

Cancer Experience Registry®

Biannual Snapshot

18    
MILLION

people are
living with
cancer



Shared voices can change
how we support **them**

May 2023



CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER



CANCER SUPPORT **COMMUNITY**[™]

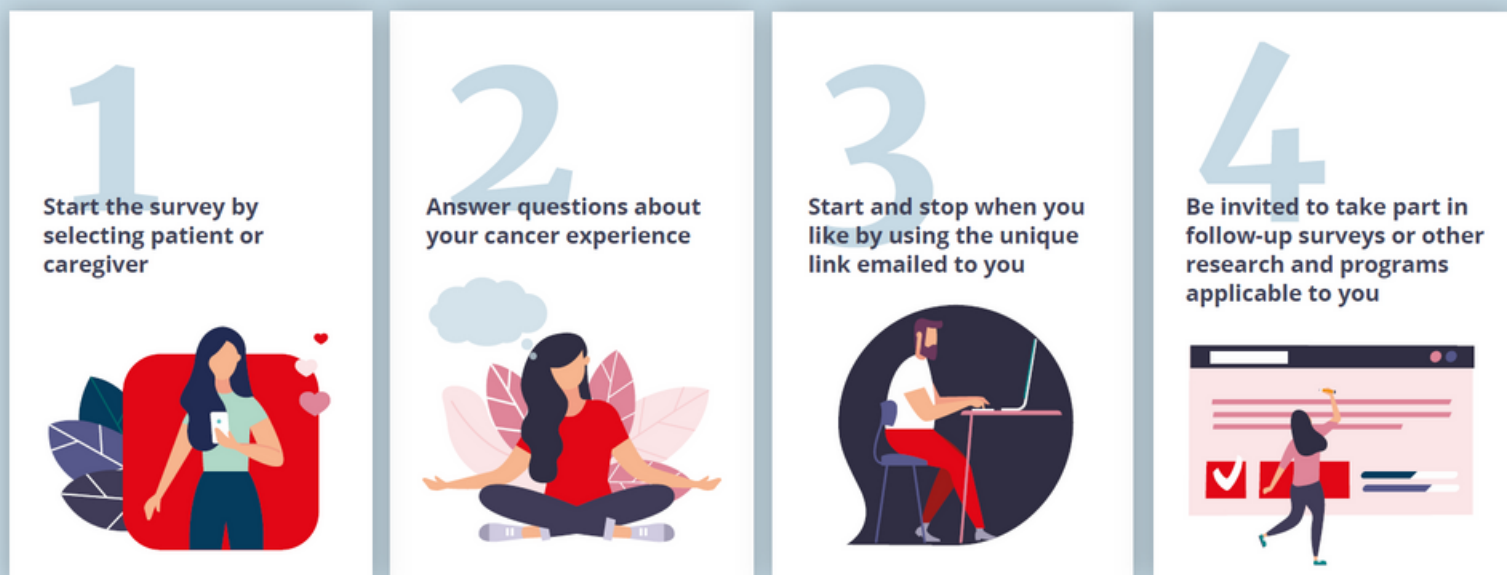
CANCER EXPERIENCE REGISTRY

The Cancer Experience Registry is an online research study for individuals with cancer and their caregivers. The surveys focus on multiple aspects of cancer to understand its emotional, physical, practical, and financial impact, so we can identify and address gaps in care and influence outcomes such as survival, quality of life, and healthcare cost.

By gathering the important insights of those affected by cancer through the CER surveys, we can create better outcomes for patients, survivors, and caregivers today, and for future generations.



How the CER Works



CancerSupportCommunity.org/Registry

Frequently Asked Questions

What is the Cancer Experience Registry?

The Cancer Experience Registry (CER) is an online research survey that helps enhance cancer care, improve health care policies, and ensure support services better reflect the needs of people affected by cancer.

Who can take the survey? The CER is open to any adult who has been diagnosed with cancer at any point in their life or has been a family or informal caregiver to someone with cancer. Participants must live in the United States, a U.S. territory, or Canada and be able to read and understand English.

What about my privacy? The survey is an Institutional Review Board (IRB) approved research study, which means that the confidentiality, rights and welfare of participants are protected.

Is there a cost to take part? No, there is no cost to take part in this research.

What is the benefit to taking part? By generously giving your time for this important research, your contributions help deliver better outcomes for those impacted by cancer, now and in the future.

What happens when I've finished the survey?

Once you complete the survey, you become part of a registry of patients and caregivers with the opportunity to complete follow-up surveys that track changes over time, or additional surveys that ask about emerging topics in cancer care.

Help change the future of cancer support by taking the CER survey

CER Biannual Activity

Highlighting data
collected from
October 2021 through
March 2023

1,959 Patients & Survivors
792 Caregivers
268 Dyadic Pairs

Cancer Experience Registry Highlights

18-month Longitudinal Survey
Launched May 1, 2023

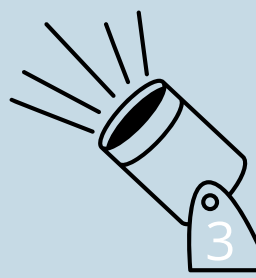


Cancer Experience Registry State Initiative

In response to a call for more **state-level cancer survivorship and caregiver data**, **Cancer Support Community** has begun partnering with **state cancer coalitions** to recruit more participants into the CER.

State-specific data from the CER will provide unique insights on cancer patient, survivor, and caregiver needs in each state that can be used to **support the development of tailored, state-specific educational resources and inform state healthcare policies and programs** that address patient, survivor, and caregiver needs. So far, we have started the process with:

- **Alaska**
- **Arizona**
- **Colorado**
- **Iowa**
- **Virginia**
- **West Virginia**
- **Wisconsin**



A NOTE ON USING DATA IN THIS REPORT

The data in this report are specific to the
Cancer Experience Registry sample
since the October 2021 relaunch.

When discussing these findings, it is important to specify that they reflect a sample and cannot be generalized to all people impacted by cancer.

Please reach out to the RTI Team with any questions!

"One out of three caregivers *who were surveyed* reported that..."

For example...

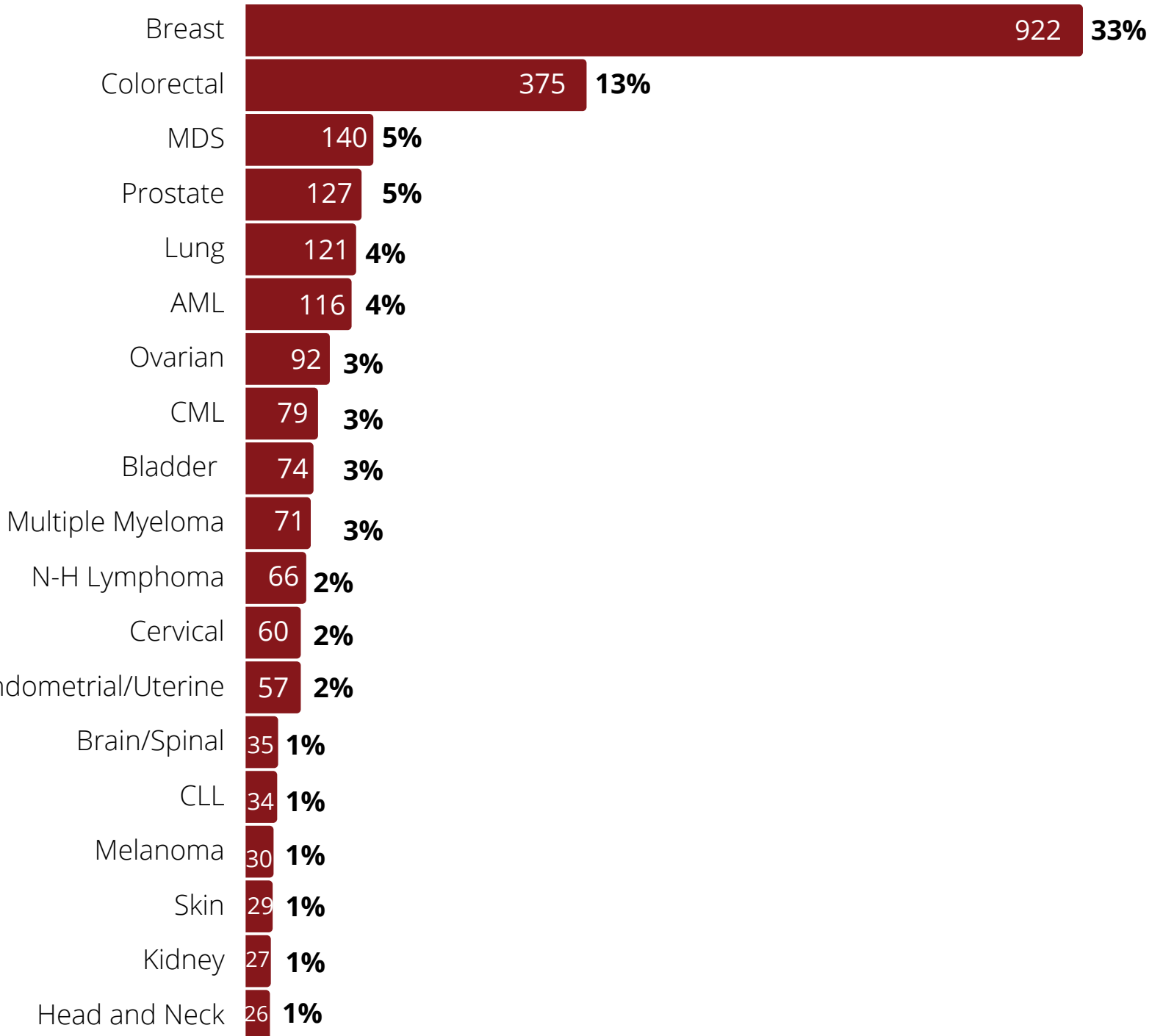
"Half of the patients and survivors *who completed the Registry* said that..."

