

Improving Cancer Care for Underserved Populations

Considerations to Inform Health Policy



The Alliance to Advance Patient-Centered Cancer Care National Program Office

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The Alliance to Advance Patient-Centered Cancer Care (Alliance), an initiative funded by the Merck Foundation, comprises six program partners working to advance health equity. Their interventions have demonstrated that multiple components are required to address disparities in cancer care. Interventions implemented by Alliance program partners included technology solutions to identify underserved and at-risk patients, specially trained personnel working with patients to reduce barriers to care, and community partners to support health promotion activities. Comprehensive, multifaceted programs like these can improve access to high-quality cancer care. State and federal policy strategies are essential to improve cancer care delivery and to support the work of addressing disparities for vulnerable and historically underserved populations.

The Need

The U.S. cancer care system is highly fragmented, often described as “siloed” (Hewitt, Greenfield, & Stovall, 2005), with poor coordination between patients and providers and between clinical specialties. This fragmented system poses notable challenges, particularly for underserved patients. For providers, the lack of coordination between specialties can translate to care delays, missed cancer screening and surveillance appointments, poor management of comorbidities, and inadequate health promotion (Snyder, et al., 2009; Earle & Neville, 2004).

For patients, the hypertechnical and fragmented system of cancer care in the United States presents both barriers and delays that worsen patients’ stress, reduce quality of life, and potentially affect survival (Nordin & Glimelius, 1999; Hamlyn, et al., 2016). Barriers, such as poor communication between patients and providers, lead to less personalized cancer treatment plans (Hewitt, Greenfield, & Stovall, 2005). Once cancer care treatment begins, supportive care needs (treatment of physical symptoms, such as cancer fatigue, as well as psychological care for anxiety and depression) are often not met (Harrison, Young, Price, Butow, & Solomon, 2009).

Although all patients experience challenges in cancer care, the burden of cancer falls disproportionately on some segments of the U.S. population, including racial and ethnic minorities; gender and sexual minorities; lower-income, uninsured, and underinsured populations; and rural populations (Nelson, 2020; Lockhart, Oberleitner, & Nolfi, 2019; Kisely, Crowe, & Lawrence, 2013; Bergamo, Sigel, Mhango, Kale, & Wisnivesky, 2014).

In 2017, the Merck Foundation funded six program grantees as part of a 5-year initiative—the *Alliance to Advance Patient-Centered Cancer Care*. The Alliance works to increase timely access to patient-centered care and reduce disparities in cancer care for underserved populations in the United States. The Merck Foundation aimed to fund interventions focusing on coordination of care, patient-provider communication, and patient engagement. Six grantees or program partners were selected to participate in the Alliance:



- [The Georgia Cancer Center for Excellence at Grady Health System](#) in Atlanta, Georgia
- [The Johns Hopkins University School of Medicine](#) in Baltimore, Maryland
- [The Massachusetts General Hospital Cancer Center](#) in Boston, Massachusetts
- [The Feinberg School of Medicine at Northwestern University](#) in Chicago, Illinois
- [The Ohio State University Comprehensive Cancer Center](#) in Columbus, Ohio
- [The University of Arizona Cancer Center](#) in Tucson, Arizona

The Alliance National Program Office (NPO), located at the University of Michigan School of Nursing in Ann Arbor, Michigan, supported these six program partners. They provided technical assistance, convened program partners for peer-to-peer learning opportunities, and led evaluation and dissemination efforts.

Following evidence-based recommendations (Patel, et al., 2020), the Alliance program partners implemented multicomponent interventions to improve cancer health equity with a shared goal: To improve patient access, minimize health disparities, and enhance the quality of patient-centered cancer care. With a special focus on underserved and at-risk populations, Alliance program partners identified a number of ways to improve their regional cancer care delivery system, including improving screening and referral processes, improving care coordination, creating more opportunities for patients to communicate with their clinical teams, and focusing significant energy on community engagement.

Together, these six Alliance program partners serve a large population, estimated at 11 million. As such, they identified specific catchment areas and populations that they wished to reach and serve. Alliance program partners implemented important clinical practice and health system changes to improve patient outcomes. Although each grantee implemented and evaluated a unique suite of interventions, all were aimed at improving access and patient engagement in cancer care. Furthermore, data from the Alliance's evaluation noted encouraging trends over the project period. Patients were more likely to keep their clinical appointments, and time from diagnosis to start of treatment decreased.

Alliance program partners gleaned important lessons about caring for underserved populations and advancing health equity. In this report, we share those lessons, along with the impact of the Alliance initiative on patient and provider experiences, and policy considerations that would support successful strategies to promote cancer health equity.

Promising Strategies to Increase Access to Cancer Care

Research scientists, professional organizations, and patient organizations have spent decades identifying the most effective strategies to reduce disparities in cancer and increase access to cancer care.

