

# STRATEGIES FOR COMMUNITY PARTICIPATION IN CANCER PREVENTION

Groesbeck Parham, MD; Claudia Hardy, MPA;  
Freddie White-Johnson, MPPA

## INTRODUCTION

In developing strategies to encourage community participation in cancer prevention, it is fundamental to remain open-minded, self-critical, and creative. Often times, our level of creativity and flexibility will determine a community's willingness to cooperate, and often theory, as told to us by university experts, does not work well without creativity in the real world. We must keep our minds open and approach a community as we would an individual; not with preconceived notions of what that community is, but ready and willing to learn what has made the community what it is. There are several key aspects of a community that should be understood if a project is to succeed.

## UNDERSTANDING THE COMMUNITY

### Community Organization

Perhaps the organization of a community is the most fundamental aspect that should be understood before attempting project implementation. Every community has a social hierarchy, even poor ones. There are families who are influential, individuals who are well respected, and institutions, that are integral to the community's existence. Understanding this type of structure can shape the direction of a project; it requires continual effort to ensure that the community and the project remain in step as the project grows.

### Community History

To understand the social organization of a particular community, review the community's history. A community's history can lead to a better conception of the character of its people. The his-

tory of many neighborhoods dictates its personality, which gives insights into the character of the individuals living there. For example, a community located in the poorest part of Jefferson County, Alabama, might, at first look, reveal that its inhabitants suffered from the social ills of poverty: high crime rates, poor education, illiteracy, poor health, absence of motivation and self-esteem. Yet, the people from this community may have a tremendous reputation for being extremely bright, very well dressed, and of high moral character. Perhaps this scenario is due to one influential person (a high school principal) who helped to implant these important characteristics into the community's children for years. As result, in one of the most destitute parts of the county, the people may dress better than anyone around them and the children may study harder and graduate at the top of the high school class. This is an important part of the history and character of that community.

### Community Infrastructure

It is also important to understand a community's communication infrastructure to know how information gets from one place or person to another within the community. For poor or minority communities, this becomes even more vital as communication is often spread in very informal ways. For some communities, the key communicators may be found in barbershops, hair salons, what we once called "shot houses," or liquor houses, and churches. There has been much in the literature about the importance of the church in the Black community. Although it is significant, it is not the only place that's important to the community. We must understand how communication moves *and* who

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From the University of Alabama School of Medicine (GP); and the University of Southern Mississippi (CH, FWJ).

moves it. To distribute effective messages about the prevention of cancer, we must understand the validity and reputation of the messenger; the medium is as important as the message.

### Community Empowerment

Lastly, it is important to know how and when to empower other people in the community who have the skills and influence to coordinate various aspects of a project. A description of the Deep South Network for Cancer Control follows and illustrates empowerment strategies.

## THE DEEP SOUTH NETWORK FOR CANCER CONTROL

The University of Alabama School of Medicine is sponsoring a program, the *Deep South Network for Cancer Control* (The Network), which is designed to incorporate many of the basic tenets cited above, about communities. It is a collaborative effort between the University of Alabama School of Medicine and the University of Southern Mississippi. The Network is one of 19 special population networks funded by the National Cancer Institute (NCI) to try to find innovative ways of decreasing racial disparities in cancer incidence and mortality in the United States. In developing The Network, the principal investigators chose to target cancer of the cervix and breast because mortality rates are excessively high among African Americans, but can be significantly reduced with early and regular screening. Additionally, the CDC-funded Breast and Cervical Cancer Early Detection Program provides free screening, diagnosis, and treatment of these cancers in medically under-served indigent women.

The target population of this effort is medically under-served African-American women in Alabama and Mississippi. In Mississippi, urban areas served by the program are Hattiesburg and Laurel,

and the rural area are in the Mississippi Delta area. In Alabama, Jefferson County, an urban area, and the rural Alabama Black Belt are target areas in the program. The Alabama Black Belt and the Mississippi Delta areas were selected because they house the poorest African-American populations in the United States. The per capita income in most of these areas hovers around \$12,000 and approximately 60% of the population is African-American. In some of these counties, the African-American population reaches 80% to 90%.