Patient Clinical Characteristics

Over 50 unique cancer diagnoses are represented in the Patient CER



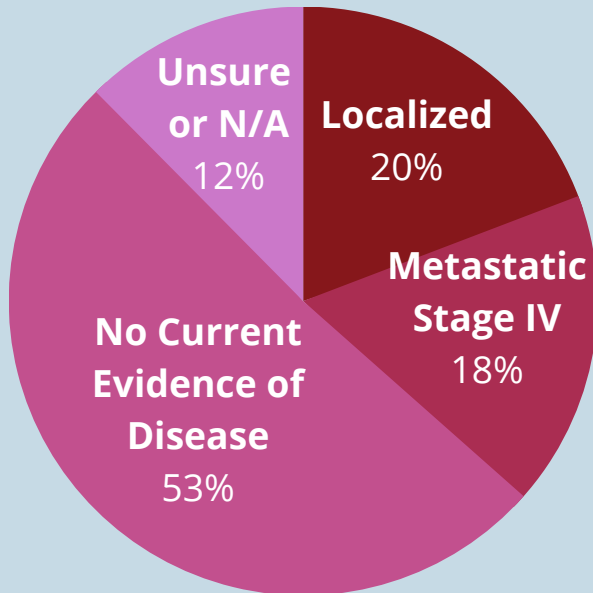
Most commonly represented cancer diagnoses include:



*Only diagnoses with ≥ 20 participants are displayed

Patient Clinical Characteristics

Current Cancer Status

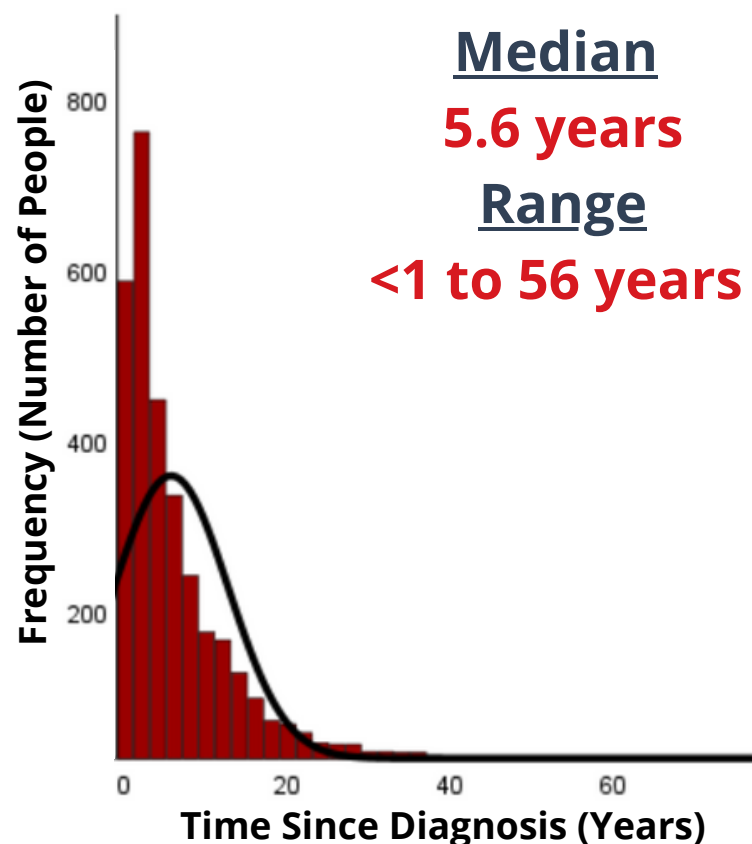


94% had *ever* received treatment

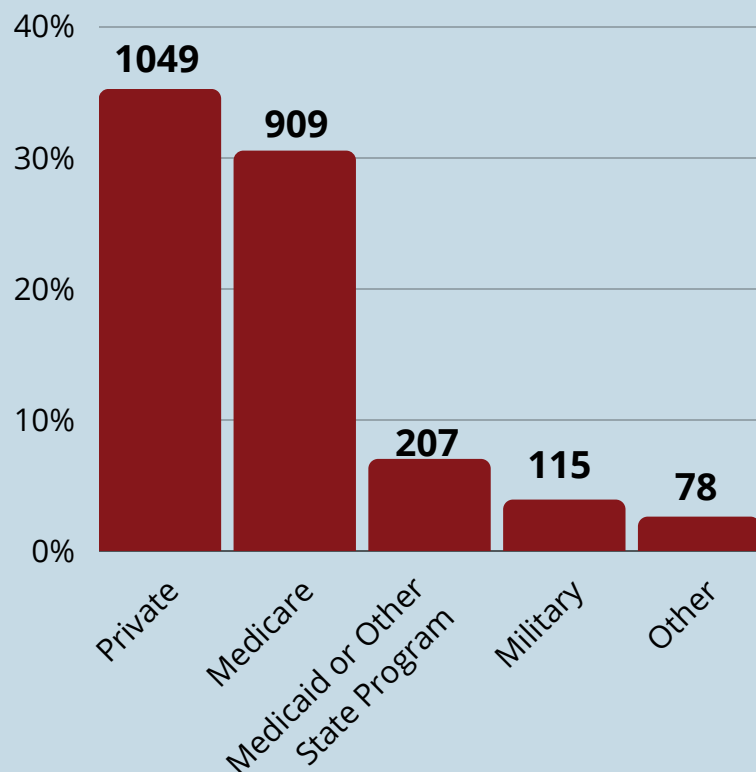
53% were *currently* receiving treatment

