



Translating Community-Based Participatory Research into

Practical Solutions



About the Highmark Foundation

The Highmark Foundation, created in 2000 as an affiliate of Highmark Inc., is a charitable organization and a private foundation that supports initiatives and programs aimed at improving community health. The foundation's mission is to improve the health, well-being and quality of life for individuals who reside in the Pennsylvania communities served by Highmark Inc. The foundation awards two types of grants: Highmark Healthy High 5, which includes a focus on the health and well-being of children in the areas of physical activity, nutrition, self-esteem, bullying and grieving; and its traditional four areas of general health focus, which include chronic disease, communicable disease, family health and service delivery systems. Where possible, the foundation looks to support evidence-based programs that impact multiple counties and work collaboratively to leverage additional funding to achieve replicable models. For more information about the Highmark Foundation, visit www.highmark.com.

Executive Summary

This brief, *Translating Community-Based Research into Practical Solutions*, is part of a series that addresses issues of importance to the Highmark Foundation and its commitment to the health, well-being and quality of life of individuals and communities in the 49-county region of Pennsylvania served by Highmark Inc.

It will review evidence-based, practical solutions or programs created from community-based participatory research (CBPR) that are designed to reduce the burden of chronic disease in underserved populations. These programs offer sustainable, replicable and viable solutions that address health issues through multidisciplinary approaches. The featured programs acknowledge the importance of individual and community empowerment to address health disparities and are offered at no-cost to participants.

CBPR is differentiated from traditional research in that it completely involves the community as a partner in every aspect of evaluation – from identifying issues of greatest importance to assisting with research and translation of findings. Involving the community in the research enhances opportunities for acceptability, trust and achieving social change to improve health outcomes.

Since 1998, multi-year grants totaling approximately \$1.1 million, including \$756,450 from the Highmark Foundation and almost \$400,000 from Highmark Inc., assisted three organizations with implementing multidisciplinary approaches for improving community health. The programs began as community-based, participatory research projects with the intention of meeting the health needs of underserved populations and eliminating health disparities. With the support of partners, including funders, communities, corporations and universities, these programs continue to have a significant impact. Each of these organizations is currently sustaining program activities and expansion into other communities.

The Highmark Foundation is supporting practical solutions from CBPR that have been developed with community input. These programs use innovative strategies to reach underserved communities with the overall goal of improving participants' health and well-being. The programs are cost effective, have the potential to reduce disparities in health and improve clinical outcomes for individuals with chronic disease.



Background

There is increased interest in research that aims to improve the health of disadvantaged populations such as minorities, low-income individuals, people living in rural and urban areas and individuals with special health care needs. Conventional or traditional research in these communities, however, has a contentious history and offers limited opportunities to improve the health and well-being of the target population. Three factors require a look toward community-based participatory research (CBPR) to improve the health of disadvantaged communities.

1. Local community knowledge increases understanding of the complex interactions among economic, social and behavioral factors that contribute to disparities and, therefore, should inform the design of interventions aimed at reducing these disparities.
2. There is a gap between the knowledge produced in research and practiced in these communities.
3. Members of these communities are increasingly reluctant to participate in research and are organizing to monitor and/or prevent such activities.¹

CBPR has its roots in social and political movements of the 1940s, which saw a revitalization in the 1960s and 1970s. In the 1940s, Kurt Lewin began talking about action research as a means to overcoming social inequalities; he also rejected the notion that in order for researchers to be “objective” they needed to remove themselves from the community of interest. Later writings by educator Paulo Freire in the 1970s brought to the forefront issues of having communities identify their own problems and solutions. The rationale for CBPR builds on this history.²

In recent years, national organizations, funding agencies and researchers have called for a renewed focus on an approach to public health research that recognizes the importance of social, political and economic systems to health behaviors and outcomes. This renewed focus is due to many converging factors, including our increased understanding of complex issues that affect health, the importance of both qualitative and quantitative research methods and the need to translate the findings, if basis, interventional and applied research into changes in practice and policy. As a result, participatory models of research in which communities are actively engaged in the research process through academic institutions have become central to the national prevention research agenda.³



What Is Community-based Participatory Research?

CBPR is not a method or set of methods. It is typically viewed as a qualitative approach with fewer epidemiologic examples with promising results. The goal of CBPR is to influence change in community health, norms, systems, programs and policies.⁴ CBPR usually involves a working relationship between one institution’s academic research and one community-based organization with public health concerns, such as a church or neighborhood association. The community-based organizations of interest are those from and representing underserved communities.⁵

CBPR is a collaborative approach to research, or orientation to conducting research, that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and what is practiced in communities to improve health. This approach is particularly attractive for academics and public health professionals struggling to address the persistent problems of health care disparities in a variety of populations that are identified by factors such as social or economic status, lack of health insurance, or membership in various racial or ethnic groups.^{6,7}

Distinct from research conducted in a community, CBPR seeks to conduct initiatives with community members by beginning with a research topic of importance to the community, having the goal of combining knowledge with action and achieving social change to improve health outcomes and eliminating health disparities.⁸ CBPR challenges researchers to listen to, learn from, solicit and respect the contributions of, and share power, information and credit for accomplishments that they are trying to learn about and help.⁹ The challenge of the coming years will be to link lessons learned from involving communities in research to the daily work of programs in public health.¹⁰

CBPR partnerships often codify their partner relationships through signed memoranda of understanding (MOU) or memoranda of agreement (MOA). MOAs or MOUs are essential in keeping the partnership together by setting up a strong infrastructure, policies and procedures from the start. These documents encourage meaningful planning processes that ensure each partner is respected and heard.¹¹

Accumulating evidence suggests that the most effective public health prevention strategies are those that actively engage the communities that are intended to be served.¹² The inclusiveness of CBPR is the reason it is more widely accepted than traditional research methods.¹³



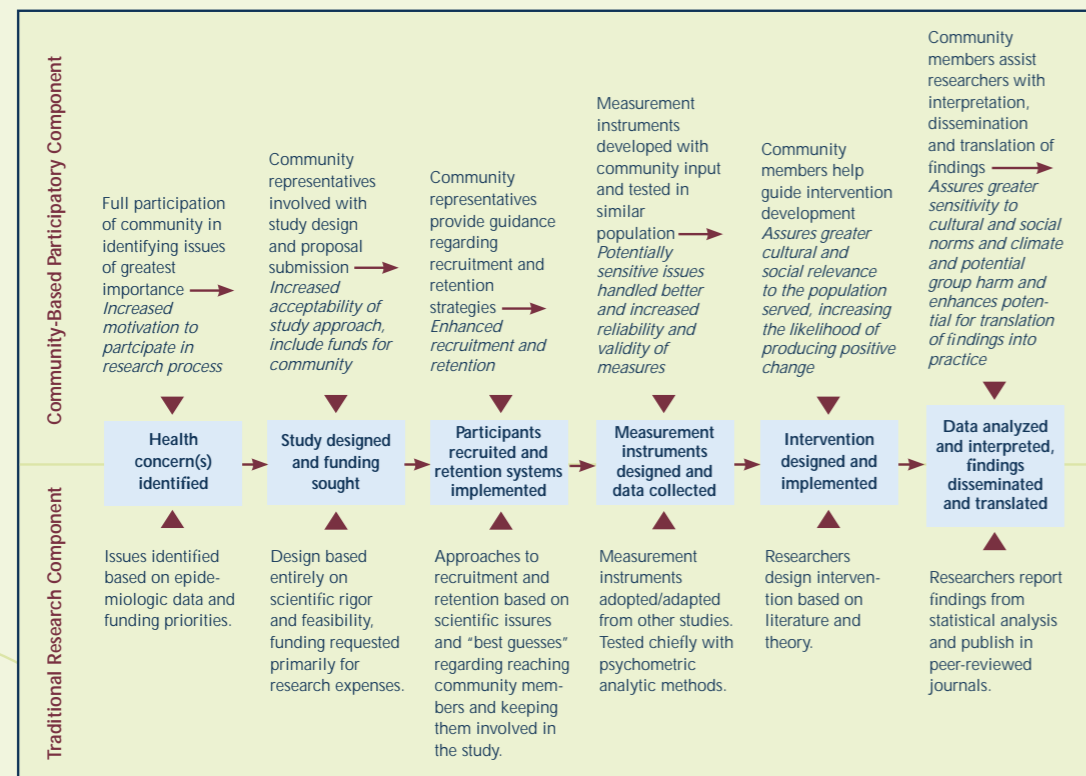
New Solutions to Old Problems: CBPR versus Traditional Research

