



## Assessing needs and assets for building a regional network infrastructure to reduce cancer related health disparities



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### ABSTRACT

Significant cancer health disparities exist in the United States and Puerto Rico. While numerous initiatives have been implemented to reduce cancer disparities, regional coordination of these efforts between institutions is often limited. To address cancer health disparities nation-wide, a series of regional transdisciplinary networks through the Geographic Management Program (GMaP) and the Minority Biospecimen/Biobanking Geographic Management Program (BMaP) were established in six regions across the country. This paper describes the development of the Region 3 GMaP/BMaP network composed of over 100 investigators from nine institutions in five Southeastern states and Puerto Rico to develop a state-of-the-art network for cancer health disparities research and training.

We describe a series of partnership activities that led to the formation of the infrastructure for this network, recount the participatory processes utilized to develop and implement a needs and assets assessment and implementation plan, and describe our approach to data collection. Completion, by all nine institutions, of the needs and assets assessment resulted in several beneficial outcomes for Region 3 GMaP/BMaP. This network entails ongoing commitment from the institutions and institutional leaders, continuous participatory and engagement activities, and effective coordination and communication centered on team science goals.

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### 1. Introduction

Significant cancer health disparities exist in the Southeast region of the United States, which includes Alabama, Florida,

Georgia, Louisiana, Mississippi, and Puerto Rico (Departamento de Salud, 2007; U.S. Cancer Statistics Working Group, 2010). The two racial/ethnic minority populations most affected by cancer health disparities in this region are African Americans and Hispanics (U.S. Cancer Statistics Working Group, 2010). A recent report from the American Cancer Society found that more Hispanics in the United States die of cancer each year than any other cause (American Cancer Society, 2012). Factors contributing to cancer health disparities in this region include a high proportion of individuals without health insurance, high poverty rates, large rural areas with limited access to quality cancer care, and communication and

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health literacy barriers (Partridge et al., 2005; Drewry et al., 2010; Gwede et al., 2011; Hidalgo et al., 2012; Haynes & Smedley, 1999; Jacobs, Karavolos, Rathouz, Ferris, & Powell, 2005; Kaiser Family Foundation, 2009; Ryan & Siebens, 2012; Shin & Kominski, 2010).

Numerous initiatives in the Southeastern United States are underway to reduce cancer disparities and train future researchers from underrepresented groups, (Partridge et al., 2005; Wynn et al., 2006; Scarinci et al., 2009; Gwede et al., 2010; Gwede et al., 2011; Simmons et al., 2011; Wells et al., 2012; Wells et al., 2012; White et al., 2012; Wilson et al., 2012; Satcher et al., 2006; Wynn et al., 2011) but with minimal regional collaborations or coordination. Strengthening cancer research across the continuum from basic science to population-based studies is critical to the advancement of cancer health disparities research.

As such, a number of inter-institutional networks have been established to reduce cancer health disparities, including Community Network Program Centers (CNPCs). For instance, the Deep South Network, (Partridge et al., 2005; Lisovicz et al., 2006; Wynn et al., 2011) the Tampa Bay Community Cancer Network (Meade et al., 2011), and the National Black Leadership Initiative on Cancer II: Network Project (Satcher et al., 2006) are all inter-institutional networks. In addition to CNPCs, partnerships between minority institutions and cancer centers through the Partnerships to Advance Cancer Health Equity (PACHE) have a direct focus on cancer health disparities at an inter-institutional level (National Cancer Institute, 2012).

Population-based molecular studies are important to cancer health disparities research, and team science is vital to address these disparities. Moreover, development of biobanks is also essential for effective translational research by allowing researchers to uncover genetic causes of complex diseases and subsequently develop new therapies and prevention strategies (Flores et al., 2011; Khoury, Millikan, Little, & Gwinn, 2004; Morente, Fernandez, & de Atava, 2008). By obtaining diverse samples (e.g., disease status, racial/ethnic composition), biobanks may serve as key resources to address the issue of limited generalizability that plagues much of the current clinical and genomics research, and allow for powerful interpretation of differences between diverse racial/ethnic groups and their association with disease processes. Partnerships with minority-serving institutions may help to identify and overcome barriers to research, establish biobanking models unique from those at comprehensive cancer centers, and create opportunities for research, training and outreach (Flores et al., 2011).