In 2020, The American Society of Clinical Oncology (ASCO) Health Equity Committee (HEC) (Patel, et al., 2020) issued a statement that recommended multiple strategies to decrease cancer disparities:

1. **Ensure Equitable Access to High-Quality Care**, from prevention, early detection, diagnosis, and treatment to survivorship and end-of-life care.
2. **Ensure Equitable Access to Research**. Conduct research that fully reflects the diversity of our society, which will allow all patients to benefit from the movement toward precision and personalized medicine.
3. **Address Structural Barriers**. Promote the interpersonal, institutional, and systemic drivers that advance health equity. The ASCO HEC denotes three specific areas of interest:
 - a. **Community partnerships**. Collaborate with community organizations to support health promotion activities and address social determinants of health (SDOH).
 - b. **Addressing institutional discrimination**. End discrimination—both implicit and explicit biases—in clinical settings, tackling bias within institutional structures and interpersonal relationships.
 - c. **Workforce diversity**. Improve inclusion and diversity of the workforce in cancer care delivery and biomedical research.
4. **Increase Awareness and Action** by developing communication efforts that strive to inform, educate, and empower all individuals.

Alliance program partners identified and implemented strategies that address these ASCO HEC recommendations for promoting health equity. They implemented programs that emphasized community participation and combined technological solutions with human touch. The following sections delve into Alliance program partner efforts to expand access to patient-centered cancer care.

Ensure Equitable Access to High-Quality Care

Delivering high-quality cancer care requires excellence across the care continuum, from prevention, early detection, diagnosis, and treatment to survivorship and end-of-life care. However, cancer care that is unequal in quality is a persistent concern, particularly with the emergence of novel diagnostics and treatments that remain “inequitably delivered” (Patel, et al., 2020). Alliance program partners implemented interventions to engage patients from underserved populations.

Massachusetts General Hospital (MGH) Cancer Center

- The MGH Cancer Center uses direct physician referral and the TopCare (Technology for Optimizing Population Care in a Resource-limited Environment) registry to identify patients at higher risk of facing barriers to cancer care.
- Multicultural and multilingual patient navigators work with referred patients during their cancer treatment to overcome identified barriers to care.
- Before the state of Massachusetts' first COVID-19 outbreak (November 2017 – February 2020), navigators delivered approximately 65 interventions per month. During the pandemic, navigators virtually delivered 162 interventions per month (Percac-Lima, et al., 2020).

Most of the populations served by the MGH Cancer Center navigation program tended to reside in the city of Chelsea, Massachusetts, one of the hardest hit pandemic hot spots in the state.



Estimates place the total number of COVID cases in the city at about 9,054, against a total population of approximately 39,000 people (City of Chelsea, 2021). In June of 2020, COVID-19 positivity rates in the city were as high as 35% (Massachusetts Department of Public Health, 2020).

Johns Hopkins University School of Medicine (Johns Hopkins)

- Developed, refined, implemented, and evaluated TimeToTalk4Health, a video-based training program to enhance communication between patients, patient caregivers, and clinical providers during cancer treatment.
- Preliminary findings suggested that TimeToTalk4Health is associated with improved communication outcomes.
- The Johns Hopkins Primary Care for Cancer Survivor (PCCS) Clinic has been successfully operating for 6 years, helping patients with cancer in a multidisciplinary setting.
- The PCCS clinic helps patients manage long-term side effects of cancer treatment, such as providing referrals to specialty services, psychosocial support, and community organizations centered on cancer survivorship (Choi, et al., 2020).
- Johns Hopkins is also working as a Project ECHO (Extension for Community Healthcare Outcomes) site to train physicians in cancer survivorship.

When a patient's care partner helps facilitate communication behaviors, patients rate their physicians 42% higher on clarity and 29% higher on interpersonal skills than patients with less facilitative care partners (Wolff & Roter, 2011).



Results from a survey administered at the Johns Hopkins Primary Care for Cancer Survivor (PCCS) Clinic reflect national data on the challenges of cancer survivorship.



61.7% expressed concern about their cancer returning



Patients also reported **fatigue (18.6%)** and **weight change (17.3%)**



51.3% were seeking help to improve their **memory and concentration**

Choi, et al., 2020

The Ohio State University Comprehensive Cancer Center (Ohio State)

- A symptom management text-based program (a voluntary quality improvement program) collects a brief symptom assessment and needs survey on a monthly basis. The program uses smartphones, provided at no cost to patients who lack them (Naughton, et al., 2020).
- Data from approximately 300 patients with endometrial, ovarian, and breast cancer showed that average adherence with monthly surveys was 75%. At 6 months, 71-77% of all patients believed the text-based program was useful to them and their health care team (Naughton, et al., 2020).

Oncologists and lead staff also provided feedback on the program. Several respondents were surprised to learn that some patients were more forthcoming on the surveys than during clinic visits, which opened up better communication with their patients (Naughton, et al., 2020).



