

# **Communiversality**

**The Institute for Immigrant & Refugee  
Health and Wellness**

Prepared in partnership with  
West Side Community Health Services

Prepared by  
Karen Moe  
Research Assistant

University of Minnesota  
July, 2008

CMV Report 012

July 2008

CMV is coordinated and funded by the Center for Urban and Regional Affairs at the University of Minnesota.

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Center for Urban and Regional Affairs (CURA)  
University of Minnesota  
330 HHH Center  
301--19th Avenue South  
Minneapolis, Minnesota 55455  
Phone: (612) 625-1551  
Fax: (612) 626-0273  
E-mail: [cura@umn.edu](mailto:cura@umn.edu)  
Web site: <http://www.cura.umn.edu>

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## SECTION I: Lessons Learned

### **Introduction**

West Side Community Health Services is the largest community clinic organization in Minnesota, with multiple locations in the metro area. West Side provides innovative and multicultural / multilingual health care services and education to immigrant and low-income communities. The mission of West Side is “Caring for the Health of Diverse Communities.”

Founded in 1972, West Side Community Health Services is one of the largest and most established community health care organizations. Few organizations serve so many sectors of the population so sensitively and effectively – improving the health of our region for the benefit of all.

In the last 35 years, WSCHS has become an expert in increasing access to health care and related services through the systematic breakdown of barriers related to trust, cost, location, culture and language.

Recognizing the benefits that research offers health service providers, their clients, and the community, West Side initiated discussions with other service oriented community-based organizations and the University of Minnesota. Conversations focused on finding ways to formalize these relationships while considering the feeling of invasiveness or intrusion felt by many community members during the research process. West Side raised concerns as well about the number of fragmented research projects already underway within their community.

The discussions led to a growing interest in the development of a “organization” that would facilitate research being conducted in the communities that West Side served, predominately Latino, Asian (Hmong, in particular), and increasingly African (Somali, Eritrean, and Ethiopian). The organization would promote community-based research, develop long-lasting relationships with researchers, and focus on health disparity issues. To facilitate the process, a name was given to the concept: The Institute for Immigrant and Refugee Health and Wellness.

The following report is the result of initial research conducted during the Fall of 2007 by a University of Minnesota graduate student, who was hired in October of 2007. The following report is in three sections:

1. Lessons Learned from Case Studies
2. Organizations
3. Resources

There are two appendices: A list of included documents from other organizations that may be helpful during the formation of “The Institute” and an extended Literature Cited with abstracts and key words.

## SECTION I: Lessons Learned

### Methods

Research was conducted in two main areas: researching existing Community-Based Organizations (CBOs) and reviewing peer reviewed published articles. Some articles were accessible to the public (through PubMed or by the journals themselves, such as Journal of Public Health); items that were not accessible to the public were obtained via the University of Minnesota library system.

Initially, searches focused on identifying and researching existing CBOs that were involved with community-based participatory research or health disparity issues. Subsequently, literature searches were conducted, with a focus on community-based participatory research and community-engagement. Specifically, articles were sought that discussed in detail the work of the CBO in the partnership.

During the process, there were multiple avenues discussed and thus the research evolved during the initial phase. General key words searched include:

- Community-based participatory research
- Participatory action research
- Community Internal Review Board

Specific additional key words were searched in pairings with the above, such as:

- Health Disparities
- Immigrant & Refugee
- Infrastructure
- Coalition Building

At first, organizations were sought that had a focus on community-based participatory research, health disparities, or serviced immigrants and refugees. Foundations, funding sources, local and state health agencies were also included initially. Organizations could be based throughout the United States. The initial list included a handful of organizations acted as starting points:

- Sinai Urban Health Institute
- The Institute for Community Research
- Center for Cultural Understanding and Change
- Hispanic Health Council
- Neighborhood House
- CLUES

## SECTION I: Lessons Learned

- LaFamilia

The initial research resulted in identifying a number of organizations working in these fields. There were few though that had published materials discussing the participatory process from their (the community-based) aspect. Documents that were accessible included workplans, assessment tools, timelines, examples of Memorandums of Understandings, etc.

Along with researching organizations, literature searches were done on the abovementioned topics. In particular, case studies of organizations were sought that either were similar to the concept of “The Institute” or that explicitly discussed and offered insight into the forming phase of the organization.

