Evolution of community outreach and engagement at National Cancer Institute-Designated Cancer Centers, an evolving journey

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Abstract
Cancer mortality rates have declined during the last 28 years, but that process is not equitably shared. Disparities in cancer outcomes by race, ethnicity, socioeconomic status, sexual orientation and gender identity, and geographic location persist across the cancer care continuum. Consequently, community outreach and engagement (COE) efforts within National Cancer Institute-Designated Cancer Center (NCI-DCC) catchment areas have intensified during the last 10 years as has the emphasis on COE and catchment areas in NCI’s Cancer Center Support Grant applications. This review article attempts to provide a historic perspective of COE within NCI-DCCs. Improving COE has long been an important initiative for the NCI, but it was not until 2012 and 2016 that NCI-DCCs were required to define their catchment areas rigorously and to provide specific descriptions of COE interventions, respectively. NCI-DCCs had previously lacked adequate focus on the inclusion of historically marginalized patients in cancer innovation efforts. Integrating COE efforts throughout the research and operational aspects of the cancer centers, at both the patient and community levels, will expand the footprint of COE efforts within NCI-DCCs. Achieving this change requires sustained commitment by the centers to adjust their activities and improve access and outcomes for historically marginalized communities.

KEYWORDS
access to care, community outreach, health equity, health disparities, National Cancer Institute, patient engagement

INTRODUCTION
Cancer mortality rates have been declining over the last 28 years, however, disparities in cancer care outcomes persist in many historically marginalized communities. We are defining minoritized/marginalized communities as communities disadvantaged by race, ethnicity, lower socioeconomic status, sexual orientation and gender identity (SOGI), and geographic location. Barriers are prevalent at each stage of the cancer care continuum. The impact of disparities in cancer among historically marginalized groups in the United States

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has been well described for decades in multiple reviews and published studies.\(^6\)\(^-\)\(^9\) Unfortunately, most issues described in the 2003 Institute of Medicine (IOM) report *Unequal Treatment* are extant today.\(^3\)

Our health care delivery system is beset with infrastructural barriers that complicate care delivery.\(^3\)\(^-\)\(^9\) These have the greatest impact on our historically marginalized communities.\(^1\)\(^-\)\(^3\)\(^-\)\(^5\)\(^-\)\(^11\) *Unequal Treatment* describes the disparity in cancer care and outcomes felt by these communities. It reports that women of African American and Hispanic backgrounds are both more likely to begin breast cancer treatment at a later stage and less likely to live as long as White women.\(^3\)\(^12\)\(^-\)\(^13\) In addition, a study by Cornell Medicine found that multiple social determinants of health (SDOHs; i.e., geographic poverty and low household income) correlate with a higher risk of cancer mortality.\(^5\) Although that study did not categorize race as a SDOH, it did indicate that individuals from Black communities were more likely to have more than one SDOH compared with White individuals and thus might carry higher risks of cancer mortality.\(^6\)

Oncology treatment centers with a National Cancer Institute (NCI) designation play a pivotal role in how cancer care is delivered in their respective communities.\(^14\) NCI-Designated Cancer Centers (NCI-DCCs) diagnose about 250,000 patients with cancer annually and also provide cancer treatment to an even greater patient volume each year.\(^15\)\(^-\)\(^16\) Clearly, the appropriate focus on cancer diagnosis and treatment must be complemented by novel approaches that serve these disadvantaged communities.

Community outreach and engagement (COE) is an approach used to engage patients at all stages of the cancer control continuum, including etiology, cancer prevention, early cancer detection, diagnosis, treatment, survivorship, and the end of life.\(^15\) COE is now a necessary part of the NCI-DCCs’ scientific missions. NCI-DCCs have a responsibility to work alongside stakeholders in the community to identify the needs of the community, to catalyze those needs across the cancer center’s research programs and leadership (i.e., in-reach), and to catalyze activities of special importance to the geographic catchment area (CA) population, as defined by the cancer center (outreach).\(^16\)

NCI guidelines and programs related to COE have evolved over the years (Figure 1),\(^17\)\(^-\)\(^34\) as have the approaches taken by NCI-DCCs. In this review, we address the historical background and evolution of NCI-DCCs’ roles in their COE efforts and documents NCI-DCCs’ gradually increasing emphasis on interventional research and COE efforts in historically marginalized communities. We survey the successes, gaps, challenges, and impact of COE activities within NCI-DCCs and offer recommendations on where we believe NCI-DCCs should be heading in their COE work.