A growing awareness that traditional research approaches are not able to solve complex health disparities is apparent. Many research designs do not incorporate multilevel explanations of health, and the researchers themselves do not understand many of the social complexities motivating the behaviors of individuals and families. Moreover, researchers and communities alike are often unaware of the fundamental differences between CBPR and traditional methods.¹⁴

CBPR differs from traditional research in many ways within traditional research, where researchers have more power and control over resources and decisions than the community. CBPR, in contrast, is a more modern, equal approach in which the researchers and community members recognize and build on each other's strengths and share resources and responsibilities. People in communities seen as patients and research subjects benefitting from medical advances are now invaluable partners and experts who can shed light on the root causes of illness and galvanize their communities to develop effective, novel, sustainable interventions to improve health and eliminate disparities.¹⁵

Another fundamental difference is, instead of creating knowledge for the advancement of a field for knowledge's sake, CBPR is an iterative process, incorporating research, reflection and action in a cyclical process.¹⁶ Figure 1 illustrates the key differences between traditional research and CBPR.¹⁷

Figure 1: Analytic Framework for Community-based Participatory Research



Challenges/Barriers to CBPR

Although CBPR offers new hope to old solutions, it is not perfect and may not be appropriate for every community-based research project. There is a growing recognition of the importance and promise of this type of research within health services and public health institutions and funding organizations. In spite of the increased interest expressed by these groups, CBPR is underutilized. Institutional barriers have sometimes prevented CBPR from becoming an accepted research model in many academic institutions, and there are very few researchers who have had formal training in the method or role models from whom they could learn.

Practitioners of CBPR have identified several barriers that may adversely affect its effectiveness, including:^{18, 19, 20}

- Prior shameful abuses of human subjects in the past cause skepticism among community leaders, resulting in beneficial research outcomes that are not translated into ongoing community programs, practices or policies, often driving these studies to dead-end leads.
- Experts, policymakers, funders and community leaders' frustration with the inability, lack of capacity or lack of knowledge among investigators to translate findings into practical solutions to improve the health of various groups, especially minority communities and other disadvantaged populations are a matter of growing concern.
- Relationship building often takes longer than clinical research, resulting in a greater amount of time to demonstrate successful outcomes.
- Inadequate funding or lack of funding flexibility. Funders often do not understand that CBPR is a long-term process that may require years before successful outcomes are demonstrated. Moreover, still less is known about the degree to which CBPR has been effective in sustaining long-term university-community partnerships and generating high-quality data to guide further research.
- Limited understanding of the CBPR concept and perception that it lacks rigor can cause difficulty with program evaluation.

Only when these challenges are resolved and researchers and communities develop a greater understanding of CBPR can it be effectively integrated into existing interventions to successfully create practical solutions and opportunities for behavior change.



Benefits of CBPR

Despite the challenges and barriers, when properly implemented, CBPR has huge benefits for community participants, health care practitioners and researchers alike by increasing translation of evidence-based research into successful, sustainable community change. Collaboration among these entities further lends itself to making projects more effective and efficient. The following benefits make CBPR worthwhile:²¹

- Creates bridges and builds trust between scientists and communities through the use of shared knowledge and valuable experiences
- Enhances relevance of research questions
- Enhances reliability and validity of measurement instruments
- Improves response rates
- Enhances recruitment and retention and strengthens interventions by incorporating cultural beliefs into scientifically valid approaches
- Provides immediate benefits from research results to the community

CBPR is beneficial only when it works to effect worthwhile changes and immediate benefits are realized. This is also a significant difference from traditional research, where results may not be disseminated until years after the project has been concluded and the issue(s) that it intended to solve either still exists or has worsened.

The Role of Funders and Funding in CBPR

Other than providing grant support to initiatives, funders may have difficulty defining their role in the project. Although funders consider themselves to be an integral part of the process, it has been suggested by researchers that once funders have judged the merit of the project, they move aside allowing autonomy for the community and research partners, limiting themselves to providing accountability for the project.²²

Funders have resources that can act as a catalyst; however, they are challenged to build capacity in communities with multiple needs and few assets. They struggle with the need to balance unique insights into one community and knowledge that can be transferred to other communities. Funders need benchmarks for success and guidance from researchers when these benchmarks are not achieved. If benchmarks are not achieved, funders are less likely to support other CBPR projects, even those with merit. Therefore, CBPR must demonstrate its value through clear metrics, develop appropriate benchmarks to measure success and clarify the types of research questions for which it has the most value.²³

Funding has been identified as a barrier to successful CBPR because few guidelines exist to indicate how research proposals should be evaluated and what financial resources are required to promote successful efforts. Therefore, private and public funders face challenges in determining how to support and/or sustain outcomes and the practical solutions. Funding for community-based participatory research must focus on achieving equitable outcomes and examining the process to reverse power dynamics. For this to occur, funders must understand that flexible methods are needed to solve community problems and funding/incentives must be connected to measures of authentic, deserving work.²⁴

Funding non-traditional projects such as CBPR can cause concern for funders, particularly if the outcomes do not meet their expectations or demonstrate a significant impact. Both large and small philanthropic organizations, including the W.K. Kellogg Foundation, the Ford Foundation, the Annie E. Casey Foundation, the California Endowment and the Aspen Institute, have provided substantial funding support for action-oriented CBPR approaches in health and related fields. In addition, other local foundations have played leadership roles in advocating and funding a form of CBPR – participatory evaluation or “empowerment evaluation” – as a means of increasing community capacity while actively engaging those affected by a particular program intervention in ongoing efforts to assess and improve its outcomes and effectiveness.²⁵

While foundations often pride themselves on their commitment to “results-oriented philanthropy” and are increasingly viewing CBPR as an action-oriented approach that fits within this framework, it has been federal government funding, rather than foundation funding that has played the biggest role in spurring CBPR in the United States.²⁶ Although the amount of federal and private foundation support continues to increase, studies have documented that researchers continue to have considerably more difficulty obtaining funding to support CBPR than obtaining funding for other research.²⁷ Part of that difficulty stems from the ability to effectively assess project activities, which helps funders, determine the size of the grant, whether the project meets eligibility of the respective foundation, and more importantly, whether the benefits can be translated into replicable solutions.