25% had *ever* experienced a recurrence

Time Since Diagnosis

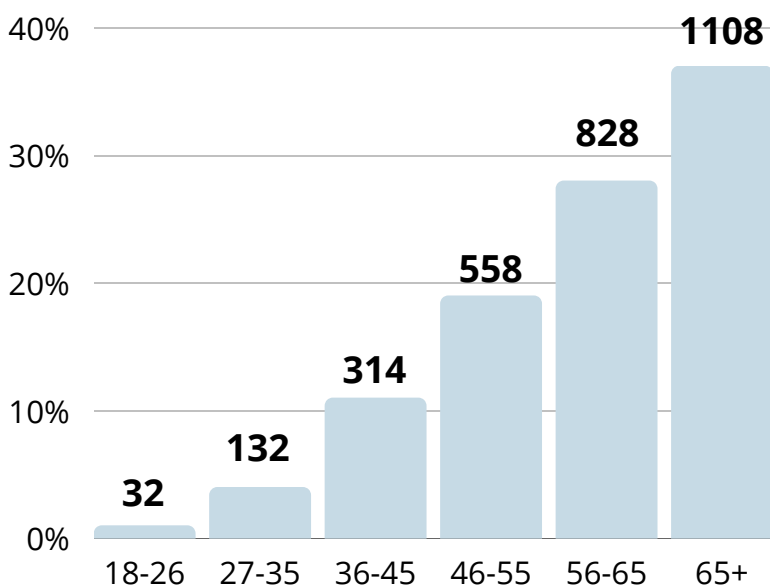


98% had current health insurance



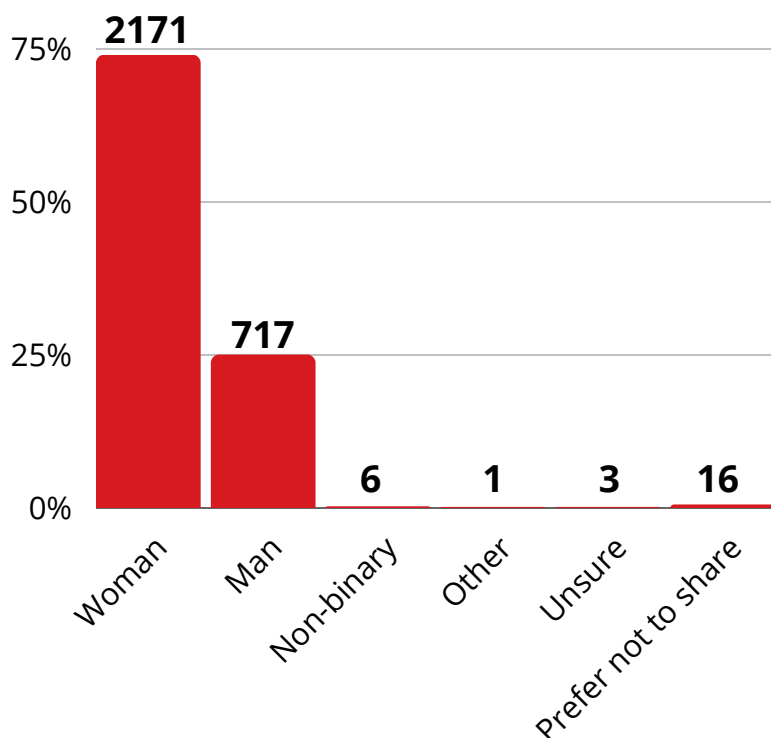
Patient Sociodemographics

Age in Years

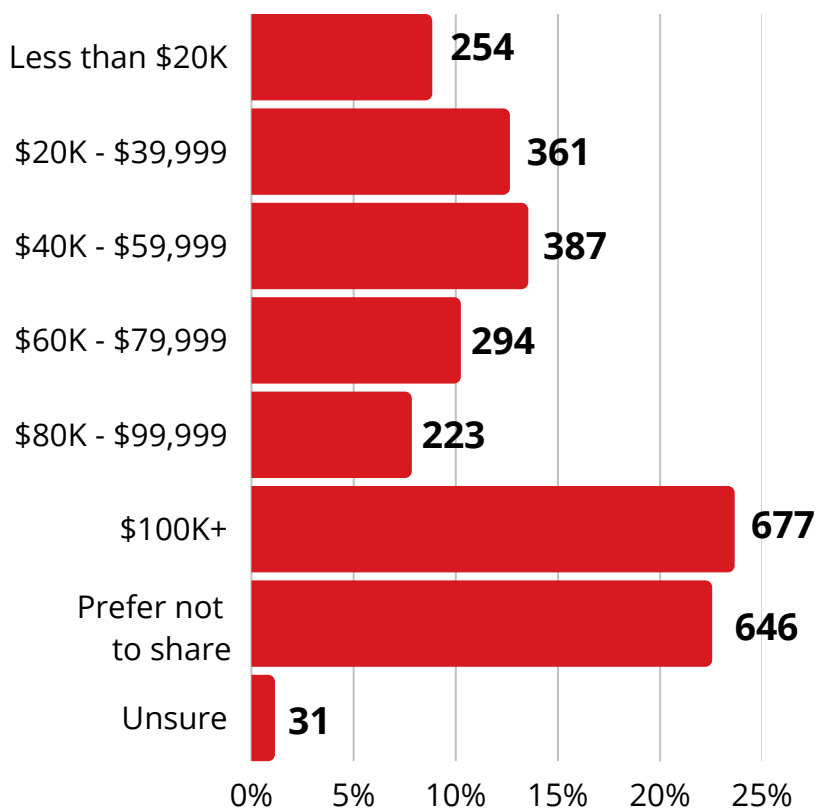


Average Age: 60 years
Range: 18-97 years

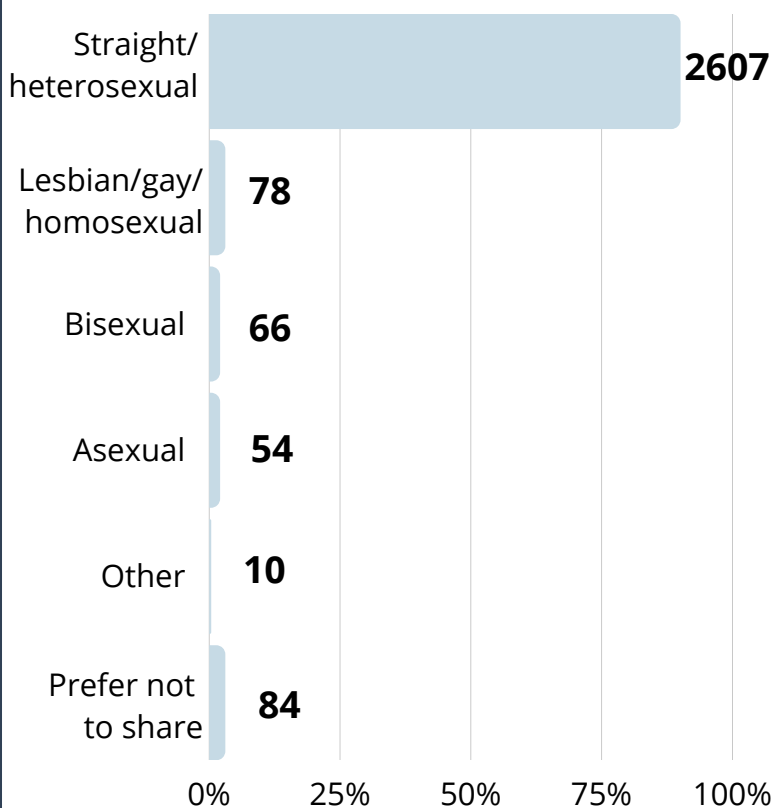
Gender Identity



Annual Household Income

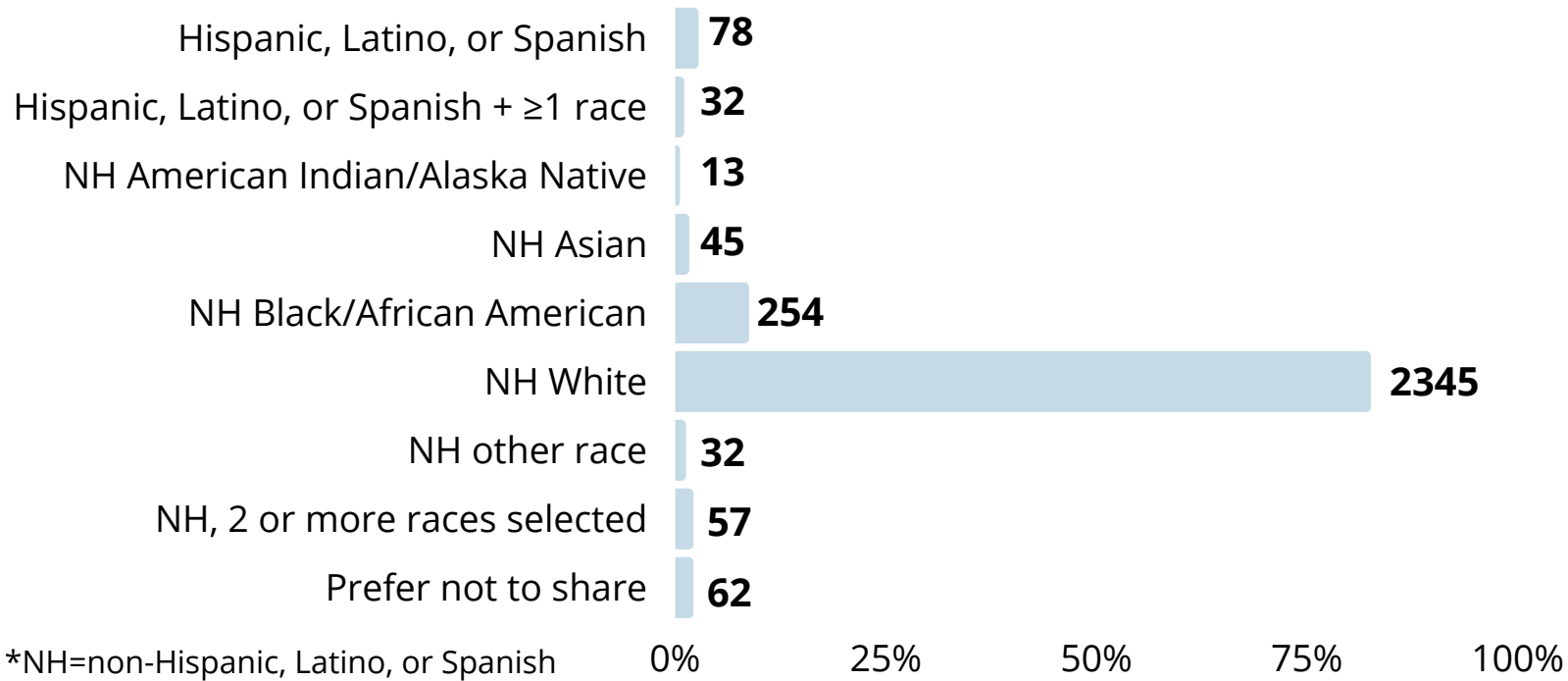


