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Author manuscript

*Adv Cancer Res.* Author manuscript; available in PMC 2021 March 19.

Published in final edited form as:

*Adv Cancer Res.* 2020 ; 146: 167–188. doi:10.1016/bs.acr.2020.01.009.

## **Project PLACE: Population level approaches to cancer elimination:**

**Enhancing academic and community partnerships to describe and address health disparities**

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### **Abstract**

Achieving cancer health equity is a national imperative. Cancer is the second leading cause of death in the United States and in North Carolina (NC), where the disease disproportionately impacts traditionally underrepresented race and ethnic groups, those who live in rural communities, the impoverished, and medically disenfranchised and/or health-disparate populations at high-risk for cancer. These populations have worse cancer outcomes and are less likely to be participants in clinical research and trials. It is critical for cancer centers and other academic health centers to understand the factors that contribute to poor cancer outcomes, the extent to which they

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impact the cancer burden, and develop effective interventions to address them. Key to this process is engaging diverse stakeholders in the development and execution of community and population health assessments, and the subsequent programs and interventions designed to address the need across the catchment area. This chapter describes the processes and lessons learned of the Duke Cancer Institute's (DCI) long standing community partnerships that led to Project PLACE (Population Level Approaches to Cancer Elimination), a National Cancer Institute (NCI)-funded community health assessment reaching 2315 respondents in 7 months, resulting in a community partnered research agenda to advance cancer equity within the DCI catchment area. We illustrate the application of a community partnered health assessment and offer examples of strategic opportunities, successes, lessons learned, and implications for practice.

### Keywords

Community engagement; Community health assessment; Partnerships; Health disparities; Health equity; Capacity

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## 1. Introduction

Achieving cancer health equity is a national imperative. Cancer is the second leading cause of death in the United States (US) and the National Cancer Institute (NCI) predicts an estimated 1,762,450 new cancer cases and approximately 606,880 cancer deaths in the United States in 2019 (SEER, 2019). Likewise, cancer is the leading cause of death with estimates of almost 60,000 new cases and 20,410 deaths in North Carolina (NC), which has a significant number of counties and communities comprised of a high proportion of racially and ethnically diverse, rural, impoverished, medically disenfranchised and/or health-disparate populations at high-risk for cancer with limited access to resources and services (SEER, 2019). These populations have worse cancer outcomes and are less likely to be participants in clinical research and trials. For effective cancer control, it is critical for cancer centers and other academic health centers to understand the factors that contribute to poor cancer outcomes and the extent to which they impact the cancer burden and develop effective interventions to address them (Paskett & Hiatt, 2018). The key to this process is engaging diverse stakeholders in the development and execution of community and population health assessments, and the subsequent programs and interventions designed to address the need across patient and population catchment areas (Washington, Coye, & Boulware, 2016).

This chapter describes the processes and lessons learned of the Duke Cancer Institute's (DCI) long standing community partnerships that led to Project PLACE (Population Level Approaches to Cancer Elimination), an NCI-funded community health assessment designed to identify, describe, and develop a community partnered research agenda to advance cancer equity within the DCI catchment area. The capacity to address disparities vary from one cancer center to another and the strategies outlined in this chapter can serve as a scalable example of a community outreach and engagement model to improve population and community health, particularly for the underserved. We illustrate the application of a

community partnered health assessment model and offer examples of strategic collaborations, successes, challenges, lessons learned and implications for practice.

