Development of an Ethnic/Cultural Health

Research Agenda for Ohio

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Health disparities research agendas can be important tools to improve knowledge of how to prevent disease and injury, identify and treat illnesses, and reduce premature death among the nation's ethnic, racial, and cultural groups who disproportionately suffer from their burden. Although such research agendas have been created at the national level, there are few examples of health disparities research agendas at the state level. This article describes the development of a statewide health disparities research agenda in Ohio. The agenda was created with input from academic researchers, health professionals, staff of government agencies, community-based organizations, and representatives from ethnic communities across the state. The process of research agenda development will be described and the major research topics and critical questions identified will be summarized.

Keywords: health disparities, research agenda, prevention, intervention, Ohio

Despite increased attention to the health disparities affecting the nation's ethnic / cultural populations, these groups continue to bear a disproportionate burden of illness and premature death (Institute of Medicine, 2003). There is widespread belief that health disparities research can provide the knowledge base needed to improve efforts to prevent, detect, and treat illnesses and injuries that threaten the health and life expectancy of these vulnerable groups.

To stimulate such research, many federal agencies, professional associations, and health researchers have proposed or developed health disparities research agendas. These research agendas have been identified potentially effective vehicles for as prioritizing research needs and influencing what will be funded by public and private grant-making agencies (Gambescia et al, 2006). The functions of health disparity research agendas include: identifying gaps in existing data (Ramos-Gomez, Cruz, Watson, Canto & Boneto, 2005); focusing attention on issues related to methodology, study design, instrumentation, and data sources for health disparity research (Office of Minority Health [OMH], 2004); and promoting consistency in the direction of research (Horn & Beal, 2004).

At the national level health disparity research agendas have been developed to address specific health areas or diseases such as cancer (Krieger, Emmons & White, 2005), oral health (Ramos-Gomez et al, 2005), neurological disease and stroke (National Institute of Neurological Disorders and Stroke [NINDS), 2001), environmental health (National Institute of Environmental Health Sciences, ND), and mental health (Lopez,

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2002; Okazaki, 1998); and, targeted ethnic populations (Marin, Amaro, Eisenberg & Opava-Stitzer, 1993) or particular age groups ranging from children (Flores et al, 2002; Horn & Beal. 2004) to adults in late life (Bulatao & Anderson, 2004). More broadbased health disparity research agendas have been developed by federal agencies or by professional associations. The National Center on Minority Health and Health Disparities (NCMHHD) is charged with moving forward the National Institutes of Health strategic health disparities research program (NCMHHD, 2001). The Office of Minority Health (2004)created а comprehensive cultural competence research agenda and the Society for Public Health developed Educators (SOPHE) а transdisciplinary health disparities research agenda in 1995 and updated it in 2005 (Gambescia et al, 2006).

There has been no similar movement to develop health disparities research agendas at the state level. States have played important roles in advancing progress in other health arenas such as health policy or building infrastructure for minority health initiatives. For example. state innovation and experimentation in child health insurance coverage influenced federal action to create new legislation to expand child health insurance programs (McDonough et al, 2004). In addition, states were responsible for the creation of state level offices of minority health which take a leadership role in supporting programs directed to the reduction of health disparities (Association of State and Territorial Health Officials, 2004). The creation of minority health research agendas at the state level would move forward responses to health disparities by identifying and prioritizing state and local health disparity research needs and by setting the direction of state research and funding.

This article will describe the creation of an ethnic/cultural research agenda for Ohio. Following a brief description of Ohio's population and health disparity indicators, the process of developing the statewide agenda will be described. Themes of the completed research agenda will be summarized, along with suggested sample research questions for the agenda's major categories and subcategories. Conclusions will stress the value of creating state health disparity research agendas and suggest guidelines that other states might follow.

Profile of Ohio's Population

Ohio's current population is estimated at 11,459,011 (Ohio Department of Development, 2005). At present racial and ethnic minorities currently make up more than 18% of Ohio's population. Based on 2004 estimates, African Americans represent the largest of these groups at 11.6%, followed by 2.8% Latino, 1.5% Asian American, 1.4 % mixed race, .8% other race, and .2% Native American (Kaiser Family Foundation, 2004).