Sexual Identity

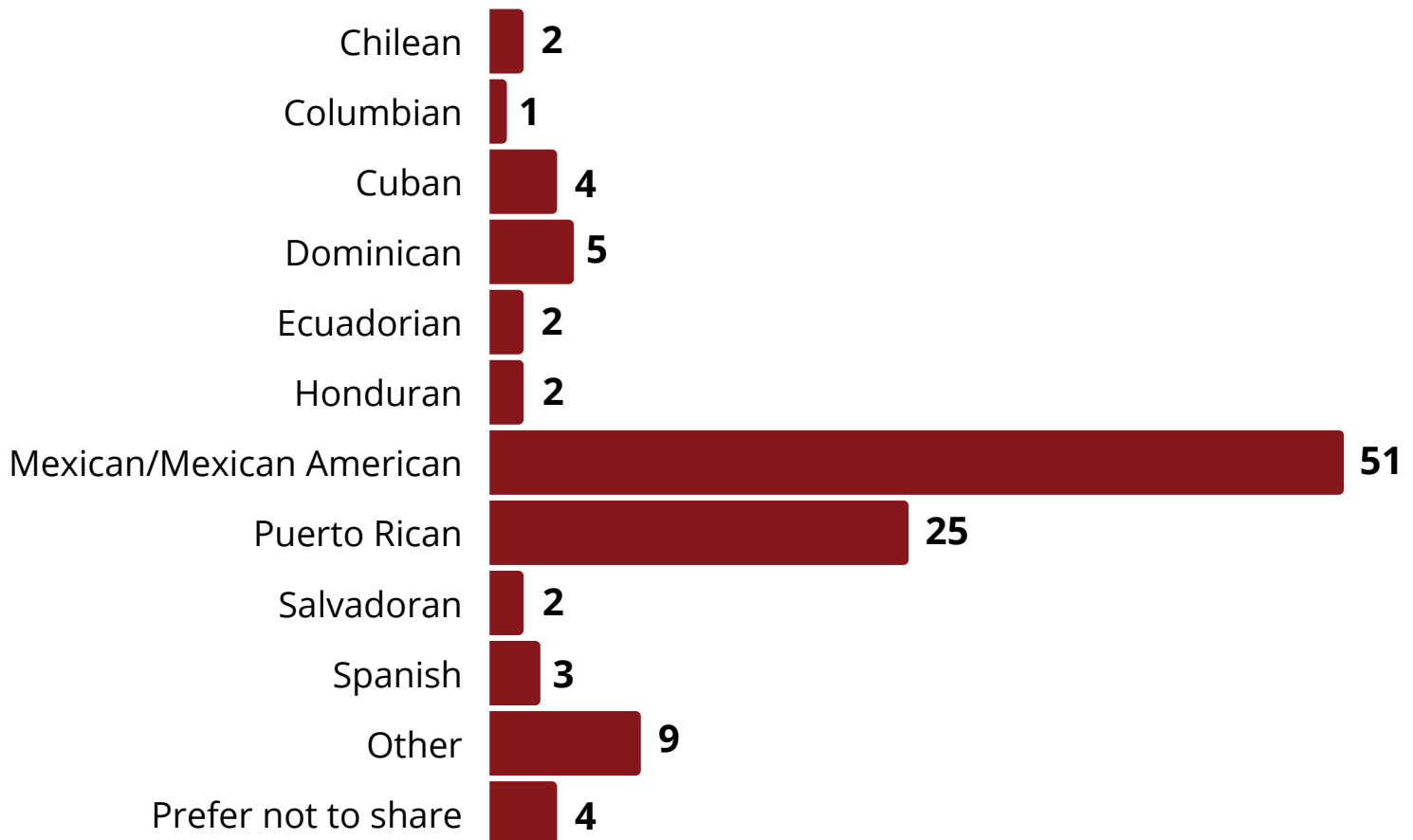


Patient Sociodemographics

Race & Ethnicity



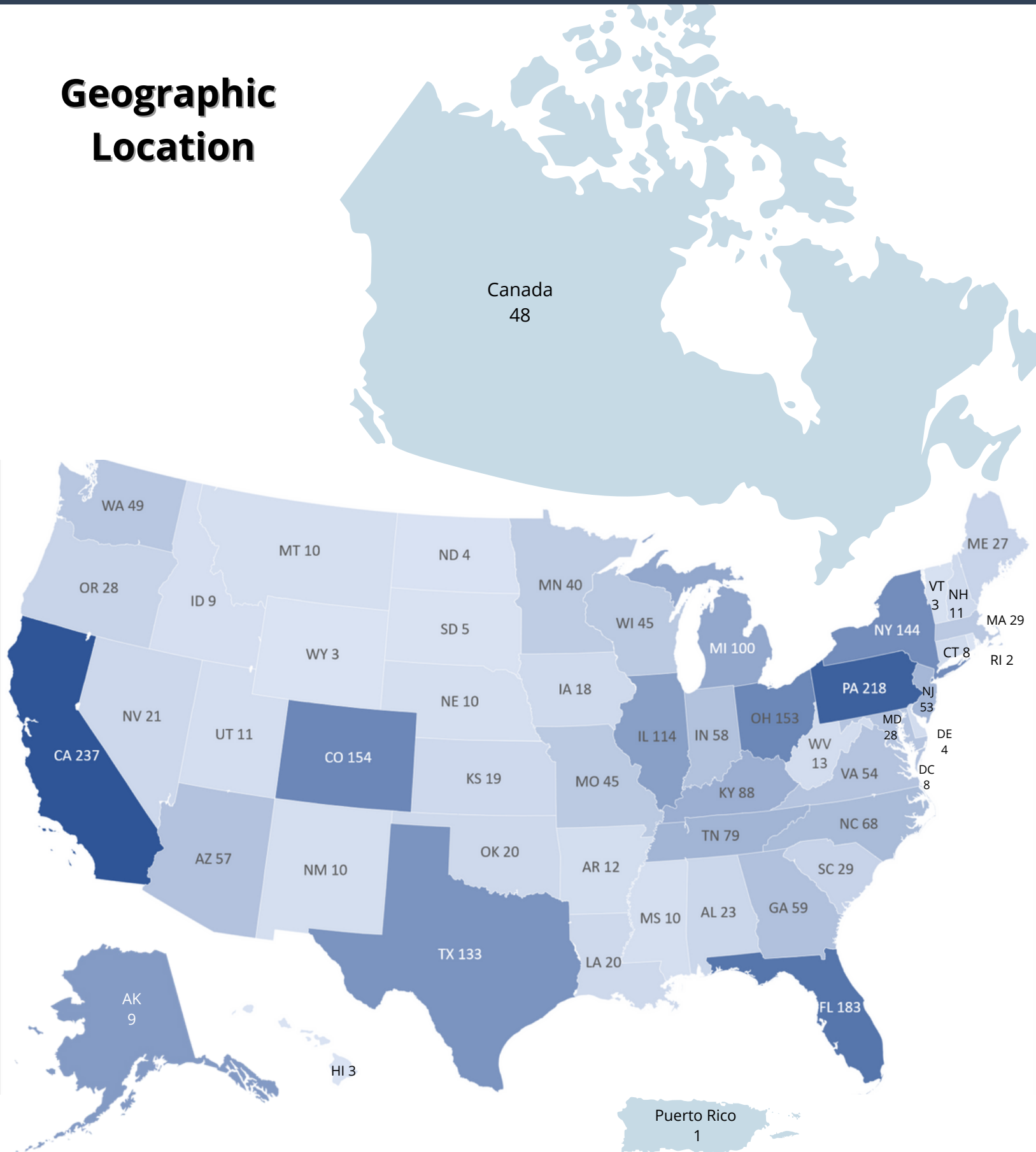
Hispanic, Latino, or Spanish Ethnicity ‡



‡n=110 participants who identified as Hispanic, Latino, or Spanish ethnicity

Patient Sociodemographics

Geographic Location

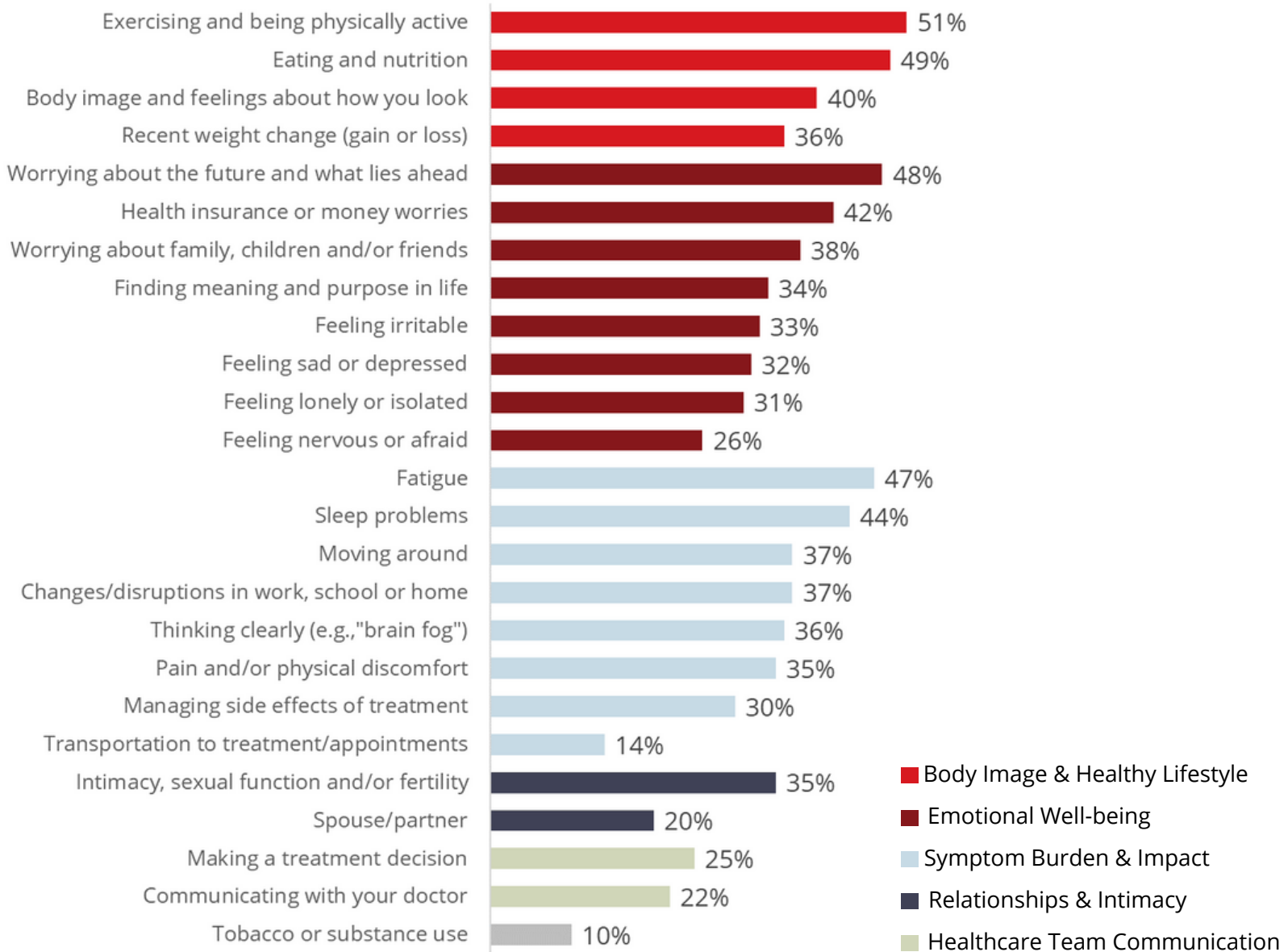


*Not all participants provided their location.

