

ASSOCIATION OF COMMUNITY
CANCER CENTERS

PERSONALIZING CARE
FOR PATIENTS OF ALL
BACKGROUNDS:

INSIGHTS FOR THE
MULTIDISCIPLINARY
CANCER CARE TEAM



EXECUTIVE SUMMARY



Association of Community Cancer Centers

Program Background

Advancements in cancer diagnostics have led to significant breakthroughs in precision medicine, genomics, and targeted immunotherapies in recent years. While these advancements have meant a steady decline in overall cancer mortality rates, progress has not been equitable across all populations: racial and ethnic minorities experience a greater burden of cancer,¹ individuals with lower education levels, lower income levels, or living in impoverished areas experience higher cancer mortality and incidence rates than their more affluent counterparts, and socioeconomic disparities in cancer mortality continue to widen.²

Understanding health inequities and implicit bias—based on race/ethnicity, ability, gender identity, geographic location, income, education, age, sexual orientation, national origin, and/or other personal characteristics—and understanding their underlying causes can lead to more effective prevention strategies and can help to manage and reduce existing disparities in cancer incidence, treatment, and mortality.

The Association of Community Cancer Centers (ACCC) has done a tremendous amount of work regarding health disparities and implicit bias. In a joint effort with the American Society of Clinical Oncology (ASCO), ACCC released resources to promote racial and ethnic diversity, equity, and inclusion (DEI) in cancer clinical trials. This includes the **Just ASK™ Training Program**, **ASCO-ACCC Equity, Diversity, and Inclusion Research Site Self-Assessment**, and the **Just ASK™ Training Facilitation Guide**. These outline key DEI concepts and the role of implicit bias in clinical trial recruitment, and identify opportunities and real-world examples providers can utilize in practice. Other ACCC education programs have sought to address mitigating disparities in precision medicine, relative to specific cancer types such as lung, breast, and prostate, as well as provide role-specific tips and effective practices to address both regional and national disparities.

In 2021, ACCC—with its partners the Virginia Mae King Foundation, SHARE Cancer Support, the Latino Cancer Institute, Cancer Support Community, Stupid Cancer, and in collaboration with Pfizer—launched a program to explore how well care teams identify and honor patients' goals and preferences.

As part of this program, comprehensive patient (n=148) and provider (n=85) surveys were conducted in 2022 to gauge perceptions on health care injustice and implicit bias, to identify patients' goals and preferences, and through this lens, highlight opportunities to personalize care for patients in the community oncology setting.

Findings from these surveys have guided the development of a suite of tools and resources that cancer teams can use to further personalize care towards a patient's unique goals and preferences. These include a video series that demonstrates best practices like gender-inclusive care, overcoming implicit bias, and clear communication; a curated resource library that multidisciplinary care teams can use to understand health care injustices and guide personalized care; and a downloadable infographic highlighting best practices for personalizing care.

These resources, together with expert insights from ACCC's advisory committee, which include senior leaders in health equity from both academic and community-based cancer programs, can help prepare multidisciplinary care teams to identify and address health care injustice and to personalize care around patients' unique characteristics, goals, and preferences.

Snapshot of Current Landscape

Health disparities, health literacy, and implicit bias continue to impact cancer care and cancer mortality rates, particularly among medically underserved populations. According to the World Health Organization (WHO), numerous studies suggest that social determinants of health (SDOH) account for 30% to 55% of poor health outcomes.³ SDOH are defined as the nonmedical factors and conditions in which people are born, grow, work, live, and age that shape the conditions of daily life and influence health outcomes.³ These factors create more frequent and multilevel barriers to quality cancer care, such as lack of access to treatment, lack of health insurance, higher rates of financial toxicity, and significant transportation obstacles.

Implicit bias, a form of bias that occurs automatically and unintentionally, can affect judgements, decisions, and behaviors. Studies have shown that the implicit biases of health care providers (eg, physicians, nurses, and other members of the care team) can be associated with diagnostic uncertainty, negative clinical interactions, less patient-centeredness, poor provider communication, undertreatment of pain, and other ill effects.⁴

Despite strides to reduce disparities, these factors continue to critically impact delivery of cancer care. While the overall cancer death rate continues to decline in the United States,⁵ Black populations continue to carry a high cancer burden; in fact, Black people have the highest cancer mortality rate and the shortest survival of any racial/ethnic group in the United States for most cancers.⁶ The cancer mortality rate of Black men (221 per 100,000) is 19% higher than White men (186 per 100,000) and nearly twice that of Asian and Pacific Islander men (113 per 100,000).¹ Black women have a 40% higher breast cancer mortality rate than White women, despite similar rates of incidence, and are almost twice as likely as White women to experience delays in surgery longer than 90 days.⁷ These substantial gaps in mortality compared to incidence rates spotlight the ongoing disparities among the Black population stemming from SDOH.¹