The University of Arizona Cancer Center (the University of Arizona)

- COPE-D (Collaborative Oncology Project to Enhance Depression Care) is a depression screening program (in English and Spanish) that pairs patients experiencing severe depressive symptoms with social workers acting as depression care managers.
- Data showed a net decrease in depressive symptoms after 12 weeks of treatment. More than 80% of participants choose to stay in the program long term.

The Ohio State University's symptom management text-based program, a quality improvement program, monitors psychosocial symptoms of ovarian, endometrial, and breast cancer patients.

75% response adherence achieved through use of user-friendly tools

79% of patients indicated that surveys helped them better communicate with providers

90% of patients thought that others would benefit from this program

Naughton, et al., 2020

Ensure Equitable Access to Cancer Research

Cancer research is increasingly moving towards molecular and precision medicine. Yet without intentional strategies, patients from underserved populations face limited opportunities to participate in cancer research and/or benefit from important discoveries (Patel, et al., 2020).

Navigators working for Alliance program partners employ multiple efforts to ensure all patients have equitable access to cancer care, including facilitating patient introductions to clinicians with active clinical trials. Alliance program partners also routinely collect patient data on demographic and clinical characteristics to explore and remedy disparities in clinical research participation (Patel, et al., 2020).

Address Structural Barriers to Equitable Cancer Care

Addressing structural barriers requires addressing interpersonal, institutional, and systemic factors that prevent the advancement of health equity (Patel, et al., 2020). Multilevel interventions are needed, including health care organizations and communities that surround health care systems.

Several Alliance program partners assess barriers to care and provide patients with additional support.

The Georgia Cancer Center for Excellence at Grady Health System (GCCE)

- The GCCE deployed an electronic health records (EHR)-backed solution to screen for barriers to care and developed a protocol to match patients newly diagnosed with cancer with a registered nurse (RN) patient navigator.
- Preliminary data from over 600 patients who presented to breast, gynecologic, and aerodigestive cancer clinics showed a decrease in time patients spent between diagnosis and treatment (Rehr, et al., 2020).
- RN patient navigators formalized an existing lay patient navigation program led by cancer survivors. These lay navigators were able to speak from a prospective of lived experience:

... We have breast lay navigators in clinic and these lay navigators are survivors themselves and that to me is huge. Because when we had one patient recently where she just didn't want to hear the provider's words. It just wasn't sinking in, and the lay navigator stepped in and talked about receiving her cancer diagnosis and showed her scar to the patient and talked about her journey and that's what got through to the patient, and that was recognized as a big intervention so to speak, because if this

The Grady Health System is a safety-net hospital assisting uninsured and underinsured patients:  In 2020, 26% of patients were uninsured, 16% were on Medicaid, and 37% were on Medicare. Seventy-eight percent of patients served were Black. Compared with National Cancer Database data (2019), patients at the GCCE are 46% more likely to receive a stage IV (advanced) cancer diagnosis.

patient hadn't had that, that person relaying the message in a way that was coming across, this patient may have walked off into the abyss.

- The GCCE implemented a new nutrition and wellness service for patients, which included bi-weekly deliveries of fresh produce,^a nutrition education, and an exercise coach to help patients with cancer develop personalized fitness plans.

Johns Hopkins University School of Medicine (Johns Hopkins)

- Johns Hopkins employs community health workers (CHWs) who screen patients for barriers to care; 532 patients (60% female) were referred over the past 6 months.
- Of these, 9% had immediate needs, and 22% delayed request for assistance. Top barriers reported included lack of financial support, transportation, pain concerns, and need for mental health support.

Workforce diversity

The ASCO HEC highlighted multiple strategies to improve the diversity of the oncology workforce, including educational opportunities addressing health equity to remove barriers for individuals from underrepresented groups that prevented them from pursuing a career in cancer care (Patel, et al., 2020).

The University of Arizona Cancer Center (the University of Arizona)

- The University of Arizona developed and implemented a novel training program to address implicit bias in health care encounters (Stone, Moskowitz, Zestcott, & Wolsiefer, 2020). The evaluative data suggest that the training could help to reduce bias in majority-group medical students.
- Following positive results, the implicit bias training, originally designed for medical students, was integrated across the entire College of Medicine (faculty, trainees, staff, and administrators). Department-level diversity champions support the program.

Massachusetts General Hospital (MGH) Cancer Center

- The MGH Cancer Center delivered four workshops per year for personnel who work with adults with serious mental illness (SMI) to raise awareness of barriers to equitable cancer care for individuals with SMI. The workshops included clinical and policy strategies to improve outcomes for this population.

Community partnerships

Social determinants of health (SDOH), conditions in which people are born, grow, live, work, and age and factors such as socioeconomic status, education, neighborhood, employment, and social support affect a wide range of outcomes and health risks, including access to care (U.S. Department of Health and Human Services, 2021). Addressing SDOH is critical to achieving health equity. The ASCO HEC recommended utilizing community-minded strategies to support health equity and address SDOH (Patel, et al., 2020).