Patient Emotional Distress

Key Areas of Concern

Percent moderately to very seriously concerned



Additional Concerns in the Cancer Experience Registry

58% were concerned about cancer progressing or coming back

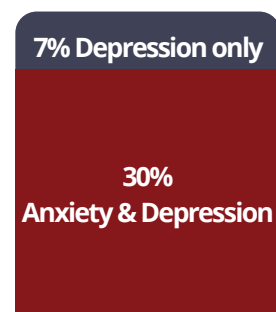
31% were concerned about preparing for the end of life

21% were concerned about their spirituality, faith, or religion

Risk for Anxiety & Depression



At Risk for Anxiety



At Risk for Depression



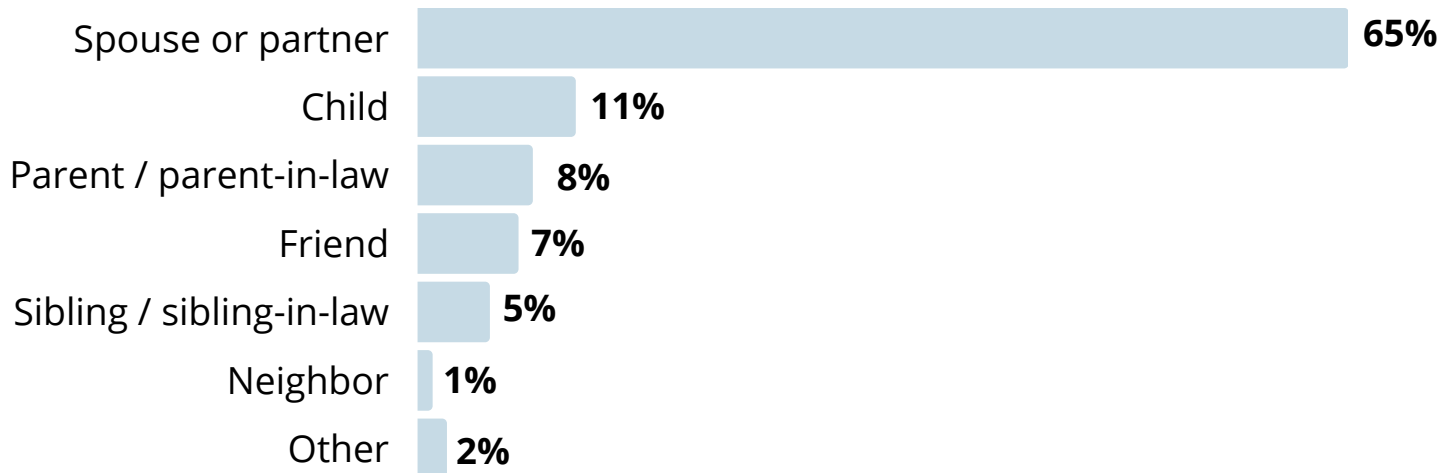
Not at Risk

Social Support among Patients

82% had a caregiver at some point since their cancer diagnosis

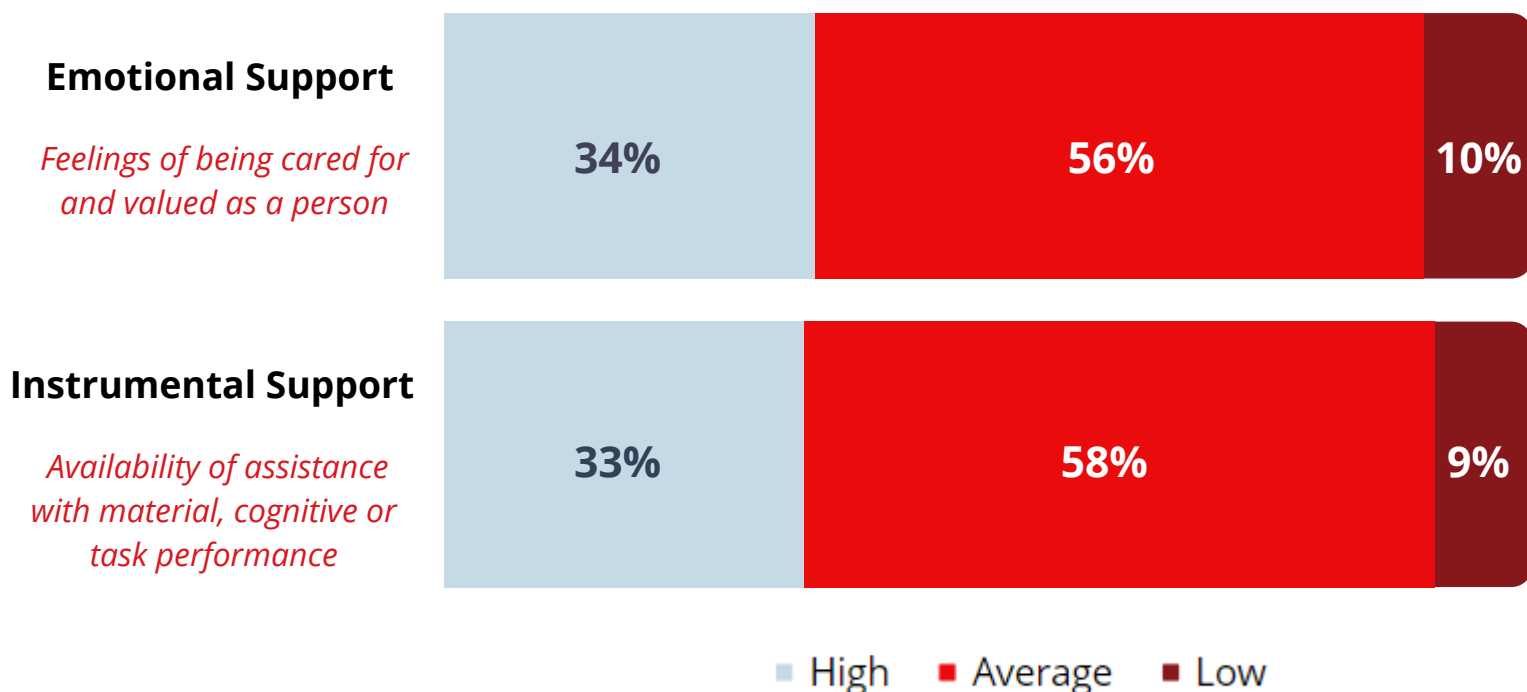


Primary caregivers included:



Perceptions of Available Support

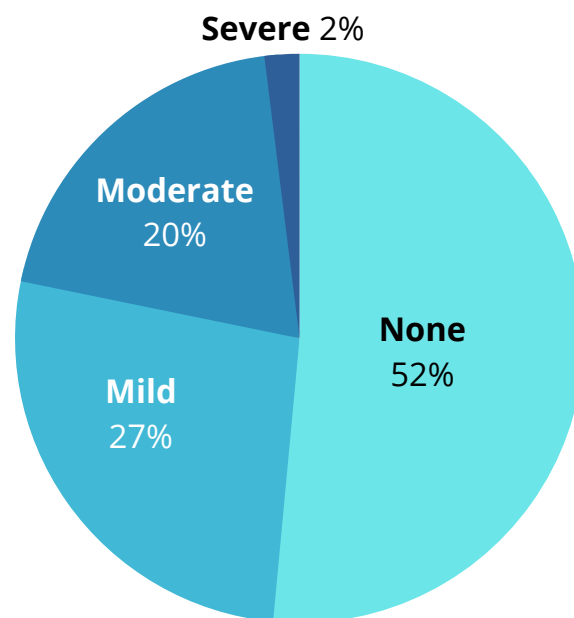
1 in 10 reported low levels of emotional and instrumental support



The Financial Burden of Cancer

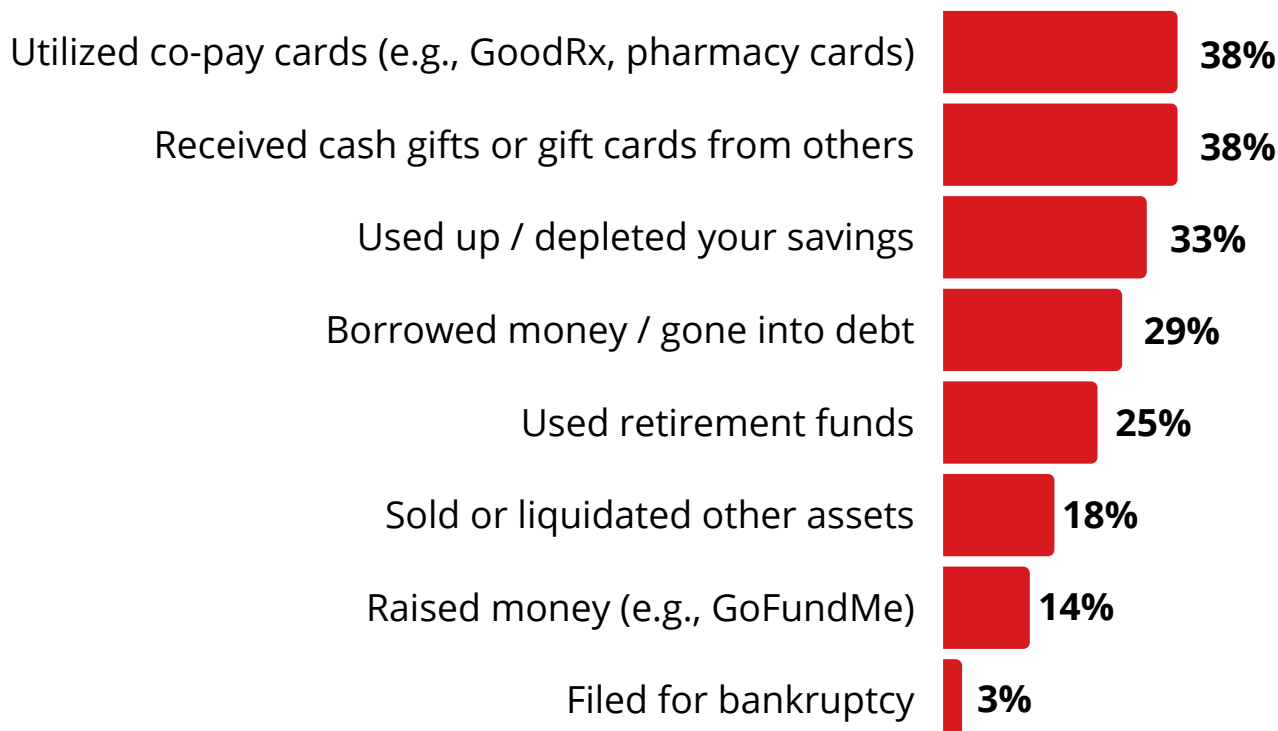
Level of Financial Toxicity

Financial Toxicity refers to the objective monetary burden and subjective psychological distress that cancer patients face as a result of their care.



At the time patients took the survey, **7%** reported engaging in *medication scrimping to save money in the past year* skipping doses, taking less medication, or delaying a refill.