Patients living in rural Appalachia have a higher incidence of colorectal, lung, and cervical cancer than those living in urban areas. According to the American Association for Cancer Research (AACR) Cancer Disparities Progress Report 2022, lack of access or limited access to surgical facilities continues to be a significant barrier for patients needing cancer surgery, rendering patients from rural areas across the United States extremely vulnerable. Studies have shown that the density of surgical specialists is considerably lower in rural areas compared with urban areas. That gap widened significantly between 2004 and 2017, with the largest increase in disparity among colorectal surgeons, specifically.⁷

Lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) minority populations also experience significant disparities across the cancer care continuum, from increased cancer risk to end-of-life care. According to a 2022 survey by ASCO on sexual orientation and gender identity data collection in oncology practices, sexual and gender minority (SGM) populations (ie, LGBTQIA+ populations and those whose gender identity differs from their sex assigned at birth) experience greater cancer risk than the general population because of higher rates of smoking, sexual minorities with breast cancer are diagnosed at later stages and at younger ages than heterosexual/cisgender counterparts, and sexual minorities with prostate cancer experience greater psychological distress and sexual dysfunction following treatment than heterosexual/

cisgender counterparts.⁸ Moreover, the National Institutes of Health have declared SGM populations as a health disparities population, with national organizations (including the American Medical Association and ASCO) calling for increased attention to these populations in oncology care.⁸

Pre-Summit Survey

To inform the current program, ACCC conducted two comprehensive surveys in 2022 to explore patients' and providers' understanding of health care injustice in the community oncology setting. Surveys probed whether and how well care teams identified and honored patients' goals and preferences, and identified opportunities to personalize care for patients in the community oncology setting.

Provider Survey Methodology

The online provider survey, conducted during the first 6 months of 2022, included 85 cancer care providers. For inclusion in the survey, providers must have been clinical or nonclinical health care professionals employed by an ACCC-member cancer program or practice who provided care and support services to patients with cancer.

Providers, 60% of whom practiced in urban areas, reported working in community cancer programs, hospital systems, or academic programs. Program administrators and nurses represented the largest number of respondents (30% and 25%, respectively), however respondents also included physicians, financial advocates, navigators, and social workers.

(See Figure 1.)

Provider Survey Objectives

The provider survey, which was shared with multidisciplinary cancer care providers, sought to:

- Identify care team strategies for building trust with all patient groups
- Gauge understanding of the concepts of health care equity, equality, and justice
- Gauge whether social determinants of health are identified and addressed in practice
- Determine the percentage of practices that offered training to care team members related to equity, diversity, and inclusion; as well as the nature of the training and the rate of provider participation

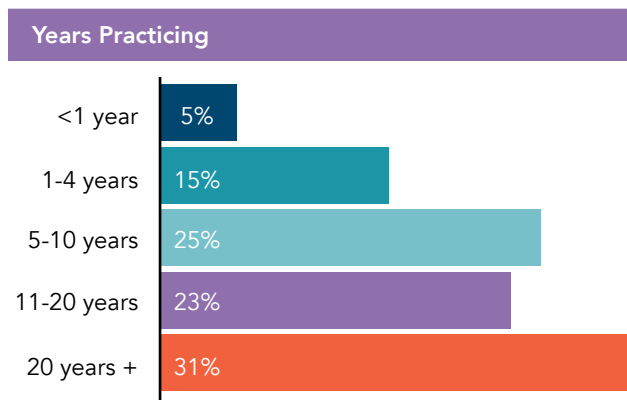
Figure 1. ACCC Cancer Program Respondent Demographics (n= 85)

Role	
Program Administrator	30%
Nurse	25%
Financial Advocate/Navigator/Counselor	13%
Social Worker	11%
Physician	8%

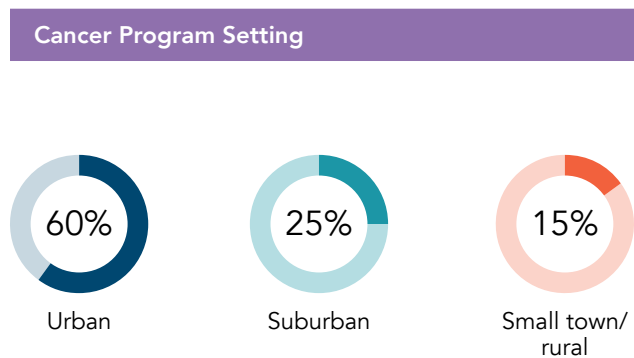
*13% represented other multidisciplinary roles or did not identify a specific role.

Area of Practice	
Community Cancer Program	30%
Hospital/Hospital System	25%
Academic/NCI Cancer Program	13%
Private/Physician Practice	11%
Veteran Affairs Cancer Program	8%

*13% did not identify a specific area of practice.



