Development of an Actionable Framework to Address Cancer Care Disparities in Medically Underserved Populations in the United States: Expert Roundtable Recommendations

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original contributions

QUESTION ASKED: What effective strategies, approaches, and policies along the CCC will help local healthcare providers, health systems, researchers, care partners, and community leaders facilitate and deliver optimal care for medically underserved populations?

SUMMARY ANSWER: The highest cross-cancer-continuum areas of impact with effective notable practices were identified across three major functions: (1) patient navigation, which addresses barriers to successful patient progression along the cancer care continuum (CCC); (2) excellence in community engagement, necessary to build trust among medically underserved populations; and (3) implementation of healthcare system changes. Additionally, experts focused on opportunities to engage patients through transitions in care and close gaps between the domains of the cancer continuum. There is specific emphasis on best practices in screening, diagnosis, treatment, and survivorship, recognizing that healthcare system change is often effectively sustained by policy implementation that ultimately increases access, utilization, and standardization across the care continuum.

WHAT WE DID: We conducted an environmental scan to identify strategies and associated experts who successfully provided community- and/or patient-centric standards in care domains (Institute of Medicine/National Academies of Sciences, Engineering, and Medicine [IOM/NAS] defined) in our population of interest, which included racial and ethnic minority groups and medically underserved populations (including rural, aged, adolescent or young adult [age 15-39 years], LGBTQ, differently abled, immigrants and refugees, and under- and uninsured). Drawing from our environmental scan, we engaged experts and patient advocacy organization leaders to develop the theoretical foundation for a practical, evidence-based framework for the CCC. The result, designed for multistakeholder action, focuses on evidence-based practices and procedures to facilitate patient access and care delivery along the CCC and especially in-between domains where patients may be lost to follow-up.

WHAT WE FOUND: We found that our unique methodology involved distilling multistakeholder recommendations without overtly steering the group toward consensus. Our findings included, but were not limited to, the following: 25 high impact practices across the CCC in the areas of community engagement, patient navigation, data collection, health equity, funding support, education or training, and clinical trials. Seventeen priority actions between domains (screening to diagnosis, diagnosis to treatment, and treatment to survivorship) were identified for multistakeholder adoption at a local level. In addition, we delivered consensus recommendations for continuous policy change.

BIAS, CONFOUNDING FACTOR(S): Limitations of our findings included the following: domains of prevention, risk reduction, and end-of-life care were not covered; successful local community approaches not discovered, documented, or published would not have been captured. The focus of identified practices was on the application to high-prevalence cancers versus rare cancers. Another potential limitation is that experts were invited rather than self-nominated, which may mean that some views and experiences were not represented.

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abstract

PURPOSE Cancer disparities persist among medically underserved populations despite widespread efforts to address them. We describe the development of a framework for addressing cancer care disparities across the cancer care continuum (CCC), guided by the CCC domains established by the Institute of Medicine/National Academies of Sciences, Engineering, and Medicine (IOM/NAS).

MATERIALS AND METHODS An environmental scan was conducted to identify strategies and associated experts who are providing or have successfully provided community- and/or patient-centric IOM/NAS-defined domain standards to our target populations. A multistakeholder expert roundtable working group was convened for framework development. A premeeting survey informed agenda development, documented expert practices for target populations, and identified priority areas for meeting focus.

RESULTS The environmental scan identified 84 unique experts across 8 stakeholder groups and 44 patient organizations; 50 were invited to the roundtable and 33 participated. They broadly represented disease sites, geography, and experience with target populations and all CCC domains. The premeeting survey (16 responses) identified coordination of care or patient navigation (66.7%), community engagement (60.0%), and healthcare system changes (53.3%) as priority focus areas. The experts identified access and treatment barriers or gaps within and between CCC domains, specified key notable practices to address these, and developed an actionable framework and recommendations for each priority focus area.

CONCLUSION The framework and recommendations are intended to guide researchers, healthcare leaders, advocates, community- and patient-focused service organizations, and policy leaders to address and promote health equity in cancer care access and treatment outcomes.

INTRODUCTION

Disparities in cancer burden and access to care among different populations in the United States and the resultant outcome disparities are well-documented.[1-3] Contributing factors include social determinants of health (SDOH)—the conditions in which people work, live, and play,[4-7] disparities in insurance coverage and access to care,[8-10] and variable quality of care.[11-14] Implicit bias and patient- and system-level factors play a role.[15-18] Although the higher incidence of some cancers in certain populations is not fully understood,[19-22] other disparities are clearly related to differences in treatment and other external factors.[20,23-27] Data show that inequities in health care exist across the entire cancer care continuum (CCC) and are disproportionately affecting medically underserved populations who may encounter cultural, linguistic, economic, and other barriers to care.[28-31]

Greater effort is being placed upon the importance of achieving health equity. Increasingly, initiatives across different sectors of the US healthcare system and in a variety of medical practice settings aim to address disparities in cancer care and improve outcomes for traditionally underserved populations. National efforts seek to increase underrepresented populations in clinical trials,[32-34] to ensure Medicaid coverage of clinical trial participation,[35] and to reduce cancer burden through improved preventative services.[36]

Other initiatives, such as the National Cancer Institute's Community Network Program, focus on partnering with community-based organizations to develop targeted interventions to address cancer disparities among racial and ethnic populations.[37] Despite both national and local efforts, gaps in the CCC persist.