### **Process**

A handful of “institutions” that developed out of community-academic partnerships using the CBPR process as a foundation were identified. The discussion below is based primarily on the following: The Detroit URC, Community Action Against Asthma, the PATH Project, Chicago Southeast Diabetes Community Action Coalition. It does include points taken from other projects.

No prescribed set of steps to create a successful collaborative partnership was given. Israel et al. (1998) suggest breaking discussion components into three parts: (a) issues relating to developing community research partnerships; (b) methodological issues involved in community-based research; and (c) broader social, political, economic, institutional, and cultural issues. For this research, common phases or stages were elicited from the literature. These were divided into three phases: (1) The Exploratory Phase; (2) The Assessment Phase, and; (3) The Project Development & Implementation Phase.

- Phase I: Exploratory
  - Bringing together interested parties
  - Initiating discussion around a health topic, a community, an interest, etc.
  - Creating a “board”, e.g. Steering Committee, Community Advisory Board, Community Coalition Board.
  - Establishing operating norms and CBPR principles, mission statement, etc.
  - Evaluating the process
- Phase II: Assessment

## SECTION I: Lessons Learned

- Mapping of community assets
- Developing strategies for identifying common issues
- Setting priorities
- Collecting data
- Evaluating the process
- Phase III: Project Development & Implementation
  - Developing a “Community Action Plan” or intervention efforts
  - Adapting plan/intervention to specific communities
  - Adopting of plan/intervention by communities
  - Implementing plan/intervention
  - Interpreting data
  - Disseminating findings
  - Evaluating process

### **Lessons Learned**

Significant components or characteristics of the first phase were identified and discussed here. A comprehensive Literature Review was completed in 2006 for the Centers for Disease Control and Prevention (Souffel et al, 2006) entitled *Identifying Characteristics of Successful Research/Community-Based Organization Collaboration in the Development of Behavioral Interventions to Prevent HIV Infection*. In their report, they created a list of “Significant Components.” They are as follows:

1. Trusting relationships
2. Equitable processes and procedures
3. Diverse membership
4. Tangible benefits to all partners
5. Significant community involvement in scientifically sound research
6. Supportive organizational policies and reward structures

## SECTION I: Lessons Learned

7. Leadership at multiple levels
8. Culturally competent and appropriately skilled staff and researchers
9. Collaborative dissemination
10. Ongoing partnership assessment, improvement and celebration
11. Sustainable impact

In comparing these to other literature and case studies, it was noted that these accurately and concisely described the Lessons Learned from many of the other projects. Therefore, these are used as a framework for the following discussion.

### **\*1. Trusting relationships**

Relationships of communities, institutions, individuals, and organizations, are affected by feelings of power and control among and between these entities. Community-based participatory research (CBPR) purposefully works to address these issues by encouraging an empowering and power-sharing process (Fowles 2007). Building trust is commonly noted as one of the crucial components of successful CBPR and as one its advantages in that it increases the likelihood of overcoming issues of distrust between researchers and communities (Israel et al. 2001).

The benefits of the CBPR process of developing a level of trust between the community and researchers are both immediate and long term. In the case of the Detroit URC (Israel et al. 2001), the organization formalized a partnership between researchers from an academic institution and community members in Detroit. The relationship led to subsequent other projects and the formation of other organizations. The level of trust that developed during the development of URC contributed to the willingness, interest and ability to pursue future projects in the long term.

The achievement of establishing trust between partners is often attributed to the involvement of partners in the decision making process from the beginning or at least very early on (Giachello et al 2003). Including partners in the development of the process avoids feelings of unbalanced power or control.

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\* The terms “academic” or “researcher” and “community” are used frequently throughout the discussion. Much of the CBPR literature uses the term academic or researcher to identify an outside participant in the research process, usually affiliated with a university or other research institution. Community member is used to refer to a member of a community, a Community-Based organization, or some other non-academic or non-research person/position. By no means is the use of these terms meant to suggest that there only exists two sides in the process. Nor are they in any way meant to be divisive, in that they are often presented at odds. It is strictly their ease of use and suggestive nature for which they are used.

## SECTION I: Lessons Learned

Schell et al (2005) point out the need for partners to take time to learn about one another. They suggest that if researchers view the partnership as just a way of conducting another project the relationship may be undermined. The time dedicated to building relationships though may seem to initially overshadow the purpose of the partnership (Israel et al 1998). Especially as it is recommended that building trust should occur both in professional and personal ways.