Evaluating CBPR²⁸

Funders may benefit from using the detailed set of guidelines and criteria developed by a health researcher from the Centers for Disease Control and Prevention (CDC) for assessing the goodness of fit between CBPR research proposals and the principles of participatory research. The guidelines include a range of scaled question items for funders to consider, among them:

- Did the impetus for the research come from the community?
- Is attention given to barriers to participation, with consideration of those who have been underrepresented in the past?
- Can the research facilitate collaboration between community participants and resources external to the community?
- Do community participants benefit from the research outcomes?
- Is there attention to or an explicit agreement between researchers and community participants with respect to ownership and dissemination of the research findings?

These guidelines formed the basis of discussions and decision-making regarding the feasibility of beginning a CBPR research agenda in Alberta, Canada, and a modified version is being used in the University of California's funding programs in tobacco control and breast cancer prevention research. The guidelines also were posted on the CDC web site in conjunction and were used by some members of an external review panel to help guide funding decisions.

Evaluation of CBPR efforts should include greater attention to such intermediate outcomes as the effects of community participation itself. Are new community structures or problem-solving mechanisms in place as a result of the project? Have new leaders emerged? Is there evidence of a deeper sense of community ownership or civic participation? Questions such as these may help capture critical mediating variables between the implementation of CBPR efforts and the achievement of distal health and social change outcomes.

These questions could also be helpful in assisting funders in determining the merit of a project for funding consideration and also determining sustainability, which is critical to the success of CBPR.



Sustaining CBPR²⁹

The literature has contributed greatly to understanding the challenges and facilitating factors associated with developing partnerships. Issues, however, related to the long-term sustainability of partnerships and activities have received limited attention. Sustainability has been discussed in the public health literature in terms of both partnerships and specific health programs or interventions. Sustainability depends on numerous factors that impact the formation and maintenance of CBPR partnerships. Sustainability is important; however, there is little consensus among funders and researchers on how it is defined or conceptualized. Three broad dimensions important for sustainability have been identified:

1. Sustaining relationships and commitments among the partners involved
2. Sustaining the knowledge, capacity and values generated from the partnerships
3. Sustaining funding, staff, programs, policy changes and the partnership itself

The presence or absence of core funding affects each of these dimensions of sustainability. It may also be necessary to sustain the partnership by other means, particularly the health benefits of a program over time.



Best Practices

The real world challenges to CBPR are to ensure that all parties are equal contributors to the project and that the project is planned by those who will be most affected. There are many best practices to reduce health disparities that have been successfully replicated in communities across the United States. These best practices include programs and projects involving community health and wellness, physical activity programs, cardiovascular/heart health, mammography intervention for African American women, Native American health, colorectal cancer education and screening, immunization, cancer research, cultural diabetes, breast and cervical cancer screening intervention, and ethnic research.

Urban Research Centers (URCs) located in Detroit, New York City and Seattle, established in 1995 with core support from the CDC, are the most widely documented successful approaches to CBPR. The goal of the URCs is to improve the quality of life of disadvantaged urban residents through research and intervention using a CBPR approach. Although these centers experienced challenges similar to other CBPR, the findings were translated into replicable community-based practical solutions.³⁰

In addition, The Evidence Report/Technology Assessment, Number 99 of the Agency for Health Care Research Quality contains detailed program descriptions of successful and unsuccessful CBPR, such as study participants, data collection methods, study design, measurement and evidence that research findings were used to address intended health issues.³¹

Role of CBPR and Social Determinants of Health

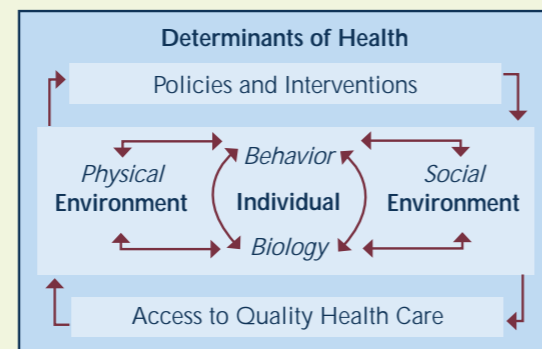
There is no doubt that social factors often addressed by public health practitioners, such as biology, education level, socioeconomic status, the condition of housing, the healthfulness of physical environments, employ-

ment, and the effects of stress and racism, contribute to health outcomes. The effect of these *social determinants of health* should be the concern of the entire health community. The negative effect of certain social factors on people's health is especially pronounced among some minority groups, and the health disparities that these groups have experienced are now garnering attention.³²

Social determinants of health contribute to or detract from the health of individuals and communities. CBPR can be a response to genetics or health behaviors derived from the social determinants of health by developing and implementing policies and preventive interventions that effectively address these determinants. Health behaviors affect the social environment, which, in turn, affects the larger community. These interventions and their practical solutions can reduce the burden of illness and improve health by targeting factors related to individuals, including access to quality health care. Figure 2 illustrates the social determinants of health and the implications for CBPR.³³

Generally, organizations incorporate a conceptual model of the social determinants of health and their indicators to guide their research and intervention efforts, assess the health needs and established priority areas to address, conduct an evaluation of its partnership process, conduct a demonstration project, and establish a core infrastructure.³⁴

Figure 2: Social Determinants of Health



Highmark Foundation's Approach to Funding CBPR Projects

CBPR has proven to be effective in reducing health disparities and improving health outcomes for disadvantaged communities. The Highmark Foundation (Foundation) is committed to improving community health with grants to demonstrate replicable and sustainable ways to address health issues that impact underserved communities. For this reason, funding projects that involve community engagement and participation to advance health equity are aligned with the Foundation's mission. These organizations implemented different multi-disciplinary approaches to address social determinants of health using CBPR through different strategies with the same goal – improving community health status of underserved populations.

Since 2002, the Foundation has awarded grants to the University of Pittsburgh Graduate School of Public Health Center for Minority Health's Healthy Black Family Project (\$200,000), Washington County Health Partners WellLife™ and Health Ministry Initiatives (\$310,450) and Centers for Healthy Hearts and Souls Healthy Individual, Family and Community Program (\$246,000), totaling \$756,450 to support programs/interventions which began as CBPR. In addition, through the Corporate Giving Program, Highmark Inc. awarded start-up grants totaling approximately \$400,000 to Washington County Health Partners (\$24,937) and the Centers for Healthy Hearts and Souls (\$375,000). These community-based organizations turned years of research, focus group responses, pilot projects and community assessments into practical solutions to address health disparities in minority and low-income communities. Outcomes have been disseminated via monthly newsletters, brochures, newspaper articles, community meetings, and television and radio programs.

The second grant awarded to Washington County Health Partners and the grant awarded to Centers for Healthy Hearts and Souls are currently active. The first grant to Washington County Health Partners concluded in 2004, while the Healthy Black Family Project grant concluded in 2007. Each of these projects continues to remain viable in the communities it serves. As a funder, the Foundation's role is serving in an advisory capacity, monitoring program progress and providing technical assistance to grantees when necessary. Outcomes reported from grantees indicate that these programs are successful in reducing the burden of chronic diseases.

Local Funding Strategies

One funder alone cannot support every project or issue. Therefore, the Foundation has positioned itself as a leader by forging collaborations with other funders in the region to strengthen grant funding to organizations that provide programs and services for underserved communities at risk for poor health outcomes. Funding assists with designing, implementing and delivering programs and services that are designed to build strong individuals, families and communities. Described below are three organizations – two faith-based and a university – and their efforts to implement and sustain interventions developed as a result of CBPR.