Because of the complexity of US health care, a collaborative approach is needed to address disparities along the CCC. The continuum of care cannot be viewed as discrete domains or silos; rather, each domain is interrelated and affects patient outcomes. Therefore, a holistic approach is required to develop systemic changes that can provide coordinated care to address barriers within each domain while helping implement programs that bridge care from one domain to the next. A coordinated multistakeholder focus on sometimes simultaneously occurring multilevel interventions that affect health—interpersonal, organizational, community, educational, occupational, environmental, and policy—is required to enable high-impact CCC practices at a local level.[38]

Although our earlier work described notable practices for recruiting racial and ethnic minority groups into cancer clinical trials,[39,40] this paper explains the development of a framework for addressing cancer care disparities across the CCC, guided by the Institute of Medicine/National Academies of Sciences, Engineering, and Medicine (IOM/NAS)–established CCC domains.[41] Because practices and efforts are not routinely documented or published, we selected a workshop approach bringing together experts across the CCC as an effective method for framework development. A table of definitions for commonly used terms is provided in the Appendix Table A1, online only.

MATERIALS AND METHODS

Framework Focus and Scope

The 21 members of the CCC Steering Committee agreed on the focus of the framework. Target populations were racial and ethnic minority groups (African American, Hispanic, Asian American, American Indian, and Alaska Native) and medically underserved populations (including rural, aged, adolescent or young adult [age 15-39 years[42]], LGBTQ, differently abled, immigrants and refugees, and under- and uninsured).

We agreed that the framework should be especially germane to high-prevalence cancer conditions (ie, breast, lung, blood, prostate, and colorectal cancers) and that it should center on four of the six IOM/NAS CCC domains—screening, diagnosis, treatment, and survivorship—with emphasis on addressing barriers to access within and between those domains.

The Steering Committee developed core themes for questions to be addressed by roundtable participants. The themes covered barriers within the CCC for included populations, roles and responsibilities of diverse stakeholders in

promoting health equity, initiatives and strategies that may bridge gaps in the CCC and overcome challenges to achieving health equity, research imperatives, and policy changes required to facilitate adoption of best practices. The unique methodology used to arrive at the conclusions made herein involved synthesizing multistakeholder recommendations without driving the group toward consensus.

Environmental Scan to Identify Experts for Framework Co-Creation

From March to September 2018, Google searches on the IOM/NAS CCC domains, including patient navigation, were used to identify experts associated with pertinent clinical or research programs underway or completed in the previous 5 years (January 2013 to December 2018). Search terms and Boolean logic combinations were used; for each target population, search terms included cancer AND diversity, health equity, prevention, screening, diagnosis, treatment, clinical trials, research, SDOH, financial, health literacy, health systems, survivorship, and end-of-life care.

Experts were further evaluated based on their biographies (from organization websites) and publications (PubMed search). The scan included speakers and authorities who had participated in the past 3 years in public meetings regarding diversity and inclusion in cancer research and efforts by patient organizations, foundations, and government agencies focused on high-prevalence cancers among racial and ethnic minorities. Experts were invited to participate in the roundtable Working Group based on the CCC Steering Committee-approved criteria: most appearances in the environmental scan and documented work in target populations related to the CCC domains.

Premeeting Survey and Development of Roundtable Preparation Materials

The CCC Steering Committee developed and distributed a survey to confirmed attendees 5 weeks before the roundtable meeting. Anonymized survey responses were used to inform agenda development, generate a discussion guide, and document expert practices to highlight programs with the greatest impact (Appendix Fig A1, online only).

Relevant literature regarding initiatives, submitted by the experts (n = 20) before the meeting or identified through the environmental scan, was provided to participants. They were asked to review these publications prior to the meeting and identify notable practices in the care of racial and ethnic minorities and other underserved populations for discussion at the roundtable. Publications were grouped into focus areas for the meeting: screening (n = 26), diagnosis (n = 9), treatment or clinical trials (n = 23), survivorship (n = 5), coordinated care or patient navigation (n = 26), healthcare system changes (n = 5), community engagement (n = 13), resources for patients or providers (n = 10), nontherapeutic trials (n = 2), and another category including data-driven approaches, measurement,

and technology (n = 13). Participants were also provided with other relevant documents to provide context (eg, the IOM/NAS report).

Identification of Barriers Within or Between Selected Domains

Barriers preventing equitable access to cancer care were identified by the participants through roundtable breakouts (of five to six experts). They answered CCC Steering Committee-generated questions and provided feedback to the larger group. Discussions were recorded and transcribed by a professional writer who ranked the barriers based on the number of mentions.

Development of Recommendations on Policy Interventions

In the premeeting survey, the experts identified policy solutions that demonstrated a positive impact on overcoming barriers along the CCC for the target populations; these were discussed and consolidated during the meeting. Participants prioritized policy interventions with examples to develop specific recommendations. Discussion was captured and transcribed.

RESULTS

Environmental Scan and Premeeting Survey

The environmental scan identified 84 unique experts across 8 stakeholder groups (Appendix Fig A2, online only) and 44 unique patient organizations (representing prostate, breast, lung, and colorectal cancers and pan-cancer). Identified experts had documented processes and best practices across all CCC domains, comprising prevention and risk reduction (28.6%), screening (29.8%), diagnosis (10.7%), treatment (8.3%), survivorship (17.9%), and end-of-life care (4.8%). In addition, 26.2% were experts in all 6 domains, 35.7% in multiple domains, and 14.3% in Patient Navigator Research Programs. In total, 50 experts met selection criteria and were invited to participate in the roundtable meeting; 33 (66%) invitees attended (4 from the pharmaceutical industry). The premeeting survey was sent to 22 confirmed participants (number confirmed by the survey distribution date) representing all 8 stakeholder groups, and 16 responses were received (73% response rate) (Appendix Fig A3, online only).