**THE EVOLUTION OF COE AT NCI-DESIGNATED CANCER CENTERS**

COE efforts have been integral to the NCI’s goals since its inception.\(^16\) The nomenclature and approaches of COE have evolved over time. When the National Cancer Act of 1971 was signed, early outreach initiatives were embedded in the NCI’s Population

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**FIGURE 1** Evolution of National Cancer Institute (NCI) community outreach and engagement (COE) initiatives and milestones timeline. The timeline illustrates the NCI’s progressive development of COE, detailing program names, objectives, and outcomes, with a focus on milestones. Colors convey specific program outcomes and milestones. The timeline provides a snapshot of the NCI’s commitment to engaging communities in the fight against cancer.
Science/Cancer Prevention and Control Research Programs. During that time, NCI research funding priorities fostered prevention efforts in addition to the focus on biomedical research and treatment. More recently, there has been an increasing focus on how best to engage neighboring communities to reduce cancer disparities. The Cancer Center Support Grant (CCSG) is a 5-year to 7-year, competitive, renewable grant that provides funding for: cancer research programs, shared resources, scientific and administrative management, planning and evaluation activities, development of new scientific opportunities, community outreach and engagement, coordination of cancer training and education, and centralized clinical trial oversight and functions at NCI-DCCs. Intensive reviews, including site visits with internal and external advisory boards, determine NCI designation status and CCSG renewal. The NCI has intensified its focus on the important role NCI-DCCs play in their respective communities and has broadened the requirements of the CCSG to include detailed plans for COE. These new requirements were intended to incentivize NCI-DCCs to better serve the needs of their surrounding communities, particularly among underrepresented and minority communities.

In the sections below, we review the evolution of the NCI-DCCs' COE efforts.

1970s–1990s

Community benefits versus COE

In 1969, before the inception of the National Cancer Act of 1971, hospitals with nonprofit status were required to undertake activities that would benefit the communities they were serving. At that time, hospitals were required to invest in spending that, along with charity care, would serve to promote community health. The resulting Community Benefits offices complement and differ from COE efforts within NCI-DCCs. The establishment of a Community Benefits office in a nonprofit hospital is a requirement by law, whereas COE efforts are required only when a cancer center is awarded status as an NCI-DCC.

Patient and Family Advisory Councils

Patients' engagement with health care institutions historically arose from individual cancer experiences, whether it was their own or that of a family member. Evolving from the formation of a Parent Advisory Council in the early 1980s, Patient and Family Advisory Councils (PFACs) gained popularity among hospitals, including some NCI-DCCs. PFACs are typically made up of patients, patients' families, and health professionals at respective hospitals/health centers. They allow for a space where patients and their families can voice their opinions and give their perspective on hospital program development. In concept, the existence of PFACs is a good example of bidirectionality—engaging patients and their communities in hospital projects that ultimately affect the patients themselves. PFACs enable hospitals to learn about areas of strengths and weakness that they may not have recognized otherwise. The Dana-Farber Cancer Institute, an NCI-DCC, was the first adopter of the PFAC program in 1998. before the 2010 Massachusetts mandate that all hospitals have PFACs. In the same year, the Karmanos Cancer Center formed their PFAC. Other NCI-DCCs, such as the Memorial Sloan Kettering Cancer Center, followed suit during the next few decades.

Community outreach and engagement

Early COE initiatives mainly focused on bringing cancer treatment and clinical trials to the community, followed by education and early cancer risk awareness. For example, the NCI funded an initiative called the Community Clinical Oncology Program (CCOP) in 1983. This program aimed to increase community-based physicians' familiarity with clinical trials in the hope that patients within these respective communities would have improved access and that this would enhance the quality of community-based cancer care. In the 10 years after the CCOP was launched, 59 CCOPs were funded across 17 NCI-DCC hubs. The implementation and execution of CCOPs did expedite clinical trial accrual and, although difficult to measure, likely improved the uptake of cancer-related information and the quality of cancer care among physicians and community members. Later on, the NCI implemented the National Black Leadership Initiative on Cancer in 1989 with the goal of educating Black communities regarding their risk of cancer.