Centers for Healthy Hearts and Souls (CHHS)

The mission of CHHS is to motivate individuals, families and communities to reach their achievable optimum health status through health education, prevention and wellness activities to stimulate personal growth and societal change.

Background

CHHS began as a faith-based health initiative under the umbrella of the Pittsburgh Pastoral Institute located in the East Liberty section of Pittsburgh. CHHS evolved as a result of local pastors and churches' focus on meeting the needs of minority populations with the goal of eliminating health disparities.

Developed originally to address the high incidence of heart disease in the African American community, CHHS brought together the local church and health care communities to conduct prevention and education programs to enhance the physical and spiritual well-being of Pittsburgh's minority residents. CHHS has since grown to incorporate an expanded health and wellness mission that includes many partners, ranging from universities and health associations to schools, community collaboratives, corporations and unions. The project has become a resource to the community, improving medical access and sponsoring smoking cessation groups, fitness programs, youth health educators, diabetes education, support groups and health education.

In 2005, CHHS formed a partnership with the University of Pittsburgh Graduate School of Public Health Center for Minority Health's Healthy Black Family Project. The purpose of the collaboration is to offer families additional opportunities to improve health status by engaging in preventive health activities that address chronic conditions prevalent among minority populations. The collaboration remains strong and viable today.



Project Description

CHHS uses a community-driven participatory model that directs the implementation and operation of wellness programs. Its programs and services combine evidence-based methods using culturally competent strategies, trusted volunteers, trained lay facilitators and messengers to provide another pathway to improve health outcomes. CHHS program coordinators reporting to the executive director have oversight for each CHHS program. The coordinators, who are typically licensed nurses or health professionals, supervise trained and certified adult and youth program facilitators, who are generally residents of local communities.

Lay facilitators are committed to supporting these programs in various communities. CHHS recruits, trains and certifies program facilitators from within the communities it serves to provide a trusted means of health promotion and disease prevention to reduce health disparities. Use of community residents helps to promote permanency and sustainability of best practices in the targeted communities. Lay facilitators must have the capacity to be certified and receive ongoing training to participate in the following activities:

- Recruiting individuals and families into community-based wellness and prevention programs.
- Facilitating smoking cessation, exercise and nutrition information sessions for youth ages 6-16 during afterschool programs, in churches, in community organizations and during community events (with an adult facilitator also present) using Youth Health Corp Educators.
- Addressing fitness and nutrition needs of adult men and women through the Healthy Lifestyles program. Certified lay facilitators lead low-impact aerobics and cardiovascular exercises such as kickboxing.
- Facilitating diabetes management support by co-leading the Diabetes Education and Support Initiative with a nurse and the CHHS medical director.

In 2008, the Highmark Foundation awarded a three-year \$246,000 grant to CHHS to support the expansion of the Healthy Individual, Family and Community Program to the North Side, Hill District, Beltzhoover and Braddock communities in Allegheny County. An assessment of these communities showed low rates of physical activity and high rates of diabetes, childhood obesity and tobacco use among youth and adults. There are few facilities in these communities where families can participate in comprehensive wellness activities. As a result, CHHS was asked by churches and community groups to replicate the program in the expansion communities to give residents the best possible advantages to achieve optimal health.

The Foundation grant was leveraged in 2008 by a \$300,000 three-year grant from the Pittsburgh Foundation, which assisted CHHS in meeting its total expansion budget. This expansion is filling a gap by providing approximately 1,500 individuals with opportunities to participate in organized wellness activities and to improve health habits. With the expansion and funding from Highmark Foundation and the Pittsburgh Foundation, CHHS will have a presence in seven communities within Allegheny County.

Project Outcomes

Outcomes demonstrate that the program is meeting its targets. The goal was to serve 500 participants per year. Table 1 shows more than 2,100 new participants received services in year one, October 2008 through September 2009. Moreover, funding from the Highmark Foundation has also allowed CHHS to hire two additional nurses who will provide consultation to lay staff and program participants.

Table 1: CHHS Attendance October 1, 2008 - September 30, 2009

Program Activity	Number Enrolled
Exercise and Nutrition	259
Diabetes Support and Education	62
Youth Health Education presented at 38 presentations, including health fairs, community days	1,677
Youth health educators conducted six tobacco education training sessions and 38 presentations in the expansion site communities serving youth ages 13-18	121
Total new participants October 2008 - September 2009	2,119

Testimonials from participants indicate that the program is helping them to stay motivated, lose weight, set and reach goals, engage in physical activity and meet the needs of their communities.