The Northwestern University Feinberg School of Medicine (Northwestern)

- Northwestern refined the 4R (the Right information and Right care for the Right patient at the Right time) care coordination model. The 4R model and associated care plan were developed to follow patients all along the continuum of cancer care.
- Northwestern partnered with AllianceChicago to adapt 4R for individuals who receive care from Federally Qualified Health Centers (FQHCs).

Since its inception, the 4R model has been progressively enhanced through a series of multidisciplinary studies; work with over 30 cancer treatment centers and 50 imaging centers in Chicago; several multidisciplinary roundtables that included providers, payers, and patient advocates; and patient focus groups.



^a These programs are especially important for patients who reside in food deserts, or locations that lack accessibility to fresh produce and other dietary staples, as is the case for many patients served by the Grady Health System (Fong, Lafaro, Ituarte, & Fong, 2021).

Massachusetts General Hospital (MGH) Cancer Center

- The Collaborative Care and Community Engagement Program (ENGAGE) is a coalition with leadership based at the MGH Cancer Center that brings together the Massachusetts Department of Mental Health, the National Alliance on Mental Illness of Massachusetts, North Suffolk Mental Health Association, and other collaborations. The coalition has more than 800 members with a shared dedication to ensuring that mental illness is never a barrier to cancer care.

The University of Arizona Cancer Center (the University of Arizona)

- *Un Abrazo Para La Familia™* (Embracing the Family) expands existing collaborations between the University of Arizona and the Arizona Community Health Workers Association (AzCHOW). *Un Abrazo* empowers CHWs to support patients with cancer and their families (Marshall, et al., 2020).
- Data demonstrate a decline in levels of distress, anxiety, and depression after the intervention (Marshall, et al., 2021). Patient families report higher self-efficacy in supporting patients with cancer.

The majority of *Un Abrazo* participants were Latinx and preferred Spanish as their spoken language. Participants reported clinically significant levels of distress, anxiety, and depression. A higher proportion of participants showed significant levels of distress compared with samples of white, middle-income cancer survivors (Marshall, et al., 2021).



Addressing institutional discrimination

The ASCO HEC suggested that, to address institutional discrimination, health systems should promote access to socially, culturally, and linguistically appropriate, respectful, and high-quality cancer care (Patel, et al., 2020).

The University of Arizona Cancer Center (the University of Arizona)

- The University of Arizona developed a bilingual, culturally sensitive patient navigation program led by lay navigators. Data from over 200 participants showed that about 60% of participants identified as Hispanic or Latino and 40% selected Spanish as their primary language (Ver Hoeve, et al., 2021).
- Navigators addressed 75% of the barriers identified for each participant (Ver Hoeve, et al., 2021).

Underserved patients with cancer treated at the University of Arizona Cancer Center most commonly identified the following barriers to care:

	43% declared they couldn't afford utilities		35% declared that they couldn't afford housing		32% expressed the need for prescription glasses
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Ver Hoeve, et al., 2021

Johns Hopkins University School of Medicine (Johns Hopkins)

- Johns Hopkins implemented a novel digital health technology solution to automate the creation of survivorship care plans (SCPs). *Transition of Care Plus (ToC+)* works with existing EHR to generate guideline-concordant SCPs.
- ToC+ is generated in Epic, approved by clinicians, and distributed to patients. To date, it is available to patients with lung and breast cancers and will soon be expanded to those with colon and prostate cancer.

Increase Awareness and Action

The ASCO HEC recommended curricular development to share successful strategies to advance health equity (Patel, et al., 2020). The Alliance NPO has disseminated the work of Alliance program partners through an ongoing webinar series and a set of video explainers. Over 700 unique attendees have participated in Alliance webinars, and the video explainers garnered approximately 27,000 views.

Multicomponent Interventions as a Key to Health Equity

Alliance program partner experiences suggest that no single approach is sufficient for sustainable impact on cancer health equity. As a clinician from MGH Cancer Center shares, technology, coupled with human resources, are needed to ensure high-quality care:

"... We really want to capture everyone that we possibly can and we have a few ways to do that. One is this IT solution [the TopCare registry] that we have where we can actually figure out from an IT program who's been referred to the cancer center who have primary care physicians at the community health centers. The other is working with community health center primary care physicians so that they're aware of this program, so that if they [diagnose] a patient with cancer, they can communicate with us to make sure that they're enrolled. So, there are a lot of things to make sure they get in."

Methods to Evaluate Alliance Impact

The NPO led qualitative and quantitative evaluations of the impact of Alliance programs.

