

Implementing Community-Based Participatory Research with Two Ethnic Minority Communities in Kansas City, Missouri

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Abstract

Community-based participatory research (CBPR) has been shown to improve aspects of health promotion initiatives. This case study examines the effects of a CBPR intervention on intermediate outcomes (changes in the community) related to preventing health disparities and chronic disease. We describe how the Kansas City-Chronic Disease Coalition used CBPR methods to help bring about community changes to reduce risk for cardiovascular diseases and diabetes among African Americans and Hispanics in Kansas City, Missouri. Using an empirical case study design, communities and scientific partners documented and analyzed the contribution of community changes (new or modified programs, policies or practices) facilitated by the coalition in two racial/ethnic communities: African American and Hispanic. Follow-up interviews suggest that the coalition did a better job of implementing a CBPR intervention in the African American community than in the Hispanic community. Challenges to implementing CBPR interventions in multiple and diverse ethnic communities are discussed.

Key words

community-based participatory research; health promotion; ethnic minority; health disparities

Introduction

Health disparities associated with race and ethnicity continue to be major challenges for health promotion in the United States and globally. In the U.S., mortality rates of African Americans, Latinos and whites remained largely unchanged from 1960 to 2000 (Satcher *et al*, 2005). The gap between racial minorities and whites also remains unchanged. In 2003, the U.S. Centers for Disease Control and Prevention (CDC) reported that the risk for diabetes was 1.6 times as high among African Americans and 1.5 times as high among Hispanics as it was among whites (CDC, 2003). The CDC also reported that in 2001 the rate of death from heart disease was 31% higher among African Americans than among whites. Hispanic women are 1.4 times as likely to be obese as whites

(CDC, 2004). Accordingly, Healthy People 2010 set the goal of reducing health disparities and improving risk factors such as poor nutrition and little physical activity that affect diabetes and cardiovascular disease (CVD) as objectives for the nation (Department of Health and Human Services, 2008).

Addressing the multiple and inter-related causes of health disparities requires collaboration between many individuals and organisations, and engagement of the community in the prevention effort (Fawcett *et al*, 2000a). Engagement of the community can lead to trust, improved interventions, greater participation in the effort, and higher participant satisfaction with the effort (Ammerman *et al*, 2003). Community-based participatory

research (CBPR) engages community members as equal and essential partners in the process of understanding and improving health and development (Horowitz *et al*, 2004). This has multiple advantages to the research process (Minkler *et al*, 2003; Wallerstein & Duran, 2006), which is why CBPR is increasingly recognised as essential to addressing and eliminating health disparities (Minkler *et al*, 2003; Wallerstein & Duran, 2006).

This empirical case study examines the process by which those working together share responsibility for sustaining a community-based process addressing health disparities. This case example uses a REACH 2010 initiative, the Kansas City-Chronic Disease Coalition (KC-CDC), to illustrate the process and outcomes of community-based participatory research (CBPR), outlining how implementation of the KC-CDC attempted to adhere to CBPR principles. It describes activities within a six-component participatory research framework (for example naming and framing the problem or goal, developing a logic model). The results describe the pattern of community changes facilitated by the KC-CDC effort.

KC-CDC CBPR approach

The purpose of CBPR is to ensure that key stakeholders of the community are directly involved in the process of understanding and improving community health initiatives (Horowitz *et al*, 2004; Fawcett *et al*, 2003; Minkler & Wallerstein, 2003). **Table 1**, opposite, presents the key principles of CBPR and illustrates how implementation of the KC-CDC Intervention adhered to the principles.

Framework for participatory research within communities

Figure 1, below, outlines a framework and core components for the process of community-based participatory research (CBPR) in community initiatives (Fawcett *et al*, 2003) based on related participatory approaches, prior research and experience of the Work Group for Community Health and Development at the University of Kansas (KU Work Group) (Fawcett *et al*, 1996, 2000a) and its many different community partners.