The emphasis on developing - both professional and personal - relationships may be different, and perhaps challenging, to members that are not accustomed to the time required. The issue of the time consuming nature of establishing and maintaining relationship of trust is pointed out repeatedly. All of the literature, as discussed further below, suggests the activity of jointly establishing operating norms and procedures as one way to facilitate trust amongst partners. The time required to accomplish this depended on the nature of the relationships already established, the funding, and the nature of the project, ranging from two to six months. While the time dedicated to the process is not categorical, the crucial issue is that enough time is allotted to allow relationships to develop.

Additional issues identified that can affect a sense of trust amongst partners, either positively or negatively, include considerations such as who attends meetings, who facilitates meetings, how meetings are conducted or where meetings are held. All these decisions can influence the relationships developing between partners. CBPR is based on the principle of shared control and shared benefits. Issues such as these and the influence they have on the process and outcome need to be considered.

Once trust has been established amongst partners, it should not be taken for granted though. Parker et al (2003) mention that in the work of the Coalition Action Against Asthma (CAAA), the establishment of trust in the formation stage of the project did not prevent a level of mistrust from arising during the implementation stage. They point out the danger of “assuming that trust, once established, is easily maintained.” Issues of trust and influence must be reviewed and assessed throughout all of the stages of development of the project.

Some partners may enter into the process with a level of mistrust which may prohibit them from participating fully. One case shared reflections from a representative of a CBO. They explained, at the onset of the process, all members were asked to suspend their concerns of mistrust and unbalanced power (between the researchers and the community) and to give the benefit of doubt to the researchers involved. They were asked to believe that all partners were truly interested in working toward a relationship of trust and equality. The representative from the CBO admitted they did so with reservations but were later rewarded by the success of the project. It may be important to consider that individuals not only bring their own pre-conceived biases or mistrusts to the

## SECTION I: Lessons Learned

process but also that they may not all feel comfortable in openly admitting these biases or level of mistrust.

### 2. **Equitable processes and procedures**

Setting operating norms as a group was critical to ensuring equitable processes and procedures. This is discussed and emphasized in the literature. The act of doing this is identified as a critical component by all the projects reviewed (Israel 1998; Israel 2001; Blumenthal 2006; Parker 2003; Giachello 2003). Agreeing upon formalized overarching CBPR principles or core values as well as developing organizational statements jointly, such as the mission, vision, and operating norms, was significant in all cases. The process of jointly negotiating these facilitates trust and shapes the relationship between group members. During this process, the groundwork for group dynamics is initiated. Schell et al. (2005) state, “outlining mutually agreed-upon protocols...provides a road map of each partner’s expectations.”

Each partner (i.e. organization) may have their own respective mission, vision, and goals, yet a common purpose – mission, vision, goals - of the group needs to be identified, prioritized, agreed upon, and established. Norms and principles cannot be imposed on the partnership, but rather the collective needs to determine these. This process needs to be facilitated, aspects of which may be decided upon by the collaborative. Questions as to will decisions be made by majority rule or by consensus (most cases suggest consensus), what should be written and distributed, can be decided by the collective (Israel et al. 1998). Partners bring varied knowledge and expertise that will be recognized and revealed during this process.

Jointly defining operating norms and procedures fosters the bridging between cultural differences. It establishes a style of working together (Giachello et al. 2003). “Articulating and agreeing on a common purpose for the group” is one of the major challenges of CBPR research, according to Israel and her colleagues (Israel et al. 2001). A commonly accepted ethical code may reveal itself during the process of joint negotiation. This sharing of the leadership, power, and decision making from “design to dissemination” will enhance the research conducted (Macauley et al. 1999).

The operating norms, and other articles such as the mission, vision, etc, should reflect and reinforce the principles of community-based participatory research. Many of the cases adopted their own set of CBPR principles.

- Common terms that appear in the literature include: fostering listening, openness, caring, inclusiveness, agreement to disagree, identifying and addressing conflicts, opportunity (Israel et al. 1998).

