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Title: Patient Voices Fights Cancer: Creating a community-based initiative to address high cancer incidence rates in a disproportionately affected community

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Background: High incidence rates of six cancers (lung, prostate, colorectal, esophageal, kidney and oral) were identified in a low-economic, predominately Black neighborhood in the East Side and West Cheektowaga area, highlighting a need for increased cancer messaging and awareness. The Patient Voices Network (PVN), a group of empowered patients who advocate for themselves and others, collaborated with researchers from University at Buffalo to create a community-based, patient-driven cancer awareness initiative using Community-Based Participatory Research (CBPR) methods.

Objective: To describe the process of developing a cancer awareness initiative by using a CBPR approach with collaboration among the local health department, community-based organizations, practices and researchers.

Design: Process evaluation using CBPR approach

Setting: East Side of Buffalo and West Cheektowaga, NY

Program: Patient Voices Fights Cancer (PVFC), a patient-powered, community-based cancer awareness campaign, encourages patients to talk to their doctors about cancer risk and preventative screening. PVN met bi-weekly with the Research Team (RT) over a six-month period to develop and implement an action-oriented campaign based on the needs of the community. As interest in the campaign increased, PVN gained new members from the affected neighborhoods, willing to learn and advocate for their community.

Results: Thirteen PVN meetings were held with an average of 21 participants in attendance from July 1st to March 31st, 2019. PVN members voiced opinions, gave feedback on materials, planned events, and brainstormed ideas for various aspects of the campaign. PVN members gained information to share and become their own self-advocates, as well as, becoming advocates for their community. Specifically, PVN revised an appointment planning worksheet (APW) for PVFC that focused on how to talk to your doctor about cancer prevention, assisted the RT in the development of cancer tool kits for community organizations and providers and six specific 9x5 cancer summary cards (lung, prostate, colorectal, esophageal, kidney and oral) to disseminate into the community. The cancer summary cards incorporated the key components of each cancer, including local resources within Erie County to combat cancer screening barriers and specific questions to ask your doctor. These elements were specifically recommended and vetted through PVN with assistance from local providers and health agencies to ensure accuracy of the information provided. The vetting process was iterative and continuous, ensuring community voice was represented throughout the campaign. Additionally, PVFC collaborated with a media team to create a marketing campaign surrounding culturally relevant cancer messaging focusing on the idea of understanding cancer risk and discussing cancer screening with a primary care provider.

Conclusion: Community based groups are an integral part of public health initiatives; representing the collective voice of communities facing adverse challenges. Incorporating community involvement in public health campaigns ultimately leads to greater buy-in from community members, organizations, and practices while also increasing connectivity and resonance between intended audience and overall messaging. Involvement of patients, community members, or groups from development to implementation can be replicated in a variety of research-based programs and the role of community engagement in research adds value in creating trust and long-lasting partnerships that can facilitate future programs and grants.