Actions Taken by Patients Because of Medical Costs



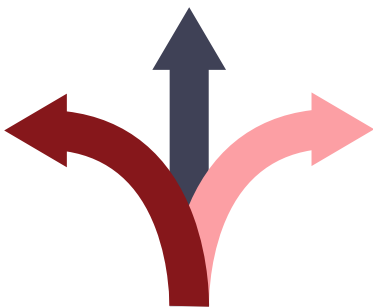
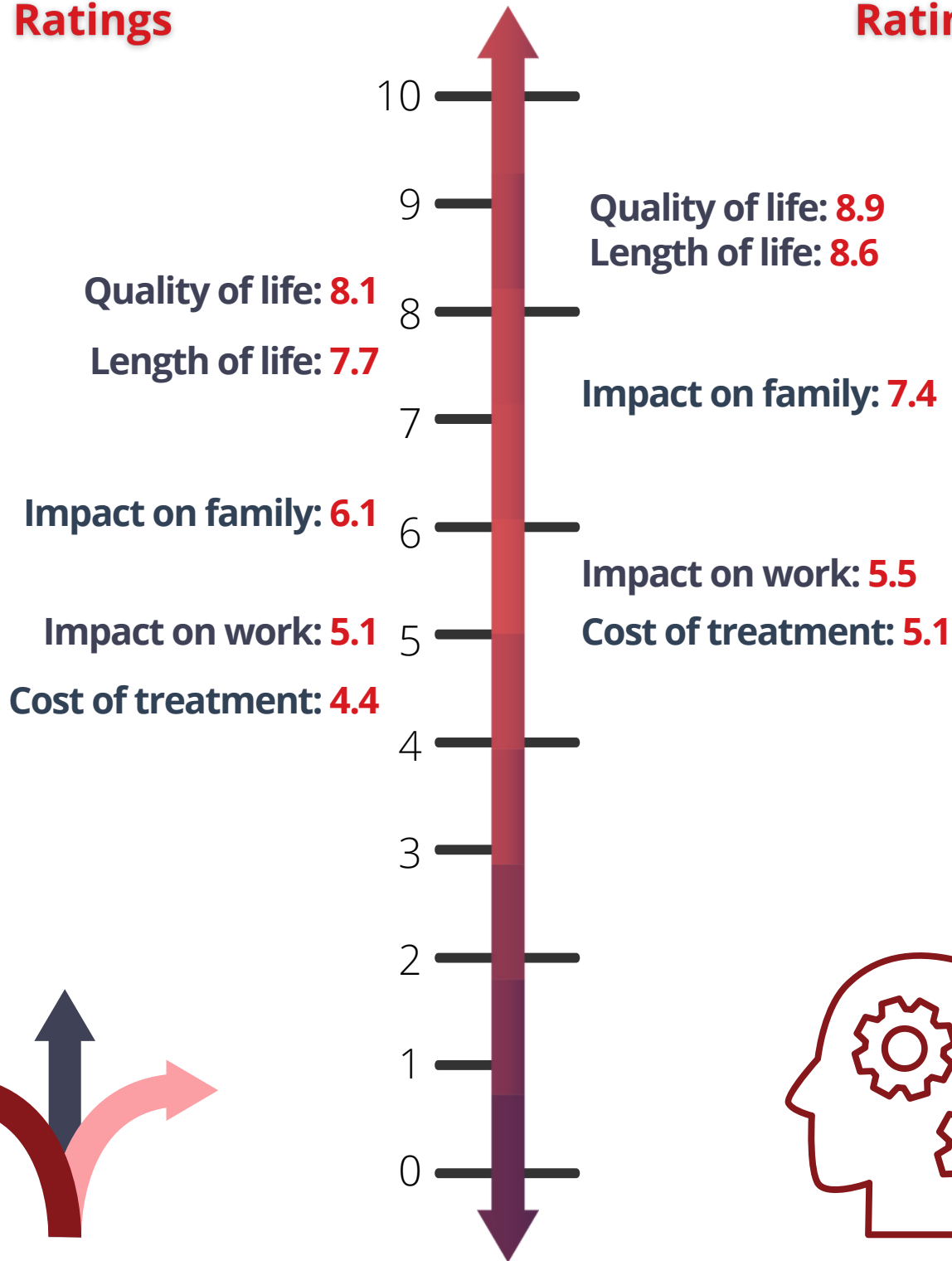
Decision-Making & Adherence

How important are the following factors when making a decision about cancer treatment?

Caregiver Average Ratings

Extremely important to me

Patient Average Ratings



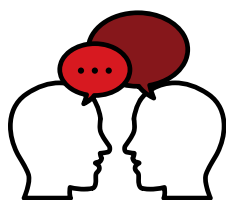
Not at all important to me

Quality of Care among Patients

Satisfaction with Cancer Care Team

78% Made the patient feel comfortable asking questions.

77% Ensured the patient understood the steps in their care.



77% Engaged in open and honest communication.

70% Provide adequate information and resources to make treatment decisions.



54% Helped them deal with uncertainties.

46% Did well when talking to the patient about how to cope with fears, stress, and other feelings.

76%

Did not feel knowledgeable about the financial impact of each cancer treatment option before making a decision.

60%

Did not feel knowledgeable about each cancer treatment option before making a decision.

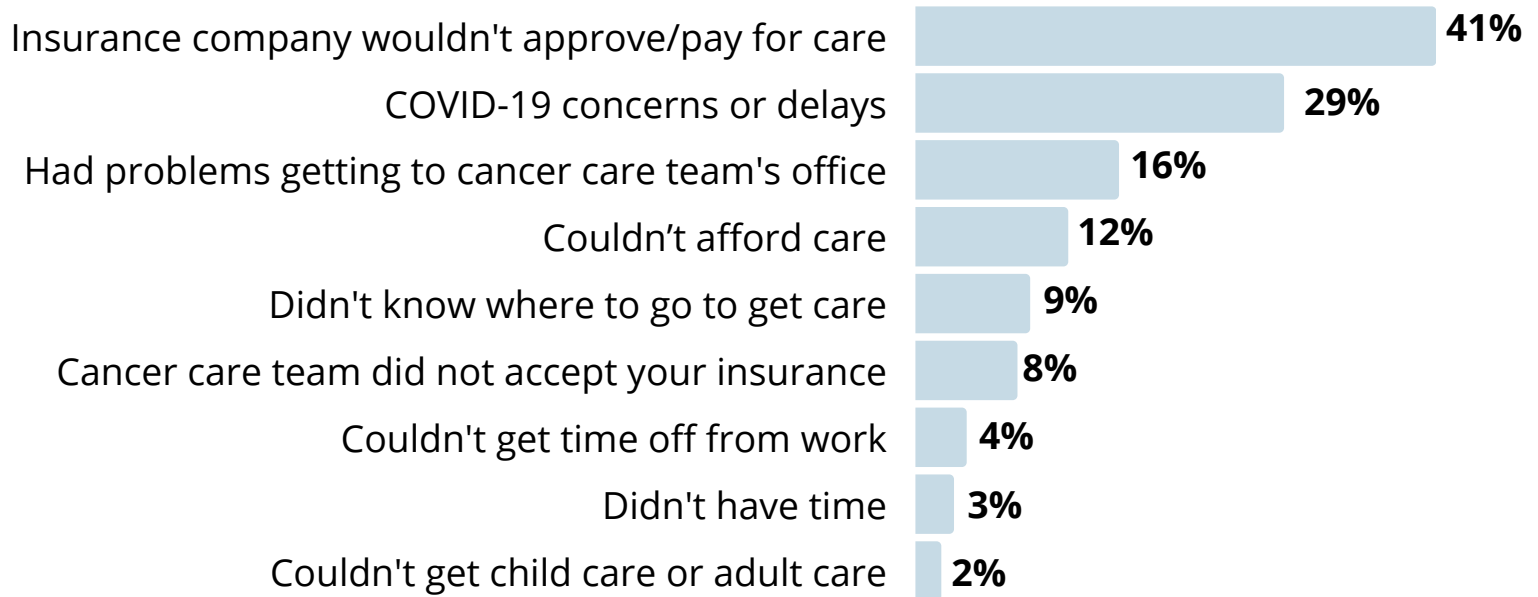
57%

Did not feel prepared to make cancer treatment decisions.

Access to Care

29% Experienced delays or barriers to accessing cancer care or treatment.

Among those who experienced delay, barriers included:



Cancer Clinical Trials

37% Reported that a member of their cancer care team spoke to them about cancer clinical trial options.

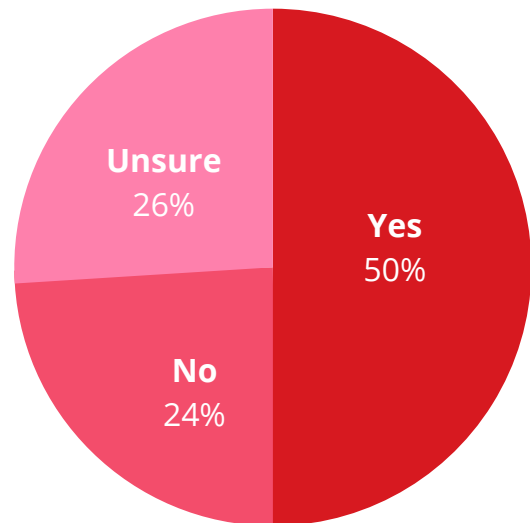


17% Have participated in a cancer clinical trial.

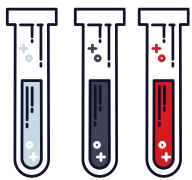
Testing and Screening

Biomarker Testing

To the best of your knowledge, did any of your doctors ever do any biomarker testing on your tumor tissue?