This profile is rapidly shifting. Within the past decade Ohio has experienced unprecedented growth in Asian American, Latino, and African immigrant (primarily Somali) populations, particularly in areas that have not traditionally had large immigrant populations. Between the 1990 and the 2000 census, the Asian American population in Ohio grew by 62.8%, with Southeast Asians constituting nearly 40% of the newly arriving population (Association of Asian Pacific Community Health Organization [AAPCHO], 2005; Ramsini, 2005). While the state's overall Latino population only grew by 55.4% during this time frame, two urban counties in southwestern Ohio had a 221% increase in Latino immigrants and other areas that previously have had little Latino presence are also showing large increases (Ohio Department of Development, 2005). In addition to these racial/ethnic immigrant or refugee populations, Columbus, Ohio, has become a favored destination for Somali refugees in recent years and the state's capital city now has the second largest Somali population in the United States. Although there is no completely reliable count of Somalis in Ohio, current estimates suggest a population of about 30,000 (United Way, 2003).

Ohio additionally has two sizeable culturally distinct populations—Amish and

Appalachians. Although Ohio is said to have the largest population of Amish in the nation, it is difficult to establish their size accurately. There is no overall census that lists the individuals and families belonging to Amish churches. Information about Amish demographics in Ohio must instead be taken from individual directories published by Amish communities that provide population information, including members (baptized adults) and nonmembers (young adults and children still living at home who have not been baptized) (Donnermeyer & Cooksey, 2004). Current estimates indicate that there are approximately 50,000 Amish in the state (Ohio Department of Transportation, 2000).

It is also difficult to determine the size of the Appalachian population in Ohio. Residents of the 29-county area of southeast Ohio that is federally designated as an Appalachian region are considered Appalachians by virtue of their geographic residence, regardless of where they were born or their self-identified cultural, racial, or ethnic affiliation. These rural Appalachian residents make up nearly 13% (nearly 1.5 million people) of the state's total population. Not included in this estimate is the population of urban Appalachians living in cities throughout Ohio. Because of the passage of time beyond initial migration to cities and the lack of institutional data collection by schools, health departments, and the census bureau on Appalachian heritage, the size of the urban Appalachian population is unknown. However, one urban county has estimated its first or second-generation Appalachian migrant population as approximately one in five county residents (Obermiller & Howe, 2000).

Ohio's demographic profile is unique, and certain features of the profile create challenges in determining health status and health disparities affecting the state's ethnic, racial, and cultural groups. There are often not enough data to report disease incidence, behavioral risk factors, or mortality rates with any degree of confidence for the state's Asian American, Native American, and Latino populations. This may occur either because data on race and ethnicity were not collected or because the sample size was not large enough to permit statistical analysis. As a result, these smaller groups may either be excluded from report results, or they may be lumped together into a meta-category of "other" which does not allow for discrimination of differences in their diverse health problems (Yung, 2005).

Geographical residence patterns contribute to the problem of collecting health data on Native Americans in Ohio. This population is widely dispersed throughout the state rather than residing in identifiable neighborhoods (Forquera, 2001). Widespread population distribution makes it difficult to carry out techniques such as oversampling, or targeting "known" ethnic communities and census tracts in order to increase their representation within a research population (U.S. Department of Health and Human Services Substance Abuse and Mental Health Service Administration [SAMSHA], 1994).

Data on ethnic subgroups such as immigrant Africans, migrant workers, Southeast Asian immigrants, and ethnic/cultural minorities living in rural areas are very There is tremendous intra-ethnic limited. diversity among these groups with regard to linguistic, cultural, sociotheir and demographic backgrounds, immigration histories, levels of acculturation, and health profiles. The lack of data on these groups in Ohio makes it difficult to evaluate risk factors, disease incidence, and health behavior patterns that may vary widely from group to group (Consedine et al, 2004; Ramsini, 2005).

There are also unique challenges for the state in identifying and addressing the health care needs of its emerging populations of Latinos, Asian Americans, and Somalis. The Kaiser Commission on Medicaid and the Uninsured has characterized regions with small but very rapidly growing immigrant populations as "new growth" communities and has documented the struggles of these communities to overcome the financial, language and cultural barriers that impede health service provision (Cunningham, Banker, Artiga & Tolbert, 2006). Indeed, Ohio is struggling to determine the types of diseases that affect these newcomer groups, their health beliefs, health-promoting and health risk behaviors, and how their health needs can best be served.

