

# Patient Voices Network: Bringing Breast Cancer Awareness and Action into Underserved Communities

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**Abstract: Background/Purpose:** African American women are diagnosed with breast cancer at later stages and have higher mortality rates than white women. The Patient Voices Network (PVN), a community group whose vision is "a community of educated and involved patients working hand in hand with physicians in making decisions about their own health care," conceived of and implemented a walk to raise awareness of breast cancer and link women to screening resources in a low-income, urban community.

**Objectives:** To describe the planning and implementation of the Concerned About You: Breast Cancer Awareness Walk & Wellness Event and its impact on an academic community partnership.

**Methods:** A narrative approach was used. Meeting minutes and event planning notes were reviewed. Community participation rates and participant satisfaction were tracked using registration records and a survey administered at the event.

**Results:** 328 community members registered and 194 attended. Responses to a satisfaction survey indicated community buy-in and interest in future events. Two women were screened at the event and 78 were screened at a follow-up opportunity at their primary care practices. The process was driven by participatory guidelines and laid the foundation for future activities.

**Conclusions:** Community input addressed the need for screening mammography in an underserved community. The partnership approach featured complementary strengths of both patients and University staff, fostered skill building and co-learning, and ultimately strengthened our partnership. A partnered approach may be effective in engaging hard-to-reach populations to address health disparities.

**Keywords:** African American ■ participatory ■ health outreach ■ breast cancer ■ Health disparities

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## INTRODUCTION

African American women are diagnosed less frequently with breast cancer, yet die more often than non-Hispanic white women, and have the lowest five-year survival of any racial/ethnic group in the United States.<sup>1,2</sup> Although incidence of breast cancer among African American women is increasing, presumably due to increased screening, they have higher rates of late stage diagnoses that non-Hispanic white women.<sup>1,2</sup> These racial disparities are compounded by socioeconomic factors including inadequate health insurance and lower family income.<sup>3,4</sup>

To address these disparities, many organizations host campaigns that aim to raise awareness of the importance of breast cancer screening. Often these events are fundraisers and are held in affluent communities, thereby limiting their impact among low-income, minority women. Without broader community involvement, such programming has the potential to fall short of reaching communities that experience a greater burden of breast cancer mortality.

Culturally tailored practice- and community-based outreach interventions have been designed and implemented to more effectively reach African American women and to address disparities in screening and breast cancer mortality.<sup>5–7</sup> Many of these interventions employ community-based participatory approaches, involving community members in their design and implementation.<sup>8–11</sup> These approaches attempt to address cultural context and issues specific to communities, adding local knowledge to the design of health intervention programming.

This manuscript tells the story of the development and implementation of one such event with particular attention on the impact of utilizing a participatory process on a community academic partnership between the University at Buffalo Department of Family Medicine researchers and the Patient Voices Network (PVN).

## Patient Voices Network (PVN)

The PVN is comprised of patients affiliated with four safety net primary care practices in the city of Buffalo. Three

practices are located on the East side of Buffalo and serve predominately low-income African American patients. The other practice is located on the West Side of Buffalo and serves a diverse patient panel comprised of Hispanic patients, predominately of Puerto Rican descent, and refugee patients from over 70 countries. PVN members are predominantly low-income, minority, and female and manage multiple chronic conditions. Their vision, “a community of educated and involved patients working hand in hand with physicians in making decisions about their own health care,” is achieved through community outreach, patient peer support, provider education and practice advisement. The PVN originated in 2010 with funding from the National Institute of Minority Health and Health Disparities (NIMHD) with the intent to develop a practice specific intervention to increase preventive cancer screening in partnership with a community based research team in the University at Buffalo’s Department of Family Medicine.<sup>12</sup> The PVN chose colorectal cancer screening as their focus, and developed a practice-based intervention to increase screening.

### *The vision*

Even though the PVN initially focused their efforts on increasing colorectal cancer screening, they strongly expressed concerns about the impact of breast cancer in their communities. After members of the PVN Steering Committee joined the research team at a lecture about breast cancer disparities among African American women, they recognized the need to reach out to the East Side of Buffalo, a predominantly low-income African American community that experiences these disparities, despite its shared border with Buffalo’s growing Buffalo Niagara Medical Campus (BNMC). The PVN felt that bringing a breast cancer awareness walk into the community would provide an opportunity to bring local health care providers and community members together and would be a positive way to talk about breast cancer, personal risk, and local screening resources. The research team was committed to working with the PVN to make this a reality.

The research team and the PVN together prepared and submitted an application for funding to the Western New York Affiliate of Susan G. Komen Foundation and were awarded a small grant to turn the idea of a breast cancer awareness walk into a reality.

The vision for this event was to create a breast cancer awareness program driven by patients for patients under the name “*Concerned About You.*” Due to community dynamics, the PVN Steering Committee realized that one single event would not effectively reach both the East Side and West Side residents. The West Side had many initiatives occurring geared towards improving the community and little was being done on the East Side. Collectively,

the PVN decided to focus this event on the East Side of Buffalo and the African American community.

The PVN members were committed to bringing information right into a community that is usually neglected. The PVN Steering Committee recognized that in this community “*most of the [media] exposure is from shootings and violence.*” PVN members felt that hosting this walk would provide an opportunity to gain positive media exposure for the East Side, and would create an opportunity to bring the community together. PVN members also wanted to showcase East Side assets, many of which are located along the walk route itself. The walk route was designed to begin and end at a park three blocks from the medical campus, and to pass by prominent East Side churches, schools, and several historic landmarks, including the former home of the Buffalo Bills, our hometown National Football League franchise. The route chosen was about 1.5 miles in length. PVN members recognized that longer distance events may discourage people from participating, particularly those with limited physical abilities.

Finally, the PVN members stressed the importance of addressing one other key barrier that prevents people from participating in similar events, fees associated with participation. PVN Steering Committee members recalled conversations with friends who wanted to participate in events like the Susan G. Komen Race for the Cure, but could not afford the registration fee. Rather than pay expensive registration fees for these events, PVN members emphasized that people in this community first needed to pay for medications, food, and clothes. PVN members believed that cost should not be a barrier, and that everyone should have access to information and resources that can help them lead a healthy life. Thus it was critical to PVN members that the event be free to register and participate.

## **METHODS**

A narrative approach is used to describe the process by which the walk was designed and implemented. Details related to planning this event were captured in PVN Steering Committee and individual project planning meeting minutes. These records were reviewed to generate a description of the tasks and decisions undertaken in planning this event.

Administrative data collected for the event were used to describe participation and satisfaction with the event. The use of this data was approved as exempt by the University at Buffalo Social and Behavioral Sciences Institutional Review Board.

### *Promotion and outreach*

Together, the PVN and the research team developed promotional materials, including door hangers, flyers,

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