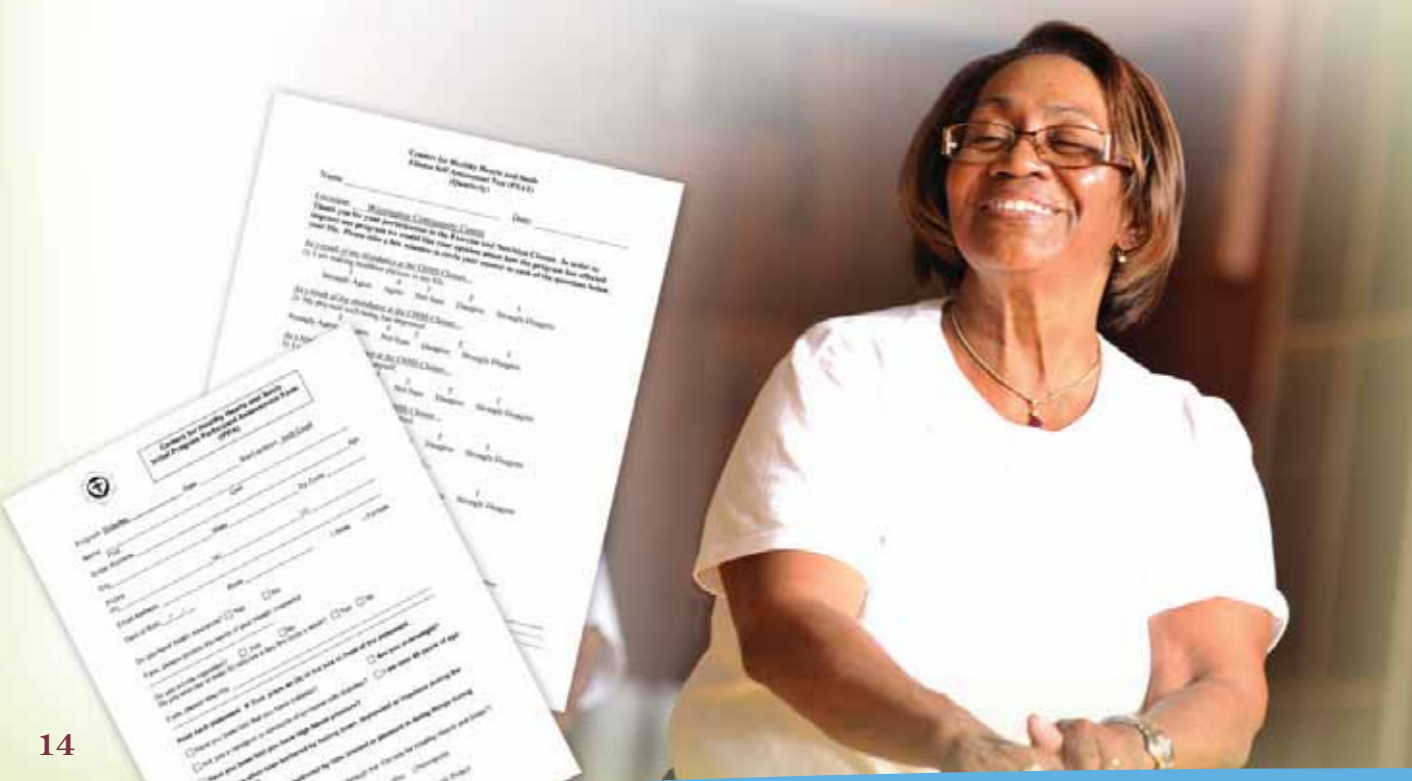
Next Steps

CHHS is in discussion with local health plans to define criteria for reimbursement of services provided through CHHS' programs. The use of best practice, evidence-based programming, structured methodologies, and the data-intensive program evaluation that characterizes CHHS' efforts should permit development of value-based agreements with health plans and employers. The expectation is that these agreements will be functional within the next two years, allowing a transition from grants to revenues and increased opportunities for sustainability.

CHHS also expects to compete successfully for grants to fund new initiatives. A major partnership with behavioral health providers around community-based depression and stress will be the first initiative.

"My weight has been an issue for years. Although I have probably been on every fad diet and have tried every temporary fix imaginable, I could even give you all the right information on proper diet, exercise and nutrition. My problem had always been following my own advice."

- CHHS Participant




Healthy Black Family Project (HBFP)

As a result of its magnitude and potential to build capacity for health promotion that reflects community input, community ownership and sustainability by the community, the Robert Wood Johnson Foundation awarded a matching grant to the Center for Minority Health (CMH) through its competitive Local Funding Partners Initiative. At the heart of the HBFP is the translation of evidence-based strategies from CBPR into an intervention acceptable and appropriate for minority populations. What makes the HBFP work are community champions. These champions have successfully integrated this program into their lives — they are living proof that behavior changes lead to positive health outcomes. These individuals also conduct community outreach efforts by bringing their friends, family and others into the program. In some cases, entire families are involved in the HBFP.

Background

With funding support from the Robert Wood Johnson Foundation (RWJ) Local Funders Initiative Partnership (\$500,000 matching grant), the Highmark Foundation, the Pittsburgh Foundation (\$346,216 over two years), DSF Charitable Trust (\$1.5 million challenge grant) and the POISE Foundation, CMH launched the HBFP in 2005. HBFP is a community-based demonstration of a culturally tailored health promotion and disease prevention program aimed at eliminating health disparities in communities located in the East End of Pittsburgh, Pa., also known as the Health Empowerment Zone (HEZ). The purpose of the HBFP is to decrease the incidence of hypertension and Type 2 diabetes in African Americans residing in the HEZ by the year 2010 through culturally appropriate and scientifically sound health promotion and disease prevention efforts. Growing scientific evidence on the desirability and feasibility of preventing and/or delaying development of diabetes and hypertension provided the foundation for CMH's minority health improvement strategy.



I have peripheral artery disease in my leg, which discouraged me from walking more than a short distance, "Now, I can walk everywhere."

- HBFP Participant



Project Description

Efforts to prevent and/or delay the onset of Type 2 diabetes could yield enormous benefits in reduced human suffering, increased quality of life and reduced costs associated with the management of and care of persons with Type 2 diabetes. Four clinical trials served as a scientific foundation for this conclusion.

The goal of the HBFP is to translate the findings from the U.S. Department of Health and Human Services' Diabetes Prevention Program clinical trial and apply the recommended interventions to everyday practice within the HEZ. This will be achieved through lifestyle behavior change; individualized health risk assessments; family health histories; individualized coaching to create tailored health promotion plans; and classes in physical activity, stress management, nutrition and smoking cessation. Certified fitness instructors meet participants in their homes as well as onsite. Additional activities include walking groups and a diabetes support group.

Although most participants are adults, several classes have been added explicitly for youth and other classes welcome their participation. Additionally, four local Federally Qualified Health Centers have partnered with HBFP to provide health care for individuals who have no medical insurance.

Project Outcomes

As of December 2008, the HBFP had enrolled 7,162 participants. A total of 2,117 individuals have provided physician permission to engage in HBFP activities, and 2,815 individuals have completed baseline fitness assessments performed by HBFP health coaches and/or a Genetic Family Health History performed by CMH graduate students. The remainder falls within one of the four operational levels of participation.

The four operational levels of participation in the HBFP include **Level 1** (N=7,162) indicates that a participant has filled out a card expressing an interest to participate in HBFP; **Level 2** (N=3,014) indicates that a participant has provided medical clearance from his/her doctor, taken a fitness assessment with an HBFP health coach, and completed a health questionnaire; **Level 3** (N=1,353) indicates that a participant engaged in either physical activities or education activities in HBFP; and **Level 4** (N= 250) indicates that a participant has completed both a baseline and follow-up fitness assessment.

While more than 7,000 people enrolled in HBFP, tracking their activities has presented challenges due to limited resources, staff capacity and the unexpected "surge" in registration. On a monthly average, a total of 795 individuals, however, engage in physical activity classes such as yoga, dance, body toning, walking and water aerobics, and 129 individuals engage in nonphysical activity such as nutrition education, cancer forums, smoking cessation and diabetes support. In some cases, as a result of active participation in HBFP activities, participants have successfully been taken off of insulin and other medications by their physicians.

Similar to the CHHS Healthy Individual, Family and Community Program, the HBFP uses lay health advocates to provide social support to individuals who may or may not be a part of an individual's social network. HBFP lay health advocates often have expertise in a particular area(s) or have completed training in health promotion and disease prevention and contribute to the health and competence of their community through information dissemination, assistance and organization of community-building activities. Community action will be sustained through the collective voice of trained, effective leaders, including lay health advocates.

HBFP is providing the means and momentum to empower individuals and communities by giving them greater control over the determinants of their health. The project is innovative in that it has the potential to change the model of funding for health promotion and disease prevention, determine how the cost benefits of the project could serve as a national model, educate funders, mobilize the commitment and resources of an entire school of public health, and demonstrate the power of building community capacity to launch and sustain a social movement to promote minority health and prevent disease in African Americans in Pittsburgh.

No student has reported more dramatic results.

When she began three years ago to take a class, she weighed 170 pounds, wore a brace on her left knee and was taking medication to control high blood pressure. Today she is almost 30 pounds lighter, has removed the brace and no longer needs high blood pressure medication. She has lost four dress sizes as a result of the class. Inspired by example set by her instructor, she is studying to become a personal trainer.