### 1.1 Burden of cancer and lack of diversity in clinical trials in North Carolina

There are 10,042,802 people living in NC, where African Americans make up the second largest race group at 22%. According to census data, the Latino/Hispanic population makes up 9% of the state population and has increased dramatically by over 300% in the last 10 years (US Census Bureau, 2018). Latinos/Hispanics have high concentrations in urban counties, such as Wake and in several rural counties where farming is one of the primary industries. Another growing and diverse community is the Asian population, although relatively small at 2.7%, this population has been steadily increasing over recent years. Native Americans are the smallest race/ethnic population in NC and are heavily concentrated in select communities such as Robertson County where the population is 39.7% Native American, 24.7% African American and 32.2% white. The average income in NC is \$25,608, and 17.2% live at or below the federal poverty level. In terms of educational attainment, 85.4% have graduated high school, and 27.8% hold a bachelor's degree or higher (US Census Bureau, 2018). Across the state, there are a significant number of counties with a higher number of underrepresented race and ethnic minority groups compared to their majority white populations. For example, in Durham County, 51% of the population is comprised of underrepresented minorities, with 39% African American. Statewide studies show urban and rural differences in the cancer burden across the state where rural communities tend to fare worse overall. Similar to national population trends, race and ethnic differences exist where minorities in general have a lower incidence in cancer, yet are more likely to be diagnosed at later stages, and present with more aggressive disease. These trends differ in some cases where the burden can be even greater in the context of incidence and mortality. For example, African American men have a 1.6-fold higher incidence of prostate cancer, and a 2.4-fold higher mortality rate compared to their white counterparts (SEER, 2019).

Lack of minority participation in oncology clinical trials and bio-repositories is a national problem. Current studies show that among the 15.5 million cancer survivors in the United States, only 9% are involved in clinical trials and even less are race and ethnic minorities, where current estimates range between 2% and 3%. Racial and ethnic minorities, the poor, and those who live in rural or low resourced communities are less likely to be involved in clinical research due to numerous factors including distance, fear, costs, or simply not being asked to participate (Baquet, Commiskey, Daniel Mullins, & Mishra, 2006; Dang et al., 2014; Paskett et al., 2002). In NC, a recent study found that men and minorities are least likely to participate in oncology clinical trials, highlighting the need to better understand these trends and develop mechanisms to address them (Hagiwara et al., 2014; Zullig et al., 2016). The under-representation of minorities and men in clinical research and trials has significant scientific implications. For example, from a biological standpoint, current studies are finding that black men are responding better to prostate cancer clinical trials than white men, underscoring the importance of diverse participation in clinical trials (Amstrong, 2017; George et al., 2019; Halabi et al., 2018). Poor minority recruitment and retention efforts can compromise generalizability of research findings, raise concerns around biased reporting of

adverse effects that may differ by race, and limit minorities and men from fully benefitting from research including access to cutting-edge and potentially life-enhancing clinical therapies (Unger, Cook, Tai, & Bleyer, 2016).

A myriad of individual, community, biological and system level barriers contribute to disparities in cancer, cancer care and research participation (Amstrong, 2017; Bandini, Preisser, & Nazzani, 2018; Barrett, Ingraham, Vann Hawkins, & Moorman, 2017; Durant et al., 2014; Ford et al., 2008). Lack of access to information, care, research, and resources, culture and communication including language, being under or uninsured, systemic racism and implicit bias in the health system, availability of cancer services and research, transportation, distrust of the medical establishment and research due to systemic racism and historical and broader social inequities all negatively impact cancer outcomes across the care continuum (Barrett et al., 2016; Durant et al., 2014; Hamel et al., 2016; Langford et al., 2014). Given higher rates of cancer morbidity and mortality among underserved populations, the growing diversity of our patient and community populations, lack of diversity in clinical trials participation, and the need for strategic collaborations and partnerships to reduce cancer disparities are heightened (Wallerstein & Duran, 2006; Washington et al., 2016).

## **1.2 The role of cancer centers and community health assessments to identify and address the need**

Among many accountability measures, cancer centers are expected to identify and assess the needs in their communities, increase clinical research participation, and ensure patients do not fall through the gaps in care (Paskett & Hiatt, 2018; Tai & Hiatt, 2017). However, barriers that prohibit access and utilization of cancer services and research vary by community, requiring cancer centers to develop and implement strategic plans to assess and respond effectively to disparities within their catchment area. One strategy to assess and describe the cancer burden and respond to the need, is by conducting community health assessments and employing key methodologies of community engagement and partnerships (Barrett et al., 2016; Wilkins Consuelo & Alberti Philip, 2019).