Community awareness and education

In the mid-1980s, research on cancer started to focus on the higher incidence and mortality rates in African Americans compared with their White counterparts. Although disparities in treatment based on race and class were previously identified, interest in health outcomes in cancer was just starting to evolve as a discipline. Early studies demonstrated that minority groups had higher rates of cancer than nonminoritized communities. In response, the National Hispanic Leadership Initiative on Cancer and the Appalachian Leadership Initiative on Cancer were formed in 1992 and became early actors in the COE space. During that time, a study by the Comprehensive Cancer Center of Wake Forest University identified research recruitment methods that resonated with African American communities with the goal of increasing inclusion of this population in research. The research showed that study recruitment among African American communities can be successful if efforts are developed specifically for the population's unique needs and its members are included in both conversations and research. Later studies also addressed the potential positive impact of diversifying the workforce on adherence.
The National Black Leadership Initiative on Cancer, the National Hispanic Leadership Initiative on Cancer, and Appalachian Leadership Initiative on Cancer concluded in 1999\textsuperscript{56} when there was a shift from solely focusing on cancer prevention/awareness as the main mechanism for educating minority populations about their cancer risk\textsuperscript{56} to a more comprehensive approach involving education, pipeline programs, access, and involvement with research activities.\textsuperscript{56,58} Examples include a program—the Special Populations Network for Cancer Awareness and Research Training Program.\textsuperscript{17,56} It was designed to create opportunities for minority researchers to be trained and mentored, community members to become lay health workers, and minoritized community members to partake in research.

2000–2011

Outreach and education

In 2000,\textsuperscript{17,56} the NCI’s Center to Reduce Cancer Health Disparities (CRCHD) provided funding for a 5-year program, the Increasing Access to Clinical and Educational Studies Project, at the Thomas Jefferson University, Kimmel Cancer Center in Philadelphia, one of the 18 Special Populations Network for Cancer Awareness and Research Training sites.\textsuperscript{65} The Increasing Access to Clinical and Educational Studies Project, one example of a CRCHD programs during this period that focused on underrepresented minorities in medicine and/or COE,\textsuperscript{64–73} aimed to mitigate cancer health disparities among Black communities in Philadelphia through the incorporation of education and community engagement.\textsuperscript{65} The process brought community members into conversations about their health care experiences with the goal of empowering patients to make informed decisions regarding engaging in cancer research.\textsuperscript{65} The program trained four African American Special Populations Investigators to deploy culturally appropriate research studies, resulting in three funded pilot studies.\textsuperscript{65,74} One of the funded studies, \textit{Preparing African American Women for Breast Biopsy}, with 23 African American women participants, showed perceptions that educational counseling sessions were informative (89%), useful (85%), and relevant (84%)\textsuperscript{75} and that an informational booklet was informative (86%), helpful (95%), and readable (90%).\textsuperscript{75} In that study, 95% of the women expressed interest in participating in future clinical research, demonstrating their willingness to take part.\textsuperscript{65,75}

Health services research and the community benefits reporting mandate

The early 2000s was a period of growth in health services research in NCI-DCCs focusing on differences in care and receipt of care.\textsuperscript{60} Although cancer prevention was still an issue, health services research was gaining traction in population sciences.\textsuperscript{60} Starting in 2008, in addition to abiding by the standard of community benefit, as mentioned above, hospitals with nonprofit status were required to provide written proof of community benefit activities to the Internal Revenue Service.\textsuperscript{45}

2012–2019

CCSG updated requirements and NCI-DCC program examples

The NCI began updating the requirements of the CCSG in 2012.\textsuperscript{26,45} The 2012 updated release required NCI-DCCs to collaborate with other NCI-funded programs, report on cancer research in the communities they serve, and define the areas they serve based on geography.\textsuperscript{26,27} The CCSG application began requiring NCI-DCCs to better describe their specific CAs: the NCI-DCC’s self-defined geographic area it serves or will serve through the research it conducts, the communities it engages, and the outreach it performs.\textsuperscript{76} Each NCI-DCC was mandated to define their geographic cancer care service area and to report on research addressing inequities among the communities in it.\textsuperscript{76,27} Some NCI-DCCs proactively created implementation strategies to incorporate community input into their programs. For example, North Carolina’s Levine Cancer Institute, which merged in 2023 with Wake Forest Comprehensive Cancer Center to form Atrium Health Levine Cancer Center,\textsuperscript{77} directly involved community members by tasking their cancer development specialists to communicate with them about their services and engage them in meaningful decision making through the hospital’s PFAC.\textsuperscript{78,79} The University of Hawaii Cancer Center sought perspectives from community advisory groups for their research efforts with the goal of incorporating their cultural values.\textsuperscript{78} Although not an NCI-DCC, the University of Illinois Cancer Center (UICC) used a different approach called \textit{benchmark to community}\textsuperscript{79} to bridge the gap between science and community by creating a voluntary group of community members and advocates to inform leadership about their priorities.\textsuperscript{78,80} These priorities served as proactive identifiers to study the connection between social barriers and colon cancer disparities.\textsuperscript{78,80} Because of this work, the National Institute of Minority Health Disparities awarded funds to develop the \textit{Center for Health Equity Research} to enhance the impact of community knowledge on research.\textsuperscript{80} Concurrently, the UICC used evidence-based patient navigation to address screening barriers, provide education on various cancer types, and integrate services across 13 Federally Qualified Health Center (FQHC) clinics and safety-net hospitals.\textsuperscript{78,80} The UICC received a $1.5 million grant in 2019 to reduce cancer disparities across its five-county CA, focusing on colorectal cancer (CRC) prevention and screening in South Shore and Englewood.\textsuperscript{80–82} Two colorectal programs, UI CANN Colorectal and Mi-CARE, distributed 299 fecal immunochemical tests, with a return rate of 71.6%.\textsuperscript{83} Outcome data are available for the Mi-CARE program, a prospective, cross-sectional quasi-experimental study. Within the study population of 254 African American or Latino American patients, 30% of the 84 participants who received lay navigation completed CRC screening, outperforming the two other intervention
arms—mailed birthday reminders and provider-delivered education. The program also demonstrated an increased rate of CRC screening, from 13% preintervention to 20%, and increased screening rates in neighborhoods with lower screening rates than the national average. These outcomes highlight the effectiveness of community-driven interventions in reducing cancer disparities.