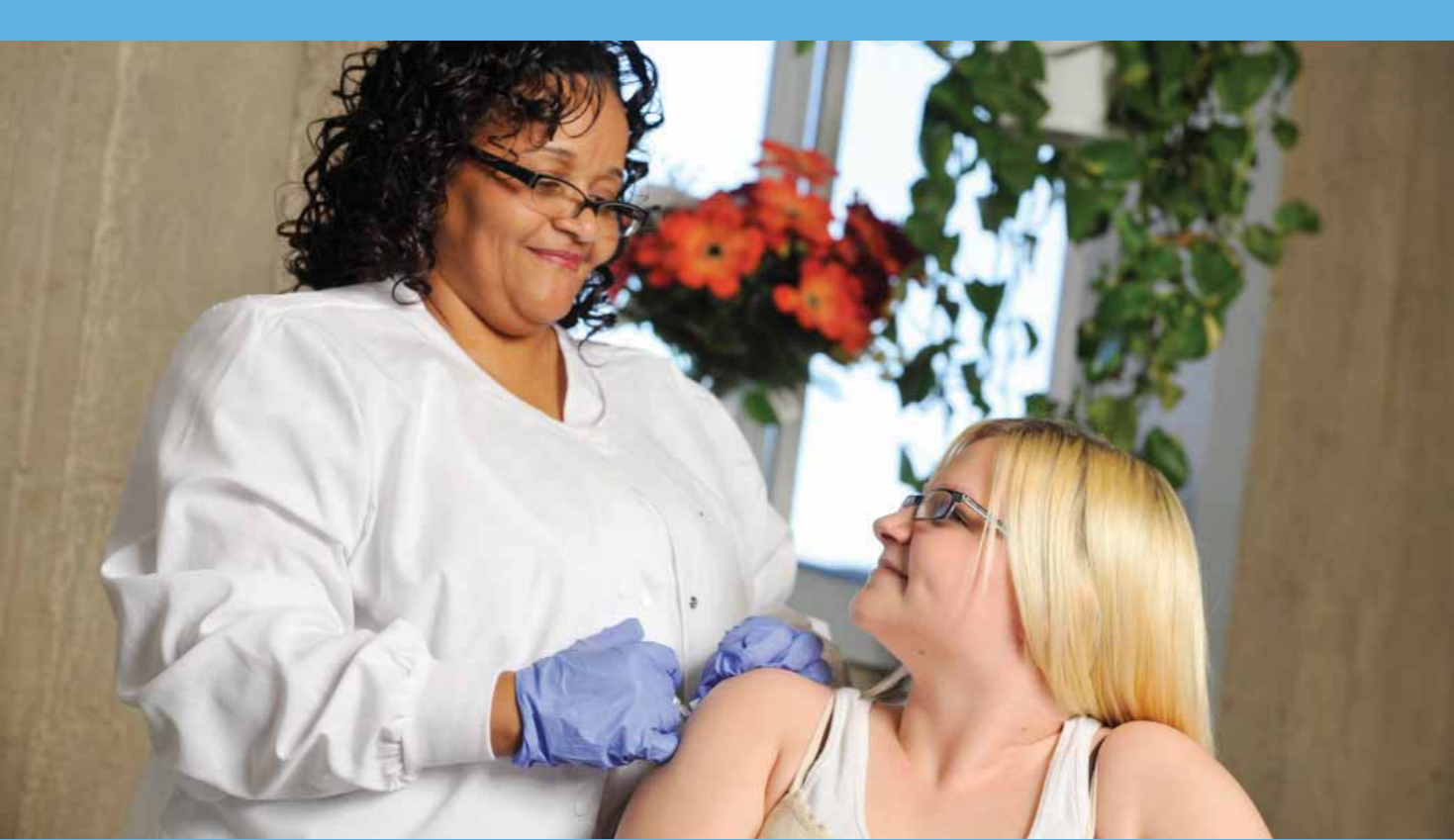
- HBFP Exercise Instructor

Next Steps

As a result of original funding from the RWJ Local Funders Initiative Partnership and local foundations drawing to a close, in 2008, the RWJ enrolled the Healthy Black Family Project into a new sustainability program developed by MissionWise, Inc. This highly competitive program is designed to facilitate the transition of innovative demonstration projects into successfully institutionalized and sustainable "start-up enterprises" complete with business plans and market-driven revenue streams.

One product of this effort is the Institute on Community Engagement and Research (ICER), a part of an existing National Institutes of Health-National Center on Minority Health and Health Disparities Research Center of Excellence. The ICER has evolved to become the primary means for disseminating the best practices and promising processes discovered within the context of the HBFP.





Washington County Health Partners (WCHP) Community Wellness Task Force: WellLife™

During the 1990s, hospitals and their communities began to form collaborative partnerships to identify and reduce community health risks. In September 1994, the Washington Hospital facilitated the creation of a Community Health Needs Assessment Committee. In 1995, this committee conducted a countywide assessment that included a mailed survey, focus groups and review of community health data. WCHP originated in 1996 based on the 1995 countywide assessment that identified specific health issues that most affected Washington County residents. The informal, volunteer leadership committee issued a report in January 1996 that called for the formation of volunteer-led collaborative task groups (now called task forces) to address identified community health risks. WCHP incorporated one of the most basic practices of CBPR, which is also the most important: asking the community what is required to meet their needs and subsequently working together to meet them. As indicated previously, this builds trust and contributes to successful outcomes.

Key findings from the Community Health Needs Assessment Committee report indicated diabetes, heart disease, hypertension, obesity, depression, insufficient access to coverage and care, and inadequate preventive services were prevalent in the population surveyed. The task forces presented action plans in early 1997 and began to implement evidence-based community-driven health promotion programs. There are currently eight active task forces of WCHP.

Background

WCHP has a successful track record of bringing together an unprecedented collaborative effort in Washington County of more than 60 community organizations and 170 professionals and community volunteers and calls upon individuals, businesses, organizations and charitable institutions to join together in a united effort to create a healthier Washington County. These individuals serve on task forces to conduct activities that will enhance community health status and encourage Washington County residents to make positive lifestyle decisions. As a result of WCHP's ability to address large-scale issues and mobilize the community, the Pennsylvania Department of Health recognized WCHP as a State Health Improvement Plan (SHIP)-approved, local community health initiative responsible for community health assessment and planning.

WCHP coordinates member organizations to facilitate programs developed by WCHP and the community-led task forces. This model of CBPR serves as a catalyst by working with other organizations, faith community, businesses, human/social service organizations, philanthropic organizations and, more importantly, community residents to lead efforts in addressing health disparities in Washington County.

The Highmark Foundation awarded grants in 2002 and 2006 to WCHP to advance the work of two task forces – the Community Wellness Task Force for its WellLife™ Program and the Minority Health Task Force for its Health Ministry Initiative. The grant awarded for the WellLife™ Program is closed; however, the Health Ministry grant is active. These practical solutions are designed to eliminate health disparities and reduce chronic disease in Washington County.



Project Description

The Community Wellness Task Force developed WellLife™, an eight-week program to teach people to be active, eat right and reduce stress. Although the base program was delivered, a WellLife™ Program was also delivered simultaneously to the African American population in Washington County and incorporated culturally specific activities.

The WellLife™ Program was developed to teach individual health and fitness lifestyle modifications. Its goal is to teach participants how to create personal health and fitness programs to fit their needs. Each lesson presents information to the participants to encourage them to set realistic goals for increased physical activity and healthy eating habits, as well as identifying and reducing psychological barriers. An additional aspect of the course is to provide hands-on skill development. This includes participatory fitness activities, cooking demonstrations and stress management skill building. Program staff consists of a registered dietitian, an exercise physiologist and a psychologist (or equivalent health professionals).

The WellLife™ Program was replicated in three sites (two in Washington city – one tailored to African Americans, and one in Canonsburg) in year one, and five sites (one in Washington city, two in Canonsburg – one tailored to African Americans, one in Monongahela and one in Donora tailored to African Americans) in year two, and three sites (one in Washington city, one in Canonsburg and one in Monongahela) in year three, the final year of implementation. In total, the 11 programs served 267 participants.