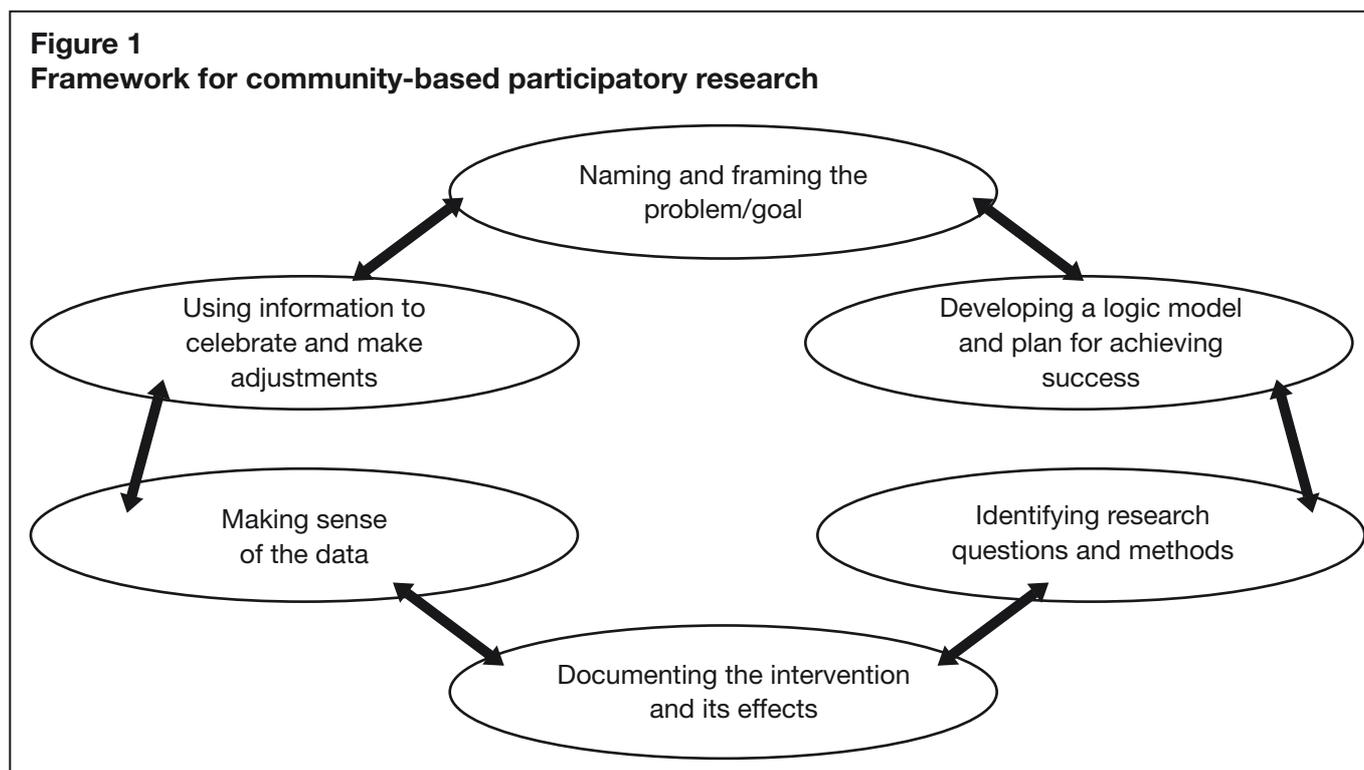


Table 1
Adherence to CBPR principles in implementing the KC-CDC intervention with community partners

Core CBPR principles (as identified by Israel <i>et al</i> , 2003)	How these principles were adhered to by KC-CDC
Recognises community as a unit of identity	Local-level groups and research partners identified a common vision and mission together to target placed-based community efforts. Representatives from community organisations were part of the Steering Committee
Builds on strengths and resources within the community	Resources were allocated through mini-grants to grassroots and community-level organisations to affect change and improvement. The project provided training and other supports for implementing local-level interventions
Facilitates a collaborative, equitable partnership in all phases of the effort	Identification of the vision, mission, objectives and community changes to be sought occurred through collaborative planning between community residents, organisations, and the research partner. Relevant sectors (such as neighborhoods, faith organisations and health care providers) were involved in choosing the types of intervention being implemented. There was multi-sector representation on the Steering Committee and they were periodically involved in making sense of data
Promotes co-learning and capacity building among all partners	Success stories and data were shared with partners during coalition meetings. Data were reviewed by the Steering Committee to assess progress and make adjustments
Emphasises local relevance of public health problems and ecological perspectives that recognise and attend to the determinants of health	The disease processes that were the focus of the effort were identified because of their local importance. Action planning was conducted to promote changes in the environment at multiple levels (individuals and relationships, organisational, community, broader system). Efforts focused on implementing community-level programs, policies and practices that addressed risk/protective factors and broader determinants
Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process	The project enabled communications between local partners through an online documentation system that permitted instant sharing of data about change and improvement in reducing chronic disease. Newsletters, conference presentations, and reports were all developed collaboratively between members of the coalition and the research partner and disseminated through the coalition