## SECTION I: Lessons Learned

- Norms and procedures should promote understanding and sensitivity to working with diverse cultures, with respect to issues such as class, gender, race, ethnicity, age, sexual orientation, etc. (Israel et al 1998). Local codes should identify the ethical and political issues; reflect local culture, needs, and interests (Macauley et al 1999).
- Issues to consider: how decisions will be made (e.g., consensus or majority vote), what issues will be decided upon (e.g., budgeting, staff hiring, staff training). They should maximize close collaboration between the researcher and community partners (Macauley et al 1999).
- Outcomes have included ongoing capacity building of collaborators, stronger receptivity to collaboration by researchers, stronger community voice in policy and a greater mutual trust (Macauley et al 1999).
- The Community Coalition Board established by The Morehouse School of Medicine Prevention Research Center developed a *Statement of Community Values* that includes concerns such as, “mutual respect and justice for all people,” “self-determination,” “community has right to participate as equal partner,” and “principles...should be strictly enforced (Blumenthal 2006).” [See Blumenthal 2006 for complete statements: Table 1. Research Priorities and Table 2. Statement of Community Values]

Some collaborative groups created a Memorandum of Agreement, specifying the roles and responsibilities of partners, desired outcomes of the research, measures of validity, control of the use of data and funding and channels to disseminate findings (Macauley et al. 1999).

Allotting appropriate time to ensuring that members wholly participate in this is essential. While some cases did report a sense of frustration at how long this part of the process took, all acknowledged the benefit, whether immediately or later in the process, of allowing enough time for this component. This issue of proper time allotment comes up repeatedly. In general the process appeared to take between two and six months. It is recommended to write the additional time required into the timeline of grant proposals.

Even in cases where trust was already established, allotting time to strengthen a new partnership is recommended. The CAAA Project extended from a previous CBPR partnership. Participants in that project acknowledge the need to “build in time and support to focus on the ‘process’ of building a partnership before focusing on the outcomes of the partnership (Parker et al. 2003).”

Along with allowing for enough time, planning ahead for participation is identified as a helpful tool. Examples of planning ahead can include

## SECTION I: Lessons Learned

communicating effectively with all partners, dedicating appropriate time to complete tasks, or documenting and reviewing processes and procedures to ensure compliance (Israel et al. 2005). This ensures that processes are accessible to all members (Lindsey 1998).

Lastly, it is important to note that conflicts may arise throughout the entire process, due to differences in language, decision-making, values, assumptions, priorities, philosophies, etc. Conflicts should be anticipated and ways to maneuver through them sought out.

### 3. **Diverse membership**

“Working together amidst ethnic, cultural, socio-economic, and organizational differences,” is a major challenge of CBPR work (Israel et al 2001).

A key tenet of CBPR is the act of defining “community.” Researchers in this field suggest that the definition may not always be the traditional or most obvious. From the onset of developing relationships, defining this term can be the source of challenges or possible conflicts. Questions to consider include: Who is included in our community? And subsequently, who not included? Who represents the community? Who participates? How do they participate? To what degree do they participate?

How the process evolves will determine the answers to these questions. Selecting initial members to discuss these and future questions were handled in a variety of ways in the reviewed cases. Factors such as time, previously established relationships, geographic location, representation of specific groups, needed expertise, were some variables or criteria used to identify members.

For example, The Chicago Southeast Diabetes Community Action Coalition started their process by holding a series of town hall meetings organized by one community-based organization. This CBO invited individuals, organizations, and agencies to participate in open discussions regarding public health issues of a specific geographic location, Southeast Chicago. Community leaders became apparent through this process and eventually 15 representatives agreed to commit to be partners. Through these town sessions, the shaping of the definition of their “community” took place. In the end it was extended to include African Americans and Latinos, where previously these two groups had not been joined together as one “community” (Giachello et al. 2003).

The PATH Project was initiated by the Orange County Asian Pacific Islander Community Alliance (OCAPICA). With a reputation for collaborative health promotion, OCAPICA included seven different ethnic groups in initial discussions of The PATH Project. Leaders were identified by OCAPICA prior to the process and asked to participate. OCAPICA conducted a series of planning

## SECTION I: Lessons Learned

discussions bringing together individuals from the different ethnic groups, staff from CBOs and researchers from two academic institutions. Considering the diversity of communities involved in the project, identifying and inviting leaders may have facilitated the process in a timely manner. The PATH Project involved different sub-communities within their community but then included additional time to tailor each community action plan to meet the specific needs of those individual communities.