*1% of participants surveyed did not respond.



Patient Survey Methodology

The patient survey, conducted during the first 3 months of 2022, included 148 patients gathered from an online survey panel and ACCC partner organizations. For inclusion in the survey, patients must have been treated for cancer in the prior 5 years and belong to at least 1 of the following populations: Black, Hispanic, other minority race, LGBTQIA+, live in rural areas, or aged 75-plus.

Over 50% of patients surveyed identified as a member of racial or ethnic minority population (inclusive of participants who identified 2 or more races/ethnicities). Approximately 15% of patients identified as LGBTQIA+. For nearly 30% of patients, a high school diploma/GED was the highest educational degree earned and reported household income was less than \$50,000 per year. Over half of patients did not work due to retirement (36%) or disability (18%). Thirty-two percent of patients lived in small towns/rural areas.

Patient Survey Objectives

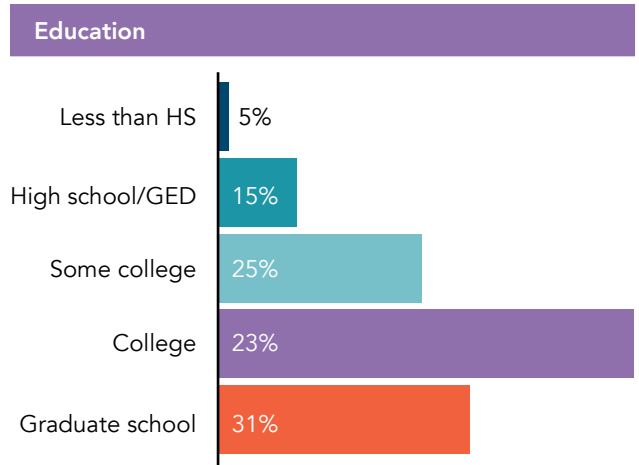
The survey of patients with cancer and cancer survivors sought to explore patient experiences and perceptions related to:

- Health care and access to health care
- Health insurance
- Cancer treatment experience and satisfaction
- Provider discussions on clinical trials
- Fair and ethical treatment by providers
- Communication with providers
- Health care equity and justice in the community oncology setting
- Diversity, equity, and inclusion in the community oncology setting
- Shared decision-making and patient goals and preferences
- Professional counseling services and patient support services

Figure 2. Patient Survey Demographics (n=148)

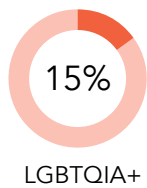
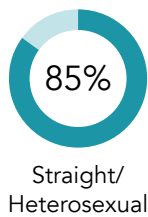
Race/Ethnicity	
White	68%
Black or African American	24%
Hispanic	17%
Asian	7%
American Indian or Alaska Native	5%
Native Hawaiian or Other Pacific Islander	1%
Different identity	2%

*Some participants chose to report 2 or more races or ethnicities.

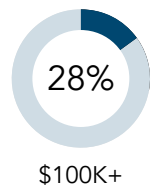
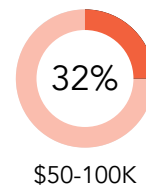
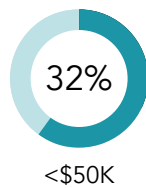


*1% of participants surveyed did not respond.

Sexual Orientation



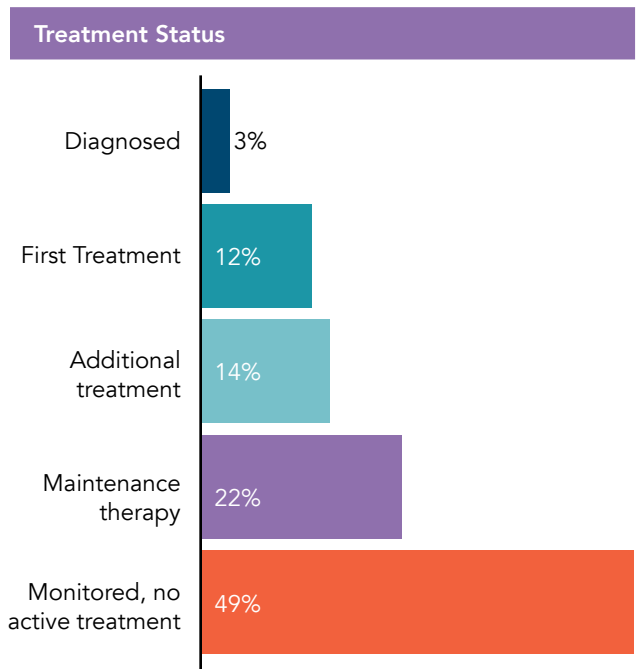
Household Income



*8% of participants did not report household income.