The opportunity to identify and develop partnered strategies to advance health equity research are critical and timely. In 2017 the NCI heightened focus on the importance of community engagement and outreach to address cancer disparities across NCI-designated Cancer Centers and their catchment areas. This priority has encouraged a renewed focus on stakeholder engagement and the importance of authentic and impactful collaborations in improving cancer outcomes through community and population health assessments, health equity research, and interventions across the cancer spectrum (Hiatt et al., 2018).

## **1.3 Addressing cancer disparities: Community engagement and community health assessments**

Community engagement encompasses methodologies designed to address health disparities by forming authentic and equally valued partnerships and collaborations between diverse stakeholders from the community, health care system including patients, and the research enterprise (Barrett et al., 2016; Gwede et al., 2012; Michener et al., 2012; Wallerstein & Duran, 2006). Within this context, the goals typically circulate around improving access and

the delivery of health care, enhancing resources and tools to promote healthy behaviors, and increasing inclusion of diverse populations in biomedical research. A robust community engagement program within cancer centers can bolster community-engaged research and has the potential to provide a dynamic platform to enhance the capacity of academic health centers including cancer centers to meet the needs of the communities and patients they serve.

Using community engagement approaches can address health disparities in ways that traditional efforts cannot and can particularly reach the most underserved in the community and within the healthcare system by valuing the perspectives of diverse stakeholders toward the elimination of health inequity (Gwede et al., 2012; Wilkins Consuelo & Alberti Philip, 2019). Uniting individuals with diverse perspectives and experiences allows for thoughtful discussion and opportunities for better understanding issues of interest (Hiatt et al., 2018). Community organizations and partners can use relationships with local residents and patients to provide insight and support when developing and implementing programs and engaging in research including clinical trials (Rodriguez, Torres, & Erwin, 2013; Wallerstein, Minkler, Carter-Edwards, Avila, & Sánchez, 2015). Moreover, with authentic collaboration from the onset, research findings and programs intended to increase screening, ensure access and utilization of services by traditionally underrepresented groups, and diversifying clinical trial participation are more likely to be implemented (Barrett et al., 2017; O'Brien & Whitaker, 2011). Critical to the community engagement process is the importance of understanding diverse community perspectives and priorities around health. Essentially, understanding the nuances of community needs provides context for researchers as they engage in projects and disseminate findings (O'Brien & Whitaker, 2011; Wallerstein & Duran, 2006).

Several studies have developed community and academic partnerships to identify and address health disparities and have led to improved outcomes in African American and Latino/Hispanic populations, and in rural and urban communities (Barrett et al., 2017; García-Rivera et al., 2017; Meade, Menard, Luque, Martinez-Tyson, & Gwede, 2011). Such studies have shown improved or promising outcomes across a variety of chronic disease interventions including cancer, diabetes, HIV and cardiovascular conditions and highlight the importance of community engagement and partnerships to reduce health disparities. By employing community engagement methods to develop institution level strategic priorities around cancer health equity research, cancer centers have the opportunity to reach the most underserved in the community and within the healthcare system in ways typically not fully afforded by traditional strategic activities. As such, community engagement is paramount to the development and implementation of community health needs assessments, and the subsequent research priorities and interventions necessary to address cancer health disparities within cancer center catchment areas (Barrett et al., 2017).

## 2. Methods

### 2.1 Building infrastructure and a health equity agenda through community engagement and partnerships

In 2012, the DCI, established the Office of Health Equity (OHE) to develop a health disparities and equity agenda to reduce cancer disparities. Two key factors triggered the prioritization of health disparities as a key strategy within the DCI. First, under the new leadership the DCI embarked on a new model of research and patient care through a coordinated effort to authentically engage the community in outreach, screening, and research as both participants and experts to inform the research process (Barrett et al., 2017).

The second factor that triggered prioritization was that accrediting entities and funding agencies were implementing policies which heighten accountability around community engagement and health disparities and equity efforts for cancer centers (Barrett et al., 2017; Hiatt et al., 2018). As a result, three areas of focus were established and include:

- Greater emphasis on the use of community assessments to understand and effectively respond to community and patient needs.
- Increased accountability in minority accrual and retention in research and clinical trials.
- The importance of engaging patients and community partners in health disparities research.