The KC-CDC's implementation of CBPR with two racial/ethnic communities

This section outlines how the KC-CDC implemented the six-phase CBPR process (outlined in *Figure 1*) in its efforts.

Naming and framing the problem by KC-CDC

The Missouri Primary Care Association (MPCA) collaborated with multiple partners, including representatives from five health centers, the United Auto Workers-Ford Community Health Care Initiative (UAW-Ford CHCI), several neighborhood organisations and the local health department to review health assessments and determine the goals and outcomes for the emerging initiative. These community partners used two health assessments conducted in the Kansas City metropolitan area to identify local health disparities (Collie-Akers *et al*, 2007).

The results of a health assessment commissioned (by the UAW-Ford CHCI) showed significant health disparities between African Americans and Hispanics and other residents of the greater Kansas City area (Lewin Group, 2006). The results of a similar assessment by the Kansas City, Missouri Health Department showed that racial/ethnic minorities in Kansas City had a life expectancy 11 years shorter than whites in the same area, and that African American residents were 2.5 times as likely as white residents to die of diabetes and 1.5 times as likely to die of cardiovascular diseases, and Hispanics were 1.5 times as likely to die of diabetes (Farakhan & Thompson, 2000).

Based on these findings, the community planning group MPCA had convened focused on two minority populations at high risk for cardiovascular disease and diabetes: African Americans and Hispanics. These groups were located predominately in economically disadvantaged areas of central Kansas City. According to the 2000 United States Census estimates (U.S. Census 2006), approximately 159,580 people resided in the targeted area, which encompasses 11 zip codes. Of this population, 57% (91,088) were African American, 8.5% (13,515) were Hispanic and 24% (38,385) were considered to be below the 'poverty line'.

Developing a logic model and action plan for KD-CDC

The KU Work Group worked with the Coalition to develop a logic model. Together with staff of the MPCA, we facilitated discussions in which Coalition members targeted more distant outcomes such as reduced incidence of diabetes and CVD. We then helped facilitate action-planning workshops in which Coalition members identified community and system changes to be sought to address risk and protective factors. Coalition representatives of urban core community health centers and other Coalition partners agreed to seek multiple changes in the environment. The Coalition's initial work, and later refinement of the plan, led to specific coalition objectives. They included increasing the percentage of adult residents who:

- could identify as having a primary care provider
- reported engaging in regular physical activity
- reported consuming five or more servings of fruits and vegetables per day
- reported having had a hemoglobinA1C test in the previous year.

The resulting logic model developed by KC-CDC had five steps including:

- collaborative planning and capacity building (process)
- community action and intervention (outputs)
- community and system change, such as new or enhanced programs, policies or practices (intermediate outcomes)
- widespread behavior change, including increased physical activity and lower fat diet (more distant outcome)
- reduced disparities in health outcomes such as cardiovascular diseases (ultimate outcome) (Fawcett *et al*, 2000; Institute of Medicine, 2003).

Learning modules and other practical guidance, such as on identifying risk and protective factors, found in the KU Work Group's online Community Tool Box (<http://ctb.ku.edu>), provided additional support for refining and using the logic model without the presence of outside researchers.