There was expert representation by disease site and geography. Respondents were experienced in the range of target populations, though mostly African-American and Hispanic (both 81.3%), elderly (62.5%), rural, and adolescent or young adult (50.0%). The majority (56.3%) had experience across all domains, most commonly in screening (62.5%) and treatment or clinical trials (56.3%) (Appendix Fig A4, online only). There was some overlap in expertise, as evidenced by biographies and survey responses for approximately 30% of confirmed experts. Almost half (47%) of the respondents identified the treatment

domain for focus in optimizing outcomes for target populations, with screening, diagnosis, and survivorship cited by 23%, 16%, and 14%, respectively. Regarding addressing gaps in best practices between domains, a higher proportion of responses focused on bridging the gap between diagnosis and treatment (41%), compared with between screening and diagnosis (32%), and treatment and survivorship (27%). Areas of focus most commonly identified as having the greatest potential impact on cancer patient outcomes in the target populations were coordination of care or patient navigation (66.7%), community engagement (60.0%), and healthcare system changes (53.3%) (Appendix Fig A5, online only).

Identification of Barriers Within or Between Selected Domains

Participants identified barriers within and between the four domains (screening, diagnosis, treatment, and survivorship) for the target populations. Some were common to all domains, including lack of coordination of multiple visits, providers, and testing especially related to transitions in care; logistical or financial barriers to care; difficulty in addressing and documenting SDOH so that data become part of the electronic medical record and are communicated to providers throughout the continuum; diverse languages spoken in community or institutional settings requiring multilingual navigators; geographic and social isolation within underserved communities; lack of familiarity with resources that address financial and other social support needs including transportation, childcare, elder care, and emotional support; distrust in the healthcare system, which may result in delayed or incomplete care; and time constraints and employment demands requiring navigators to establish individualized goals with patients and care partners.

Common barriers identified across screening, diagnosis, and treatment were ineffective approaches to navigation, including the lack of standards or metrics, delays between screening and diagnosis, and delays between diagnosis and treatment. Poor clinician-patient communications, low health literacy, unsustainable financial models for navigation programs, competition for patients in institutions or groups, and the lack of timely discussion regarding clinical research participation (ie, not during treatment consultations) were all cited as common barriers across diagnosis and treatment.

Evaluation of High-Impact Practices

Based on premeeting survey results and roundtable consensus, patient navigation, community engagement, and healthcare system changes were designated as priority focus areas. For each of these, participants reviewed relevant barriers and/or gaps, and the specific domains affected. Through discussion on documented practices (identified during the premeeting work), they reached

TABLE 1. Notable Practices and Recommendations in Patient Navigation Between the Four Domains

Screening to diagnosis[43,44]
• Supporting level: add lay navigator to the team to identify, share, and address cultural and linguistic barriers impeding care
• Individual level: support system needs to be respected; focus on information a patient needs that day
• System level: point of care and EMR—ensure that patients have a portal for access to notes and assistance to access portal so that patients are kept informed on next steps (eg, next clinic visit and lab results) and resources are shared
• Provide cancer screening; when possible, use mobile units to reach communities
• Ensure that systems are built within EMRs to enable active follow-up (via navigators) of abnormal screening results
• Systematically implement shared decision making for prostate cancer screening
• Begin assessment of SDOH and other potential barriers prior to first appointment
Diagnosis to treatment
• Develop navigation across institutions that emphasize warm handoffs from provider to provider and from service to service
• Navigation must follow the patient from screening through treatment (ideally by the same navigator since rapport and trust have been established). This is an area where patients are most likely to fall through the gap—need to focus trusted resources here
• Track patients through second opinion to ensure follow-up
• Metric tracking and reporting of days from diagnosis to treatment must trigger an active personal action by the healthcare team (navigator and outreach)
• Focus on measurement through data or IT solutions, and so the entire care team can understand milestones, progress, and gaps
• Incentivize programs addressing and supporting health equity solutions by leveraging accreditation standards, streamlining all requirements, developing a focused community needs assessment, and creating linkages between institutions with template materials and expectations
• Provide opportunity for patients to be navigated to oncology urgent care services for common treatment-related symptoms
• Develop and share best practices for patient navigation or community engagement to develop more standardized approaches and maintain up-to-date access to national and local support programs to address SDOH
• Begin assessment of SDOH and other potential barriers prior to first appointment
Treatment to survivorship
• Develop community outreach programs with a focus on survivorship (to reduce stigma and fatalistic, skeptical, and distressed perspectives and increase awareness of survivorship needs). Use digital health tools and/or social media platforms to increase accessibility and decrease burden on patients
• Build partnerships with community leaders or groups and provide training resources for developing and maintaining a network of community health workers to assist patients
• Establish an advisory council with patients and community leaders to address local barriers and resource needs
Across the entire continuum of care
• Develop and share best practices for patient navigation or community engagement to develop more standardized approaches and maintain up-to-date access to national and local support programs to address SDOH
• Hire multilingual and culturally sensitive patient navigators for service area

Abbreviations: EMR, electronic medical record; IT, information technology; SDOH, social determinants of health.

agreement on key notable practices for addressing these barriers and/or gaps. Their insights informed the development of actionable recommendations related to practices shown to positively affect each specific focus area.

Highest Impact Areas Across the CCC: Patient Navigation, Community Engagement, and Healthcare System Change

Patient navigation was defined as providing individual assistance to patients, family, and caregivers to overcome barriers to medical care and self-care and tracking patients to ensure timely access to quality care. Patient navigation comprises tactics and activities that bridge the gaps

between domains. Participants noted that navigators may be lay navigators (individuals from the community, with no clinical expertise, who relate to patients in a culturally appropriate manner and connect the community with the healthcare system), clinical navigators (nurses or social workers), or members of a multidisciplinary team of navigators who address a broad range of social and clinical needs.