Through collaborative community partnerships the DCI, OHE convened a Community Advisory Council and conducted a qualitative cancer health assessment reaching over 230 participants. The assessment led to a co-created and executed community and academic health disparities strategic plan which highlights a health system/academic and community partnered platform to serve the community, patients, researchers, and clinicians.

DCI collaborated with community-based organizations and other key stakeholders to develop a dynamic integrated infrastructure complete with initiatives to improve cancer prevention and control, increase early detection, and address cancer disparities and gaps in access to care and research within the region. This process resulted in the development of a Community Facing Navigation Program with permanent health system supported positions (not dependent on external grants), and the creation of several key outreach programs which include free community-based screening programs, community outreach and education on cancer, and biomedical research participation (Barrett et al., 2017). Building on the established infrastructure, in 2017 the DCI worked with its Community Advisory Council (CAC), as well as with additional well-established community partners, to develop and implement an NCI-funded community health assessment, entitled Project PLACE (see Fig. 1). Project PLACE is a quantitative community health assessment designed to inform and shape the roadmap for strategic research, outreach and interventions to reduce cancer disparities, and to engage in targeted efforts to increase and diversify clinical research participation within the catchment area.

## **2.2 Development and implementation of Project PLACE: An academic and community partnered health assessment**

Funded by an NCI P30 Supplement to define the cancer burden of its catchment area, the overarching goal of Project PLACE was to extend DCI's current infrastructure beyond community engagement and collaborations to include a robust data platform designed to inform and shape the roadmap for strategic research, outreach and interventions, and to engage in targeted efforts to increase clinical research participation. Salient to this venture is both understanding and describing key factors impacting cancer disparities across diverse populations, aligning the priorities of research teams and partnering organizations to build capacity through strategic collaborations to address cancer disparities, spur innovative research questions and the development of comprehensive and multi-pronged strategies to increase and diversify clinical trial participation.

## **2.3 Engaging the DCI Community Advisory Council to guide and inform Project PLACE**

The DCI's CAC is a dynamic and vital component of the health disparities work within the DCI. The council is comprised of 22 individuals representing diverse perspectives across the cancer spectrum. Collectively, the council is comprised of educators, health professionals, researchers, faith leaders, grass-roots organizers, cancer survivors/patients, community advocates, and more, while representing diversity across race, ethnicity, class, religion, geography, sexuality/identity, and many other perspectives. These partners access and engage their broader community constituency based on identified programming and research priorities. The committee serves in an advisory and collaborative capacity to provide guidance, feedback, development and execution of research projects at the DCI, and promote community and outreach programming to increase understanding and involvement in clinical trials and research programs among underrepresented groups, and improve access and the delivery of cancer screening and care across the continuum of care. The CAC plays an instrumental role in the development, execution, and outcomes of Project PLACE. In addition, the DCI has a broader network of community partners that represent national, statewide regional, and local health organizations, community-based and rooted organizations, local historically black colleges and universities (HBCUs), along with cancer patients and caregivers.

## **2.4 Survey development: Aligning NCI, DCI, and community priorities**

The survey development process of Project PLACE had to incorporate priorities and guidelines from national, regional, and local stakeholders interested in the outcomes and subsequent research, community engagement, and interventions. The DCI was one of 15 grantees who received NCI funding to describe their respective catchment areas with the plan of using the data to ultimately share strategic activities including community outreach, increase diversity in clinical trials and address patient care with a cross cutting theme of addressing disparities. NCI, in collaboration with other stakeholders including the P30 supplement grantees, selected five core measures from the Health Information National Trends Survey (HINTS) data set and all sites were expected to capture these data through their local community assessments (Gage-Bouchard & Rawl, 2019). The DCI CAC, partners in the network, and researchers across a variety of cancer related disciplines identified an

additional eight DCI-specific measures to incorporate into the survey. The final survey included 91 items with a total of 13 measures and was available in English, Spanish and Chinese (see Table 1).