In 2001, MPCA and KC-CDC applied for and received a cooperative agreement award from CDC to implement their action plan. During this REACH 2010 phase, MPCA established the KC-CDC. The Coalition was staffed and offices were opened at a local community college in a neighborhood heavily populated by African Americans. The staff included a director, one community mobiliser for each of the two target populations, and support staff. The project had a relatively large annual budget of about \$800,000 per year for five years. The coalition quickly initiated a program called Pick Six, in which coalition partners were asked to identify six community changes that they could implement. From 2001 through 2007, through Pick Six, coalition partners were awarded numerous grants. Most were minigrant (several thousand dollars each) to implement the community changes that they had identified in the action plan, while other partners received major grants of up to \$60,000 for implementation of health care and health promotion activities. The partners consisted of five community health centers, 24 neighborhood associations, 24 faith organisations and several other public and private organisations.

Identifying KC-CDC's research questions and methods

The KC-CDC Steering Committee and researchers identified research questions and methods, following development of the logic model and the strategic and action plan. As outside consultants, research partners and evaluators, the KU Work Group worked closely with the KC-CDC to frame research questions consistent with their logic model for reducing disparities in diabetes and CVD associated with race and ethnicity. We considered research questions relevant to the hypothesised relationships between elements of the model, such as the relationship between community and systems change and widespread behavior change. Staff of the KU Work Group proposed two core research questions.

- Does the initiative bring about community and system change related to the mission of reducing disparities?
- Under what conditions are community and system changes related to improvements in widespread behavior change (for example in physical activity and diet) and more distant health outcomes?

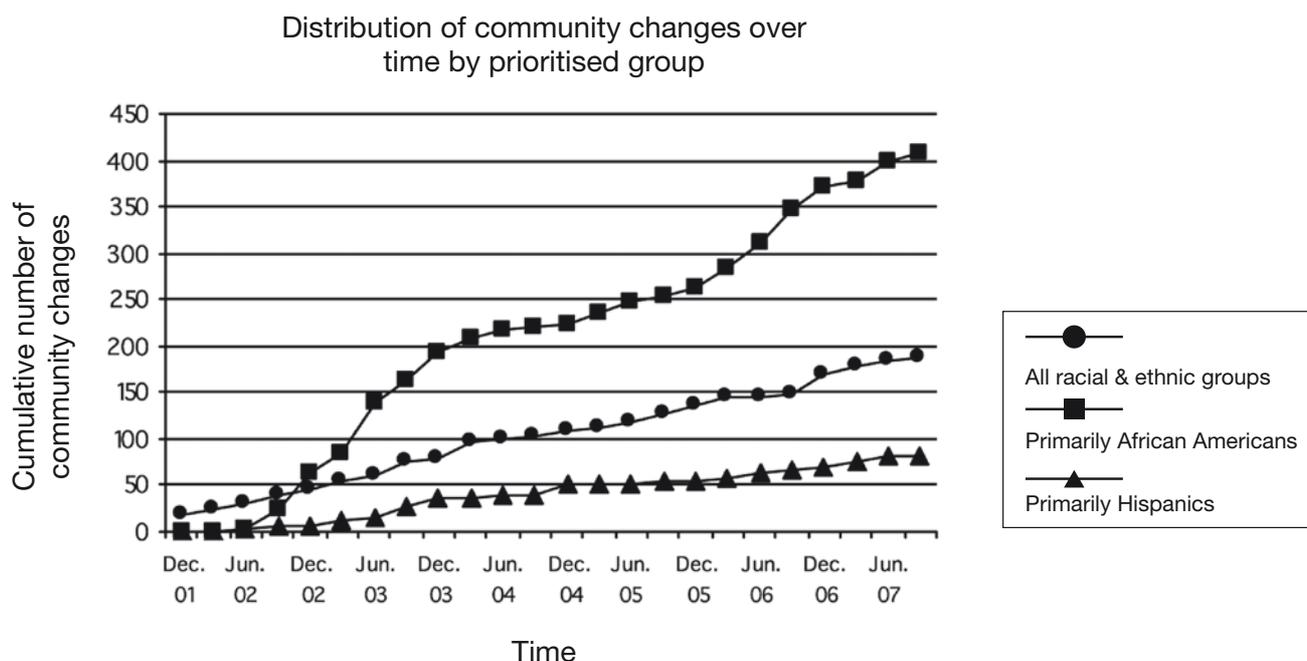
Documenting the intervention and its effects in the African American and Hispanic communities