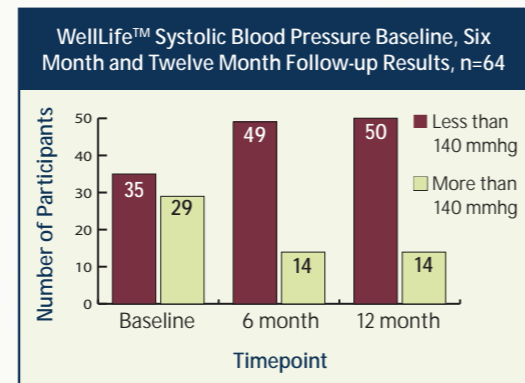
Project Outcomes

Of the 267 participants who attended the WellLife™ Program, 114, or 43 percent, completed the six-month follow-up, and of the 114 who completed the six-month follow-up, 64, or 56 percent, completed the 12-month follow-up (24 percent completed both the six and the 12-month follow-ups). Of those that completed the 6- and 12-month follow-ups, substantial and sustained positive behavioral lifestyle changes were made. The overall results highlighted below include the African American participants.

Blood Pressure

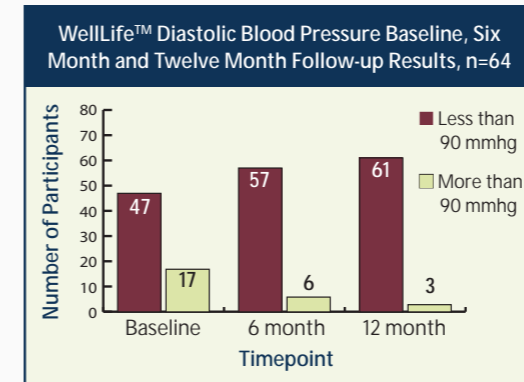
Participants with systolic blood pressure levels over 140 mmhg (above healthy guidelines) decreased from 45 percent at the start of the program to 22 percent at the 12-month follow-up.

Figure 3: Systolic Blood Pressure by Follow-up



Participants with diastolic blood pressure levels over 90 mmhg (above healthy guidelines) decreased from 27 percent at the start of the program to 5 percent at the 12-month follow-up.

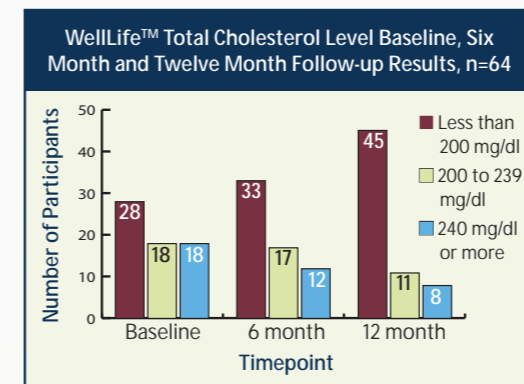
Figure 4: Diastolic Blood Pressure by Follow-up



Cholesterol

Participants with total cholesterol levels over 200 mg/dl (above healthy guidelines) decreased from 56 percent at the start of the program to 30 percent at the 12-month follow-up.

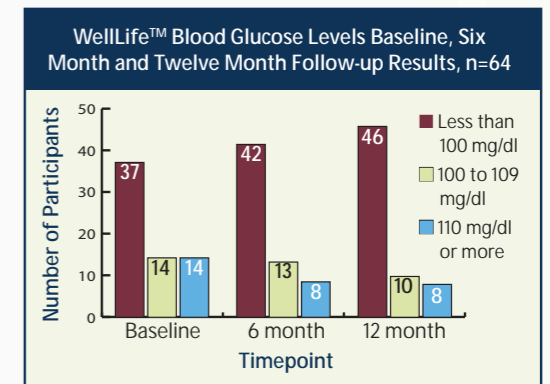
Figure 5: Total Cholesterol Levels by Follow-up



Glucose

Participants with fasting blood glucose levels over 100 mg/dl (above healthy guidelines) decreased from 43 percent at the start of the program to 28 percent at the 12-month follow-up.

Figure 6: Participant Fasting Blood Glucose Levels by Follow-up



The WellLife™ Program demonstrated that it can be successful in reducing the incidence and prevalence of chronic disease such as hypertension and diabetes and addressing health disparities. Moreover, the program demonstrated successful replication in three minority communities in Washington County, of which is another benefit of implementing CBPR. In addition, eight of the 11 groups reduced their average high-risk factors. WCHP estimated theoretic monetary savings (losses) from reduction of high-risk factors among 11 WellLife™ Programs to be \$155,891. This savings is a benefit to the participants, the community and the health care system.

Next Steps

WCHP has not been able to secure appropriate grants to sustain the WellLife™ Program as it has been developed under this grant. Alternative methods of funding and delivery continue to be explored.

Washington County Health Partners Minority Health Task Force: Health Ministry Initiative

The second Highmark Foundation grant awarded in 2006 was to support the Washington County Health Partners request to launch the Health Ministry Initiative: A program to identify and address the health issues of African Americans in Washington County.

Background

Health disparities between majority and minority groups have been well documented, but no large scale effort has been made to reduce them, especially in Washington County. The Minority Health Task Force, established in 2002, has been charged with identifying health issues in Washington County's African American community and partnering to implement programs to address these issues to improve their health. The top six currently identified priority health issues in this population are hypertension, diabetes, cancer, drug/alcohol/tobacco use, lack of health insurance and behavioral health. Barriers to good health in this population include lack of education, knowledge and awareness, fear or mistrust due to bad experiences, community disengagement and lack of financial resources, all of which are barriers to CBPR projects.



Project Description

To address health issues, thereby reducing the burden of chronic disease, five focus groups were held in African American churches in Canonsburg, Donora and Washington as a part of WCHP's community health assessment process to begin identifying local health issues. A network of churches was created, and the first step was to engage and subsequently recruit pastors. This was a two-year process. To date, there are approximately 20 active health ministers and 10 active health ministries. Of the health ministers, two are licensed practical nurses and seven are registered nurses. Health ministers are required to attend bi-monthly meetings and annual trainings, and they must stay current on clinical standards (such as blood pressure and HbA1c guidelines).

The main objective of the Health Ministry Initiative was to identify a health ministry team within the African American faith-based community and train it to become lay health advocates for people in their churches and community. The health ministers are trusted members of their churches, which results in the congregations feeling comfortable to discuss issues with these individuals. They also use their knowledge of the church to identify health issues and determine how best to hold programs using the support of the Health Ministry Team.

Health ministers are trained to:

- Recognize risk factors associated with certain chronic diseases
- Recommend ways to detect, manage and prevent health problems
- Refer persons to community health resources
- Conduct health information, screening and referral programs for their congregation membership
- Teach simple self-help techniques
- Collect and track health assessment information

Each health minister also receives a Health Ministry Resource Box toolkit that contains items such as program forms, blood pressure cuffs, a stethoscope and teaching materials. Participant data is not maintained in these boxes, but is submitted to WCHP after each event to be tracked.

Project Outcomes

Outcomes from assessment data and suggested measurements for selected chronic diseases reported by the Minority Health Task Force Health Ministry Team from community screenings are highlighted below.