In addition, each community organization was asked if there were questions that were important to them for building capacity in their own organization that extends beyond the agreed upon measures already selected for the survey. Two partnering organizations chose to add additional questions to the instrument that were pertinent to their specific stakeholder populations and important for their own capacity building. Those items were added as an addendum to the survey. The survey was constructed using the DCI's Behavioral Science and Survey Research Shared Resource, supported by the NCI Cancer Center Support Grant (P30CA014236 45).

**2.4.1 Identifying community partners and collaborators**—DCI engaged long standing and newly established organizations and partners to develop a survey dissemination plan that would reach diverse populations cutting across key demographics including race, ethnicity, age, region, culture, and socioeconomic status. We took a novel approach in this process by partnering and incentivizing organizations rather than the individual participants. This was critical as we aimed to not just partner for the purpose of capturing surveys but to review the outcome and ultimately identify opportunities for outreach, interventions, and community-engaged research. Partners and collaborators represented diverse communities, regions, and sociodemographic groups. The reach of Project PLACE partners includes a diverse population representing the African American/Black, Asian, Latinx/Hispanic, White, Muslim/Christian, Lesbian, Gay, Bisexual, Transsexual, Queer, Intersex, and Asexual communities and respondents from both rural/urban communities across the state. Fourteen community-based organizations represented a variety of groups including fraternities and sororities, health and patient advocacy groups, the LGBTQ centers, an HBCU, and senior centers. We partnered with five (5) faith organizations which included Catholic, non-Catholic Christian, and Muslim organizations. Last, a free health clinic serving uninsured patients spanning four counties in NC, and the Duke Health system provided the opportunity to engage a diverse patient population.

## 2.5 Community partner kick-off training

A Project PLACE kick-off meeting was held with community partners involved in the development and dissemination of the survey. The 2-hour session provided an overview of the cancer burden and need in the community, the purpose of Project PLACE and the importance of partnerships and collaborations. Each organization shared details about their programs and services, who they serve and their reach. The kick-off then had an in-depth workshop that covered key survey operations such as the development and refinement of each partner's Survey Dissemination Plan, a review of research ethics, and Standard Operating Procedures (SOP's) to ensure activities were in full alignment with Duke's Institutional Review Board (IRB) and human subjects' protections.



## 2.6 Survey dissemination and compensation

The initial goal was to enroll 2000 participants across all racial and geographical groups into the study. The study was conducted within various communities, with the majority of participants recruited via health fairs and outreach endeavors sponsored by community partners. The surveys were self-administered via either paper-pen format or online using a Research Electronic Data Capture (REDCap) database. The online survey link was distributed through selected community partners and to those who request to disseminate the online survey to their constituents. Most partners disseminated pen and paper surveys which were disseminated in a variety of settings including community forums, health fairs, and outreach events, during and after church services. We employed purposeful sampling through community-based convenience sampling methods by focusing on recruiting participants from community organizations based in Durham, Wake, Vance, Granville, Alamance, and Orange counties. We provided compensation (\$10 per survey up to \$2000) to partner organizations as part of our agreement to access the data and co-develop follow-up interventions and research in which the funds could be used to offset the costs of having staff distribute and collect surveys, provide participant incentives, or to meet a specific programmatic need in their organization. DCI OHE provided planning and coordination support as needed and OHE Community Navigators attended and helped facilitate the programs. In addition, participants that completed the survey at community partner events were offered gift items valued less than \$5 such as a water bottle or a tote bag. DCI OHE provided planning and coordination support as needed and OHE Community Navigators attended the programs to answer questions.

The community health assessment posed no more than minimal risk to the participants and we were granted a waiver of consent from the DCI's IRB. In lieu of a consent process, a member of the research team provided a thorough review of the project details with instructions to complete the survey to the community partners as well as the participants completing the survey. The survey did not collect Personal Health Information (PHI) and could not be traced back to an individual. Research team members addressed any questions or concerns of the participants prior to them completing the survey.