Health Insurance/Care	
Medicare	47%
Private health insurance	46%
Medicaid (may also be called by your state's program name such as Medi-Cal in California, etc.)	17%
Medigap (supplemental insurance for Medicare)	13%
Military related health care: TRICARE (CHAMPUS)/VA	4%
State-sponsored healthplan (under Affordable Care Act/Obamacare)	1%
Other government program	1%

*Some participants chose to report 2 or more insurance types.



Topline Findings From Provider & Patient Surveys

Across all patient surveys, most respondents were satisfied with the overall quality of their care, however they reported a lack of understanding and discussion on identity factors and racially/culturally specific aspects of care; patients did not feel their care teams took the time to understand their backgrounds, values, lifestyle, or circumstances, and how those factors might impact patients' decisions about treatment. Patients also stated that their providers did not discuss or address issues related to sexual identity; racial or cultural identity; religious considerations; race-based injustices; financial situation; past negative experiences with the health care system; or personal pronouns (see Figure 3).

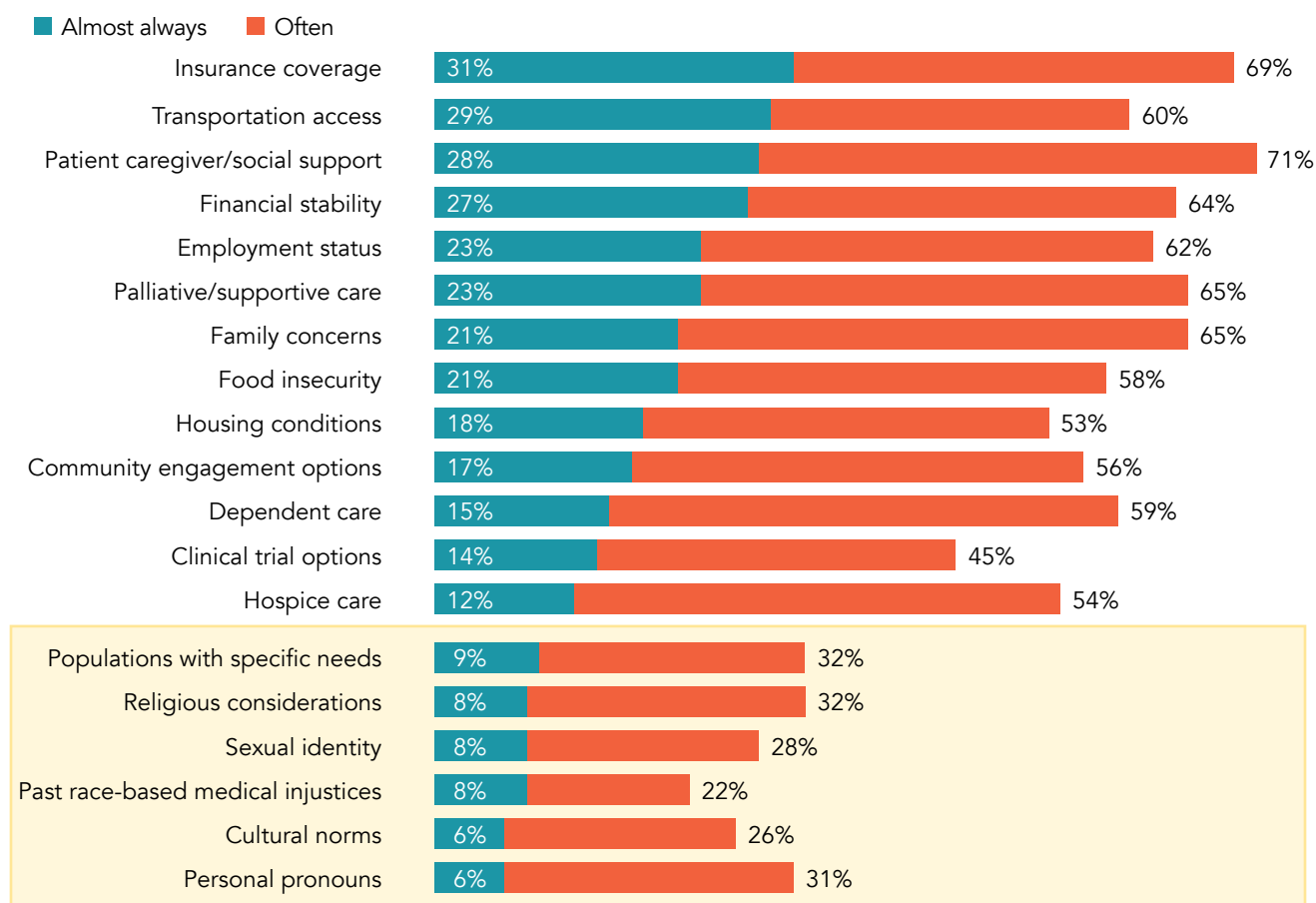
While provider and patient surveys were not in a matched sample (ie, health care providers and patients were not

from the same practice), nearly 70% of providers reported that they do not initiate conversations related to the needs of target populations.