The Community Action Against Asthma (CAAA) grew out of an already established community-academic partnership, the Detroit URC. Members of the previously established partnerships agreed to be a part of the newly formed Steering Committee. Membership was organizational (organizations were members and individuals represented those organizations) and was made up of CBOs, agencies, a health care system, and academic institutions. In addition to the original members of URC, new members were identified based on their needed expertise (Parker et al. 2003). Steering Committee meetings met monthly and were purposefully held at alternating partner organization sites (Edgren et al. 2005).

The Wai'anae Cancer Research resulted after the Wai'anae Coast Comprehensive Health Center took part in a research study which they felt relied on strictly Western methodologies. Seeking a more community driven research project, they created their own research board. The project selected members from the community "based on their involvement in community health activities, their knowledge of Hawaiian culture, and their understanding of the Wai'anae community (Matsunaga et al. 1996)." In addition, they selected elders from the community who were viewed as "keepers of cultural knowledge and wisdom."

Suggestions from lessons learned from the various projects include:

- Seek out partners from prior positive working relationships. Many of the cases rely on previously established relationship when initiating discussions about potential projects. Build on these prior positive working relationships.
- Seek out support and participation from top leadership at organizations. Israel et al. (2001) point out that, specifically, new forming CBPR partnerships will want to seek out those that have clout and authority within their organization. These individuals will be able to contribute to the decision making process without having to seek permission.
- Start small. Israel and her colleagues also suggest involving only a few highly regarded organizations within the community. Research indicates an effective group size of 8 to 12 participants. (Israel et al. 2001).

## SECTION I: Lessons Learned

Seeking out organizations that are well established and respected within their community is critical to establish validity within a community.

- Seek out organizations, versus individuals, as members. In order to ensure consistency, commitment, and effectiveness, seek out the commitment and support of the organization, not just an individual. While the same individual may represent the organization, the commitment of the organization lends authority. A back up member may want to be identified.

Working with diverse members and cultures poses serious challenges to the process. One aspect of diverse membership is the diversity in communication. Whether it is different languages, different styles, or different forms of communication, these need to be acknowledged. Without doing so, communication may be hindered, trust may be undermined, and conflicts may arise. Due to this, more time may be required to incorporate varying forms of communication. As well, the consensus process may be prolonged. This process already takes longer than many are accustomed to, and the differences in languages or communication styles may contribute to this.

Another issue to consider when working with diverse members is that the cost to participate may vary member to member, organization to organization. Seeking out ways to minimize costs or to share the burden of costs may need to be part of discussions. For example, Parker et al. (2003), explain that the CAAA participants identified different costs to different partners and then made recommendations for ways to reduce those costs through their partnership. Use the opportunity of the partnership to build the capacity of all partners.

In general, pay attention to membership issues and relationships amongst members.

### **4. Tangible benefits to all partners**

Identifying and revisiting the benefits of the collaborative will assist with keeping members involved in a process that may be new and challenging – even frustrating – for members. Many of the projects were divided into phases, with two common phases as: (1) community assessment, including the partnership “forming” phase and; (2) community action plan, including the development, adaptation, dissemination phases. By dividing up the process, it may be easier to identify short term and long term benefits.

One challenge pointed out by Israel (2001) and her colleagues in their review of the URC was the equitable and fair distribution of resources and benefits associated with the projects. CBPR offers numerous indirect advantages, such as enhancing power and control of community members in the research process or

## SECTION I: Lessons Learned

improving the quality and validity of the research by involving the local knowledge. These intangible goals may be as important to the partners as tangible ones and may need to be reiterated through the process.

### 5. **Balance between partnership process, activities and outcomes**

Community-based participatory research emphasizes process versus task in a way that many individuals are not accustomed to. Confusion or frustration may result when individuals feel that too much attention is paid to the process with no apparent outcomes. Conflicts arose when either researchers or community members experienced frustration with the unbalanced attention paid to the process. In some cases, academics were accused of being overly concerned with the outcomes or tasks (for their research purposes). In other cases, community members were frustrated with the considerable amount of time spent on process versus action, with the emphasis on the process delaying the delivering of important interventions or services to the community.

Attention needs to be paid to moving the process from development of the infrastructure to the design and implementation of projects. If mechanisms are not implemented to facilitate this process, the research practices may deviate from the CBPR principles adopted by the group (Pothukuchi 2005). This can stagnate the process, and leave partners frustrated or disappointed. This may require that tasks are carried out simultaneously during the establishing phase. Be conscious of the balance of activities within the partnership.

