n=462)	16.5%
HAVING ACCESS TO HOME HEALTH CARE (n=462)	16.2%
HAVING ACCESS TO HOSPICE CARE (n=458)	14.2%
HAVING ACCESS TO FERTILITY PRESERVATION (n=456)	3.1%

Access to Services
Psychosocial Support

A majority of patients did not receive social and/or emotional support including distress screening during cancer care

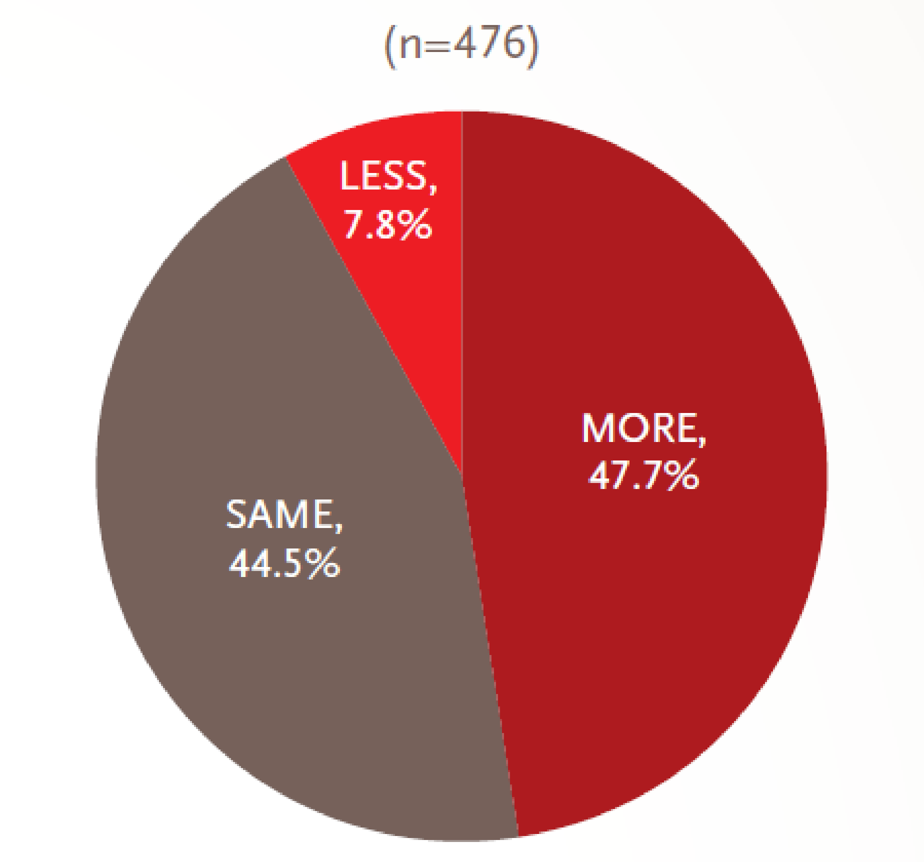


Access to Services
Psychosocial Support



Direct Costs

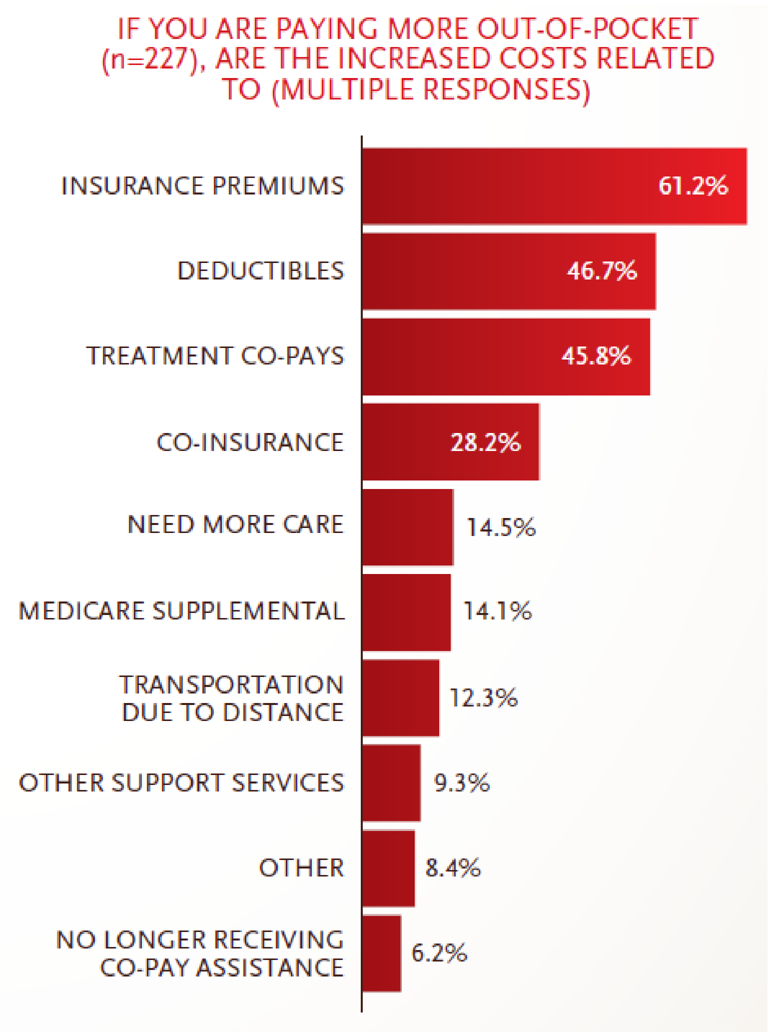
Nearly half reported paying more for health care during the past year



Direct Costs
Increased Costs

Patients report paying more for:

- Insurance premiums
- Deductibles
- Treatment co-pays
- Co-insurance


IF YOU ARE PAYING MORE OUT-OF-POCKET (n=227), ARE THE INCREASED COSTS RELATED TO (MULTIPLE RESPONSES)

Direct Costs
Top Concerns

Patients seriously or very seriously concerned about

OUT-OF-POCKET COSTS FOR HOSPITAL STAYS (n=463)	38.0%
OUT-OF-POCKET COSTS FOR MEDICATIONS (n=469)	38.0%
OUT-OF-POCKET COSTS FOR LAB TESTS OR SCANS (n=468)	37.8%
THE COST OF THE MONTHLY PREMIUM YOU PAY FOR HEALTH INSURANCE (n=467)	36.8%
OUT-OF-POCKET COSTS FOR PHYSICIAN VISITS (n=464)	31.5%
OUT-OF-POCKET FOR PALLIATIVE AND SUPPORTIVE CARE (n=464)	26.3%
OUT-OF-POCKET COSTS FOR MEDICAL CARE (n=455)	24.8%
GETTING FINANCIAL ASSISTANCE AND/OR ASSISTANCE (n=467)	24.2%

Nearly 4 in 10 (37.1%, n=467) also reported being seriously or very seriously concerned about bankrupting their family