Updated CCSG applications were reissued in 2016 and 2019, requiring NCI-DCCs to include more thorough descriptions of COE activities. Specifically, the space allotted for the required description of COE activities, which grew from just a few paragraphs to 12 pages. This allowed for a more academic approach to what had been anecdotal examples of community engagement.

In April 2019, a listening session that included many NCI-DCCs focused on the increasing emphasis of addressing health outcome inequities in the United States and sharing best practices. Examples of activities that NCI-DCCs have used to address inequities through COE discussed at the forum include using zip code to identify potential risk factors in populations, incorporating community opinions earlier in research project development, and creating true bidirectional relationships with neighboring communities.

Of the many resulting proposed, implemented interventions, only a few to date have published mature data. The University of New Mexico School of Medicine initiated a project called Extension of Community Healthcare Outcomes (Project ECHO) in 2003, leveraging telementoring to support physicians caring for patients living with hepatitis C in prisons and low-resourced rural communities. Based on the success of that program, Project ECHO expanded to other illnesses, including cancer in 2012. NCI-DCCs are among the 896 hubs that have implemented Project ECHO worldwide. The University of Texas MD Anderson Cancer Center used Project ECHO methodology for eight projects globally, five of which were United States-based. One of the projects began in 2014 and aimed to increase the uptake of human papillomavirus (HPV) vaccines in the rural communities at the Texas–Mexico border by increasing primary care capacity via ECHO telementoring strategies, educating the community, and patient navigation. During the 4 years of the program, it was reported that there were 101 ECHO telementoring sessions held with, on average, 22 participants in attendance at each session. The Cancer Institute of New Jersey conducted 3377 outreach events, provided 817 practitioner educational sessions, delivered tobacco counseling to 21,500 individuals, and facilitated or directed greater than 60,000 people to cancer screenings which identified more than 2000 cancers or pre-malignant lesions. Population-level improvements included an increase in lung cancer screening rates from 4% to 15%, a decrease in smoking prevalence from 14% to 10.8%, and an increase in HPV vaccinations among adolescents aged 13–17 years from 48.5% to 54.8%. Rates of CRC screening increased from 67.6% in 2018 to 71.9% in 2020, with decreases in racial and ethnic disparities. The Chao Family Comprehensive Cancer Center at the University of California Irvine uses patient navigators with appropriate cultural awareness to help improve screening rates among Asian American and Latino community members with Medicare insurance. As is common with this type of program building work, unfortunately, there were no downstream outcomes published.

Access to diagnostic cancer care was addressed by the Dana-Farber Cancer Institute through partnership with FQHCs as a way to broaden access to care among historically marginalized communities using a co-location model involving patient navigation. Recent findings of this program highlight efficient treatment plans with a shorter median time to diagnostic resolution and indicate the potential of integrating cancer services in community-based settings to address disparities.

Implementation science

The field of implementation science has been envisioned as a way to implement programs to mitigate racial, ethnic, and socioeconomic status disparities. It is the scientific field that closes the gap between research and implementing outcomes into practice, with the goal of improving both individual and population-based health outcomes by deploying evidence-based interventions. Implementation science must cope with the structural barriers present in our health care system and the very byzantine nature of care delivery in the United States. This will require both honest discussions of how these barriers disadvantage the underserved and conscious, proactive mitigation. Although implementation science approaches will continue to be a part of interventions, it is only through an authentic discussion of the limitations of the science that we will create useful frameworks, methods, and strategies for evidence-based interventions.