KC-CDC staff members were trained by KU Work Group staff to record their activities in using the Online Documentation and Support System (ODSS) (Fawcett & Schultz, 2008; Fawcett *et al*, 2003a) and to code their entries for graphic review by partners. Between October 2001 and July 2007, the Kansas City-Chronic Disease Coalition facilitated 677 community changes: 408 of the community changes primarily targeted African Americans, 186 of the community changes addressed all racial and ethnic groups and 83 community changes primarily targeted Hispanics. A community change is defined as a new or modified program (such as classes in cooking health, exercise training), policy (for example a school ban on soda in vending machines, company policy to give time for healthy activities) or practice (for example, the physician regularly asks patients about their exercise, screening is offered at local grocery store) facilitated by the KC-CDC related to the mission of reducing risk for health disparities.

Illustrative examples of community changes implemented by and with the groups include the following.

- Established an in-service training for Kansas City school district nurses that promoted Healthy Habits with students and their families. (New Program)
- Centennial United Methodist church changed their policy allowing community use of their facilities for exercise and offered healthy eating options at church functions. (New Policy)

Figure 2
Distribution of community changes facilitated by KC-CDC over time in the African American and Hispanic community



- Jesu Christo El Buen Church’s Pastor began the practice of providing healthy food and information about healthy eating at church functions by serving healthy holiday meals. (New Practice)

Figure 2, above, displays the cumulative number of community changes as they occurred over time for the three groupings. Plotted as a cumulative record, each new change (such as a new policy or expanded program) is added to all previous events at the time of onset, and the steeper the slope, the higher the rate of change in the community.

In reviewing the descriptions of community changes that targeted all racial/ethnic groups, we found that, for group-specific changes, nearly five times as many addressed African Americans (408) as Hispanics (83). Most of the changes implemented by partners were changes in programs and practices, with a smaller number of policies implemented. Overall, the African American community received a much higher dose of intervention than did the Hispanic community.

These data helped the partners to answer the research question earlier posed by the coalition and researcher: Is the initiative being a catalyst for change in the community? During review of the data, the leadership became very concerned with the limited impact the coalition was having with the Hispanic community.

Making sense of the KC-CDC data

Another important question that the coalition and researchers posed was: How did the community changes that were implemented contribute to better health? The 677 documented community changes facilitated by KC-CDC were analyzed to determine how they might have contributed to the longer-term outcomes of prevention of diabetes and CVD. A secondary scoring of community changes by the scientific partner analyzed the hypothesised contributions of community changes to different dimensions. This involved examining the distribution of community changes by:

- goal (for example cardiovascular diseases, diabetes and general health disparities)

- duration of the event (for example one-time event, multiple occurrences, and ongoing)
- intensity of behavior change strategy (for example providing information and enhancing skills)
- enhancing services and support
- modifying access, opportunities and barriers
- modifying consequences
- modifying policies
- modifying the sectors through which the intervention was delivered (for example neighborhood networks, faith organisations, private organisations, businesses media).

Table 2, overleaf, displays the distribution of community change by **goal or health condition** to be addressed (diabetes or cardiovascular diseases) for each of the three groups: all racial/ethnic groups, primarily African American, and primarily Hispanic. In all three groups, the community changes implemented by the initiative focused heavily on both cardiovascular disease and diabetes, though the percentage was highest among the African American group. This suggests that these community changes were mostly targeting risk and protective factors such as physical activity and healthy eating.

Table 2 also shows the distribution of community changes by **sector** (faith organisations, media, neighborhood networks, schools and education, health care providers, neighborhood organisations, human service providers and other). Six sectors were the primary channels for delivering change in the communities. Faith groups, health care organisations, neighborhood networks, the private sector, human services and schools had the highest amount of change. However, in the All Racial/Ethnic category, health providers (21%), private sector (31%) and schools (16%) were most often targeted. Faith groups (29%), neighborhoods (37%) and schools (13%) were targeted for change in the African American group, but in the Hispanic group it was faith organisations (25%), health care providers (21%), human services (25%) and schools (15%) that were experiencing the most change. The most critical difference is the importance

of engagement of the faith and neighborhood networks for the African American community. They were not targeted for the Hispanic community.