Notable practices in patient navigation were identified across all four domains. Table 1 summarizes those identified as helping to bridge the gap between domains, which are therefore recommended for use by navigation teams. These practices included tracking patients through

TABLE 2. Actionable Recommendations for Community Engagement and Healthcare System Change

Actionable Recommendations for Stakeholders	Domain			
	Screening	Diagnosis	Treatment	Survivorship
Actionable recommendations for community engagement across the four domains[a]				
• Identify a primary care physician for the patient if they do not have one[b]	✓	✓	✓	✓
• Identify community-based organizations and develop clear, accountable engagement of community leaders based on demographics and background of population in service area	✓	✓	✓[c]	✓
• Evaluate how specific populations look for trusted information regarding their health care and how the health center engages them on an ongoing basis	✓	✓	✓[c]	✓
• Develop ongoing relationships with community-based organizations: traditional and nontraditional community partners (eg, churches, beauty shops, barbers, and community centers)	✓	✓	✓	✓
• Establish connectivity between community leaders, patients, and primary care physicians to help manage expectations and create stronger linkages to support patients and families		✓	✓	✓
• Coordinate with patient advocacy groups and leverage their resources		✓	✓	✓
• Include community members on hospital boards, IRBs, advisory boards, and steering committees to guide engagement activities for clinical trial education and other areas needing trusted engagement with patients	✓	✓	✓	
• Create a patient support network of cancer survivors with similar demographics, backgrounds, diagnoses, and treatments			✓	✓
• Leverage telehealth processes and capabilities to facilitate coordination with patients and families[d]		✓	✓	
• Promote clarity in cancer screening guidelines to community leadership	✓			
• Develop virtual navigation models[d]			✓	
Actionable recommendations for healthcare system change across the four domains[e]				
• Develop clear transitions of care processes, with accountability and documentation of data requirements	✓	✓	✓	✓
• Develop realistic assessment of care system operational capacity and commitment before reaching out to community leaders to optimize coordination of resources among patients, patient advocacy leaders, navigators, and providers	✓	✓	✓	✓
• Document problems with or develop broad-based sustainable solutions for unconscious bias (staff training programs)	✓	✓	✓	✓
• Evaluate and adopt best practices from other fields, eg, hiring and recruiting a diverse workforce	✓	✓	✓	✓
• Promote accountability through conduct of an environmental scan or community health assessment to promote understanding and collaboration among community organizations	✓	✓	✓	✓
• Develop Health Equity Scorecard for health systems	✓	✓	✓	✓
• Identify and store centrally appropriate, health-literate, culturally sensitive, and linguistically appropriate resources or materials for use throughout the CCC		✓	✓	✓
• Train and educate staff on the use of and access to patient education resources and optimal timing for discussion		✓	✓	✓
• Develop and implement a Cancer Health Equity audit and scorecard in geographic locations with large medically underserved populations		✓	✓	
• Begin assessment of SDOH and other potential barriers prior to first appointment		✓		
• Implement strategies for delivering patient-centric clinical trials that facilitate inclusion of representative patients (including low SES populations)	✓	✓	✓	✓
• Implement multiple cancer research opportunities in the community	✓	✓	✓[a]	✓
• Develop a system-wide campaign to promote research participation	✓	✓	✓[a]	✓
• Build infrastructure to capture patient opt-in approaches, demographics, and findings	✓	✓	✓[a]	✓
• Set up IT infrastructure that yields a *trusted* communication channel (before, during, and after the research) for research staff, patients, families and care partners, and primary care providers	✓	✓	✓[a]	✓
• Replicate the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) model for pass-through access for all high-prevalence cancers[45]	✓	✓	✓	
• Open notes: allow patient or caregiver to log in and see provider notes	✓	✓	✓	✓
• Implement a survivorship care plan (professional and patient [plain-language] versions)			✓	✓
• Train primary care providers in survivorship			✓	✓
• Involve primary care providers in decision-making process with patient	✓	✓	✓	✓

Abbreviations: CCC, cancer care continuum; CDC, Centers for Disease Control and Prevention; IRB, institutional review board; IT, information technology; SDOH, social determinants of health; SES, socioeconomic status.

[a]Applicable to all populations.

[b]Ideally to occur early in the continuum of cancer care process.

[c]Including clinical trials.

[d]Especially applicable to rural or socially isolated populations.

[e]Specifically noninterventional and interventional research trials.

TABLE 3. Recommendations for Refinements to Policy Interventions and Priority Actions Across the Cancer Care Continuum

Recommendations for Refinements to Policy Interventions

National policy guidelines
- Conduct a needs assessment and then leverage the navigation guideline from CDC (or similar body) on a number of days to first treatment. Make it specific to health equity and measuring outcomes. The onus would then be on practices to meet and follow through on implementation of that guideline to level the care-delivery playing field
- Develop US Preventive Services Task Force guidelines that are group-specific based on the evidence[46]

Medicaid expansion, medicaid payment rate enhancement, prevention of limitations in medicaid that restrict access to next-generation sequencing, oral parity, tobacco control, and out-of-pocket spending caps
- Work to expand these efforts at state and federal levels. Many states are further ahead on these topics than others; those that are lagging have large underserved populations. This requires a concerted policy advocacy effort

CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
- Efforts are needed at state level to educate key stakeholders about the program and how best to access its resources. At the federal level, efforts are needed to maintain funding and support for the program, as well as to look for ways to expand its reach to other cancer types within the underserved populations