2020 to present day

COE activities at NCI-DCCs

Since 2019, NCI-DCCs have been mandated to incorporate COE throughout all of its programs in addition to basic, clinical, translational, and population research. The centers are required to show how they work with community partners to learn the greatest needs of their CAs, share them with the NCI-DCC leadership, and create activities
applicable to their CAs. A bidirectional relationship between the NCI-DCCs and the community is the goal. The work is to be highlighted through the CCSSG application process. For example, the Abramson Cancer Center’s 5-year COE program uses multilevel strategies combining navigation and informatics to create culturally tailored marketing strategies in addition to collaborating with faith-based organizations that serve Black communities, with the goal of increasing enrollment of Black patients into cancer clinical trials. The program achieved increased clinical trial enrollment among Black patients. Black participation in treatment trials increased from 12.2% to 23.9% over the 5 years. When done well, this approach yields impressive results, such as the aforementioned increased clinical trial enrollment and increased uptake of HPV vaccines.

Inequities in rural communities

Low-income communities, disabled communities, and patients living in more rural areas are also affected by disparities. Many rural patients of all different races, education levels, and income levels experienced limited access to cancer care. Disparities remain between rural and urban populations, and national declines in cancer incidence and mortality are not shared by rural communities. This speaks to the intersectionality and additive nature of the structural barriers to cancer care and treatment. Some programs found success in creating access to care in rural communities by forming relationships with community members and providers, creating opportunities for participation in clinical trials. The Ohio State University Comprehensive Cancer Center CA includes all of Ohio. Rural areas are home to about one third of the state’s patients with cancer. This center formed the Center for Cancer Health Equity, comprised of clinicians, lay health workers, and community members, to enhance cancer education and awareness in their communities and create health programs that prioritized the community’s needs. These efforts increased rural resident participation in clinical trials and enhanced diagnostic follow-up and screening.

Efforts to diversify NCI-DCC workforces and patient populations

With a nationally heightened focus on racial inequity beginning in 2020 after the murder of George Floyd, there was greater pressure for the NCI-DCCs to intensify their efforts to increase diversity in their workforce. This process was necessary to better match their CA patient population and to demonstrate durable, bidirectional, and effective efforts that improve access and outcomes in the vulnerable communities often adjacent to the centers themselves. While some NCI-DCCs were taking on this issue, many struggled with the shift from more descriptive research on disparities, to the much more challenging need to improve the health of those who, although historically excluded, have the highest disease effect. This conversation is only now moving to the forefront of discussions and goals at NCI-DCCs. Beyond the COE work, the NCI-DCCs are often a source of biomedical training across many disciplines. It is recognized that there is a responsibility both to improve representation of the community acutely and to expand the pipeline for health professionals. In October 2020, a call for more diversity at the leadership level of high-resourced NCI-DCCs emerged from a survey conducted by The Cancer Letter and the Association of American Cancer Institutes. The survey identified that, of the 61 NCI-DCCs that responded to the survey, less than 16% of NCI-DCC directors identified as non-White race. Compared with cancer centers without an NCI designation, this was 15% less racially and ethnically diverse. Urgency to act upon inequities within the NCI-DCCs’ leadership structure itself did not gain momentum until after the Association of American Cancer Institutes’ survey conducted by Caryn Lerman was published in 2021.

Like many other institutions and organizations in the United States, NCI-DCCs needed to expand their focus on building diversity, equity, and inclusion (DEI) into their programs. Based on the use of the DEI terminology in publications and articles written by and about NCI-DCCs, we define diversity as pertaining to NCI-DCC workforces, equity in reference to NCI-DCC patients and CA communities, and inclusion in relation to both workforce and patient communities. Since 2021, NCI-DCCs are required to create a Plan to Enhance Diversity in their respective workforces, with the goal of reflecting the CAs that the NCI-DCCs serve. Many NCI-DCCs have attempted to diversify their leadership beyond establishing DEI offices. Recognizing the importance of a diverse workforce, leaders in this space recommend diversifying NCI-DCC membership, creating an equitable hiring process to encourage diverse applicants, and ensuring that DEI offices aid employee-rentention efforts. Programs like the Fred Hutchinson Cancer Center named their first Associate Director of Diversity, Equity, and Inclusion in 2021 to help incorporate and advance DEI efforts within the NCI-DCC and through research. The Sidney Kimmel Cancer Center named an Enterprise Vice President of Cancer Disparities. In addition to the updated CCSSG requirements, the NCI established the NCI Equity and Inclusion Program in 2021 to focus on activities that will strengthen cancer disparities research and diversify workforce members in the cancer research space. Some NCI-DCCs were ahead of the curve when including leaders in terms of efforts to diversify leadership. For example, the O’Neal Cancer Center created its office for COE in 1995 and elevated the role with the creation of its first Associate Director of Outreach and Engagement at the cancer center appointed in 2018. Members from the NCI-DCCs who participated in the listening session regarding COE expressed that having leadership dedicated to COE was pivotal to being part of successful efforts.