The qualitative evaluators monitored health system and policy changes that occurred at all six Alliance program partners and conducted semi-structured key informant interviews with stakeholders at each site. Each Alliance program partner's principal investigator identified interviewees to ensure a mix of participants from various roles and levels of experience. Sixty-five interviews were conducted, recorded, and transcribed. The verbatim transcripts were coded and analyzed thematically.

Health system and policy changes were monitored through a tracking tool developed by the evaluation team and completed by each Alliance program partner. Key components included: Descriptions of health system and policy change efforts; identified stage of change (development, adoption, implementation, or maintenance); groups and individuals involved in the effort; strategies used; and outcomes achieved to date. Data were collected in May 2020 and updated in May 2021.

The quantitative evaluators collected data from Alliance program partners in 2018, 2019, and 2020, at the aggregate level to safeguard participant confidentiality. Descriptive statistics were used to compare values from Alliance samples with norms, where available. Because participants varied across years, longitudinal analyses were not possible.

The quantitative evaluation addressed the reach and effectiveness components of the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (RE-AIM, 2021). For reach, each program partner reported demographic data from the partner's catchment area, populations eligible for interventions, and enrolled participants. For effectiveness, the team measured five variables: access to care, patient engagement, quality of life, adherence to cancer treatment, and utilization of health care system resources.

Alliance Program Participant Experiences

Benefits of Navigation



A nurse navigator with a patient at Grady Health

Alliance program partners provided valued support to patients with cancer and their loved ones. In interviews, program staff and participants shared poignant experiences. People with cancer who participated in Alliance interventions established close relationships with RN and lay patient navigators. One patient from the GCCE relayed their story:

"[Navigator] held my hand through my diagnosis and my surgery. She conducted education and explained anything I didn't understand. She was responsive any time that I called. She helped me with transportation to appointments and even with making sure I could get a grant to assist with my housing."

Another patient shared how a navigator improved their interaction with physicians:

"If they wouldn't be here it just would have been so stressful! They really prepared me...and they would coach me through it and how to let my doctor know what I was experiencing."

Patients from the University of Arizona described the benefits of navigators as well:

“The navigator system is very important for cancer treatment because it encompasses the patient as a whole and helps them deal with more personal barriers that sometimes doctors do not understand.”

Physicians also shared their experiences with navigators:

“... the fact that we've had a navigator who is able to get them the services that they needed, to get them transportation... to get them you know basic needs—food, clothing, shelter—has been a huge, huge boon to them completing their treatment... [S]ome of them have very treatable cancers and if they just had a little help like our [navigator], they could succeed, and we have seen that happen”

These findings support a systematic review of patient navigation, which shows the effectiveness of these programs along the continuum of cancer care (Bernardo, Zhang, Hery, Meadows, & Paskett, 2019).

Benefits of Communication

Health care providers at the Ohio State described the value of their symptom management text-based program that helps to address patient concerns:

“During a clinic visit, you're so focused on the cancer, the disease, the treatment, and you have limited time... And so what this did is kind of afforded a connection between the cancer team and the patient to discuss depression or sleep issues or other issues that maybe weren't as urgent or emergent that you didn't have time to address...”

At Johns Hopkins, the PCCS clinic comprises primary care physicians with cancer expertise to support patients with cancer. Talking to primary care physicians can help patients understand the importance of managing their comorbidities and their cancer treatment at the same time:

“[PCCS Provider] made me understand that yes you should be fighting your cancer, especially, you know, my first, my year up to surgery and all that, that's most important but all these other things that happen, you need to not ignore them.”

Another way to support holistic care is to standardize health-related communications using evidence-based tools. At the GCCE, the team worked with their Patient and Family Advisory Council and health communication experts to standardize patient education materials and website content.

Health System Policy Changes

Alliance program partners have implemented and sustained systemic changes in health care delivery. These changes are centered on increasing care coordination, developing novel care protocols, and establishing new trainings within the health system. Alliance program partners were able to translate successful efforts into new staff positions to extend more support to patients.

- The University of Arizona implemented a Distress Thermometer screening tool for patients to complete before outpatient visits. High distress scores produce an automated referral to lay navigators.
- Given promising results, the University of Arizona partnered with leaders at Banner – University Medical Center Tucson to create permanent positions for bilingual staff to provide lay navigation and psychosocial (COPE-D) services.
- The MGH Cancer Center formalized patient navigator roles and job descriptions.
- The Ohio State's symptom management text-based program with patient navigation expanded beyond the clinics that originally participated.
- At Northwestern, the 4R tool was adapted to support both newly diagnosed patients and cancer survivors. The FQHCs that partnered with Northwestern developed protocols, scripts, and documentation guides to facilitate the implementation of the intervention.
- At Johns Hopkins, the ToC+ tool was chosen by Cancer Center leaders as the preferred tool for survivorship care planning.

Enacting health systems and policy changes to provide coordination and psychosocial support can improve the patient experience, as summarized by a patient from Arizona:

“My counselor has been a life saver in helping me with coping mechanisms. I have a stressful life on top of cancer, and I have learned so many ways to come off the ledge. I am extremely grateful.”