Health Disparities in Ohio

Although data on health disparities are far from complete, there are clear widespread indicators of disparities endangering the health and longevity prospects of Ohio's ethnic/cultural residents. In many cases, the rates for particular diseases affecting these groups exceed not only the state and national rates for Caucasians but also the national rates for their ethnic peers. Mortality rates for Ohio's African American population exceed those of their national peers in deaths from lung, colorectal, cervical, and breast cancers, from diabetes, and from cardiovascular disease (Centers for Disease Control [CDC], 2004a; CDC, 2004b; Kaiser Family Foundation, 2003; Ohio Department of Health, 2004). African American and Latino rates of low birth weight babies (13.9 and 7.3, respectively) exceed national rates of 13.4 for African Americans and 6.5 for Latinos (Kaiser Family Foundation, 2003).

Behavioral risk factors are evident in Ohio's Latinos and many health areas. African Americans are more likely to report not meeting the recommended guidelines for moderate physical activity than the state's Caucasian population (CDC, 2004b) and are more likely to be obese (Ohio Department of Health, 2001). Cigarette smoking is high among the state's ethnic/cultural groups with African American, Native American, Latino, and Appalachian rates exceeding national smoking rates (CDC, 2005a). Rates of Native American tobacco use have been reported to be nearly double those of national rates, and pregnant Native American women reported smoking at nearly one and a half times the national pattern (Ramsini, 2005).

Health disparity indicators extend to intentional and unintentional injuries for African American children and adults. In 2003 pediatric trauma centers in Ohio reported that African American children were 7.7 times more likely to be struck by a car, 6 times more likely to be intentionally injured, and more than twice as likely to be killed by an injury as Caucasian children (Hayes & Groner, 2003). The 2002 rates for African American homicide victimization exceeded overall state and national homicide rates as well as the national rates for African Americans (CDC, 2005b).

The persistence of these health disparities, the lack of health data on many ethnic/cultural groups and subgroups, and the fragmentation of current research efforts within the state served as the impetus for the creation of an ethnic/cultural health disparities research agenda for Ohio.

Process for Development of the Ohio Health Disparities Research Agenda

In 2004, the Ohio Commission on Minority Health funded Wright State University to establish the Research and Evaluation Enhancement Program (REEP), a network of Ohio academic research faculty from multiple disciplines with common interests and expertise in ethnic/cultural health disparity research and community organizations serving the state's ethnic / cultural groups. Among the chief purposes of REEP was the creation of a statewide ethnic/cultural health research agenda as a tool to move forward research efforts to learn more about the health disparities in the state, why these disparities exist, and what can be done to address the health needs of African Americans, Appalachians, Asian Americans, Amish, Latinos, and Native Americans and other underserved populations in Ohio.

The process for developing the ethnic/cultural health research agenda included reviewing demographic data on Ohio's ethnic/cultural populations, health databases for Ohio, professional literature on health disparities, selected Ohio research studies, and other published health research agendas. Project leadership also considered it to be especially important to seek widespread input for the research agenda from health professionals, academic researchers, staff of government agency and community-based organizations, and representatives from ethnic communities across the state.

A series of statewide and regional meetings were held for the purpose of hearing community perspectives about the research needed to identify and address ethnic/cultural health disparities in the state more effectively. One statewide forum and six regional meetings were convened in the first year of the project. Because Native Americans had not been represented in earlier meetings, one of these meetings was held in a local church specifically for the Native American community. After a draft of the research agenda had been created, it was distributed for review and comments to all who had participated and to other state leaders. It was also presented for group review at a second year health disparities research forum that also included showcasing of ethnic/cultural health research projects in Ohio through presentations and poster sessions.

The meetings were attended by more than 300 participants and included representation from public and private academic institutions, health service providers, state and local government agencies, private funding community leaders, health organizations, consumers, and advocates from ethnic communities throughout the state. All of the targeted communities were represented at these meetings. Each of the regional meetings followed the same process of large and small group discussion around the topics of research needs in Ohio related to: the nature and extent of health disparities; contributors to health disparities; and prevention and intervention programs to reduce health disparities. Although each discussion was unique, several overarching themes emerged.

Themes Emerging from the State and Regional Forums

The statewide and regional meetings held as part of the REEP project were designed to give participants the opportunity to voice their perceptions on the topics most needed for an ethnic/cultural health research agenda for Ohio. Although participants indeed made important contributions in defining needed research content areas, they also wanted to discuss various aspects of the research process that have significant impact on health disparities research.