DEI efforts are reflected in the National Clinical Trials Network (NCTN). The NCTN is defined as a collection of organizations and clinicians that coordinate and support cancer clinical trials in the United States and Canada. One group in the NCTN, the Southwest
Oncology Group, named its first Vice Chair of Diversity, Equity, Inclusion, and Professional Integrity in 2022.\textsuperscript{125} NRG Oncology chartered a DEI Committee in 2022,\textsuperscript{126} and the Alliance for Clinical Trials in Oncology assembled the Alliance Health Disparities Committee even before 2020.\textsuperscript{127} Although these efforts are a good first step, continued support of and long-term commitment to the work are needed to change the current dynamics.

**Community advisory boards**

In 2021, the NCI further updated the CCSG. The main adjustment to this CCSG was the clarification of guidelines on defining cancer center CAs.\textsuperscript{34} Explicit themes that emerged from this updated grant included greater emphasis on sustainable, bidirectional relationships between the NCI-DCCs and their CAs, collaboration within the NCI-DCCs, and the installation of Community Advisory Boards (CABs).\textsuperscript{34,44} CABs allow space for stakeholders, such as local politicians, community organizers, cancer survivors, and community-based organizations and leaders, to have a voice in NCI-DCC activity decision making.\textsuperscript{44} In theory, this creates the opportunity for bidirectional communication between the NCI-DCCs and their CAs. The goal of most CABs is to have a mechanism to understand the community’s needs, challenges, and priorities and provide input to research and clinical projects.\textsuperscript{44} Two recent internal surveys administered by the Dana-Farber/Harvard Cancer Center to better understand the extent of NCI-DCC COE activities revealed that a high percentage of NCI-DCCs had a CAB.\textsuperscript{129,130}

COE efforts at NCI-DCCs have evolved significantly since the signing of the National Cancer Act of 1971, with exponential development over the last decade. Even with the changes in the system and understanding of the process, meaningful improvement is a challenge. There is a way forward, but it requires will and patience, and both can be challenging to come by.

**DISCUSSION**

Improved preventive and diagnostic approaches, new therapeutic modalities, and the more precise use of cancer therapeutics are allowing patients to live longer and better with their cancers.\textsuperscript{131} This work did not simply spring into existence fully formed, but was built on the back of previous painstaking research.\textsuperscript{132} Often, the groundbreaking basic research that changes cancer care is not recognized at the time. The rigorous and painstakingly slow scientific process that leads to clinical impact is supported largely by the National Institutes of Health/NCI. Much of this research work started at the NCI-DCCs. Most scientists and clinicians would point to recent improvements in outcomes evidence for the continued need for durable investments in prevention, screening, and therapeutics.

Until recently, NCI-DCCs have not matched their scientific focus with an intense focus on the inclusion of historically marginalized patients in research trials, access to treatment advances, and development of innovative care-delivery interventions to improve access in marginalized communities.\textsuperscript{133} The newer emphasis on COE must be expanded to embrace the unaddressed communities whose data are yet to be collected nationally, including sexual and gender minorities (SGMs), veterans, and people with disabilities (PwDs).\textsuperscript{134–143} The SGM community represents 7.2% of the US population and faces disparities in cancer care, with limited data available on their experiences and health outcomes.\textsuperscript{134,135} The absence of SOGI data in major clinical databases limits research and inclusive care recommendations.\textsuperscript{136} SOGI data should be collected and reported as mandated by the US Bureau of Primary Health Care, the Health Resources, and Services Administration.\textsuperscript{144} Similarly, veterans, who represent 7% of the adult population, face a lack of systematically included cancer data in state and national registries, compromising the accuracy and completeness of the national cancer burden estimates.\textsuperscript{137–139} Legislative efforts aimed to rectify this. These include the Veterans’ Cancer Act of 2023, which would require Veterans Health Administration facilities to share cancer data with the state cancer registries, and the historic partnership between the Department of Veterans Affairs and the NCI to share cancer registry information.\textsuperscript{140,141} PwDs, a marginalized and rapidly growing population, experience cancer health disparities because of inadequate training of medical professionals, inaccessible facilities, and limited health care policies.\textsuperscript{142} There is little published information on understanding and reducing PwD disparities.\textsuperscript{142} Treatment decisions are restrained by insufficient scientific evidence because clinical trials typically exclude them, and health care service data provide limited information about their specific needs.\textsuperscript{143} It would be valuable for all NCI-DCCs to implement a comprehensive SOGI inclusivity program by building a supportive environment for SGM employees, involving community advisers, systematically collecting SOGI data, and providing cultural humility training to staff to foster inclusivity.\textsuperscript{145}