Besides avoiding frustration and stagnation, finding the balance between processes and goals may be a way to quell tensions between and among members. The Wai'anae Cancer Project admits that conflict continued to arise throughout the project. In addition to using dialogue and consensus decision making to resolve tensions, members found common agreement and purpose when they were able to focus on the final project goals (Watsunaga et al 1996).

### 6. **Significant community involvement in scientifically sound research**

CBPR literature emphasizes the involvement of community members in the research process. How this was accomplished varied greatly, from case to case. What was common were two components. First, all the projects emphasized involving the community in the research (in identifying research priorities, developing research questions, collecting data, facilitating meetings with wider community, interpreting results, etc.). Second, the CBPR partners established the terms of involvement. Involving community members in the process improves the research process by ensuring that accurate questions are being asked, increases the quality and quantity of data, improves the translation or interpretation of the data, and ensures intervention activities that are more aligned and therefore more likely to be adopted by the community.

## SECTION I: Lessons Learned

### 7. **Supportive organizational policies and reward structures**

Creating organizational policies and reward structures that align with the function, mission, and goals of a collaboratively structured organization is recommended. The CBPR principles and operating norms need to be applied to all actions of the partnership. The CBPR principles and tenets agreed upon by the partnership establish the infrastructure of the organization. Supportive organizational policies and reward structures that are aligned with those maintain the infrastructure.

In her review of various forms of collaborative work in organizations, Seifer (2006) points out the need to advance a “developmental trajectory from problem setting to direction setting to structuring” in order to facilitate the progress from one stage of collaboration to the next.

In the case of the Detroit URC, an organizational structure developed during the stage when partners were setting operating norms, adopting CBPR principles, and selecting priorities (Israel et al. 2001). The URC identified a horizontal organizational structure with steering committees or boards overseeing the actions of the staff affiliated with the respective projects.

As the project staff is often responsible for communicating with members, visiting members, establishing and maintaining relationships, they play a role in establishing the infrastructure of the collaborative.

### 8. **Leadership at multiple levels**

“In CBPR, all partners contribute their expertise and share responsibilities and ownership of projects designed to enhance understanding of a given phenomenon as well as integrate the knowledge gained with action to improve the health and well-being of community members. (Israel et al. 2001)”

A benefit of community-based participatory research is that it brings together different sets of skills, knowledge and expertise to address the complex problems. These diverse set of skills and strengths should be relied upon throughout the process. It may mean that different members of the collaboration take lead or participate more at different stages, but this is one of the purposes of such collaboratively based processes.

The cases reviewed implemented various forms of organizational structure to invite participation and leadership at different levels. Some implemented Steering Committees which included members of all stakeholder groups; others formed Community Advisory Boards that included members of the community; The Morehouse School of Medicine Prevention Research Center established a Community Coalition Board. Which reviewed all research proposals. The governing body is comprised of representatives from the partnering medical

## SECTION I: Lessons Learned

school, other academic institutions, agencies and community groups and members (Blumenthal 2005).

As with establishing the infrastructure, building the capacity for leadership at different levels of the organization also relies on the work of the support staff and researchers involved. The leadership of a collaborative partnership has the responsibility to fostering the democratic process, and their hiring of staff must support the process.

### **9. Culturally competent and appropriately skilled staff and researchers**

Many of the cases discuss the hiring of a Project Coordinator and support staff. They placed a great deal of emphasis on the importance of the Project Coordinator, who is responsible for much of the communication, meeting planning, and working between and among partners. Their work has a great deal of influence on how the process and organization evolves.

Activities of the Project Coordinator that were linked to the success in CBPR partnerships varied but included some of the following: mailing or dropping off documents for review; visiting partners at their places of employment or in their communities; making frequent telephone calls and; attending many informal in-person consultations (Matasunaga et al. 1996).

Hiring community members as staff is highly recommended. Members of the local community were hired as project coordinators, support staff, data collectors, facilitators, implementers, etc. The nature of the project, the partnership, as well as a myriad of other factors determine the qualifications and skill set of who is hired, but it is recommended to consider using training as an opportunity to hire local staff. Some cases discuss training researchers (about the community) while others discuss training community members with specific skills required, such as meeting facilitation, data collection, interpretation, etc. Many organizations explained that one goal of a CBPR partnership is to build capacity within the community. Therefore, devoting the extra time required to train unskilled staff is not only justified, but required.