In an effort to better coordinate cancer disparities activities, the National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities (CRCHD) issued a call through American Recovery and Reinvestment Act (ARRA) supplementary funding for regional transdisciplinary networks through the Geographic Management Program (GMAP) and the Minority Biospecimen/Biobanking-Geographic Management Program (BMAP). The purpose of GMAP/BMAP was to establish multi-institutional networks to develop infrastructure for research and training for the purpose of reducing cancer related health disparities. Specifically, for BMAP, development of a state-of-the-art network lays the needed foundation and infrastructure for ensuring the adequate and continuous supply of high-quality human biospecimens (neoplastic and nonneoplastic tissues) for cancer research that takes into account "cultural sensitivities of diverse communities" in the region (National Cancer Institute, 2009). This paper details efforts toward the development of the Region 3 GMAP/BMAP network composed of over 100 investigators from nine institutions in five Southeastern states (Florida, Georgia, Alabama, Mississippi, Louisiana) and Puerto Rico who have assiduously worked to develop a regional plan for tackling cancer health disparities.

Our goals in this paper are to: (1) describe a series of partnership activities leading to the formation of infrastructure for Region 3 GMAP/BMAP network, (2) recount the participatory processes used to develop and implement a Region 3 needs and

assets assessment to inform a comprehensive regional implementation plan, and (3) report lessons learned. We detail the application of the principles of community-based participatory research to the implementation of the network and the assessment. The blueprint of ideas outlined in this paper may be useful for other institutions and researchers who seek to create regional plans for impacting health disparities.

## 2. Methods

### 2.1. Infrastructure development of Region 3 GMAP/BMAP network

A regional GMAP/BMAP teleconference hosted by CRCHD in Spring 2009 initiated discussions between investigators in Region 3. Universities and cancer centers in Region 3 already had significant infrastructure to contribute to a regional network. Most of the institutions had CRCHD funding at the time, and the nine partner institutions were identified: Winship Cancer Institute of Emory University, H. Lee Moffitt Cancer Center & Research Institute, Morehouse School of Medicine, Ponce School of Medicine, Tulane University, Tuskegee University, University of Alabama at Birmingham, University of Mississippi Medical Center, and Xavier University of Louisiana. The partner institutions included those with a demonstrated excellence in cancer [one NCI-designated cancer center; two NCI-designated comprehensive cancer centers; and two Commission on Cancer (CoC) accredited programs], and four minority-serving institutions. This make-up of the partner institutions was intended to provide a base of expertise in cancer health disparities from biobanking to clinical trials to community engagement. A subsequent series of regional teleconferences among institutional leaders at the nine institutions was held to determine how Region 3 would respond to the call for applications. An Administrative Core of the leaders at each institution was formed through these teleconferences. Senior leadership, such as cancer center directors, deans and/or Principal Investigators of center grants in health disparities, made up the Administrative Core. While the title of the leaders may have varied, the qualifier of the institutional leadership across the network was that they be the responsible contact for cancer health disparities research at their institutions. In addition to institutional leaders, the Administrative Core consisted of the core leaders who had a strong track record of professional experience in the area of their core and included investigators from both cancer centers and minority serving institutions. Institutional leaders also served as contacts to their institution in identifying investigators that would be core members. While the program strived to have at least one investigator from each institution in each core, it was recognized that the base of investigators at minority-serving institutions and teaching demands limited the number of investigators and their time commitment. Even though the number of investigators participating in Region 3 GMAP and BMAP was not equal between each institution, an Administrative Core made up of institutional leaders from every institution in the network served to balance participation by having representation from all partners in a core with the responsibility for network-level decision-making. Also, decisions on next steps of the network, the needs and assets assessment, implementation plan, and general formation of the network, were brought up in plenary sessions of retreats for transparency and participation across the network.

During a teleconference of the institutional leaders, it was decided by consensus that the University of Alabama at Birmingham (UAB) would submit the GMAP supplement on behalf of Region 3 due to extensive experience of the institution's investigators in health disparities research. Moffitt Cancer Center (MCC) was selected by consensus to submit the BMAP supplement because of prior work in biospecimen donation and biobanking

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