

Reaching Populations to Address Disparities in Cancer Care Delivery: Results From a Six-Site Initiative

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ABSTRACT

Background: Large segments of the US population do not receive quality cancer care due to pervasive and systemic inequities, which can increase morbidity and mortality. Multicomponent, multilevel interventions can address inequities and improve care, but only if they reach communities with suboptimal access. Intervention studies often underenroll individuals from historically excluded groups. **Methods:** The Alliance to Advance Patient-Centered Cancer Care includes 6 grantees across the United States who implemented unique multicomponent, multilevel intervention programs with common goals of reducing disparities, increasing engagement, and improving the quality of care for targeted populations. The Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework informed the evaluation efforts across sites. Each Alliance site identified their intended populations, which included underrepresented minorities (eg, Black and Latinx persons), individuals who prefer a language other than English, and rural residents. We evaluated the demographic characteristics of participants to determine program reach. **Results:** Between 2018 and 2020, a total of 2,390 of 5,309 potentially eligible participants were enrolled across the 6 sites. The proportion of enrolled individuals with selected characteristics included 38% (n=908) Black adults, 24% (n=574) Latinx adults, 19% (n=454) preferring a language other than English, and 30% (n=717) rural residents. The proportion of those enrolled who were the intended population was commensurate to the proportion with desired characteristics in those identified as potentially eligible. **Conclusions:** The grantees met or exceeded enrollments from their intended populations who have been underserved by quality cancer care into patient-centered intervention programs. Intentional application of recruitment/engagement strategies is needed to reach individuals from historically underserved communities.

J Natl Compr Canc Netw 2023;21(5):481–486
doi: 10.6004/jnccn.2023.7006

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Background

Disparities in cancer care delivery systems result in the death of millions of patients each year in the United States.^{1,2} These disparities stem from social, economic, environmental, and/or structural inequities.^{1,2} Due to these inequities, disproportionately affected groups, people who are under/uninsured, and/or people with a lower social economic standing often receive lower-quality cancer care that results in disparities in treatment outcomes.^{1,3–6} The higher morbidity seen in Black and Latinx patients with cancer compared with their White counterparts is associated with these disparities.^{5–7}

One reason for these treatment disparities may be the relatively higher enrollment of non-Hispanic White populations into cancer treatment studies. It is estimated that individuals from groups other than non-Hispanic Whites represent only 10% of study participants in National Cancer Institute trials.⁸ Low recruitment of underrepresented populations in cancer research^{9–11} may limit the generalizability of findings and perpetuate these inequities.¹² Multicomponent, multilevel interventions to improve access to care have the potential to address these inequities and improve care, but only if they reach the intended populations.³

To address these pervasive challenges, 6 grantees across the United States formed the Alliance to Advance Patient-Centered Cancer Care (Alliance) with an aim to address the structural inequities in cancer care by implementing diverse multicomponent (eg, access, symptom monitoring, wellness, survivorship), multilevel (eg, patients, clinicians, caregivers, health system) evidence-based practice intervention programs of varying lengths. Table 1 lists examples of the types of interventions that have been implemented. Participation in Alliance initiatives was predicated on the ability to reach and provide access to the specific populations of people who have been underserved by quality cancer care, an essential first step in overcoming health inequities. The Alliance members used 4 key evidence-based strategies to improve enrollment of

Table 1. Alliance to Advance Patient-Centered Cancer Care: Examples of Interventions

Navigation examples	Sites (n)
<ul style="list-style-type: none"> Registered nurse navigators focus on concerns about cancer diagnosis and treatment, such as symptom management, communication with healthcare team, adherence to cancer treatments, self-care management, referral to supportive services Lay navigators focus on nonclinical needs, such as transportation, accessing community resources, financial concerns, insurance issues Hybrid approach using both nurse and lay navigators Patient navigation program for community health workers 	4
Communication examples	
<ul style="list-style-type: none"> Implicit bias training for medical students and residents Computer-mediated communication skills training for providers, patients, and caregivers Patient and Family Advisory Councils Coordination between primary care and specialty care Electronic health records communication tools Care transitions communication tools 	All 6
Community partnership examples	
<ul style="list-style-type: none"> Community advisory boards Steering committees Community alliances (eg, community health workers association) Community health clinics Federally qualified health centers (FQHCs) Planetree International, Inc. Mental health agencies Mental health associations Food markets and community foodbanks 	5
Supportive care examples	
<ul style="list-style-type: none"> Depression screening and management Family-based supportive care intervention Nutrition counseling Exercise and physical activity coaching Symptom monitoring and symptom management Community-based education and support programs for families 	5

