

HOW TO

Community Engagement to Advance Equitable Cardio-Oncology Care



A Call to Action: JACC: CardioOncology How To

Vanessa B. Sheppard, PhD,^a Arnethea L. Sutton, PhD,^b Shiva Salehian, MD, PhD,^a Anika L. Hines, PhD, MPH,^a Karen Patricia Williams, PhD,^c Megan C. Edmonds, PhD, MPH,^a Alisa Brewer, MSPH,^d Marcie S. Wright, PhD,^a Avirup Guha, MBBS, MPH^{e,f}

The World Health Organization defines community engagement as “a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes.”¹ Community engagement is salient for cardio-oncology populations given the variability in care that cancer survivors receive after active treatment.² This includes relying on community partners to provide expertise on the lived experiences of disparity-affected populations and employing community members along the care continuum, from the point of diagnosis through long-term survivorship. In this regard, it is important to note that survivorship is operationalized according to the National Cancer Institute (NCI) definition as the point of diagnosis to the end of life.

TRUST ENGAGEMENT FRAMEWORK FOR CARDIO-ONCOLOGY

The TRUST framework was developed in collaboration with researchers; community-based organizations; and individuals from diverse racial/ethnic, socioeconomic, and geographic backgrounds for cancer prevention and control efforts in diverse Latinx subgroups. It was then expanded to Black, White, rural, and urban populations to enhance participation

in cancer research.³ In this call to action, we adapt components of this framework to describe opportunities to engage community members to address cardio-oncology disparities. **Figure 1** depicts adaptation within the context of cardio-oncology disparities.

T: TEAMS SHOULD BE INTERDISCIPLINARY AND INCLUDE DIVERSE LEADERSHIP. Cancer survivors require multidisciplinary care throughout their survivorship journey. Unfortunately, for many survivors at risk of cardiovascular disease, multidisciplinary care ends after active treatment. Most survivors do not receive care within academic centers, highlighting the need to expand and engage the diverse group of professionals in community settings who treat, support, and conduct research involving survivors. Including training related to community engagement for interdisciplinary team members is critical and should include leaders from diverse backgrounds and individuals with expertise in community engagement. Notably, expertise and experience in community outreach and engagement are often underappreciated and approached with health equity tourism, “the practice of investigators—without prior experience or commitment to health equity research—parachuting into the field in response to timely and often temporary increases in public interest and resources.”⁴ The Patient-Centered

From the ^aSchool of Population Health, Virginia Commonwealth University, Richmond, Virginia, USA; ^bDepartment of Kinesiology and Health Sciences, Virginia Commonwealth University, Richmond, Virginia, USA; ^cOhio State University, Columbus, Ohio, USA; ^dSchool of Population Health, Center on Health Disparities, Virginia Commonwealth University, Richmond, Virginia, USA; ^eDepartment of Medicine, Medical College of Georgia, Augusta University, Augusta, Georgia; and the ^fCardio-Oncology Program, Medical College of Georgia, Augusta University, Augusta, Georgia, USA.

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ABBREVIATIONS AND ACRONYMS

CAB = community advisory board

CBO = community-based organization

FQHC = Federally Qualified Health Center

NCI = National Cancer Institute

Outcomes Research Institute has guidelines for developing community partnerships highlighting key principles related to reciprocal relationships; colearning; and transparency, honesty, and trust that are translated to research and care delivery within cardio-oncology.⁵ In collaboration with community partners, we developed tools and training curricula (eg, videos and tool kits) to increase researchers' self-efficacy

and knowledge about implementing these community principles within their studies.

Building on expertise within and outside of clinical centers is crucial. For example, cancer navigators are available within many hospitals and other clinic settings, and navigation has been shown to reduce gaps in care, improve receipt of timely care, and enhance cancer outcomes.⁶ There is an opportunity to extend navigation from centers to community settings (eg, primary care practices). Rather than developing completely new models of care, there are opportunities to build on models of complex care coordination to support survivors within their community environments and dynamic bidirectional pathways among community constituent groups. Financial reimbursement of engagement models that connect system navigators with community connectors is necessary. These "community connectors," along with community outreach and engagement leaders and staff, may serve as natural bridges between the multifaceted nature of cancer care and risk reduction strategies during survivorship. Partnerships with clinical entities such as Federally Qualified Health Centers (FQHCs) and other safety net providers are needed to expand reach to those who care for survivors.

R: RECRUIT AND ENGAGE BICULTURAL STAFF, BILINGUAL STAFF, AND COMMUNITY CHAMPIONS.