Patient navigation
- Federal legislative efforts are under way to expand support for patient navigation and identify opportunities to promote reimbursement for navigation services, including lay navigation services

Underserved population representation in patient-reported outcomes
- Work with sponsors and regulators to ensure that PRO tools and patient preference data are used to capture elements relevant to underserved and vulnerable populations[47]

Inclusion or exclusion criteria in clinical trials
- Work to include a focus on the impact of overly restrictive exclusion criteria on underserved and vulnerable populations (who often carry a disproportionate burden of comorbidities) in the ongoing activities, to expand access to clinical trials[34]
- Evaluate draft guidance with a health equity lens. Work with researchers and pharmaceutical companies on stratified enrollment strategies that allow assessment of treatment impact with and without comorbidities
- Work to reduce complexity of cancer therapies through clinical trials that test simplified regimens and to reduce the burden on vulnerable populations of numerous healthcare visits and treatments

Coverage of routine care costs in clinical trials
- Medicare and private insurance already do much of this. There is a need to advocate and expand this to Medicaid[48]

National requirement for certified medical interpreters
- Amplify need for consistent funding sources to implement the national requirement for Medicaid interpreters (Culturally and Linguistically Appropriate Services Standard[49] requirement and Joint Commission recommendation)

Improve high-prevalence cancer screening in underserved communities with quality data
- Evaluate and replicate successful state-level efforts

Medicare advantage resources
- Leverage opportunity to use these resources for certain needs (eg, food or transportation) to help underserved populations access the care they need. Advocate with payers and identify opportunities for policy action to allow this flexibility

Incorporate technology
- Evaluate and adapt relevant existing policies to maximize the use of new technologies that can help expand access to and improve care along the continuum for underserved and vulnerable populations

SDOH
- Work toward securing increased reimbursement rates (ICD-10 codes) for providers working with populations that have the greatest social need and/or comorbidities (as is the case for patients with high physical or disease comorbidities burden)

Oncology care model, bundled care payments
- Identify ways to use these models to expand access to care for underserved populations (eg, American Indian)

Priority Actions Across the Cancer Care Continuum

Community engagement
- Engage a broader group of nontraditional (nonhealth-related) stakeholders to bridge gaps in the care continuum (eg, private sector to provide services or resources via collaboration)
- Build advocacy coalitions with a broader set of partners focused on shared policy objectives, to create a more effective voice with decision makers
- Engage directly with patients of all socioeconomic backgrounds to ensure best understanding of their needs; incorporate findings into care continuum practices
- Leverage novel technologies and engagement platforms to improve care coordination and close gaps along the continuum
- Conduct demonstration programs to show success through community engagement

TABLE 3. Recommendations for Refinements to Policy Interventions and Priority Actions Across the Cancer Care Continuum (continued)

Priority Actions Across the Cancer Care Continuum

Patient navigation
- Standardize best practice approaches for lay navigation programs, where lay navigation is standard of care from diagnosis through the continuum
- Include patient navigation in cancer treatment guidelines, clinical trial protocols, CMMI initiatives, and clinical care teams
- Establish community-academic partnerships to support patient navigation
- Enhance or ensure reimbursement for patient navigators and emphasize cross-institutional navigation efforts
- Emphasize empowerment for patients or caregivers via navigation programs (lay or clinical)

Data collection
- Develop toolkits to collect SDOH data
- Work with payers to access claims data that highlight gaps in the continuum of care; use this evidence to support programs that will reduce the gaps
- Incentivize efforts to gather data from patients directly and to inform research and development of effective programs
- Conduct benchmarking projects to document what is already being done in these areas that can be shared and expanded into other avenues

Health equity
- Implement guidelines outlined in the health and human services action plan to reduce racial and ethnic health disparities[50]
- Build addressing SDOH impact into accreditation programs with teeth, to incentivize institutions to make progress
- Develop health equity scorecard for health systems
- Build capacity to conduct effective programs aimed at health equity and improve communications with the community (to build and maintain trust)

Generating funding support
- Incentivize multidisciplinary team approach to integrate clinical research or care teams
- Leverage grant funding mechanisms to incentivize and reward efforts that address gaps in the continuum of care for underserved and vulnerable populations
- Identify ways that federal funders can support clinical research programs that reach rural and isolated communities, including broadband access and telehealth

Education and training
- Focus on addressing bias through awareness and education
- Emphasize cultural sensitivity training for all members of the care and engagement teams
- Build health literacy across the continuum by developing user-friendly educational resources and tools

Clinical trials
- Evaluate and revise inclusion and exclusion criteria for clinical trials; the emphasis should be on expanding access to trials for underserved and vulnerable populations
- Educate and engage trusted partners (both community and providers) on the importance of clinical research and their role in the process

Abbreviations: CDC, Centers for Disease Control and Prevention; CMMI, Center for Medicare and Medicaid Innovation; ICD-10, International Statistical Classification of Diseases and Related Health Problems, Tenth Revision; PRO, patient-reported outcomes; SDOH, social determinants of health.

transitions of care, including second opinions and warm handoffs from one provider or service to the next (especially from surgery to medical oncology), use of data and information technology solutions to track metrics and effective navigation throughout the CCC, and screening for cancer-related distress and SDOH (even prior to the first appointment), with ongoing assessment along the CCC to adapt to changing needs.