people who have been underserved by quality cancer care in their programs: nurse and lay navigators, community-based participatory approaches, electronic health record (EHR) data algorithms, and the provision of key resources, such as transportation and technology.¹³ The use of culturally tailored navigation, in which nurse or lay navigators provide a communication link to the care team and referrals to community services to facilitate access to care and emotional support, addresses some treatment-related barriers and increases enrollment in research.^{14,15} Community-engaged research approaches, including focus groups, community advisory boards, and community partnerships, are effective strategies that can increase underrepresented minorities' engagement and enrollment in research as well as access to care.^{16,17} Additionally, use of EHR algorithms has supported the identification of and communication with potential participants, resulting in cost-effective recruitment strategies.¹⁸ Furthermore, the provision of key resources such as transportation and technology addresses some social determinants of health and economic stability, which can increase access to quality care among underrepresented populations.^{19–21}

The Alliance programs participated in a cross-site evaluation effort that used the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM)

framework.²² The RE-AIM framework is a systematic approach to assess how a program and/or intervention translates into real-world settings.²² The Reach component evaluates the representativeness of the population that participates in an intervention/program by assessing the number, characteristics, and proportions of those who participated.²³ The purpose of this publication is to report the collective results of the Alliance's programs related to the "R" (Reach) in RE-AIM.

Methods

Context

The 6 Alliance sites—Georgia Cancer Center for Excellence at Grady Health System (Grady) in Atlanta, Georgia; The Johns Hopkins University School of Medicine (JH) in Baltimore, Maryland; Massachusetts General Hospital Cancer Center (MGH) in Boston, Massachusetts; Northwestern University Feinberg School of Medicine (NU) in Chicago, Illinois; The Ohio State University Comprehensive Cancer Center (OSU) in Columbus, Ohio; and University of Arizona Cancer Center (AZ) in Tucson, Arizona—represent 4 regions of the United States: the Midwest, Northeast, South, and Southwest.

Each site identified one or more opportunities within their cancer programs to increase their reach to underrepresented populations. Each Alliance member decided

which population(s) they would focus on, determined their unique approaches aimed at increasing Reach, and their assessment methods. These populations ranged from rural residents, people with lower economic standing, ethnically and racially diverse populations, and/or populations in which English was not the preferred language (Table 2). Alliance members developed multilevel, multicomponent interventions aimed at addressing structural inequities and improving cancer care for underrepresented populations; however, the interventions and eligibility criteria were developed by each individual site based on a needs assessment of their populations.

Strategies to Promote Reach

Patient navigation included the use of nurse navigators, lay navigators, or both. This strategy was used by 4 Alliance sites (Grady, MGH, OSU, AZ), each of which had existing navigation programs. However, through the Alliance initiative, sites increased their navigation services to expand the reach of services to populations of interest. For example, AZ added lay navigators fluent in Spanish as well as community health workers. MGH expanded their patient navigation program to community health centers and surrounding communities to focus on linguistic, cultural, and economic barriers to care.

Five Alliance members used community-engaged approaches. These approaches included preparatory focus groups, community advisory boards, community partnerships, and steering committees (Grady, JH, MGH, NU, AZ). Two Alliance sites (NU, AZ) developed or built on strong relationships with Federally Qualified Health Centers to improve cancer care access and communication throughout the cancer care trajectory. Grady integrated a strong community advisory board called the Patient & Family Advisory Council that assisted with the development of a resource guide for newly diagnosed patients, as well as engagement with local nonprofit agencies such as

the American Cancer Society. The fifth site, MGH, worked closely with a community agency to develop processes and tools, such as shared electronic databases and automatic referrals, to identify and document activities for the prevention and detection of individuals with housing insecurity and suboptimal insurance, and those who migrated from other countries.

EHR data algorithms were developed to identify and communicate with potential participants; 4 Alliance sites (Grady, JH, MGH, NU) used this strategy. Potentially eligible participants in the catchment area of 3 institutions (JH, MGH, NU) were identified through locally developed, population-based software platforms. In both cases, the platform already existed in the form of a type of registry, but the investigators expanded their functions to meet the needs of the Alliance project. Grady developed a dashboard to track patients at risk for poor outcomes as they interacted with the health system.

Provision of key resources was used by 2 sites (Grady, OSU). In the early years of the Alliance initiative, Grady provided participants prepaid rideshare services. OSU collaborated with an existing vendor to provide smartphones and data plans at no cost to participants with no access to these resources in order to facilitate project participation. The smartphone application provided an effective mechanism for patients and providers to communicate about symptom management concerns and other unmet needs during and after treatment.