Surveys also identified differences between the services providers believe are offered to patients at each visit versus the services patients report being offered during visits. In fact, regarding the provision of information on financial support for medical and transportation services—both critical considerations for patients from underserved populations—this difference was over 50 percentage points.

From these surveys, opportunities for core improvements were identified along 3 key themes: Building Conversations and Personalizing Care Around Patient Identity; Recognizing Signs and Employing Strategies to Overcome Implicit Bias; and Enhancing Provider and Patient Communication.

Figure 3. Providers: Frequency initiating conversations with patients



Core Improvement: Building Conversations and Personalizing Care Around Patient Identity

Both patient and provider surveys revealed that while important conversations with patients are happening on topics such as insurance coverage; transportation access; caregiver and social support; and financial stability, few providers are initiating conversations about the specific needs of target populations.

Only 32% of providers reported regularly addressing the specific needs or religious considerations of patients in target populations. Even fewer discussed sexual identity (28%), personal pronouns (31%), previous race-based medical injustices (22%), or cultural norms (26%) (see Figure 3).

Less than half (45%) of providers reported discussing clinical trial options with patients, an area which already suffers from low participation of minority groups and underserved populations. In fact, according to recent analysis of cancer treatment clinical trials, only 4% to 6% of clinical trial participants are Black and 3% to 6% are Latino.⁹

Patients also reported mixed feelings and feelings of dissatisfaction with their level of involvement in the

decision-making process about tests and treatments they received.

These findings point to a need to have conversations and personalize care based on patients’ backgrounds, values, and lifestyles.

Core Improvement: Recognizing Signs and Employing Strategies to Overcome Implicit Bias

Patient surveys revealed that feeling included and understood by providers was limited. While approximately 60% of patients felt that they received appropriate accommodations and support to meet challenges they faced (eg, economic, age-related, language barriers, etc), approximately 20% of respondents were not satisfied and did not feel understood by providers.

Nearly a quarter of patients surveyed felt their racial or ethnic identity was not understood and 20% felt similarly about their cultural identity. Another 14% of patients felt their gender and/or sexual identity was not understood, and 17% of patients felt that their disabilities were not understood (see Figure 4).