The distribution of community changes by **duration** is also presented in **Table 2**. Events were coded as a one-time event, occurring more than once, and being an ongoing activity. Most of the community changes implemented in the three groups were either one-time events or events that occurred more than once for all three groups. Events that occurred more than once were most common in the primarily African American (60%) and primarily Hispanic groups (53%).

The distribution of community changes was also analyzed by **strategy** used (providing information and enhancing skills, enhancing services and support, modifying access, barriers and opportunities, modifying consequences, and modifying policies). The results shown in **Table 2** suggest some commonality across groups. Changes that used the strategy of providing information and enhancing skills (All - 46%, African American - 53%, Hispanic - 46%) and modifying access, barriers and opportunities (All - 24%, African American - 45%, Hispanic - 43%) were most common across the three groups. Information provision may be among the weakest of known strategies, with greater effects obtained more by modifying access, barriers and opportunities. Few policies were changed by KC-CDC.

Using the information to celebrate and make adjustments in KC-CDC

The KC-CDC used the documented community changes to highlight improvement in community conditions that might lead to their desired outcomes of healthier behaviours. These data were shared regularly at community coalition meetings to remind participants of their successes. When it was learned that there was improvement among African American women in increasing physical activity and healthier eating habits, KC-CDC shared that information during coalition meetings. These successes were used to recognise the efforts of the coalition.

KC-CDC's efforts were not distributed equitably to populations. The initiative intended to distribute its efforts more equitably to ensure the amount and kind of change needed to improve outcomes in the Hispanic

Table 2
Dimensions of community changes implemented in the African American and Hispanic community

	All racial/ ethnic groups (N = 186)	Primarily African American population (N = 408)	Primarily Hispanic population (N = 83)
Goal addressed			
Cardiovascular disease (CVD)	11.3	5.2	3.6
Diabetes	17.7	6.4	14.5
CVD and diabetes	60.7	85.8	75.9
General access/ disparities	10.2	2.7	6.0
Sector in which change implemented			
Faith/religious organisations	2.7	29.4	25.3
Health care providers/organisations	21.0	9.6	20.5
Health departments	3.2	0.0	0.0
Human services	6.5	2.9	25.3
Media	6.5	0.0	1.2
Neighborhood networks	2.2	36.5	0.0
Other	9.7	6.4	7.2
Private sector	30.7	1.0	3.6
Schools/education	16.1	13.0	14.5
Worksites/businesses	1.6	1.2	2.4
Duration of change			
One-time event	45.2	32.4	37.4
More than once	31.7	59.8	53.0
Ongoing	23.1	7.8	9.6
Strategy			
Providing information and enhancing skills	46.2	52.5	45.8
Enhancing services and support	6.5	1.2	8.4
Modifying access, opportunities and barriers	24.2	44.9	43.4
Changing the consequences	10.2	0.0	1.2
Modifying policies and broader system	12.9	1.5	1.2

community. Because of ongoing sense-making efforts, Coalition members were aware of this disparity in change efforts. They requested that qualitative data be collected from key informants within the Hispanic community. Data were collected between July and September 2007 from 14 key informants. Information from these interviews identified several features of the community context

and implementation approaches that created barriers to engaging members of the Hispanic community.

Discussion

The Coalition and researchers reviewed the data that were presented and felt that they told two different stories, depending on the target community. The data showed

good progress in the African American community, but concern was expressed about the limited interventions in the Hispanic community. In making sense of the data available from the documentation efforts, the Coalition members concluded that community changes were insufficient to improve population-level outcomes among Hispanics. KC-CDC identified this disparity as an area for improvement.

Systematic reflection by community and scientific partners suggests a number of contextual factors that may have led to strong implementation and participation in the African American community, but less in the Hispanic community.

Participation and implementation in the African American community

One strength of KC-CDC's effort was the participation of African Americans in the Coalition efforts, and subsequent effective implementation of the initiative in the African-American community. We believe several factors contributed to this success. First, the Coalition effectively mobilised sectors with organisations and networks that were deeply rooted in the African-American community. Neighborhood groups and faith organisations are institutions central to the African American community in Kansas City, Missouri (Collie-Akers *et al.*, in press). These two sectors were powerful in creating change that targeted the African American community, accounting for 65.9% of the changes targeting that community.