- Of the 48 percent participants who have been told they have high blood pressure, 40.3 percent had high readings.
- Of the 44 percent who thought their high blood pressure was under control, 29 percent had high readings.
- Comparison between races from 1996-2006 shows, 40.1 percent of African American women were diagnosed with late-stage breast cancer compared to 29.2 percent of Caucasian women. Although this was a decrease, African American women continue to receive breast cancer diagnoses later than Caucasian women. This was a decrease to 45 percent (African American) and 33 percent (Caucasian) in 1990-1998.
- Of the 108 health ministry participants, 19.3 percent are diabetic compared to 9 percent of Washington County adults.

Next Steps

One of WCHP's goals is to ensure that health ministers attend meetings, hold programs and screenings, and submit data in a timely manner. To accomplish this goal, an incentive system has been established. Each task is associated with a certain number of points. When health ministers earn a certain amount of points, they will be able to purchase supplies and equipment to use in their programs. WCHP's administrative staff tracks and monitors each health minister's points. For example, one health minister earned enough points to purchase a projector that she will use during presentations to churches and community groups.

The health ministry concept has been well-received. Participating churches and organizations recognize the value of the initiative and dedication of the health ministers. Health ministers are making a difference in their churches. In fact, one Health Ministry Team formed an independent unit within its church. The Team separated from the Christian Education Committee, expanded membership from three health ministers to six and elected a slate of officers. If this model is successful, it could become the future of health ministries in Washington County.

Conclusion

Grants from the Highmark Foundation provided funding to three local organizations to advance practical solutions created from CBPR into programs that were able to be successfully replicated, and in most cases sustained. Grants were used to support staff salaries, health screenings and small equipment. These grant-funded programs have realized success in identifying the health needs of populations and working with them to create innovative solutions to meet those needs.

CBPR establishes a mutual trust that enhances the quantity and quality of data collected. The ultimate benefit to emerge from such collaborations is a deeper understanding of a community's unique circumstances and a more accurate framework for testing and adapting best practices to the community's needs. It gives the community a voice.

It will take years for CBPR interventions to demonstrate that improving living conditions will change behaviors and improve community health. As communities address broader social determinants of health, researchers could work with them to measure intermediate outcomes in order to capture the process by which behavior change is accomplished.

Next steps for CBPR are educating the philanthropic community, developing guidelines and/or standard measures for evaluating CBPR and ensuring that these projects as designed are effective in meeting the needs of the intended community. If communities are held accountable for demonstrating effective public health interventions, public health leaders, funders and agencies must also be responsive to the realities these communities face as they address complex health problems today and in the future.

Source Information:

- ¹ Viswanathan, M., et al. (2004). Community-based participatory research: Assessing the evidence. Evidence Report/Technology Assessment No. 99 (Prepared by RTI–University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication 04-E022- 2. Rockville, MD: Agency for Healthcare Research and Quality.
- ² Hartwig K., Calleson, D. & Williams, M. Unit 1: In: The Examining Community-Institutional Partnerships for Prevention Research Group. *Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum*. 2006. Retrieved from www.cbprcurriculum.info.
- ³ Community-based participatory research. (2009). Retrieved October 15, 2009, from <http://depts.washington.edu/ccph/commbas.html>.
- ⁴ Wallerstein, N., & Parker, T. (n.d.). *Community-based participatory research: A foundation and building-blocks for academic-based partners* [PowerPoint slides]. Retrieved from University of New Mexico website: http://hsc.unm.edu/som/fcm/cpr/docs/CBPR_Intro.ppt.
- ⁵ Washington, W.N. (2004). Collaborative/participatory research. *Journal of Health Care for the Poor and Underserved*, 15(1) 18-29. doi:10.1353/hpu.2004.0015.
- ⁶ Horowitz, C.R., Robinson, M., & Seifer, A. (2009) Community-based participatory research from the margin to the mainstream: Are researchers prepared? *Circulation*, 119: 2633-2642. doi:10.1161/CIRCULATIONHA.107.729863.
- ⁷ Viswanathan, M., et al. (2004).
- ⁸ Katz, D.L. (2004). Representing your community in community-based participatory research: Differences made and measured. *Preventing Chronic Disease*, 1(1)1-4. Retrieved from http://www.cdc.gov/pcd/issues/2004/jan/03_2004.htm.
- ⁹ Horowitz, Robinson, & Seifer, 2009, p. 2634.
- ¹⁰ Collins, J.L., Giles, H.W., & Homles-Chavez, A. (2007). Old dilemmas, new commitments: Toward a 21st century strategy for community health promotion. *Preventing Chronic Disease*, 4(3) 1-2. Retrieved from http://www.cdc.gov/pcd/issues/2007/jul/07_0037.htm.
- ¹¹ Palermo, A., McGranaghan, R., & Travers, R. Unit 3. In: The Examining Community-Institutional Partnerships for Prevention Research Group. *Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum*. 2006. Retrieved from www.cbprcurriculum.info.
- ¹² Katz, 2004, p. 2.
- ¹³ Wallerstein, N., & Parker, T. (n.d.).
- ¹⁴ Hartwig, K., Calleson, D., & Williams, M. 2006.
- ¹⁵ Horowitz, Robinson, & Seifer, 2009, p. 2635.
- ¹⁶ Community-based participatory research. (n.d.) in Wikipedia. Retrieved October 15, 2009, from http://en.wikipedia.org/wiki/Community-based_participatory_research.
- ¹⁷ In: The Examining Community-Institutional Partnerships for Prevention Research Group. *Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum*. 2006. Retrieved from www.cbprcurriculum.info.
- ¹⁸ *Community-Based Participatory Research*. Conference Summary, July 2002. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/about/cpcr/cbpr/>.
- ¹⁹ Ahmed, S.A., Beck, B., Maurana, C., & Newton, G. (2004). Overcoming barriers to effective community-based participatory research in US medical schools. *Education for Health*, 17(2), 141-151. doi:10.1080/13576280410001710969.
- ²⁰ Katz, 2004, p. 2.
- ²¹ Wallerstein, N., & Parker, T. (n.d.).
- ²² Minkler, M., Backwell, A., Thompson, M., & Tamir, H. (2003). Community-based participatory research: Implications for public health funding. *American Journal of Public Health*, 93 (8): p. 1211.
- ²³ *Community-Based Participatory Research*. Conference Summary. July 2002. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/about/cpcr/cbpr/>.
- ²⁴ *Community-Based Participatory Research*. Conference Summary. July 2002.
- ²⁵ Minkler, et al., 2003, p. 1210-1213.
- ²⁶ Minkler, et al., 2003, p. 1211.
- ²⁷ Minkler, et al., 2003, p. 1211.
- ²⁸ Minkler, et al., 2003, p. 1212.
- ²⁹ Israel, B.A., Krieger, J., Vlahov, D., Ciske, S., Foley, M., Fortin, P., Guzman, R., et al. (2006). Challenges and facilitating factors in sustaining community-based research partnerships: Lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. 83(6), 1022-1040. doi:10.1007/s11524-006-9110-1.
- ³⁰ Israel, et al., 2006, p. 1023.
- ³¹ Viswanathan, M., et al. (2004).
- ³² Betancourt, J.R., & Quinlan, J. (2007). Personal responsibility versus responsible options: Health care, community health promotion, and the battle against chronic disease. *Preventing Chronic Disease*, 4(3), http://www.cdc.gov/pcd/issues/2007/oct/07_0126.htm.
- ³³ U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and improving health*. Washington, DC: U.S. Department of Health and Human Services. Government Printing Office. 2000.
- ³⁴ Israel, et al., 2006, p. 1024.



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