Recruiting staff and personnel with relevant lived cultural experiences can advance community engagement in cardio-oncology. This is of the utmost importance because studies continue to demonstrate the association between poor health literacy and poor cancer and cardiovascular outcomes among racial/ethnic underserved groups, including Spanish-speaking adults in the United States. One contributor to this problem is the lack of effective resources, including culturally relevant materials and engagement. Although the inclusion of those with lived experiences may include individuals who have been diagnosed with cancer and cardiovascular disease, it

HIGHLIGHTS

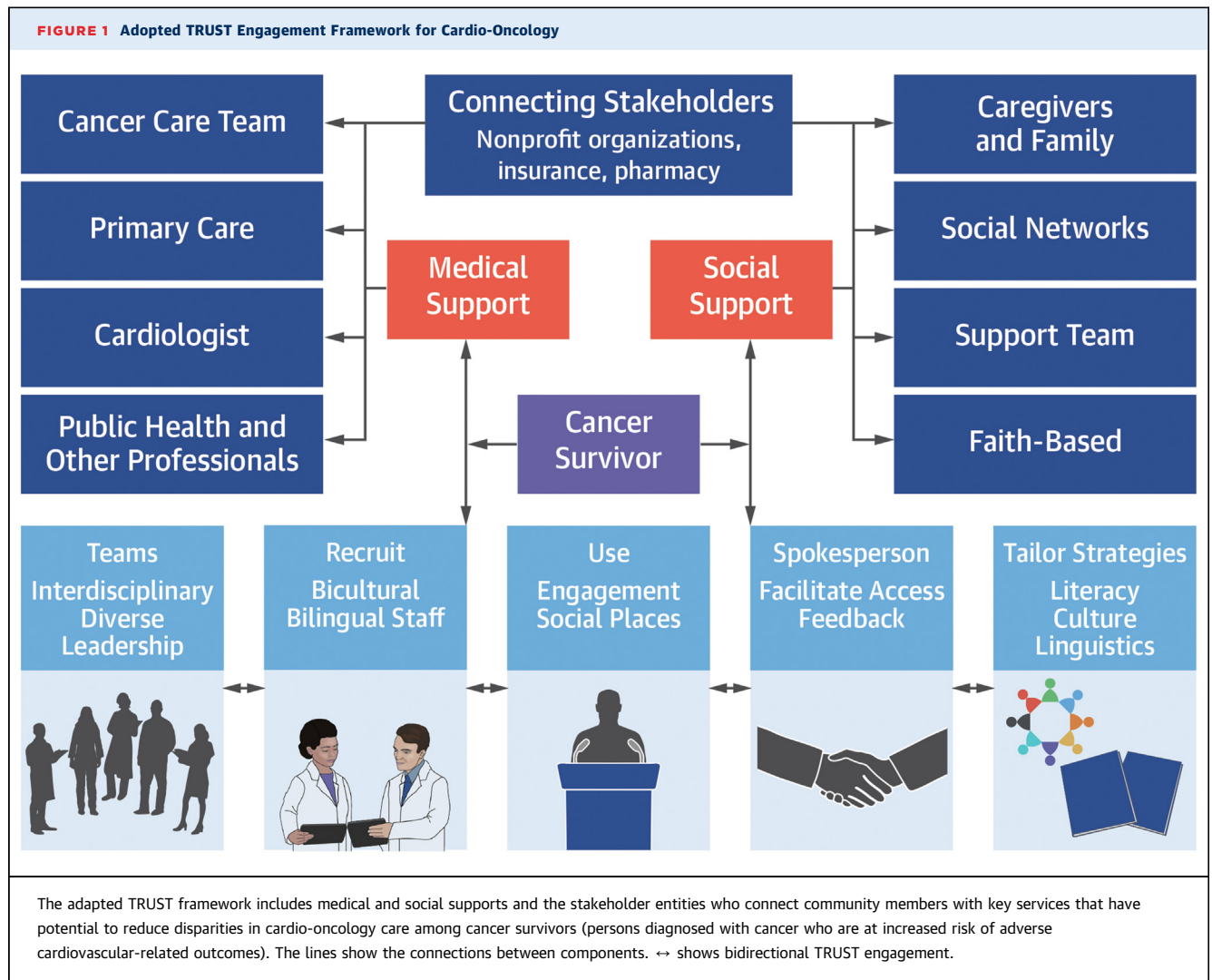
- Situating engagement within the experience and priorities of survivors will enhance translational research and health equity.
- The TRUST framework provides a guide to expand opportunities for community engagement in cardio-oncology for multiple constituents and across the care continuum.
- Training community members as cardio-oncology champions may promote stakeholder representation.
- Community connectors can support bidirectional engagement and support for survivors as they transition from active treatment.

should certainly include bilingual staff and those with knowledge or who share the cultural background, religion, and/or language of the community members being engaged. FQHCs and community-based organizations (CBOs) often have staff from diverse backgrounds who are familiar with the communities they serve. Partnerships with community-based and nonprofit organizations have enhanced diversity in clinical research and promoted education among survivors. Thus, FQHCs, CBOs, and so on may be crucial anchor organizations to forge partnerships within cardio-oncology.

Community members serving as champions of cardio-oncology can help promote engagement within their spheres of influence. Champions are community members who receive training in cancer prevention and control (screening and research) and specialized training per their interests (eg, tobacco cessation and clinical trials). They serve as a touchpoint with their respective community and places of influence to share research information and bring community intelligence back to care and research teams.⁷ They may or may not be based within CBOs or other organizations.