### Methodology

The methodology of this cancer prevention program builds upon existing community infrastructures—it does not create new ones, but goes into selected communities to build upon indigenous infrastructures that already exist. The objectives of The Network are to: 1) develop community-based infrastructures to promote cancer awareness; 2) stimulate community-based cancer control research; and 3) increase the number of African Americans, specifically poor African Americans, who participate in clinical trials.

One of the most important elements of the program's structure is the Community Health Advisor (CHA). The CHAs are the heart of this program; they are volunteers who were identified because they were known as "natural helpers" in the targeted communities. They are grass-roots political and social activists and are well-known and respected in the community. From this group of women, we selected county leaders. Of the CHAs, 93% are female; 96% are African-American; approximately 50% are married; and the average age is 50. Education and employment levels of the CHA team vary widely: approximately 40% of the women have less than a high school education, about one third have completed high school, and 40% have attended community college and higher. Nearly 60% of the women are currently employed

full or part-time; about a third of the women report that they have problems maintaining adequate housing. The CHAs list the following reasons for participating in the program: 1) to help people; 2) to help my community; and 3) to get involved with health issues. Most were recruited through organizations or friends.

CHAs attend an 8-week community health advisory training course presented by university professors. Topics during the course include: the nature of cancer; breast health and cancer; cervical cancer; the physiology and anatomy of the cancers; cancer treatments; clinical trials; how to plan cancer awareness strategies; and how to increase the awareness of breast and cervical cancer within the community. The 8-week program encourages the CHAs to return to the community to preach the "gospel" about cervical and breast cancer and to encourage individuals to be screened.

Using the CHAs as the driving force of the program offers a method that provides a lasting impact on the community; advocacy of this type will not and cannot be turned off once funding comes to an end. The CHAs are women who, once empowered, will continue their work through their commitment and dedication to the community. It appears their commitment may also lead them to become activists for cancer control policy change.

### Project Results

The project is currently in year 3 of a 5-year plan. Eight hundred forty-five CHAs have been trained and are actively conducting awareness activities. The Network has also mobilized partnerships with "majority" organizations, such as the state and local health departments, the Breast and Cervical Cancer Early Detection Program and the Cancer Information Service, and a new partnership of various grassroots organizations, the Alabama-Mississippi Partnership for Cancer Control for the Under-served.

While it is difficult to determine the

true success of the cancer awareness efforts, we can monitor the number of women who report for cancer screening. When The Network first started, (1997), only 1% of the women eligible for free pap smears and free mammograms in Alabama were signed up. As of 2000, that number was up to 15%. The state of Mississippi reports that, with a few exceptions, for communities with CHAs, mammography rates are increasing in African Americans.

### Improvements Needed

In terms of community-based cancer research, one goal is to encourage and train more minority investigators or scientific investigators who are interested in studying racial health disparities. To be most effective, research ideas should

originate from the community, but it unfortunately starts at the top and trickles down. Young investigators at the universities conceive research projects and then go to the community to find community health advisors who are interested in supporting it. We need to work harder at generating research ideas from the community. Perhaps if more people at the community level were taught how to frame a problem as a research issue, as opposed to a service issue, we could reach the objective of tapping into the creative intellectual forces that exist in these communities to help solve the problems.

In terms of enrollment of African Americans into clinical trials, the University of Alabama enrolled more than 6,000 people in the prostate, lung, co-

lon, ovarian (PLCO) cancer clinical trial. Six hundred of these participants resided in 4 of the counties where CHAs worked; of the individuals recruited from these areas, 90% were African-American.

### CONCLUSION

In summary, the CHAs of The Network have been empowered to make a difference in the health of their communities. Early evidence suggests positive results; yet sustainability of the program remains a critical determinant of its long-term effect. We must ensure the continuity of the program to prevent its demise. For any program, it is critical to discuss strategies for sustainability before it can be considered a true success.