## 3. Project PLACE results and outcomes

### 3.1 Data collection outcomes by organization type

Project PLACE data collection spanned from April 2017 to December 2017. A total of 2315 surveys were completed, exceeding our goal of 2000. Most participants were recruited from community organizations primarily located in Durham, Wake, Vance, Alamance, and Johnston counties in Central NC, representing 24 diverse organizations including clinics, community-based organizations, faith organizations and community outreach events and programs (see Fig. 2).

Fourteen community organizations held 29 events capturing a total of 1119 surveys. We partnered with one health clinic that held an event capturing 152 surveys. Five faith organizations held 11 events and captured a total of 795 surveys. Programs at faith organizations varied from bible studies, health fairs, church services and Eid Al-Fitr within a

Muslim mosque. We also partnered with organizations to host two annual health screenings and outreach programs targeting men and women in Durham and the Greater Triangle region. Programs included the Women's Health Awareness Day, the Men's Health Initiative, Sister's Network Tea for Two, the LGBTQ Center's 2nd Anniversary Celebration, the NC Cancer Prevention & Control Branch Survivorship Summit, and the Lung Cancer Initiative Summit. Collectively the outreach programs collected 249 surveys. It is important to note, that 10 Project PLACE partners were a direct result of the collaborations with, or were facilitated by members of the DCI Community Advisory Council. In summary, our 24 partners held 47 events reaching 2315 diverse respondents (see Table 2).

### 3.2 Survey outcomes and demographics

The Project PLACE partnership led to 2315 respondents completing surveys in diverse community settings. Surveys were completed in three languages: English (88%), Spanish (9.7%), and Mandarin (2.1%). Survey respondents represent significant racial and ethnic diversity. African Americans and whites had similar representation at 36% (840), and 37% (850), respectively. Asians made up 10% of the survey respondents and Native Americans the remaining 2%. Regarding ethnicity, 14% of the sample identified as Hispanic. Females were 61% of the respondents. Six percent of the respondents identified as a sexual minority (lesbian, gay, and bisexual) and 84% identified as straight/heterosexual. Twenty-eight of the sample had a vocational training or less, and 46% had a college degree or higher. The average age of participants was 51 with a range from 18 to 99 years old. Eighty-one percent had health insurance (public or private), and 78% were in metro/urban communities whereas 17% were from non-metro/rural communities (see Table 3).

### 3.3 Project PLACE outcomes: Stakeholder report outs and partnered strategies

An important aspect of community partnered and engaged research is to ensure findings and outcomes are reported back to the community in a meaningful and timely manner. Consistent with this important principle of engagement, the DCI co-presented the data and outcomes for the individual organizations and the whole sample. A total of 12 report back sessions were held, reaching over 1200 people in the community. Where some partners wanted to meet with a small leadership team to discuss highlights of the findings, others requested a full co-presentation. All partners wanted to be connected to resources to promote access to care and awareness through the Community Facing Navigation Program and about 50% ( $n = 12$ ) were ready to conduct some level of intervention or program based on the findings from their constituents. To date, eight Health Equity Strategy Groups have formed around Project PLACE data and are at various stages of productivity ranging from publications, small grants, further community data collection through focus groups and listening sessions, and planning fundable interventions using the Project PLACE data for preliminary data. Strategy group topics include: Hospice and Palliative Care, Women's Cancer and Screening Behaviors, Prostate, and Colorectal Cancer Screening Knowledge and Behaviors, Genetic Testing and Cancer Diagnosis and History of Cancer, Rural Health and Cancer, Race Disparities in Biomedical Research Participation, Medical Mistrust and Research Participation, Community-Based Screening Program and Biomedical Research Participation, Health Information, Communication, and Technology, and Promoting Men's Health and Reducing Cancer Risk.