U: USE ENGAGEMENT, OUTREACH, AND RECRUITMENT STRATEGIES IN SOCIAL PLACES.

Engaging survivors and other stakeholders in social places creates opportunities for a lasting impact on sectors outside of health care where community members live, learn, work, shop, worship, and play. Efforts are needed to



increase awareness about cardio-oncology among survivors and others in the general community. Leveraging social media, social networks, and digital learning platforms may expand the reach of these efforts. For example, many survivors have their “space” online because numerous online survivorship groups provide general and niche information, social support, advocacy, and connections across varied sociodemographic groups and disease types. The creation of information hubs may connect professional organizations with academics and advocates. Engagement with these groups may promote further reach and impact on risk reduction and knowledge around cardio-oncology concerns in the cancer survivor population.

S: SPOKEPERSONS WHO FACILITATE COMMUNITY ACCESS AND PROVIDE FEEDBACK TO CARE AND RESEARCH TEAMS. A priority for community engagement is recruiting individuals representing the diverse constituency. To date, little information has come from the “voice” of survivors impacted by cardiovascular disease and/or their caregivers. Identifying and connecting with key spokespersons within the various patient and survivor communities across the community constituent domain will facilitate access and engagement in the community and provide feedback to research and care teams. Prior application of the TRUST framework has included spokespersons recognized within their respective communities as leaders who tended to represent constituents or have

reach or access to influence diverse constituents. Examples include media personalities, elected officials, directors of community-based organizations, and leaders of advocacy organizations. It is possible that an individual trained as a community champion could also serve as a spokesperson; however, roles in previous projects have tended to be distinct.

Partnerships with trusted media personalities and online health influencers informed the TRUST framework.³ Faith-based leaders have been strategic partners in promoting health with several examples of large-scale projects for cardiovascular disease and overall community health. One example is Facts and Faith Fridays, a partnership between 1 NCI-designated cancer center and the African-American faith-based community. Facts and Faith Fridays started as a result of a need for accurate and timely information during the COVID-19 pandemic. It has since expanded to a bidirectional partnership whereby churches have served as sites for clinical trial recruitment, and cancer center staff serve as members of church health ministries to consult about health-related programming.⁸ The need to diversify clinical trials has increased awareness about clinical research and led to more advocates leading and engaging in research. There is a need to provide specialized training to advocates to engage in cardio-oncology research and practice. Collaborating with advocates to strategize about awareness campaigns that build on cancer awareness and heart health activities will break down some of the disease-focused silos.

T: TAILOR STRATEGIES FOR LITERACY, LINGUISTIC, AND CULTURAL APPROPRIATENESS. A key aspect of community-engaged research is the cocreation of research protocols, materials, and approaches to ensure they are understandable and relevant to the intended audience. Community advisory boards (CABs) have helped meet these goals. CABs serve as community representatives who may be invited based on organization affiliation or ties to the population(s) impacted by the disease or health state. For example, as part of the development of a multistudy program project in cardio-oncology, community members and trusted community connectors were asked to share information about the plan to develop research projects related to cardio-oncology disparities. Interested members were introduced to the proposed research team to share experiences, discuss timelines, and ask questions. Persons interested proceeded to join the CAB, which included a faith leader, a cancer survivor, a caregiver, and a healthy volunteer. The outreach staff served as a link

between researchers and the CAB, ensuring that they received relevant information ahead of scheduled meetings and allowing them the opportunity to opt into any meetings related to the various projects. CAB members provided feedback via email, phone/Zoom interviews, and Google Surveys. Except for 1 project focused on cellular pathways, all projects/cores met CAB approvals to proceed, with attention given to CAB input and comments. The CAB continued engagement throughout the submission and resubmission processes.

CALL TO ACTION

Engagement that builds trust, promotes equity, and is sustainable to avoid^{9,10} “health equity tourism” is needed. As members of the cardio-oncology community, at a minimum, we must act in the following areas:

- Implement engagement best practices and develop domains specific to cardio-oncology by understanding community’s culture, economic conditions, social networks, political structures, norms and values, demographic trends, history, and prior engagement experience.
- Implement interdisciplinary collaborations within and outside of clinical care to increase awareness of cardio-oncology in a culturally sensitive and easily accessible manner.
- Identify and mobilize community assets; develop the community’s capacity and resources to make decisions; take action; and commit time, financial, and expert resources within community structures to support long-term engagement. Advocacy should support policies that remove barriers to financial reimbursement for community-based interventionists and staff.
- Identify opportunities for sustainable collaborations with anchor institutions (faith-based, barbershops, libraries, and so on), community-based organizations, safety net providers, health departments, and professional and lay organizations.
- Prioritize addressing disparities with attention to social drivers of health.

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ADDRESS FOR CORRESPONDENCE: Dr Vanessa B. Sheppard, Virginia Commonwealth University School of Medicine, 830 Main St, NW, Richmond, Virginia 23219, USA. E-mail: vanessa.sheppard@vcuhealth.org.

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