Measures

Our collective outcome measure of Reach was operationalized by assessing population availability, which was essentially potentially eligible participants; numbers enrolled; representativeness; and intervention completion. *Population availability* was the identification of the population of interest and their representation within the catchment area of the Alliance members who were

Site	Geographic Location	Underrepresented Populations
Northwestern University	Chicagoland area, Illinois	Patients receiving primary care services from federally qualified health centers (FQHCs) in the greater Chicago area
The Ohio State University	State of Ohio, including Ohio Appalachia	Rural, Appalachia, those with fewer technological resources
University of Arizona	Southern Arizona	Latinx, Spanish as primary language population
Massachusetts General Hospital (MGH)	Communities surrounding MGH Cancer Center and its affiliate MGH North Shore Cancer Center; Boston, Massachusetts	Primary language other than English
Georgia Cancer Center for Excellence, Grady Health System	Atlanta, Georgia	Black population
Johns Hopkins University	Baltimore, Maryland; east Baltimore; rural Maryland; and Pennsylvania	Black population

potentially eligible for participation in the intervention. This was determined and reported by each site. Sites each had unique eligibility criteria for their programs. The commonality was that all participants would have a diagnosis of cancer and were either starting or receiving cancer treatment. *Enrollment* was the absolute number of participants who agreed to participate. *Representativeness* of enrolled participants was assessed by calculating the percentages of the population of interest who enrolled and comparing them to the representativeness of those potentially eligible to participate that was reported by each site.

Data Collection and Analysis

The National Program Office (NPO), which was based at the University of Michigan School of Nursing, served as the coordinating center for the Alliance and collected and analyzed the data for the cross-site evaluation. The NPO collected deidentified aggregate patient- and center-level data longitudinally per site during the 3-year study, reviewed data for accuracy with key personnel at each site, and reported aggregate information to all sites during regularly scheduled intervals to share knowledge and potentially inform ongoing adjustments to the various Reach strategies. Each site provided data as agreed upon in the cross-site evaluation, which included the number of potentially eligible participants, enrollment, and completion information in the program.

Cross-site evaluation data related to Reach were collected during 2018, 2019, and 2020, at prespecified intervals. Interventions delivered by sites had variable time frames. For several sites, interventions were implemented throughout cancer treatment (different types of cancer requiring different treatments for differing lengths of time); for other sites, there was a specified time frame of 12 months. Therefore, data collection that included an aggregate group of participants may or may not have coincided with the completion of an intervention for an individual participant. Data for 2020 were collected at the start of 2021. These data were impacted by the first year of the COVID-19 pandemic. In-person activities, including quality improvement initiatives and research activities, were curtailed at the cancer centers. Some of the sites made modifications to their recruitment strategies and interventions that enabled remote recruitment and delivery of their interventions. However, this was not possible for all sites in a timely fashion, which necessitated that cross-site data collection did not occur for 2021, the last year of the initiative.

The data were available by each type of intervention as applicable (navigation, communication, psychosocial care, and coordination of care) and by participant characteristics, such as race, ethnicity, gender, primary language, and rurality. The participant characteristic information was used to

compare the Reach rates for the specific population that has been underserved by quality cancer care and the general population for each site. This information was pooled across sites to extract the overall eligibility and enrollment numbers, as well as for the specific population of people who have been underserved by quality cancer care and the general population. Individual patient-level data were not collected due to the framing of the work being quality improvement and not human subject research. The analysis included descriptive statistics (count and percentage) and bar graphs for each of the 3 years, as well as a cumulative total of all 3 years for all sites.

Ethical Considerations

Most Alliance sites received exempt status from their Institutional Review Board (IRB) and did not obtain written consent, but 2 sites (JH, MGH) did obtain written consent. All data shared with the NPO were aggregated; identifiable patient-level data were not provided. Similarly, no protected health information was shared with the NPO or across sites. The cross-site evaluation protocol received exempt status from the University of Michigan IRB (HUM00142621).

Results

Population Availability

Each Alliance site identified its own specific population(s) of interest (Table 2). Potentially eligible participants (n=5,309) across the 6 sites demonstrated the demographic characteristics of interest (Figure 1).

Enrollment

Of 5,309 potentially eligible participants, the 6 sites reported a total enrollment of 2,390. Fewer people were enrolled than were eligible due to the capacity of the programs.