Roundtable participants agreed upon actionable recommendations for community engagement, including identifying target populations and domains of focus (Table 2). Recommendations included identification and collaboration with trusted community organizations to disseminate health information and inclusion of community members on hospital boards and patient or family advocacy or advisory committees, to leverage community strengths and networks. Actionable recommendations for healthcare system change, with emphasis on specific domains of focus, were also debated and are summarized in Table 2. These include developing a realistic assessment of operational capacity or commitment *before* outreaching to target populations; ensuring

workforce diversity and cultural awareness training; identifying and sharing appropriate health-literate, culturally sensitive, and linguistically appropriate resources; developing clear transitions of care processes that include accountability and documentation; and developing health equity metrics as part of the institutional performance scorecard against which senior leaders are measured.

Recommendations for Refinements to Policy Interventions

The participants reviewed policy solutions known to be effective in improving cancer care for target populations and developed recommendations for further policy refinement (Table 3). The need for adequate insurance coverage and increased focus on SDOH in cancer care were identified as the two overarching themes and critical challenges. Specific recommendations included extending current health insurance and enhancement initiatives to state and federal levels, strategic support and reimbursement of navigation services as a cancer care essential benefit (including lay navigation), and securing higher reimbursement rates for clinicians caring for these populations.

Identification of Priority Actions Across the CCC

Participants were asked to identify priority actions for near-term implementation to help address disparities among target populations across the CCC (Table 3). These were segmented according to seven core themes: community engagement, patient navigation, data collection, health equity, generating funding support, education and training, and clinical trials. The priority actions included establishing community-academic partnerships to support patient navigation and implementation of guidelines outlined by HHS.

DISCUSSION

There is an urgent need to address disparities across the entire CCC, especially in an environment of increasing complexity with expanded healthcare teams and treatment options.[50-52] The complicated and interconnected nature of the CCC means that everyone in the cancer care community is jointly responsible for ensuring access to high-quality care across the entire continuum—not just within their own domain. If dipartites are not addressed, health inequity will be exacerbated, increasing the burdens for underserved and vulnerable populations.

The roundtable was convened to facilitate collaboration and sharing of best practices and to identify effective practices that address disparities along the CCC, which may not yet been documented in the medical literature. Convened experts identified community engagement, patient navigation, and healthcare system changes as key issues to address to deliver equitable cancer care and highlighted the importance of partnering with community organizations. They also emphasized the need for adequate insurance coverage and for SDOH-focused strategies to be at the heart of policy improvements (two key challenges exposed by COVID-19).

Our recommendations have potential limitations. Per results of the premeeting survey, we intentionally focused on CCC domains that involved components of the healthcare system; domains of prevention, risk reduction, and end-of-life care were not covered. The literature review, though comprehensive, was not exhaustive; in addition, successful local community approaches not documented or published would not have been captured. Another potential limitation is that experts were invited rather than self-nominated, which may mean that not all views and experiences were represented.

The COVID-19 pandemic and its disproportionate impact on communities of color and other vulnerable populations underscore the critical importance of addressing inequities in health care. The higher infection and death rates within racial and ethnic minority communities are attributable to SDOH and inequities in healthcare access and delivery.[53-55] The pandemic has exposed long-standing deficiencies in the US healthcare system and has exacerbated disparities in care for other health conditions such as cancer. The COVID-19 experience further underscores that health equity must be a national priority and has demonstrated how quickly healthcare systems can evolve and adopt alternative care models (eg, use of telehealth).[56,57] When motivated, either by will or economic and clinical imperatives, solutions can be developed and implemented rapidly. Yet, care must be taken to ensure equitable access to any innovative approaches developed so that disparities are not exacerbated, as is highlighted by the current digital divide that prevents everyone from having access to telehealth, for example.

In summary, this multistakeholder group of expert participants, guided by the domains of the IOM/NAS-established CCC, has developed a practical, sustainable CCC framework applicable to high-prevalence cancers in racial and ethnic minority and underserved communities. Framework development was informed by collaboration with US community leaders and other stakeholders who have implemented successful programs to improve cancer-related health outcomes for the communities they serve. We believe that this framework will have a meaningful and positive impact on reducing cancer care disparities. Furthermore, we want to inspire and encourage clinicians and researchers to document their practices, ensuring more robust and evidence-led initiatives (Appendix Fig A6, Fig A7, online only).

We have also developed recommendations for national policy changes needed to support the suggested healthcare system changes and to ensure long-term sustainability of a more equitable cancer care system. A common theme across policy change recommendations is to leverage existing best practices that have guided key initiatives (eg, Medicaid expansion[58]) to different policy areas. In lieu of reinventing the wheel, building upon existing, effective practices, and adapting these to address inequities along the CCC will help reduce cancer disparities for underserved populations.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Development of an Actionable Framework to Address Cancer Care Disparities in Medically Underserved Populations in the United States: Expert Roundtable Recommendations

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

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APPENDIX

TABLE A1. Primary Roles and Stakeholder Group Affiliations of Roundtable Expert Participants