Research Design and Researcher/ Community Relationships

Divergent perspectives emerged about the design of health disparities research and the relationships between academic and ethnic communities engaged in joint research Many participants representing projects. ethnic/cultural communities felt strongly that far too much research is still being designed in university settings without participant To initiate the research, academic input. faculty must then go out and seek the buy-in and resources of community-based ethnic health agencies to locate subjects. This practice often results in agencies serving ethnic communities feeling "used." Representatives from these organizations indicated feeling particularly resentful about being approached for free recruitment services on projects they had no part in designing to answer questions that they might or might not feel were important. They also disliked the fact that, once the research is completed, many researchers did not bother sending them a copy of research results or, if they did provide reports, the reports were often not translated into language readily understandable by those who do not have a scientific background.

On the other side, academic faculty also indicated experiencing problems in the research enterprise, particularly in the area of program evaluation. Under deadline pressure, community agencies may prepare grant applications without consultation with a program evaluator. An evaluator may not in fact be called in until after a grant is awarded and services have begun, often causing baseline data to be lost. Evaluators must then struggle to develop a methodology sometimes based on objectives that may be poorly thought out, unrealistic, and difficult to measure. Service providers may also have a limited understanding of the cost and extent of effort needed to collect data to assess program outcomes and may underestimate budget needs for evaluation services. They may also

lack appreciation for the ramifications of missing data and put less effort into data collection than in the provision of services which they value more highly.

Many participants expressed an appreciation of the hard work and long hours required to gain trust and entry into ethnic/cultural communities and the need to approach these communities through their formal and informal leaders. For example, participants who work in Amish health research suggested that researchers needed to allow 3 to 5 years of relationship-building with Amish leaders before proceeding with a research project. The extra time needed for building trust presents unique problems for junior faculty who are under pressure to produce quick scholarship that will advance academic careers. In addition, the difficulties of carrying out experimental design in ethnic health research may create studies that are perceived to be less rigorous in the scientific community and are therefore more difficult to publish. Participants recognized the challenge of reconciling the career advancement needs of academia with the pace required to carry out research in ethnic community settings.

In spite of some "sector" differences, there was a remarkable consensus by all participants on the vision of ideal research as collaborative, community-based parа ticipatory endeavor that involves community members as partners in formulating the research questions and in designing, implementing, analyzing, and disseminating the research. Participants viewed this approach as helping community members on the research team develop greater trust in the researchers and be more willing to promote participation in the research within their communities. In turn, they believed that researchers using this approach will be asking more relevant questions and will gain important knowledge and insight into the conditions under which health disparities exist as well as an appreciation for the complexities involved in developing and implementing strategies for reducing these disparities. This research approach was envisioned to be more empowering, acceptable to the community,

more immediately applicable to health improvement, and easier to disseminate.

Dissemination of Research Results

Dissemination of research results was also a major theme of discussion at all regional meetings. Participants from all sectors agreed that it is unfortunate that the major vehicle for disseminating ethnic / cultural health research results continues to be the professional journal article. Primarily written for a scientific audience, these publications are generally not reader-friendly to audiences who are not expert in the field. They tend to provide technical information on research design and the methods of analysis. Findings are often not easily interpreted and the applicability of the research to community health service providers is often not made explicit.

Participants wanted ethnic/cultural health research dissemination efforts to be made available in different formats and to target diverse audiences, including ethnic community members, health professionals, policy-makers, and funders. They placed special emphasis on the need for making sure that participants in health research be provided with information on the results of that research so that they feel their participation was valued and beneficial. They believed it was important to experiment with innovative methods of disseminating research results using multimedia methods, case "stories," and face-to-face debriefings.

Health professionals and ethnic community representatives expressed additional dissemination needs. These groups felt that information to promote replication of evidence-based health disparity reduction programs and practices is difficult to access. Many different sources must be consulted and often these sources do not provide the kind of practical information needed for program planning and implementation. For example, journal articles are not typically designed to provide the reader with detailed information on how particular activities should be staffed and carried out and what costs might be

expected in establishing a new program. Replication manuals with step-by-step guidance on implementation of particular best practice models, including information on evaluation measures, were perceived to be of great benefit to health agencies serving ethnic communities.