### **10. Collaborative dissemination**

The need for addressing dissemination practices is discussed often. Many communities expressed feelings of being “subjects” in research, lacked access to research findings, and raised concerns of “outside” researchers mis-analyzing data and recommending inappropriate or misguided intervention efforts. Developing a protocol for how results are collected, interpreted, analyzed, and disseminated back to the community needs to be a part of the CBPR process. By doing so, trust in the researchers will be developed as well as reducing pressure on the

## SECTION I: Lessons Learned

researchers in presenting final results. Seifer et al. (2006) in their list of Lessons Learned pointedly state, “be strategic about dissemination.”

### 11. **Ongoing partnership assessment, improvement and celebration**

Adhering to the previously accepted CBPR principles in practice is one of the major challenges to the process (Israel et al. 2001). Repeatedly assessing operating norms and CBPR principles ensures compliance as well as identifies challenges or issues with being put into practice. Throughout CBPR literature, the process is described as an “iterative” one. Therefore the partnership requires not only ongoing assessment but in response, the ability to incorporate changes into previously established customs. Israel et al. (2001) in their history of the Detroit URC point out that, “the URC evaluation approach is both participatory (meaning that URC Board members are actively involved in evaluation activities) and formative (meaning that evaluation results routinely are fed back to Board for consideration and action).”

Assessing the partnership process provides opportunities for celebration of success as well. A periodic acknowledgement of achievements is recommended to maintain a high level of commitment (Lindsey et al. 1998) and Edgren et al. (2005) suggest the implementation of “a systematic feedback process” as one way to provide opportunities for recognition of accomplishment.

Evaluation practices must be meaningful and useful. Disagreements and conflict should be anticipated and therefore mechanisms should be in place not only to address changes but also mindsets.

### 12. **Sustainable impact**

Securing significant funding resources, building infrastructure, developing relationships built on trust, involving the community were mentioned as factors to ensure sustainability in projects.

## SECTION I: Lessons Learned

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## SECTION II: Organizations

The following is a list of organizations that conduct community-Based Participatory Research, have formalized relationships with a university or other research institution, or are focused on serving immigrants and refugees. Organizations have been prioritized. This section is broken into the following subcategories:

- A. Organizations developed out of CBPR partnership
- B. Organizations with Community IRB
- C. Organizations/projects based at University
- D. Organizations based in MN with focus on Health & Health Disparities
- E. Organizations based in MN with focus Immigrants & Refugees
- F. Organizations – general

The following information is included for each organization:

**Name:** The name of organization.

**Description:** A brief description of the organization.

**Website:** The website address.

**Electronic Links:** Links to pages on their website that may contain useful information.

**Electronic copies:** Documents that are included in electronic format. Includes name of documents. If there are not electronic copies, this is blank.

**Notes:** My notes. These are brief.

Hyperlinks have been included as a shortcut. Websites have not been listed.

A (^) next to the name of an item denotes that item has been printed and can be found in Appendix A. It has been printed due to its resourcefulness.

## SECTION II: Organizations

### A. Organizations developed out of CBPR partnership

\*\*\*\* [Detroit Community-Academic Urban Research Center \(URC\)](#)

Website: <http://www.sph.umich.edu/urc/about/index.html>

Electronic links

- [About the Detroit URC](#)

Notes

- This organization is affiliated with University of Michigan and BA Israel.
- This organization provides a good model for “The Institute” and is discussed much in the literature.

The following organizations were linked through the Detroit URC:

[Prevention Research Center of Michigan](#)

Description

The mission of the Prevention Research Center of Michigan is to create and foster knowledge resulting in more effective public health programs and policies. The Center conducts community-based prevention research to improve health and prevent disease, especially focused on populations with a disproportionate share of poor health outcomes.

Website: <http://www.sph.umich.edu/prc/about/>

Electronic links

- [About](#)

[Community-Based Public Health Caucus](#)

Description

The Community-Based Public Health Caucus is guided by the belief that Community lies at the heart of public health, and that interventions work best when they are rooted in the values, knowledge, expertise, and interests of the community itself.