Primary Role and Stakeholder Group	Roundtable Expert Participants (N = 33)
1. Diversity and inclusion clinical research leaders in cancer	4
2. Diversity and inclusion population health leaders in cancer	6
3. Patient organization leaders for high-prevalence cancers in racial and ethnic minorities and underserved populations	5
4. Experts in community outreach in cancer (programs or research)	6
5. Patient navigation experts in cancer centers	1
6. Experts who conduct research in social determinants of health	3
7. Experts with focus on vulnerable cancer populations	7
8. Leaders in diversity and inclusion in government focused on cancer	1
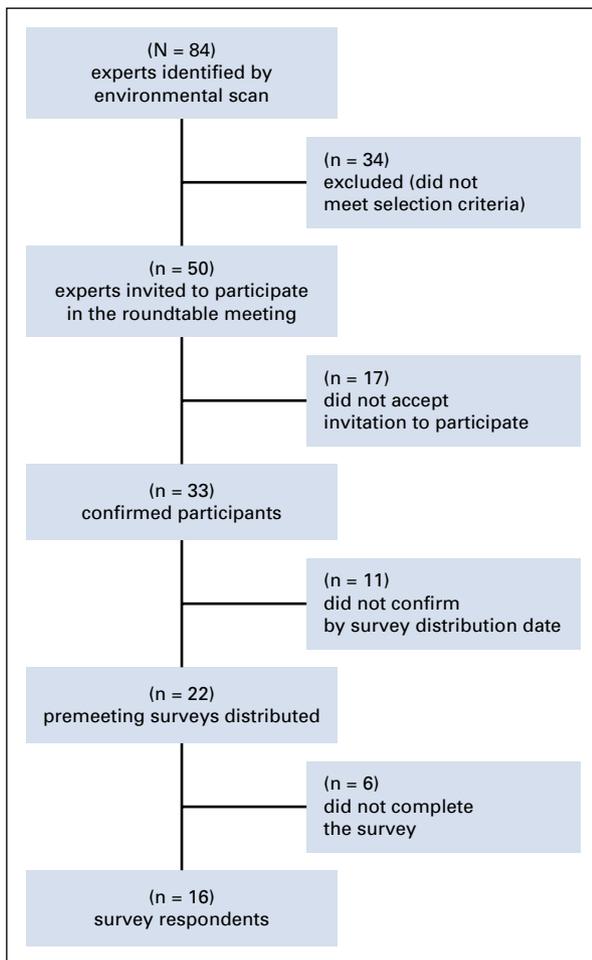
FIG A1. Flow diagram of experts invited to the roundtable meeting.
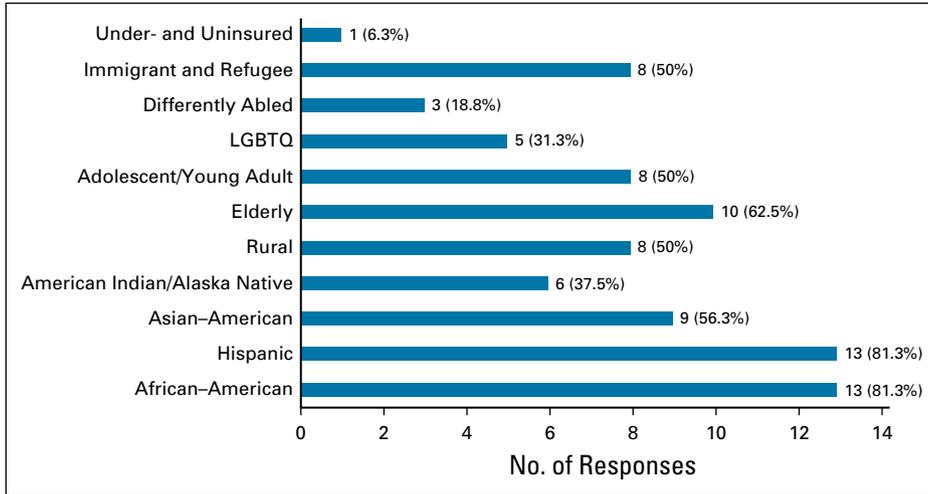
FIG A2. Experience of survey respondents in one or more of the CCC domains across target populations (based on 16 responses). CCC, cancer care continuum; LGBTQ, lesbian, gay, bisexual, transgender, and questioning.
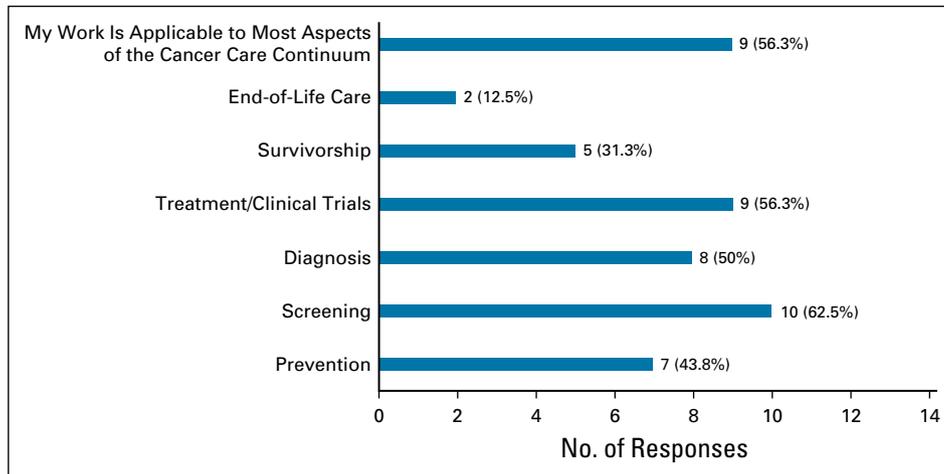
FIG A3. Domain of the CCC that was the primary focus of survey respondents (based on 16 responses). CCC, cancer care continuum.
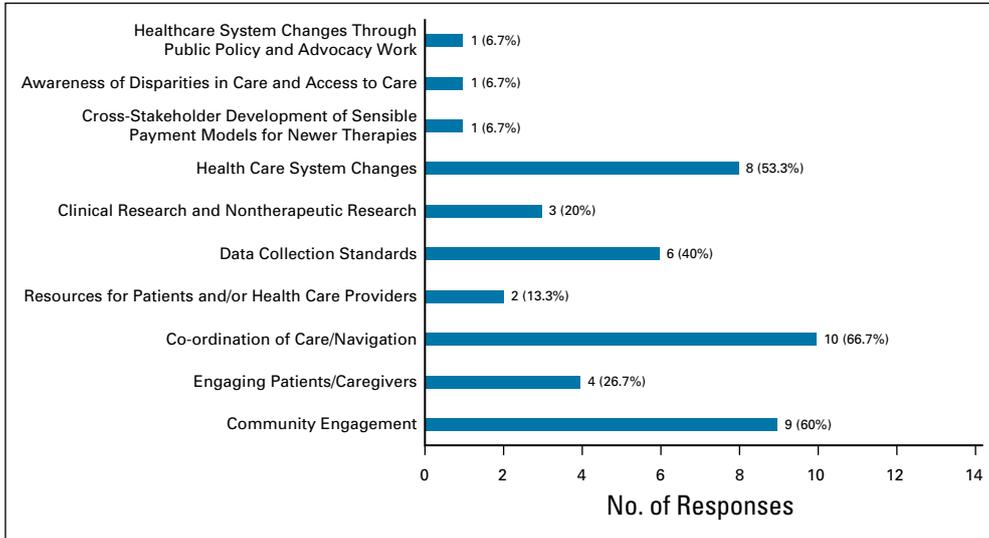
FIG A4. Areas of focus with the potential to have the greatest impact on cancer patient outcomes in target populations as a result of the expert roundtable meeting (based on 15 responses).
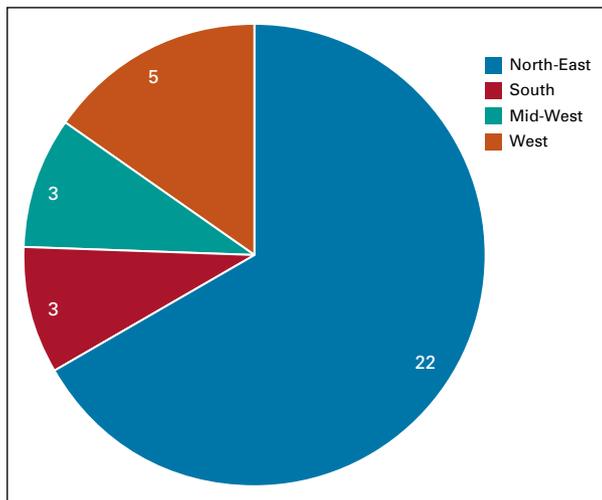
FIG A5. Geographic distribution of roundtable participants (N = 33).