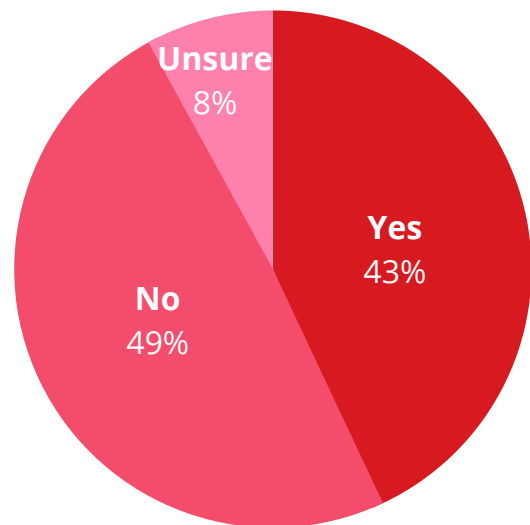
Among those who did not undergo biomarker testing:



- 64%** It was not offered to them.
- 34%** Did not know it was an option.
- 5%** Insurance did not cover it.
- 4%** Were aware of the option but chose not to.

Genetic Testing

Have you ever had a genetic test to determine if you are at high risk for cancer?



Among those who did not undergo genetic testing:



- 55%** It was not offered to them.
- 37%** Did not know it was an option.
- 12%** Were aware of the option but chose not to.
- 5%** Insurance did not cover it.

Patient Health Behaviors

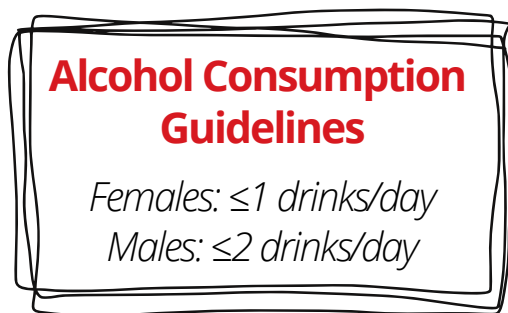
Comparisons to public health guidelines



32% met guidelines of 150+ minutes of moderate physical activity per week



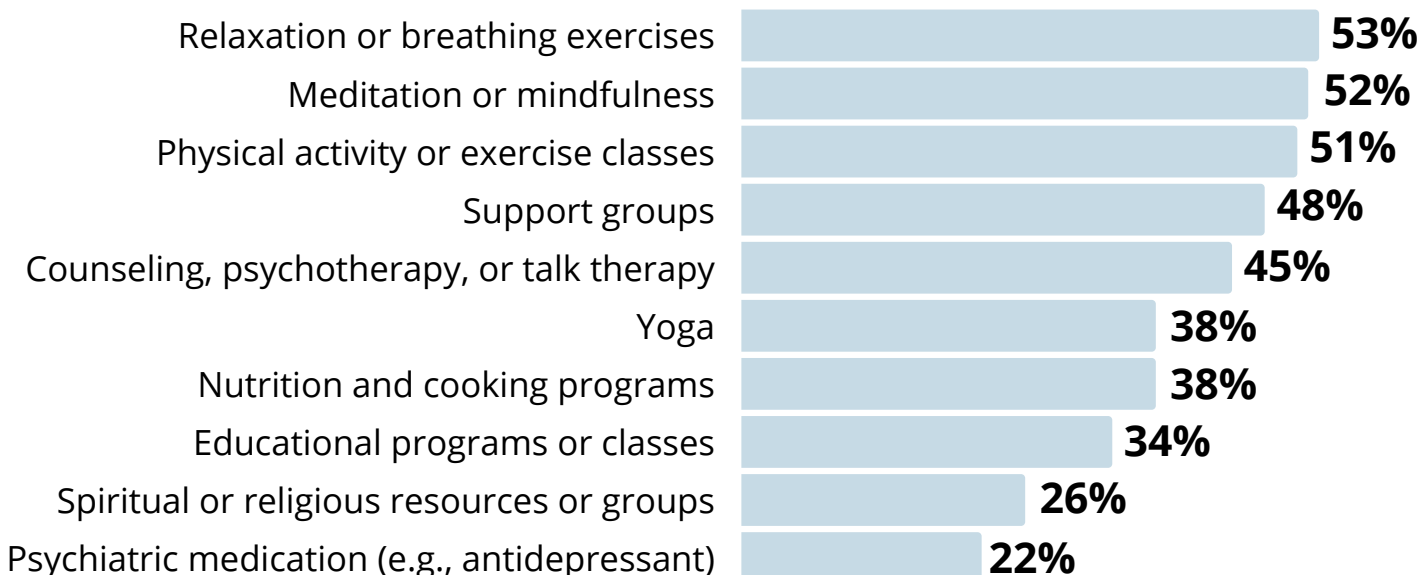
99% were within daily alcohol consumption guidelines



1 in 10 currently use tobacco products

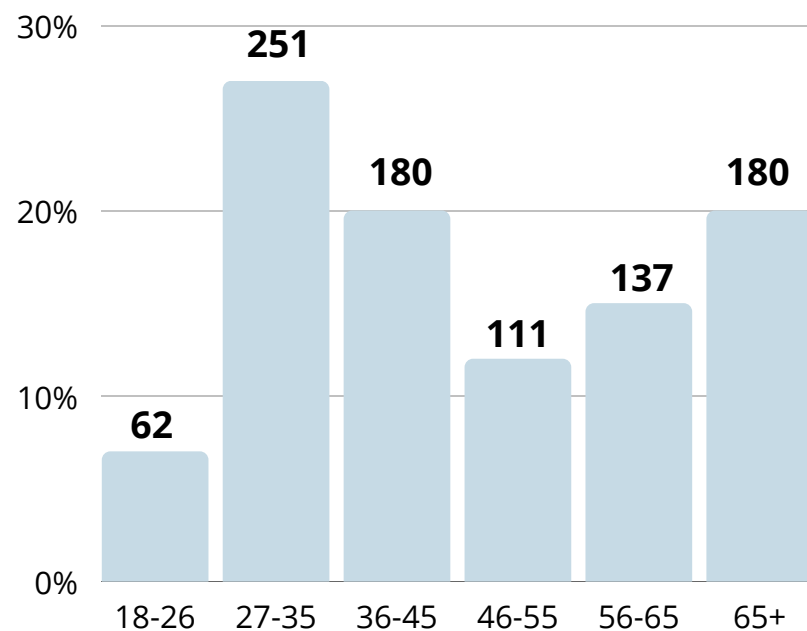


Patients were interested in the following health and wellness strategies:

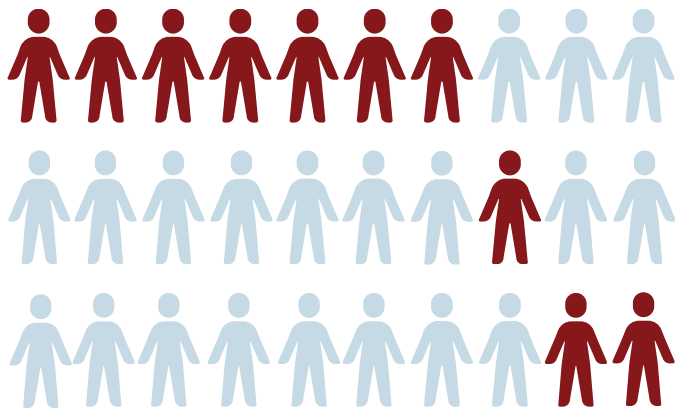
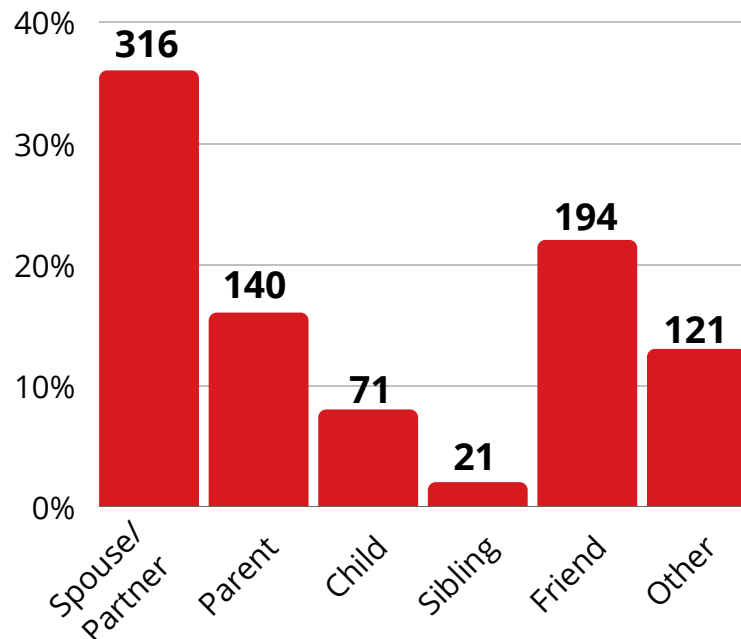


A Peek into CER Caregiver Sociodemographics

Caregiver Age in Years



Who is being cared for?