Second, the leadership in the Coalition had a lengthy history of working in and with neighborhood and faith organisations in the African American community. Partnerships with neighborhood and faith organisations, as well as organisations serving primarily African Americans, were developed almost immediately on development of the coalition. Additionally, there were effectively two mobilisers for the African American population: the community mobiliser and the director who was the principal leader for the first five years and had deep ties with the African American community.

Third, African Americans were consistently well-represented on the Coalition steering committee and executive committee.

Finally, several key choices made it more likely that African Americans would buy into the Coalition. For example, the central Coalition office, where coalition meetings were held, was located in a predominately African American neighborhood. This was a site selection that was convenient and familiar to members of the African American community, but not the Latino community.

Participation and implementation in the Hispanic community

The Hispanic community of the great Kansas City area is quite diverse in its experience. One part of the community is composed primarily of Hispanic families who have lived in the Kansas City metropolitan area for several generations. Although most residents speak English and Spanish, culture can still be a barrier to engagement in coalition effort. CBPR makes community the unit of analysis (Israel *et al.*, 2003), but there was considerable diversity within the Hispanic community. Those practicing CBPR should not assume that a community is homogeneous, but be prepared to look for diversity within community.

For example, another group within the Hispanic community is new immigrants. These first-generation Latinos also include undocumented immigrants from Mexico and other Latin American countries. This factor is a critical barrier to engagement. Language is usually Spanish only, and there may be challenges to literacy and limited experience with cultural differences in the United States. Employment and good job opportunities are of critical interest to this predominately low-income community, and longer-range concerns such as risk for chronic disease may not attract their attention. Transportation, education and health care services were also of high importance to them. Interest in health promotion is much lower (Runnels & Work Group for Community Health and Development, 2007). Access to health care is a tremendous problem for this group. They are unlikely to have health insurance, although both groups may experience culturally insensitive services. They are typically unaware of available services, lack trust and may be less likely to speak about their health problems. The conditions and situations in which new immigrants are found make it extremely challenging to implement CBPR.

Limitations to KC-CDC's engagement with Hispanic partners

Key informants identified a number of limitations, including limited engagement by Hispanics in the planning processes and in regular coalition meetings. There were some delays in bringing on bilingual staff, and by that time the coalition was deeply connected to the African American community. In addition, there was little follow-up by the bilingual staff with participants with Hispanic partners, and little awareness or engagement in the Pick Six process. Finally, many Hispanics did not have deep connection to neighborhood, and the role of faith organisations was not as central as in the African American community

Some recommendations for enhancing CBPR in racially and ethnically-diverse communities

Based on these lessons learned, this report concludes with some specific recommendations for enhancing use of CBPR with racially and culturally diverse communities.

- Engage community members to develop a deep understanding of the populations and subgroups that are prioritised in the research.
- Ensure that community assessment and action planning engage key stakeholders.
- Develop a leadership team that includes members of all populations and subgroups, allowing for all members to have an equal voice in decision making.
- Ensure that community assessment, planning, intervention and sense-making are done in a manner that is respectful, comfortable and safe for all members of the CBPR team.
- Community mobilisers should be members of the populations of interest and/or able to communicate effectively with groups of interest in a culturally appropriate manner.
- Engage the community in identifying valued institutions and social and cultural groups that influence individual behavior.

- Create opportunities for engagement in coalition activities that occur during times and in places that are convenient.
- Consider which sectors are most appropriate for delivering interventions within the prioritised community and subgroups.
- Partner with local organisations that have deep engagement locally and the ability to mobilise all the populations of interest.
- Reduce the time and effort for community members to participate in developing and implementing interventions.
- Tailor components of the initiative and intervention to fit the cultures of the prioritised populations and subgroups.
- Review data and engage in sense-making that leads to timely and relevant adjustments to the effort. Engage the community in identifying and using appropriate channels of communication to reach the prioritised population to promote engagement and healthy behaviours.

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