## 4. Discussion

### 4.1 Project PLACE successes

Project PLACE has several key strengths that should be noted. Specifically, the success of the community health assessment process is noted in several distinct but interrelated ways. First, building on DCI's extensive and long standing relationships and partners, over 2300 self-administered pen and paper surveys from a very diverse population were captured within a 7-month period. This highlights the impact of long standing and mutually beneficial community engagement when academic health centers and cancer centers are seeking to better understand, partner, and serve their constituents within the catchment area. Second, the survey was a 91-item tool and yet did not pose a collective barrier to completing the survey across a variety of settings. Providing the survey in three languages may have added to making this survey completion more reasonable for respondents.

Trust is another key aspect of this study. In most cases, community members were already familiar with the DCI from outreach activities related to access to care, cancer screening and clinical trials participation. In a few instances the DCI had minimal engagement with the organization, but worked through a "trust broker," a community leader or partner who served as the liaison to the community. This led to a significantly higher rate of participation and solidified the opportunity to conduct the subsequent report out sessions and next steps in regards to services, research, and interventions. Another key aspect that cannot be underestimated is the well-established DCI CAC. Almost 50% of the community organizations represented on the CAC were part of the Project PLACE assessment, and collectively the group provided guidance from survey development through, implementation, and report out to the community, and the next step strategies. The richness of this engagement influences both the direct work that stems from Project PLACE, and the ongoing and broader activities of the DCI.

Lastly, Project PLACE not only allowed the DCI to leverage existing relationships, it also opened the door for new ones. These new relationships create opportunities to expand the diversity of community partners and constituents. For example, through this assessment process DCI began new relations with a local mosque, a Chinese community-based organization, and some rural based senior centers. New partners were a part of the kick-off training and celebration and allowed them to see their participation as being part of a broader community, and highlighted the successes, resources, and programs that came from the first strategic assessment conducted 5 years prior, and the impact it has made on reaching diverse and underserved populations in the community.

Two additional important aspects of this program are (1) the model for incentivizing the community organization instead of the individuals and (2) the opportunity for community partnering organizations to add their own questions to the survey that can help build their capacity to identify and meet the needs of their constituents. Community organizations designed and led the survey dissemination aspects of the program with the plan to use the data to co-publish and co-develop research and programs to improve cancer outcomes with the DCI. Consequently, community organizations were compensated for the surveys as part of the development of a strategic goal and plan using the data once the survey was complete.

Likewise, as partners we capitalize on the survey process by ensuring space for community organizations to capture data that was specifically important to their mission and capacity to serve their constituents. This was important as we work to create open, transparent, and mutually beneficial opportunities within academic and community partnerships.

## 4.2 Lessons learned

The success of the program does not come without key lessons learned. The online survey link yielded very few respondents and overall was not a successful mechanism to engage community partners and their constituents. Although survey collection methods often use email to reach populations in research, given our target audience, this did not have the intended impact our partners or the DCI anticipated. It seems the pen and pencil administration of the survey had an added effect of engaging people and meeting them where they were to conduct the assessment. Face-to-face administration is also critical for relationship building and follow-up activities that will result from the survey findings. These two points should be underscored as they demonstrate key aspects to meaningful and authentic community engagement.

## 5. Conclusion

Project PLACE illustrates the impact stakeholder engagement and robust community partnerships can have when conducting community and population health assessments. Implementing community health assessments where partners share the development, dissemination, and subsequent research and programs based on the findings are important and critical to success and sustainability of programs, research, and interventions. Project PLACE created key opportunities to consider when partnering to understand and address the needs in a given community. Ensuring there is value and mutually beneficial outcomes by leveraging activities to meet the capacity building needs of the community partners as they work with the cancer center, and on their own to address key aspects of their mission, is important and should not be overlooked. Moreover, using assessment data to collaboratively co-develop programs, research, and services to improve population health and advance cancer health equity is an excellent model toward building trust, and community capacity to address cancer disparities, specifically within comprehensive cancer center catchment areas.