Until 2020, many NCI-DCC directors and policy makers had not demonstrated sustainable, bidirectional relationships within their CAs,\textsuperscript{133} although each NCI-DCC has a Community Benefits office that regularly conducts community needs assessments.\textsuperscript{45} Among many reasons for this is the reality that much of the infrastructure of NCI-DCCs is focused on the investigation and development of new therapeutics. The process to do this is complicated, slow, and resource-intensive. Those who fund these endeavors, including government, private, and corporate philanthropy, are drawn to things that will cure cancer. It is hard to compete against that with an intervention targeted to a community health center. However, this is a false competition. It is not an either or situation, but should be a yes, and... situation.

Changes in the CCSG grant mandates have incentivized the NCI-DCCs to describe their COE work in more detail and to move beyond the traditional nice-to-have approach that was regarded as sufficient. This change depended on a dedicated group of people focused on the mission of improving outcomes for those who have little voice. Prevention and health services research tended to ride in the metaphorical back seat of the drive to defeat cancer, with community engagement and the health equity work to broaden access...
somewhere in the trunk. There has been only moderate focus on broadening access pathways for marginalized communities outside of the small group of clinicians, social and behavioral scientists, public health experts, epidemiologists, and patient advocates. Their voices need to be heard more clearly.

Engagement at the patient/community level

Patient engagement in health care is meant to be a synergistic process between patients, providers, and institutions, with the shared goal of identifying key variables that affect patient care and improve patient experiences and outcomes.\(^{146}\) Engagement requires partnership and agreement within the NCI-DCCs to identify where systems, policies, programs, and relationships require change. Although there have been strides toward improving access to care among patients at NCI-DCCs through COE efforts, the question remains how best to involve patients and the community in that discussion.

Creating an environment of change that brings a palpable and durable effect requires patient engagement. This can be challenging to implement. Many patients, especially those from historically marginalized communities or those who do not have traditional political or financial capital, feel that it is difficult to share their experiences, thoughts, and ideas for change directly with institutions themselves. They worry that institutions do not often seem to embrace new approaches for establishing trust and building patient confidence.\(^{147,148}\)

PFACs provide opportunities for patients to bring their authentic voices and experiences to the leaders and staff of an organization.\(^{49}\) PFACs and CABs serve different purposes,\(^{44,49}\) but both allow for the voice of the patient or the community to be heard. Many of these councils have established charters and governance standards that are developed based on the organization’s core values and its willingness to rectify the root causes of the deficiencies revealed through the patient experience lens.\(^{52,54,55,129}\) This process, if properly used, can be a framework that establishes trust, accountability, respect, and collaborative development of strategies that facilitate problem solving.

The structure for patient engagement and feedback is affected by the known structural and hierarchical barriers of class, language, and race.\(^{3}\) PFACs and CABs can appear to be constructive, with an open engagement posture for implementing change.\(^{54,49}\) All too often, patients report that, despite offering their suggestions, the issues are not being addressed. Indeed, many have discussed the increasing fragmentation of health care delivery and how patients feel more dissatisfied, even as our treatment tools become more effective.\(^{149-151}\)

Absent an honest discussion of the limitations of the health care delivery system, responses from NCI-DCC leadership can appear to be elitist or placating, making it a challenge to demonstrate openness to new approaches.

Patients and community members recognize that there are budgetary, resource, and policy constraints that may inhibit some potential enhancements to patient care. However, frequently, interventions, standards, and guidelines of the PFACs/CABs can appear to serve as symbolic check-the-box gestures if there is not bidirectionality. Too often, middle-income to lower-income community voices cannot find a seat at the table, leading to underrepresentation of those who are often affected the most.

These issues can mute the potential benefit of theoretically balanced COE approaches meant to improve health care outcomes and reflect the patient experience. The real question for NCI-DCCs on hearing the community and the patient voice is: How do we identify the best way to truly involve the patient/community voice in a way that empowers the community and allows for better representation of voices than we currently hear?