Importantly, Alliance program partners recognized the significance of multicomponent interventions:

“One of the major accomplishments for us is the reach of the different projects... The majority of these are either patients or other people in the patients’ lives who are really underrepresented both in clinical reach and research.^b So, we have a majority Hispanic population, lower [socioeconomic status], Spanish as primary language, we have some rural patients, and so really patients who tend to be underrepresented.”

Alliance program partners were able to address multiple patient populations within their centers:

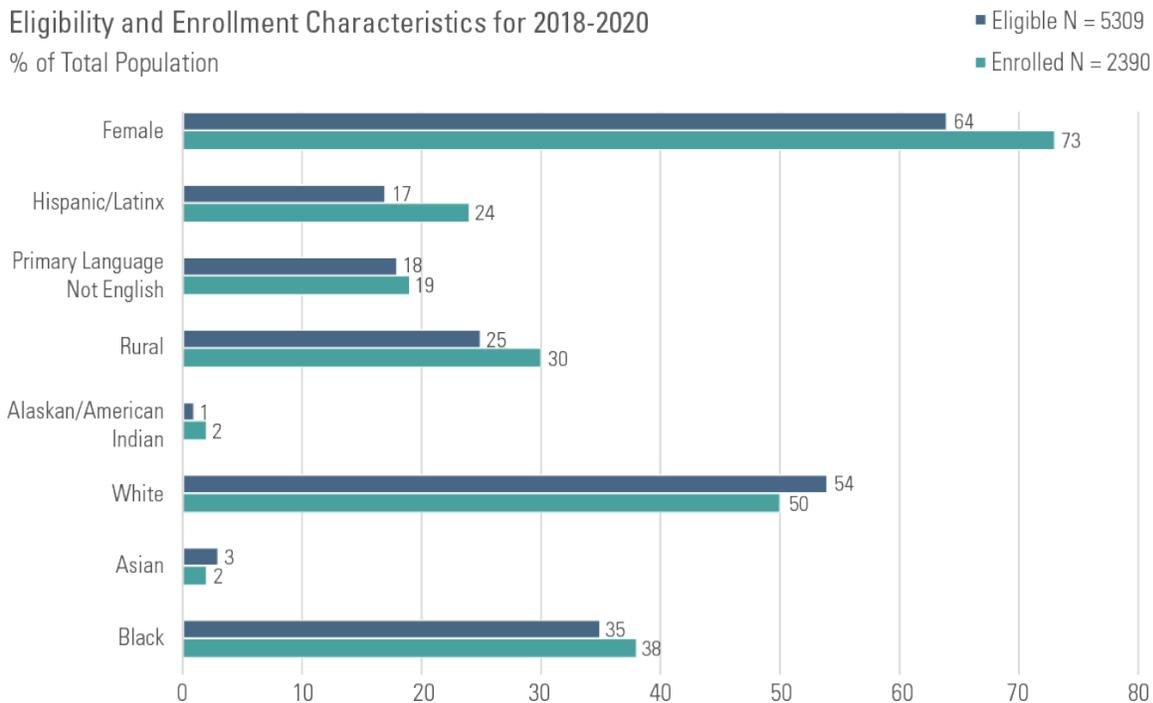
“We’ve been in breast, gynecologic oncology, and thoracic oncology now... [It] has been really wonderful in seeing how our program can be molded, the different types of cancers [it] has. I think [it] kind of shows, this is very useful for providers.”

Findings from the Cross-Site Evaluation

The following quantitative data summarize reach and effectiveness of collective efforts.^c

Reach

Alliance program partners were able to reach and recruit the populations they identified as likely to benefit from additional support. Participant characteristics closely resembled those in the identified population, although in many cases, a slightly larger percentage of those in the identified underserved demographic participated in Alliance interventions. Partners enrolled higher proportions of female, Hispanic, rural, and Black participants than the underlying population characteristics.



Effectiveness

The NPO evaluation team measured the percentage of participants who reported positive outcomes in access, engagement, quality of life, and adherence to treatment. Results were tallied across Alliance program partner sites over 3 years of data collection.^d

^b Hispanic and Latinos are consistently underrepresented in clinical trials. Less than 8% of clinical trial participants are Hispanic, even though they represent 17% of the population (Andalo, 2017).

^c The data represent different patient populations each year because different patients participated in different interventions, with varying timepoints. Not all Alliance program partner sites participated in all data collection efforts.

^d Four of the six Alliance program partners contributed effectiveness outcome data.