## Acknowledgments

This research was supported by NCI/NIH Grant Number P30 CA014236. Special appreciation to the following people who served on either the Research Council, the Community Advisory Council for the Duke Cancer Institute (DCI), and/or as collaborators or supporters of Project PLACE (Population Level Approaches to Cancer Elimination): Sue McLaurin, Ava Crawford (NCDHHS), Debi Nelson (NCDHHS), Women's Health Awareness Day (an outreach program developed and supported by National Institute of Environmental Health Sciences), Pao Hwa Lin, Pilar Rocha Rosenberg, Maritza Chirinos, Helena Cragg, Patricia Wigfall, Ping Zhang, Jenny Denai, Eric Ireland, Bo Marshall, Michael Palmer, Claudia Graham, Pastor Raj, Kerri Burnette, Awanya Davis, Marsha Edwards, Reverend Jerome Taylor, Ron Sangal, Kenisha Bethea, Steven Patierno, Terry Hyslop, Xiaomei Gao, Patricia Moorman, Charmaine Royal, Qingyi Wei, Kevin Oeffinger, Devon Noonan, Kathryn Pollack, Demetrius Harvey, and Jeffrey Ford.

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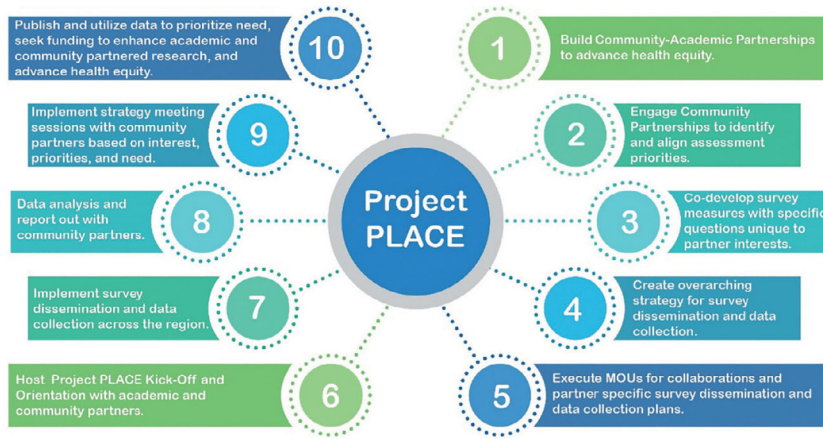
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**Fig. 1.** Partnership development, survey dissemination, data collection, and reporting process.





**Fig. 2.**  
Project PLACE: survey collection outcomes.

**Table 1**

Project PLACE core measures.

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<b>NCI core measures captured across all NCI-funded sites</b>
1. Access to care
2. Demographics
3. Accessing health information
4. Tobacco use
5. Cancer screening and knowledge

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<b>DCI and community specific core measures</b>
6. Medical research participation
7. Genetic testing
8. Beliefs about cancer
9. Medical mistrust
10. Health history
11. Awareness and use of palliative care
12. Physical activity and exercise
13. Nutrition

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**Table 2**

Survey collection by type of organization.

<b>Organization type</b>	<b>Number of organizations</b>	<b>Total surveys collected</b>	<b>Total # events</b>
Community-based	14	1119	29
Faith organization	5	795	11
Health clinic	1	152	1
Community outreach	4	249	6
Total	24	2315	47

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**Table 3**Project PLACE demographics ( $N = 2315$ ).

Demographic characteristics		N	% or mean
Race	White	850	37
	African American/Black	840	36
	Asian/Pacific Islander	243	10
	Native American	37	2
	More than 1 race	89	12
Ethnicity	Hispanic	326	14
	Non-Hispanic	1739	75
Gender	Male	783	34
	Female	1402	61
	Other	8	0
Sexual orientation/gender identity	Straight/heterosexual	1941	84
	Homosexual/gay	81	4
	Transgender, transsexual, or gender non-conforming	10	0
	More than 1 selected	12	1
Education	High-school or less	519	22
	Some college or technical school	606	26
	College graduate	466	20
	Post-graduate	148	6
Geographic location	Metro	1802	78
	Non-metro	401	17
Mean age			51
Health insurance status <sup>a</sup>	Yes	1875	81
	No	281	12
Survey language	English	2042	88
	Spanish	225	9.7
	Mandarin	8	2.1

<sup>a</sup>Do you have any kind of healthcare coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare, or Indian Health Service?