Needed Research Topics

Participant contributions on topics for the ethnic/cultural health research agenda ranged from broad-based suggestions (e.g., need for studies to explore the impact of racism on access to health care) to diseasespecific studies needed on ethnic groups and subgroups (e.g., differing asthma rates for Mexicans, Puerto Ricans, Cubans, and Central Americans).

A notable common theme that emerged from the REEP meetings was the need for better local and regional data on health needs of the ethnic groups and Participants agreed that local subgroups. health assessments are an important source of supplementary, qualitative information that provide a better understanding of health disparities at a community level. However, they were acutely aware that it is much easier to locate health disparity data at the national and, to a lesser degree, at the state level. The lack of local data is a significant barrier in planning health promotion, disease prevention and health care programs targeting the groups with highest need. At a more pragmatic level, these data are needed as justification for funding and documentation for grant proposals. Participants also indicated that it was difficult to identify funding for local health assessments, particularly in smaller communities.

As an overall theme, participants wanted research studies that would help to explain the complex "big picture" questions of what causes health disparities, what approaches are most effective in preventing the diseases that more often affect members of ethnic/cultural groups, and how we can better treat existing illnesses to improve the health status and outcomes that now so often lead to disability and premature death. The community meetings provided a gratifying view of statewide, broad-based commitment to health equality from multiple sectors involved with minority health. They also indicated that participants were realistic in their appraisal of the practical and conceptual challenges in learning why health disparities exist and what we can do to address them. Observations from these meetings provided a solid base from which to craft a health disparities research agenda.

Overview of the Research Agenda

The health disparities research agenda was completed in 2005. It is organized into the broad categories of Nature and Scope of Health Disparities, Contributors to Health Disparities, and Prevention and Intervention Programs to Reduce Health Disparities. Each of these categories identifies a set of major research areas and sample research questions to be addressed. The sample research questions that were developed were not intended to be comprehensive nor were they meant to exclude other topics that would fit into each research area.

Nature and Scope of Health Disparities

This category emphasizes that the first step in addressing health disparities is to gain a more complete understanding of the extent of health disparities and more accurate evidence of which populations are most affected by which diseases and health concerns. It acknowledges the complexities in designing studies to identify health disparities and for creative calls methodologies, increased consumer participation, and better instrumentation to further health disparity research. The category includes four major research areas:

- 1. Better information on the extent and types of health problems that affect ethnic/cultural groups and subgroups and contribute to health disparities
- 2. Improved methodology for identifying health disparities
- 3. Improved screening, assessment, and evaluation measures that are valid and

reliable for specific age, group, gender, cultural, language, and ethnic groups

4. More participation of diverse ethnic/cultural groups in health research.

Sample research questions suggested under this category include: What is the health disparities extent of among racial/ethnic minorities living in rural areas and how do they differ from disparities affecting their urban peers? How do health disparities differ among ethnic group members who do and who do not have health insurance? Among those who are insured, how do health disparities differ among those with private insurance and those who receive Medicaid?

How can we design sampling techniques that increase the collection of health data on "rare" population groups? What are best practices in reducing respondent errors and increasing response rates in health surveys with ethnic/cultural groups? How can we create, modify, and validate nutritional behavior measures to accurately reflect the range of foods, preparation techniques, recipes, and portion sizes for ethnic groups and subgroups? What are the cultural issues that influence participation in clinical and epidemiological health research? How do they differ by ethnic group, subgroup, country of origin, rural or urban residence, and length of residence in the United States?

Contributors to Health Disparities

It is widely acknowledged that biological, psychological, cultural, behavioral, and environmental, and social factors contribute to health disparities in complex interactions that are not yet well understood. Ohio's health research agenda highlighted five major areas related to contributors to health disparities.

- 1. Examination of the biological, socioeconomic, and cultural factors that underlie health disparities
- 2. Better understanding of the role of acculturation in help-seeking behavior and in health status

- 3. Better understanding of the prevalence and processes of bias, stereotyping, and prejudice and its effects on access to quality health care and health outcomes
- 4. Better understanding of the effects of the social and physical environment on ethnic/cultural health
- 5. Improved knowledge of the barriers to health care access and how they differ for different ethnic groups and subgroups.