Representativeness

Sites successfully enrolled participants in their interventions who represented the populations they were seeking to reach. The proportions enrolled were similar to or exceeded the proportions observed across the entire pool of eligible persons (Figure 1). The proportion of individuals with selected characteristics from the total enrolled included 38% (n=908) Black adults, 24% (n=574) Latinx adults, 19% (n=454) preferring a language other than English, and 30% (n=717) rural residents. Overall, the sites enrolled participants consistent with the percent of available and eligible participants for their selected underrepresented population.

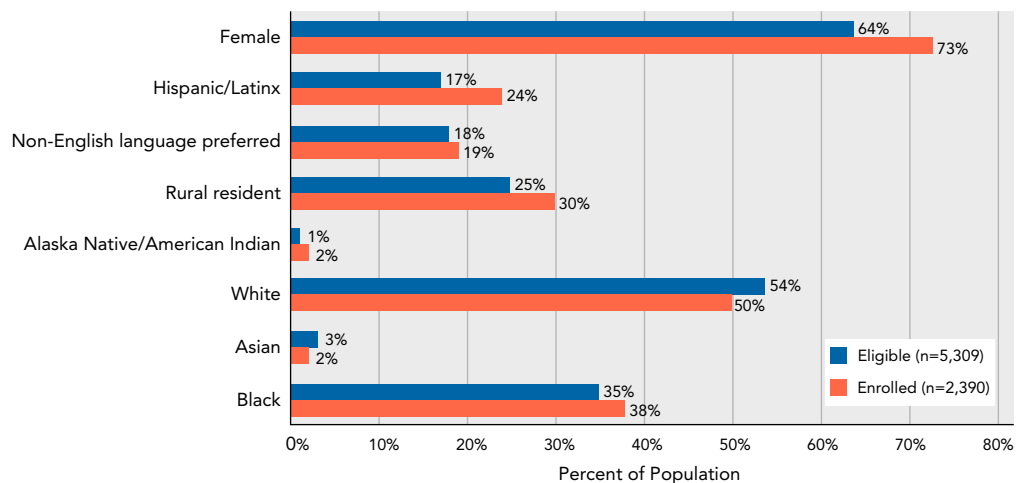


Figure 1. Eligibility and enrollment characteristics (2018–2020).

Discussion

Through use of patient navigation, community-engaged research approaches, and EHR-based algorithms, as well as provision of critical resources, the Alliance sites were able to recruit underrepresented populations to participate in their intervention programs aimed at addressing the structural inequities in cancer care. Alliance members successfully reached their populations of interest, which included individuals from historically underrepresented adult populations, including Black, Latinx, those preferring a language other than English, and rural residents.

The Alliance programs were primarily locally focused and designed to directly benefit the populations served by the local cancer programs. Each site tailored its reach interventions, and as such, there was wide variation in the interventions across Alliance sites. Use of the Reach component of the RE-AIM framework, which is intended to evaluate programs in a real-world setting, allowed us to navigate the complexities and nuances across programs. Hence, our results identify promising strategies that can be applied to different cancer care delivery systems with a shared goal of increasing reach and representativeness.

There were some limitations of this work, such as the fact that the absence of participant-level data limited the analytic approach. The heterogeneity of recruitment strategies, coupled with the diverse interventions, made it difficult to identify specific components that were more successful than others. Finally, not all sites were

able to submit requisite data due to differences in their programs, regulatory delays, and/or effects of COVID-19.

Conclusions

Our results support the need to be intentional with strategies that have the potential to reach people who have been underserved by quality cancer care, and to broadly address access barriers for quality cancer care. Alliance members were able to achieve their goals for reaching underrepresented populations in their cancer programs through the strategic use of human resources, community-engaged research approaches, and/or technology. The next steps need to thoroughly evaluate the effectiveness, adoption, implementation, and maintenance of these interventions using mixed methods to further refine and extend these interventions.

Submitted July 27, 2022; final revision received January 10, 2023; accepted for publication February 1, 2023. Published online April 11, 2023.

Disclosures: Dr. Friese has disclosed receiving grant/research support from Merck Foundation and NCCN Foundation/Pfizer. Dr. Paskett has disclosed serving as a principal investigator for Genentech, Pfizer, Merck Foundation, and Guardant Health; and serving on an advisory board for GlaxoSmithKline. The remaining authors have disclosed that they have not received any financial considerations from any person or organization to support the preparation, analysis, results, or discussion of this article.

Funding: Research reported in this publication was supported by the Merck Foundation.

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JNCCN-N-0324-0523