Key Findings from the Alliance Cross-Site Evaluation

Data on select underserved patients treated by Alliance Program Partners

Access to Care

Time between diagnosis and the first oncology specialist appointment



10.7 days in 2018
8.6 days in 2019
7.9 days in 2020

Satisfaction with Care

Extent to which a patient is content with the health care received



80% reported “feeling heard”
66% reported “being understood” by the care team

Quality of Life

Well-being and ability to carry out activities compared to general population average



35% was lower than average
46% was the same
19% was above average

Adherence to Treatment

Rate of missed appointments with cancer provider



27% missed in 2018
17% missed in 2019
18% missed in 2020

Access to care. The team evaluated the time between cancer diagnosis and first oncology specialist appointment.^e Across Alliance program partners, the average time between diagnosis and first appointment was 11.2 days in 2018, 8.4 days in 2019, and 9.1 days in COVID-year 2020.^f Data were reported by participant characteristics. Time to first appointment decreased consistently among patients from underserved^g populations. For underserved patients with cancer, the time was 10.7 days in 2018, 8.6 days in 2019, and 7.9 days in 2020.

Alliance interventions also increased access to psychosocial services.^h A total of 785 participants were screened for psychosocial need. Of those, 18% (139) met eligibility and received referrals for psychosocial support.

Engagement in care. Alliance interventions facilitated meaningful engagement in care, participating in treatment decisions and managing their conditions effectively. Across project years, 72%, 90%, and 91% of surveyed patients reported favorable engagement in 2018, 2019, and 2020, respectively.ⁱ

Satisfaction with care. A higher percentage of patients from underserved settings reported higher satisfaction scores. When combining data across the 3 years (2018-2020), 67% of all surveyed participants reported “feeling heard” by their care team.^j Among participants from underserved groups, higher proportions reported “feeling heard” (80%) and “being understood” (66%) by their care team.

Quality of life. Out of 785 surveyed participants, including many who were receiving active treatment for advanced cancer, a majority reported quality of life scores that were at or better than normative data on the general population.^k Between 2018 and 2020, 65% of underserved patients enrolled in Alliance-supported interventions had scores at or above average.

Adherence to treatment. Participants had high rates of appointment maintenance with cancer providers.^l Overall, 26% of appointments were missed in 2018, with 19% missed in 2019 and 21% missed in 2020. Among patients from underserved populations, fewer appointments were missed in both 2019 and 2020 (17% and 18%, respectively).

^e Three Alliance program partners contributed data to this measure in 2018 and 2019. In 2020, two Alliance program partners contributed data.

^f This year presented extraordinary challenges for the U.S. health care system. Alliance Program Partners were affected. Some projects were halted for a period, and others had to shift their interventions to the web or telephone. The challenges brought on by the COVID-19 pandemic may have skewed some of the results reported.

^g The term “underserved” refers to individuals with at least one of the following characteristics: Black, living in a rural setting, do not speak English as their first language.

^h Two Alliance program partners provided data in 2018, and three partners provided data in 2019 and 2020.

ⁱ Two Alliance program partners contributed data in 2018, and three partners contributed data in 2019 and 2020. All Alliance program partners that contributed data for this item provided navigation services.

^j Two Alliance program partners contributed data in 2018, and three partners contributed data in 2019 and 2020.

^k Quality of life data were submitted by three Alliance program partners in 2018 and four in 2019 and 2020. Clinical populations varied over the 3 years.

^l Two Alliance program partners provided data for this measure.

Challenges

Alliance program partners implemented successful strategies to increase health equity, reduce disparities, and make cancer care more patient-centered. However, challenges remain in ensuring equitable, patient-centered cancer care for all. Social and structural factors—including racism, poverty, and uneven service provision—threaten access to high-quality cancer care. Alliance program partners reported that their patients lack access to basic needs such as food, transportation, and health care coverage.

In addition, many patients experience financial issues following cancer treatment, often referred to as “financial toxicity.” In a sample of 103 patients who were treated for cancer and had health insurance, 18% reported facing a “significant financial burden” (Ver Hoeve, Ali-Akbarian, Price, Lothfi, & Hamann, 2021). Financial toxicity was significantly associated with patient-reported anxiety, fatigue, and poor physical functioning and social functioning, after accounting for patient characteristics. Additional impacts included quality of life deficits, such as mood and psychosocial functioning.

In addition to patient challenges, the oncology workforce is strained, with heavy administrative workloads and inadequate resources (Hlubocky, et al., 2021). The COVID-19 pandemic has added stressors to an already overburdened workforce (Hlubocky, et al., 2021). Alliance program partners reported notable service disruptions from the pandemic, necessitating program pauses or adaptations.

Without novel policy strategies, health disparities may worsen in the coming years. Recent advances in precision medicine are widening inequities. Black patients are less likely to receive early comprehensive genomic profiling, which can foster individualized treatments (Rosenberg, 2021).

Studies have also suggested that the COVID-19 pandemic may worsen health disparities, particularly in cancer screening (DeGroff, et al., 2021). During the pandemic, cancer diagnoses decreased sharply, despite no evidence that cancer rates have similarly decreased during this time (Pierce, 2021). The decline could reflect screening delays and result in cancers diagnosed at later stages. Some estimates forecast more than 10,000 additional deaths from colorectal and breast cancers over the next 10 years because of the effect of COVID-19 on cancer screening and treatment (Sharpless, 2020).