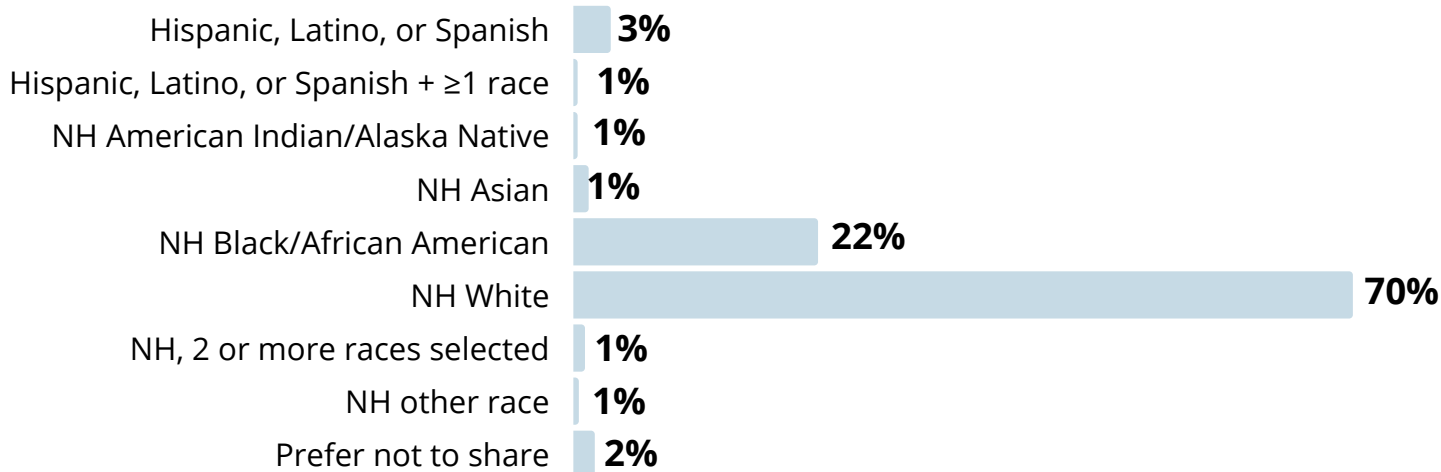


7 in 10 currently caring for a patient receiving treatment

1 in 10 currently caring for a patient not receiving treatment

2 in 10 former caregivers

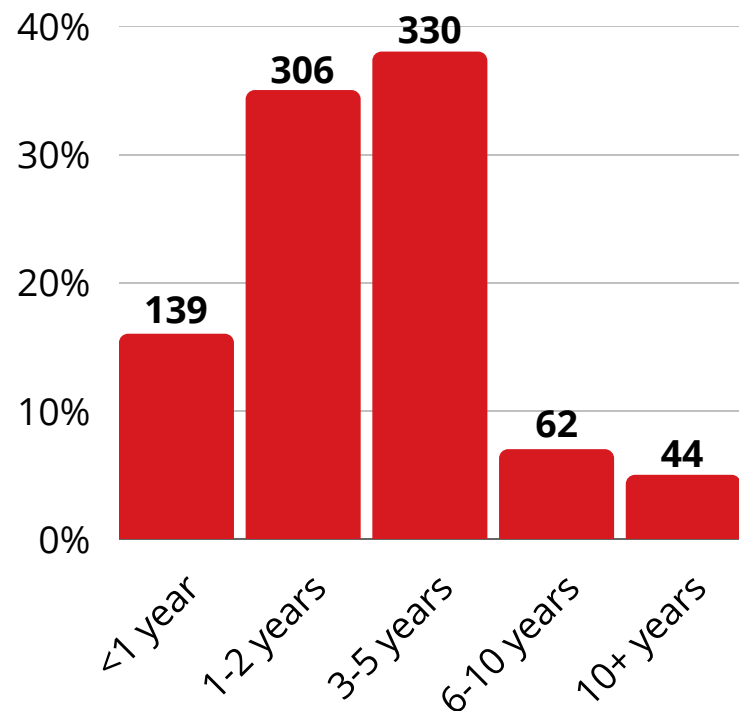
Caregiver Race & Ethnicity



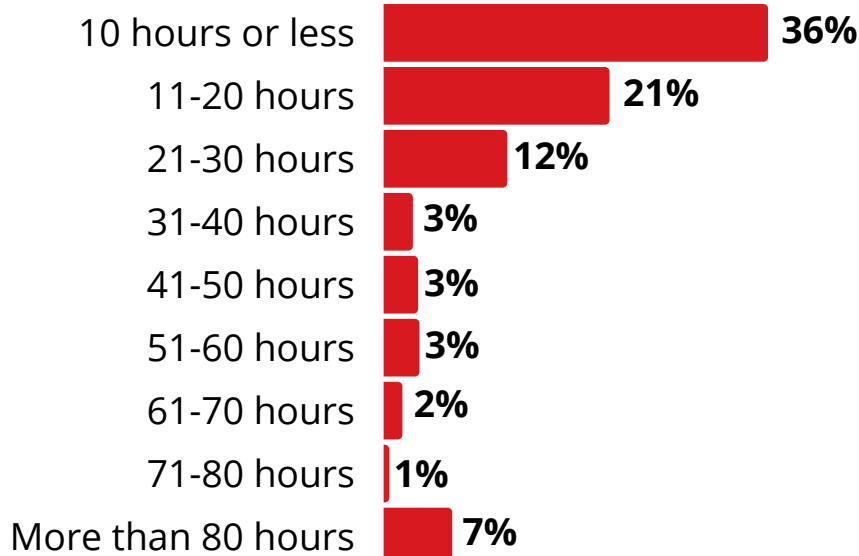
*NH=non-Hispanic, Latino, or Spanish

A Peek into CER Caregivers

Years Providing Care

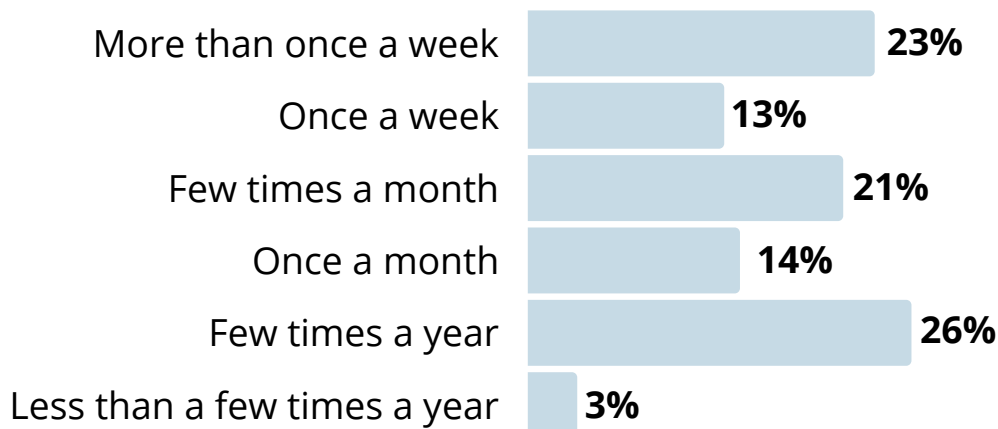


Average Hours/Week Providing Care



13% of caregivers reported providing **constant care**

Frequency of Traveling for Patient's Medical Care Appointments



53%
lived with the patient

32%
reported **always** attending medical visits with the patient

31%
care for a patient living with metastatic disease

Impact of Caregiving on Employment

37% went in late, left early, or took time off to provide care
13% went from working full-time to part-time, or cut hours
8% quit their job or retired early to provide care
6% lost job benefits, such as insurance or paid vacation
4% received a warning about performance or attendance
1% were fired or laid off

Cancer Experience Registry Value Proposition

There are nearly 18 million individuals living with cancer in the United States. Each has a story to tell, and those unique and shared experiences combined provide valuable insights.



“We use information from patients and caregivers to give us real life data about what their experiences are. We then use that data to publish and share it with Congressmen, with doctors, with researchers, anyone who can help us make laws or make changes that improve the lives of cancer patients.”

Lauren Barnes, CSC Board Chair

What is the Cancer Experience Registry?

The Cancer Experience Registry (CER) is an IRB-approved research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify critical unmet needs among cancer patients, survivors, and caregivers.

Our research is one of a kind because it captures the lived experiences of people impacted by cancer through longitudinal data collection, as well as patient and caregiver data that can be linked to understand how their experiences impact each other.

The Scientific Impact of CER Data

We advance knowledge of the cancer patient and caregiver experience through peer-reviewed publications in leading academic and medical journals, including:

- Blood, Journal of American Society of Hematology
- Journal of Clinical Oncology
- Journal of National Comprehensive Cancer Network
- Journal of Oncology Navigation and Survivorship
- Journal of Patient Experience
- Supportive Care in Cancer

“Clinical research advances science and assists with ensuring that patient care approaches the highest possible level of quality.”

Commission on Cancer, 2020

We have presented over **80** abstracts at renowned oncology and health care conferences, including:

- American Public Health Association
- American Psychosocial Oncology Society
- American Society for Clinical Oncology
- American Society of Hematology
- International Association for the Study of Lung Cancer
- International Psycho-Oncology Society
- National Comprehensive Cancer Network
- San-Antonio Breast Cancer Symposium
- Society for Behavioral Medicine
- Society of Gynecologic Oncology

Data is used in support of grant submissions to attain funding for other research:

- NIH Research Funded Grant Program
- Patient-Centered Outcomes Research Institute’s Research Support Funding

The Real-World Impact of CER Data



At the Point of Care

Enhance cancer care provided

- The CER is registered on clinicaltrials.gov under NCT02333604 and can be used by hospitals to meet Commission on Cancer accreditation standards for enrolling patients in cancer clinical trials. CER data can benchmark key elements of patient experience, including pain interference and patient-provider communication, with the goal of improving quality of care.
- CER data informed the development of CancerSupportSource® (CSS), a community-based distress screening, referral, and support program for adults diagnosed with cancer and CancerSupportSource® Caregiver, the first and only cancer caregiver distress screening, referral, and support program for family and informal cancer caregivers.



At the Local Level

Improve support services

CER data is used to create and prioritize programs nationwide that are truly meaningful to patients and their loved ones.

- CSC provides free support services to patients, families and caregivers through a large professionally led network of partners. Local participants are recruited to the CER, and the network partner receives customized data reports to inform met and unmet needs for their local communities.
- CER data collected locally supports community grant submissions for research and programming.
- CER data collected nationally provides patient and caregiver insights for Frankly Speaking About Cancer, CSC's award-winning educational series including videos, webinars, podcasts and booklets.



At the State and National Level

Influence health care policy

- CSC's Cancer Policy Institute (CPI) leverages these unique insights into the patient experience to offer policymakers the ability to evaluate potential policy changes to ensure they are helping patients.
- CPI shares CER findings with the Institute for Clinical and Economic Review (ICER) to inform value assessments that have the potential to impact patient access to the newest medications and devices.
- CER participants are invited to take part in CPI surveys that promote the patient voice and inform advocacy in issues like drug development, access, and affordability to necessary medication.

CSC is working to transform the lives of those impacted by cancer.

CancerSupportCommunity.org/Registry