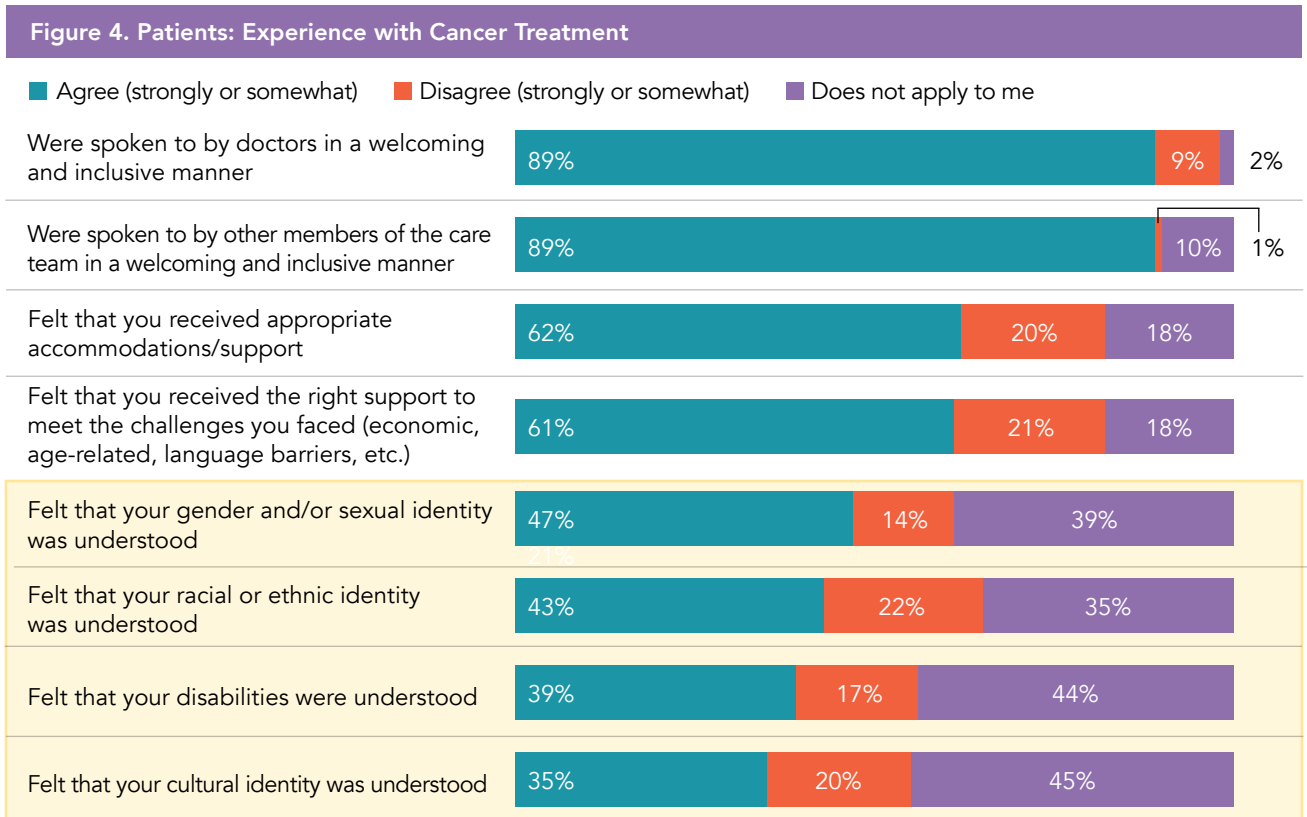
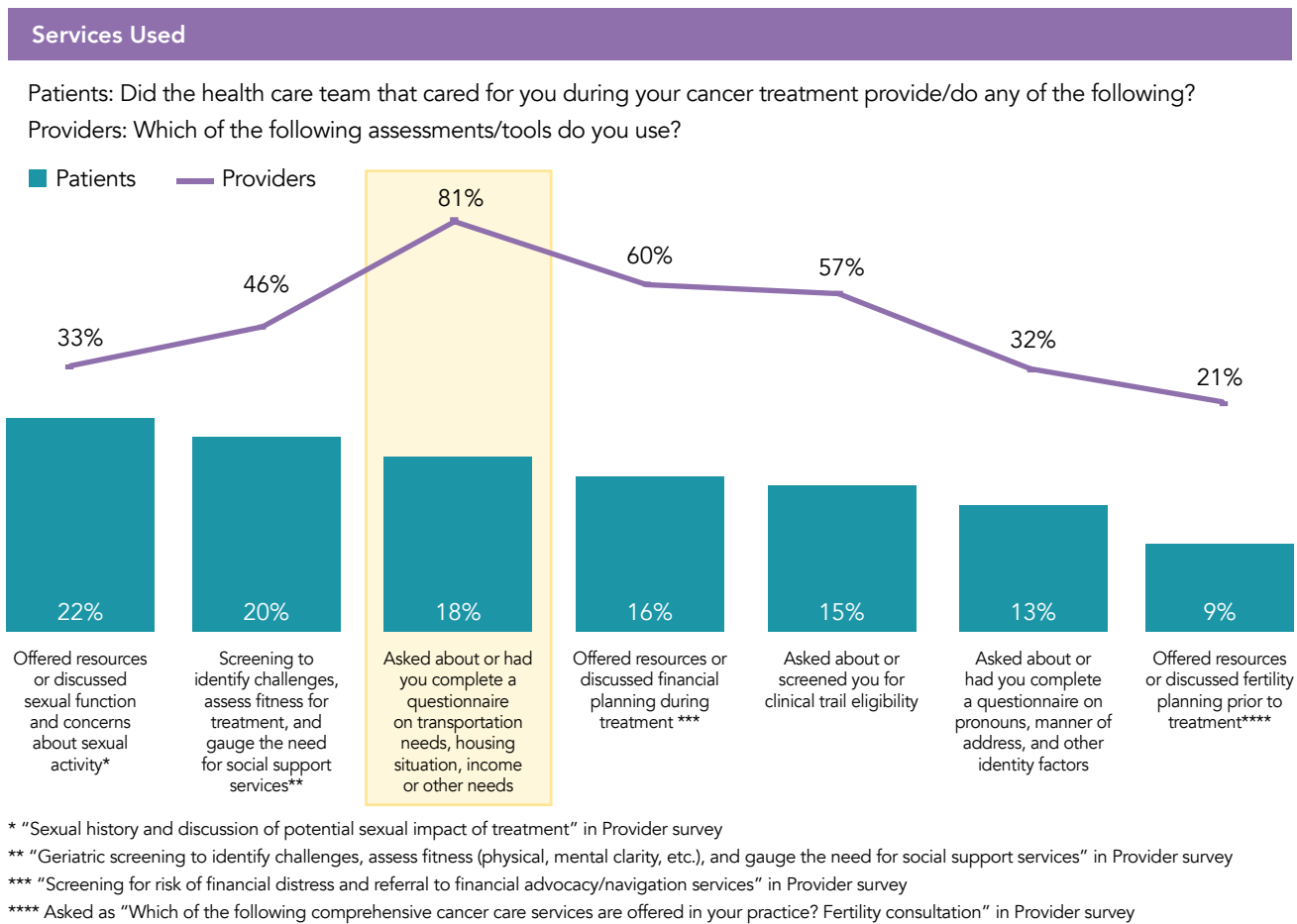