Policy Considerations

Medicaid Expansion Benefits for Cancer Patients

There are many examples in the literature of the ways in which Medicaid expansion has increased coverage for both cancer patients and survivors, specifically in underserved populations. Medicaid expansion has improved receipt of timely cancer care treatment for many Black Americans, helping to reduce racial disparities in access (Adamson, et al., 2019). States that have expanded Medicaid report lower racial- and income-related disparities than states that have not yet expanded Medicaid (Moss, Wu, Kaplan, & Zafar, 2020). Further Medicaid expansion could provide insurance coverage to over 2 million additional adults. Eight of the 12 states that have not yet expanded Medicaid have larger populations of people of color, creating coverage gaps that impact Black Americans and are roadblocks to decreasing disparities in health outcomes (Garfield & Orgera, 2021).

Community Health Workers and Patient Navigators Improve Outcomes

Support for increasing the use of CHWs and patient navigators is another approach to reducing disparities in cancer care. Patient navigators have improved outcomes for people at high risk for cancer care delays associated with socioeconomic status, employment status, income, and education level. Patient navigation services have been shown to help reduce diagnostic resolution disparities in these demographics (Rodday, et al., 2015). Patient navigators have also helped to improve screening rates among low-income and racial and ethnic minority women (Phillips, et al., 2010). Several Alliance interventions saw positive outcomes through utilizing patient navigators for their populations. Yet navigator services, particularly those provided by lay navigators, are rarely reimbursed by insurers.

CHWs help to facilitate conversations around underlying SDOH needs and help to find solutions, such as increasing access to social services (Ingram, et al., 2014). SDOH and cancer care disparities are linked, and Alliance interventions showed promise in addressing SDOH to reduce disparities. CHWs can be employed at the state level. State contracts with Medicaid Health Plans can require that plans employ or provide for CHW services and can set minimum population ratios to ensure adequate services. Other

financing mechanism options include providing incentives to private insurers for using CHWs (National Association of Community Health Workers, 2020).

Integrated Services Improve Care Coordination

The Alliance program partners developed novel solutions to manage co-occurring conditions with cancer, including integrated behavioral health approaches. A promising model to integrate behavioral health into care delivery for patients with cancer is partnerships with Certified Community Behavioral Health Clinics (CCBHCs). CCBHCs are integrated delivery approaches that ensure that people with behavioral health needs get other necessary primary care health screenings and treatments. CCBHCs are integrating the value-based care model with mental health services. They provide financial support and the infrastructure needed to improve EHR systems, increasing interoperability and community-wide coordination of care and integration. In addition to providing mental health support, CCBHCs can serve as links to cancer care for hard-to-reach populations living with severe mental illness or other mental health conditions.

Research shows that clinics with a CCBHC designation have increased their ability to reach underserved populations through targeted outreach, flexible funding to support data collection and evaluation, and expanding services for specific populations (Certified Community Behavioral Health Clinic [CCBHC] Success Center, 2021). Additional funding support to expand CCBHCs could improve coordination of care and reduce cancer disparities. Similar integrated approaches for other prevalent and/or high-risk co-occurring conditions (e.g., cancer and diabetes, cancer and cardiac disease) are worthy of additional development and evaluation.

Conclusions

Despite continued improvements in survival for cancer patients, certain populations continue to experience higher rates of cancer morbidity and mortality (Nelson, 2020). Impacts from the COVID-19 pandemic may be exacerbating these disparities (DeGroff, et al., 2021), with reduced access to cancer screening, diagnosis, and treatment. These access gaps may worsen cancer-related mortality in underserved populations (Sharpless, 2020). Early identification of patients at risk for access challenges and poor outcomes, coupled with evidence-based interventions, can improve outcomes, as the Alliance-supported efforts have shown.

The Alliance has demonstrated that multiple strategies are needed to address disparities in cancer care. Interventions implemented by Alliance program partners included an array of strategies: patient navigation, CHWs, technology solutions to identify patients at risk for poor outcomes, collaboration with community health centers, implicit bias training, and coordination of care across care delivery settings. Comprehensive, multifaceted programs like these can improve access to high-quality cancer care, particularly for those populations that have been historically underserved.

Despite the reach and effectiveness of interventions implemented by Alliance program partners, sustained efforts are needed to achieve population-level health equity for individuals with cancer. Comprehensive, culturally sensitive, multilevel programs that address barriers to care are the most promising approach to deliver lasting change to the U.S. health care system. Policy strategies that support delivery of these promising strategies hold promise for achieving timely, equitable, and patient-centered cancer care, which has the potential to reduce both the individual and societal burden of cancer.

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