NCI-DCCs should be prepared to create structures that encourage patient engagement forums to navigate difficult obstacles together, focused on how to rectify these situations. When patients share their feedback and personal experiences of care, it often brings to light missed opportunities to be more patient-centered and responsive in a way that actsuate patient engagement as a core value of the organization. As cancer care feels more fragmented because of policy, workforce, and resource challenges,\(^{150,152}\) it is even more important to engage patient and community partners to achieve effective change. The community voice will help NCI-DCCs use local resources and policy makers to address these hurdles.

Opportunities to incorporate the patient voice

The patient voice is a gift to institutions that are open to receiving feedback and to adopting new ways to provide better care and service. Hearing the patient’s voice clearly will lead to a partnership that, when embraced, will bring benefits that elevate the center’s effectiveness across the entire institution.

Institutions must demonstrate gratitude for the efforts of these volunteers. By openly recognizing the contributions of time, talent, and willingness to articulate the truth, especially when the hard realities require less flattering depictions of the center, institutions can support their volunteers through empathy, being sensitive to the experiences and observations that are shared. Applying reasoning centered around good will can bring appreciation and a sense of value and continued enthusiasm for communities’ participation. This can be a benefit to both the community and the institution. Being open to volunteers’ new ideas and new approaches to addressing challenges is one way of building an environment that appreciates and respects the patient voice and their experiences.

Evolution and next steps

Even in NCI-DCCs with robust investments in public health and prevention/education, the vast majority of equity and engagement work has been focused on education and disparities research rather than care delivery expansion and interventions.\(^{15,132}\) Currently, there is an intense focus on improving access to clinical trials research
driven by both NCI-DCCs and drug developers. Many cancer center directors have asked, “How do we get x patients on clinical trials?” The answer is always the same: clinical trial accrual for historically marginalized patients only improves if the NCI-DCCs improve access to care in a palpable manner within the community itself.99,153–156 This can only happen with sustained investment in bidirectional relationships with affected communities and the dedicated support of innovative approaches and individuals doing this work. Building trust in communities is hard and takes time. The complexity and depth of relationship building has not been traditionally embraced by those who see only through the lens of basic and translational research. The support for interventions meant to broaden access should be seen as analogous to high-risk basic research. Community-based work requires a high level of investment if one wants to move the science forward. There is still bias in emphasizing how to ensure that the resources of COE can build research careers and also create sustainable mechanisms to remove barriers to patient access and care. There are substantial resources rightly invested in NCI-DCCs. They are doing a great job of creating new therapies but far less well at making those therapies accessible to communities that need it the most. History is evolving, and the NCI-DCCs must evolve as well to focus more on coalition building and bidirectional community partnerships if they want to move the needle on access and equity.

Many recommendations described in the past are yet to be heeded. Even a cursory review of the literature reveals examples of innovative, effective work that does not get the attention it should deserve, leading to many people reinventing the wheel. What is very clear is that the status quo is no longer sufficient, and changes must be made to make the necessary impact.

RECOMMENDATIONS

1. NCI-DCCs should engage the communities most affected and marginalized in a proactive, bidirectional manner and integrate this engagement into research and diagnostic efforts across the entire cancer center.

2. NCI-DCCs should broaden clinical access for patients across the spectrum of cancer services. This includes investing in the collection of demographic data (i.e., area measures of poverty, granular race, ethnicity, SOGI data) across the enterprise and using evidence-based interventions through a highly developed implementation core that connects clinical operations, health care delivery research, and the basic/translation research enterprise. Interventions should be integrated with the health care delivery system, not exist outside of it.

3. NCI-DCCs should commit to evolving their current structure of COE by committing to using their economic power to improve local communities through job training, educational collaborations, and health promotion. They should provide health care education to their workforce and CA communities.

4. NCI-DCCs should establish and implement governance policies and standards clearly demonstrating their commitment to elevating and empowering patient voices to facilitate equitable decision making for inclusion, transparency, and professional integrity.

CONCLUSION

NCI-DCCs have begun to see COE as an institutional pillar. We have an opportunity to make a marked impact on the health outcome of historically marginalized communities, but only if the majority of NCI-DCCs apply the same sustained focus and dedication to COE, clinical access, and health equity that they apply to their traditional research foci. After all, what is the use of developing new therapies if communities that could benefit the most are the very ones that cannot access them?

CONFLICT OF INTEREST STATEMENT

Christopher S. Lathan reports grant support for professional activities from Amgen and serves as a Disparities Advisory Group Consultant for Bristol Myer Squibb and Eli Lilly Oncology outside the submitted work. The remaining authors disclosed no conflicts of interest.

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