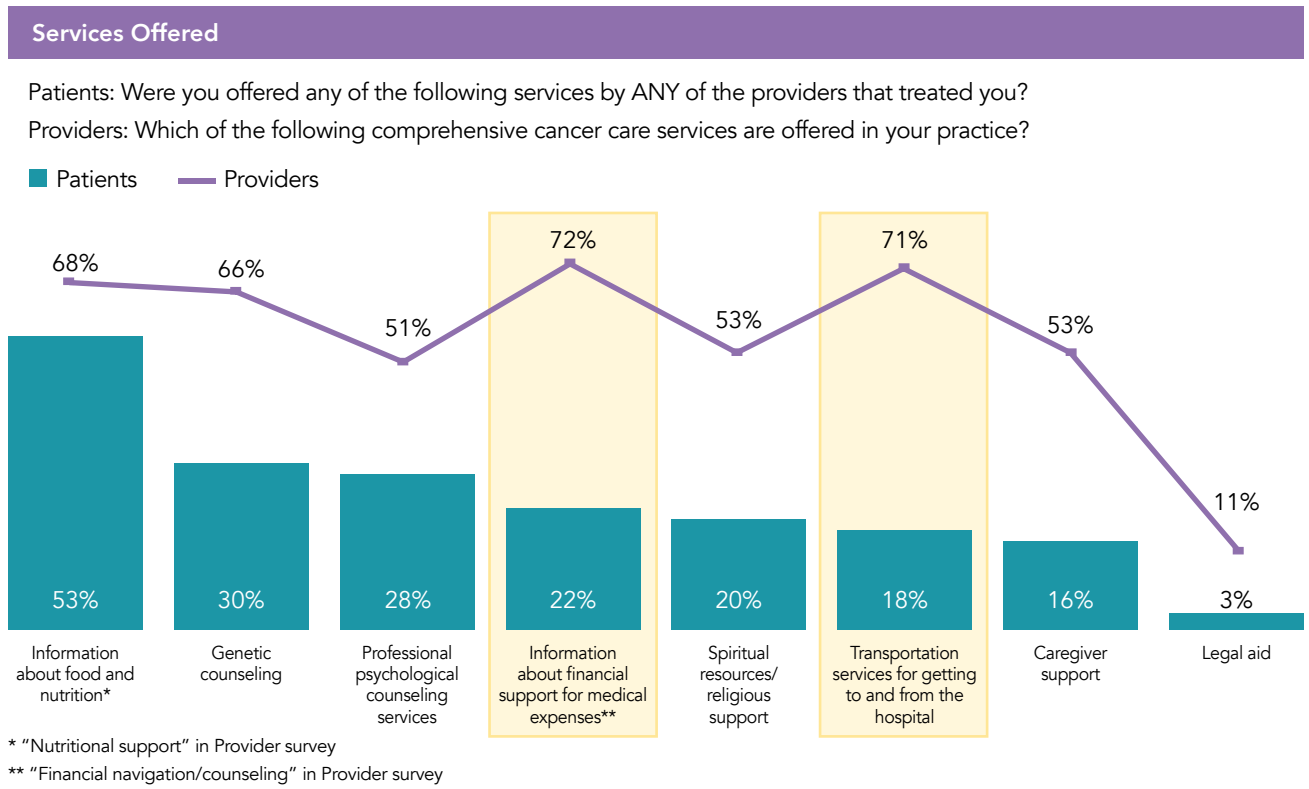