FIG A6. Summary of the approach used to develop an actionable framework to address cancer care disparities in medically underserved populations in the United States.

Development of an Actionable Framework to Address Cancer Care Disparities in Medically Underserved Populations in the United States: Expert Roundtable Recommendations

Key Findings: High Impact Practices

Screening → Diagnosis (DX) → Treatment (TX) → Survivorship

Community Engagement
Patient Navigation
Data Collection
Health Equity
Funding Support
Education and Training
Clinical Trials

Community Engagement
• Engage non-traditional stakeholders • Build advocacy coalitions • Engage patients through trusted community partners • Leverage Technology and engagement platforms

Patient Navigation (PN)
• Standardize best practices for lay navigation (focus on DX through Survivorship) • Include PN in cancer TX guidelines, clinical trial protocols, CMMI and clinical care teams • Establish community-academic partnerships to support PN • Enhance/Ensure reimbursement; emphasize and coordinate PN efforts across institutions

Data Collection
• Develop toolkits to collect SDOH data • Collect sexual orientation/gender identity (SOGI) data • Work with payors to access claims data that highlight gaps in the CCC • Gather data directly from patients to inform programs • Conduct benchmarket projects; share and expand

Health Equity
• Implement the HHS action plan to reduce racial and ethnic health disparities • Build addressing SDOH impact into accreditation programs with teeth • Develop health equity scorecard for health systems • Build capacity for trusted community engagement

Funding Support
• Incentive multi disciplinary team approach • Leverage grant mechanisms that address gaps in the CCC • Accelerate federal funding to support clinical research that reach rural communities

Education and Training
• Address unconscious bias through awareness and education • Cultural sensitivity training for all stakeholders • Build health literacy across the CCC by developing a user-friendly library

Clinical Trials
• Evaluate and revise inclusion and exclusion criteria • Set and implement guidelines for reimbursement of patient out-of-pocket expenses • Educate trusted community partners and providers on the importance of clinical research and their role

Priority Actions Between CCC Domains

Screening to Diagnosis
• Add patient navigators to identify, and address barriers
• Assess SDOH before first appt with provider
• Focus on information that a patient needs that day
• Ensure that patients have access to a portal and know what to do next
• Provide cancer screening services, use mobile units to reach communities
• Ensure systems are built within EMRs to enable active follow up (by PN) of abnormal screening results
• Systematically implement shared decision making

Diagnosis to Treatment
• Develop PN practices across institutions that ensure "warm hand offs"
• Critical: Same trusted PN is needed from screening through treatment
• Track patients through second opinion to ensure follow up
• Metric tracking of days from DX to TX must trigger active outreach
• Focus on measurements with data/IT systems ; entire care team needs to understand their roles
• Provide patients with oncology urgent care services for common treatment related symptoms
• Develop and share best practices for patient navigation and community engagement and keep up to date on national and local support programs to address SDOH

Treatment to Survivorship
• Establish an advisory council with patients and community leaders to address local barriers and resource needs
• Develop community outreach programs with a focus on Survivorship
• Build and expand on partnerships with community leaders and Community Health Workers to provide training resources

Note: The infographic highlights key findings only; for complete findings including policy recommendations, please see full publication and appendix.

FIG A7. Summary of expert informed key findings and priority actions across and between the cancer continuum of care for medically underserved populations in the United States.