Sample research questions that were identified include: What are the cultural and psychosocial factors in onset, maintenance, and cessation of ethnic group use of tobacco? What are the cultural belief factors that specifically impede participation in health screenings? How do these beliefs differ among ethnic/cultural groups and subgroups? What are the manifestations of stress in diverse ethnic/cultural groups and what is its effect on overall health and well-being? What are the effects of acculturation on specific health risk or health promoting behaviors for diverse ethnic/cultural groups and subgroups? What are the best ways to measure exposure to racial/ethnic discrimination in health care settings? How does the experience of bias and stereotyping in interactions with the health care community vary by ethnic/cultural group? What are the environmental barriers to positive health practices (e.g., less access to healthy foods and safe, inexpensive places for indoor and outdoor exercise) in different ethnic communities? What is the effect of the interpreting process on communication between health consumer and health provider and the quality of health information and care received by non-English-speaking patients?

Prevention and Intervention Programs to Reduce Health Disparities

Additional research is critically needed on health promotion/disease prevention programs and intervention programs that would work toward eliminating health disparities. Particularly needed is testing of culturally adapted interventions that take into account the customs, beliefs, attitudes, preferences, and life circumstances of racial, ethnic, and cultural health consumers. Five major research areas were identified in this category of the research agenda:

- 1. Development and testing of new or improved approaches to health education, health promotion, and disease prevention programs, including assessing the effectiveness of using non-traditional methods to deliver these services to diverse ethnic/cultural groups
- 2. Development and testing of new or improved approaches to treating diseases and disabilities that contribute to health disparities
- 3. Assessment of the impact of cultural competence training on the provision of health promotion and health care services for ethnic/cultural consumers
- 4. Research on best practices in disseminating health research information to diverse audiences, including health care providers and ethnic/cultural health consumers
- 5. Better understanding of the effects of racial, ethnic, cultural, and linguistic concordance (i.e., matching provider and consumer on characteristics such as ethnicity/race, gender, socioeconomic status or other key factors) on quality of health care and health promotion services, consumer satisfaction, and health outcomes

Some suggested research questions in this category include: What are the most effective tools for educating and motivating people to make behavior changes to maintain healthy lifestyles, improve their health status, and prevent or minimize the impact of diseases. injuries, and disabilities? Which tools are most effective with which populations? What are the effects of ethnic-specific treatment programs on retention rates and outcomes of mental health and substance abuse treatment programs? What are the health outcomes for ethnic/cultural patients of integrating psychological behavioral health services into primary care settings? What modifications are needed to adapt psychological treatment approaches that have been established to be effective with mainstream children and adolescents (e.g., cognitive behavioral therapy for social anxiety) for ethnic/cultural minority children and adolescents? What is the impact of format, content, and length of cultural competence training on trainee knowledge, skills, behaviors, and health service delivery to ethnic/cultural clients? What are the effects of creating customized public health for diverse ethnic/cultural campaigns communities on awareness of health problems and on producing behavior change? What strategies are most effective in motivating and preparing members of diverse racial, ethnic, and cultural groups to enter and complete health professions training programs?

Conclusions

Efforts to address health disparities must proceed on many fronts. State and federal policies are needed to ensure consistent health data collection on race and ethnicity, the establishment and monitoring of standards for culturally competent health service delivery, and the establishment of programs that improve access to health promotion initiatives, health screenings, and health care. Other ingredients needed to reduce health disparities include social strategies to mobilize decision-makers and communities around health equity issues and political strategies to enable support and funding of health disparity reduction programs (McDonough et al, 2004). An improved knowledge base about the extent and causes of health disparities and the effectiveness of interventions to reduce them is essential to the enactment and application of such policies and strategies. State-level health disparity research agendas can be an important tool for progress in removing the barriers that impede the access, quality, and outcomes of health care and health promotion programming for ethnic/cultural communities.

In the creation of a statewide health disparity research agenda, it is vital to provide some mechanism that allows for expression of community concerns and the inclusion of community perspectives into the final production of the document. Some of the existing health disparities research agendas were developed by health professionals, funding agency staff, and/or the academic community without input from the most affected communities (Abma, 2006). Just as individual research projects are enriched by consumer participation, the creation of an overall agenda to establish the priorities and direction of future research is also enhanced by the contributions of community expertise and shared responsibility for defining health research needs. Community participation in development research agenda invests community members in the research priorities they helped to identify and sets the stage for continued participatory research partnerships.

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