Figure 5. Patient vs. Provider Reported Services and Assessments



Approximately 13% of patients were dissatisfied with the level of diversity in their care team and 9% did not feel their concerns and questions stemming from cultural, religious, or other aspects of identity were addressed with respect. Moreover, 13% of patients did not feel that they were treated by their care teams as unique individuals.

These findings suggest that additional training for providers on recognizing implicit bias and providing strategies to overcome bias in community care settings is needed.

Core Improvement: Enhancing Provider and Patient Communication

Patient and provider surveys revealed differences between the services and support providers believe are regularly offered to patients and what services and support patients reported were offered during visits (see Figure 5). While provider and patient surveys were not in a matched sample (ie, health care providers and patients were not from the same practice), these differences highlight a need to improve communication.

While 72% of providers reported that information about financial support for medical expenses was offered to patients, only 22% of patients reported that they were offered these services. Similarly, 71% of providers believed transportation services for getting to and from the hospital were offered to patients, while only 18% of patients reported being offered transportation. Moreover, providers (81%) reported utilizing assessments/tools (eg, patient questionnaires) to gauge transportation, housing, income, or other needs, yet only 18% of patients reported being asked about or completing a questionnaire, revealing a disparity of 63 percentage points.

Furthermore, critical conversations about genetic counseling and clinical trial eligibility are not taking place as often as they should. While 66% of providers believed patients are offered genetic counseling, just 30% of patients reported being offered this service. Fifty-seven percent of providers reported that they ask about or screen patients for clinical trial eligibility, yet only 15% of patients reported being asked about or screened for clinical trials.

Resources

In order to help multidisciplinary care teams identify and address implicit bias and health care injustice and promote humility and the personalization of care around patients' identity, goals, and preferences, ACCC—in collaboration with its advisory committee and program partners—has developed an array of practical tools and resources that are available on its website.

Personalizing Care Video Series

The **Personalizing Care Video Series** is a collection of 3 short videos that have been professionally developed to help multidisciplinary care teams recognize implicit bias and health care injustice and offer effective strategies to personalize care. Through different scenarios and role-playing based on real-world experiences observed in various practice settings, these videos explore:

Building Conversations and Personalizing Care Around Patient Identity

“Beyond Labels: Personalize Care Conversations”

A young transgender woman who is concerned about a lump in her groin area undergoes an awkward experience at a cancer clinic. Watch as she and her physician find ways to overcome the awkwardness and personalize questions around her specific circumstances.

Recognizing Signs and Employing Strategies to Overcome Implicit Bias

“Beyond Bias: Promote Equity in Care”

A financial counselor makes assumptions about a patient's ability to pay for care based on his first impressions of her well-to-do appearance and arrival to the appointment in a fancy car. He does not ask her questions that adequately probe her financial situation and is unwilling to accommodate her repeated requests for financial assistance for her treatment because of his implicit bias. He later learns that the car in fact belongs to a friend from her church, who offered to drive her to the appointment because she has no car. When he also realizes that she is a widow in a desperate financial situation, he makes every effort to accommodate her. He learns that he should not make assumptions and should ask the same questions of every patient to ensure equity.

Enhancing Provider and Patient Communication

“Beyond Barriers: Speak Clearly, Care Deeply”

A well-meaning nurse who is aware of inclusivity and health equity best practices, including a patient’s preferred language, assumes that her patient would prefer to have his son translate their conversation into Spanish rather than try to understand the conversation himself in English. She addresses the patient’s son rather than the patient and speaks too quickly; thus, despite her patient’s limited ability to understand English and his son’s willingness to translate, they all realize that additional assistance through a professional interpreter is needed to address complex medical terminology and concepts to ensure the patient understands.

Care teams can use these videos to consider the level of personalized care offered in their own programs and reflect on their competence with respect to these themes.

Resource Library

ACCC has curated a comprehensive resource library of nationally available publications, tools, videos, and other assets to help multidisciplinary care teams identify and address implicit bias and health care injustice, and facilitate the personalization of care for patients. The library also includes a [downloadable infographic](#) highlighting best practices for personalized care. Access the library at acc-cancer.org/personalizing-care-library.

The resource library encompasses the following topics:

Building Conversations and Personalizing Care Around Patient Identity

This collection of articles, tools, and resources highlights the challenges experienced by disproportionately affected groups, including Black people, Indigenous people, people of color, women, the LGBTQIA+ community, bariatric patients, older adults, and adolescents and young adults.

Recognizing Signs and Employing Strategies to Overcome Implicit Bias

This comprehensive collection of articles, tools, and resources highlights key concepts related to health equity, health literacy, implicit bias, medical injustices, and social determinants of health.

Enhancing Provider and Patient Communication

This collection of articles, tools, and resources explores issues related to language and cultural barriers, culturally competent care, telemedicine, and measuring personal and organizational health equity in practice.

Key Takeaways

The findings and resources from this ACCC program are only the start of this important work. Understanding how to identify and address health care injustice and implicit bias lays the groundwork for real change, and the practical tools developed through this program can help identify and promote opportunities to personalize care for patients according to their goals, values, and preferences.

By utilizing the tools and resources from this program, providers can better:

-  Initiate patient conversations that incorporate a patient’s individual characteristics, values, lifestyle, and unique circumstances
-  Ensure patient discussions consider identity factors and social determinants of health (eg, race, culture, sexual identity, religious considerations, financial situation) that may impact care or decision-making about treatment
-  Consistently utilize universal health literacy best practices with all patients (eg, communicate clearly, use plain language, utilize teach-back method) to ensure equity in care
-  Learn to recognize the signs of implicit bias and healthcare injustice to reduce disparities in care
-  Ensure every patient is informed about available services (eg, financial support, transportation services, clinical trials) to avoid implicit bias
-  Practice humility and regularly reflect on competence level of personalizing care for patients

Acknowledgments

ACCC is grateful to its members and partners that contributed to this work.

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In partnership with:



Thank you to Pfizer Oncology for their collaboration and support in developing this resource.



A publication from the ACCC education program, "Personalizing Care for Patients of All Backgrounds." Learn more at acc-cancer.org/personalizing-care.



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