Future Direction

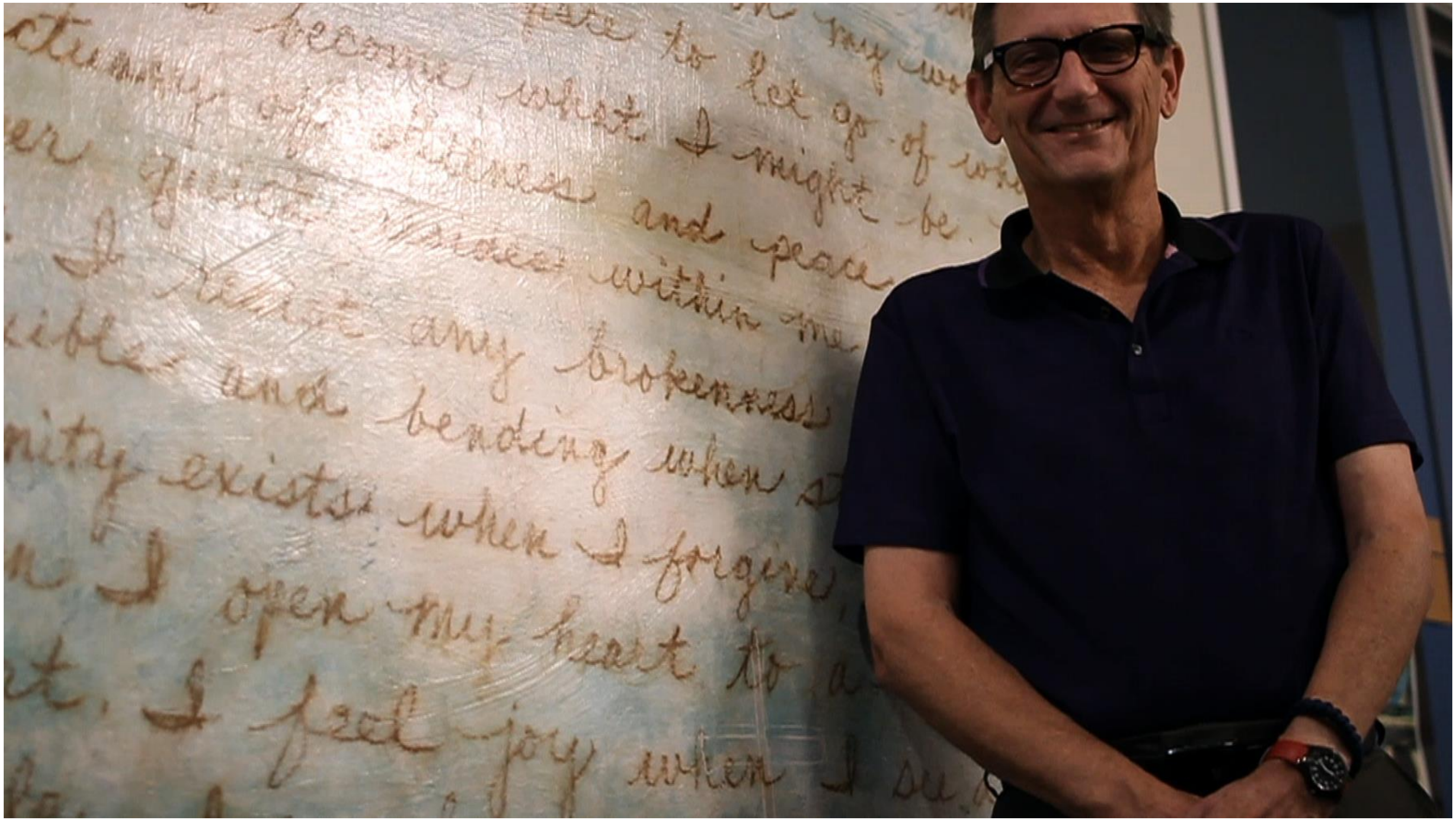
- Monitor the direct and indirect costs of cancer and related care for patients throughout the trajectory of disease
- Understand the implications of cost burden in terms of a patient's emotional health and use of health services over time
- Further explore the impact of the Affordable Care Act on the financial and emotional burden of patients
- Identify the subtleties of key elements of patient-centered care including quantity and quality of time spent with health care team and discussions on cost
- Evaluate the impact of psychosocial distress screening, referral and follow-up on patient care and costs

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Questions?

A Patient’s Perspective



Lee Tomlinson

CANCER SUPPORT COMMUNITY™

A Global Network of Education and Hope

Linda House
President, Cancer Support Community

Acknowledgment

CSC is grateful for these patients in sharing their time and voice. Our goal is to hear these voices and continue to listen so that CSC and other health care stakeholders can shape efforts that are most meaningful to patients and the health care system as a whole.

Acknowledgment

CSC thanks the sponsors of this project for their commitment to ensuring that no one faces cancer alone.

Amgen
Bristol-Myers Squibb
Genentech
Lilly Oncology
Novartis Oncology