Website: <http://www.sph.umich.edu/cbphcaucus/vision.html>

Electronic links

- [Vision](#)

\*\*\* [Community Action Against Asthma](#)

## SECTION II: Organizations

### Description:

Community Action Against Asthma (CAAA) is a community-based participatory research program which combines an investigation of environmental triggers of asthma with an intervention designed to reduce exposure to these triggers and improve the health status of children with asthma.

The program is hosted by the Michigan Center for Environment and Children's Health (MCECH) and affiliated with

Website: <http://www.sph.umich.edu/mcech/research/caaa.html>

### Electronic Links

- [MCECH CBPR Principles](#) - adopted by the Detroit URC

### Electronic Copies

### Notes

\*\*\*\* [Chicago Southeast Diabetes Community Action Coalition](#)

### Description:

Mission: Assure and enhance access to quality health services and quality of life of persons at risk and with diabetes in Chicago Southeast communities through the establishment and institutionalization of a diabetes coalition of community residents, health and human services providers, and persons living with diabetes.

Goals: The main goal of the coalition is to reduce diabetes mortality, hospitalizations, complications and diabetes related disabilities among African Americans and Latinos living in Chicago's southeast side communities. In order to accomplish this, the coalition set the following objectives:

- Mobilize communities through the establishment of the Chicago Southeast Diabetes Community Action Coalition.
- Empower communities through participatory action research by conducting a comprehensive assessment about diabetes related issues.

### Principles of Collaboration:

- Commitment to equity, collective decisions, and collective action
- High quality, ethical research and interventions
- Joint ownership of the data
- Collective interpretation and/or dissemination of results

## SECTION II: Organizations

- Welfare of coalition members - that is, no partner shall act in any manner that is considered detrimental to another partner
- Institutionalization of programs which benefit the community through pursuing new funding
- Challenging social and environmental inequalities that affect health
- Support for diabetes-related community changes, and actions that ultimately will lead to positive health and outcomes.

**Website:** <http://www.uic.edu/jaddams/csdcac/>

**Electronic Links:**

**Electronic copies:**

**Notes:**

- This is one of the cases discussed in the literature. It is based out of the University of Illinois at Chicago and affiliated with the Midwest Latino Health Research, and Training Center and the Jane Addams College of Social Work.

[Midwest Latino Health Center](#)

University of Illinois, Chicago Jane Addams College of Social Work

The Midwest Latino Health Research, Training, and Policy Center seeks to improve the health status and quality of health care to Hispanics/Latinos living in Chicago and throughout the Midwest. The Center develops and conducts health and human services research on issues affecting Latino communities. It facilitates mechanisms for communication, networking, and health information dissemination among service providers and community-based organizations.

Through internships and fellowships, the Center works to increase the number of methodologically- and culturally-competent Latino and non-Latino faculty, students, and community practitioners in health services research. The Center is also active on the policy front, conducting policy analyses, providing testimony based upon research and engaging in information dissemination activities.

The Latino Center was founded in April 1993, under the leadership of Aida L. Giachello, Ph.D., Jane Addams College of Social Work, in partnership with the Hispanic Center of Excellence at the UIC College of Medicine and the UIC School of Public Health. Over the past ten years, the Center has developed the infrastructure to conduct research on health disparities and outcomes on chronic illnesses (diabetes, asthma, hypertension), cancer, injury prevention, and maternal and child health. Research has been conducted in rural and urban areas and has included many Latino groups, including recent immigrants, Puerto Ricans, Mexicans, and Central Americans.

## SECTION II: Organizations

The Path Project – Promoting Access to Health (PATH) – a.k.a. REACH 2010-  
Promoting Access to Health for Women

### [Orange County Asian Pacific Islander Community Alliance](#)

#### Description

The Orange County Asian and Pacific Islander Community Alliance (OCAPICA) is dedicated to enhancing the health, and social and economic well-being of Asians and Pacific Islanders in Orange County, California. Established in 1997, OCAPICA works to improve and expand the community's opportunities through service, education, advocacy, organizing and research. These community-driven activities seek to empower Asians and Pacific Islanders to define and control their lives and the future of their community.

Website: <http://www.ocapica.org/>

#### Electronic Links

#### Electronic Copies

#### Notes

- The Path Project does not have a website, but the hosting organization, OCAPICA, does. There is limited information available on the website.

## SECTION II: Organizations

### \*\*\*\* [Community Campus Partnerships for Health](#)

#### Description

Community-Campus Partnerships for Health (CCPH) is a nonprofit organization that promotes health (broadly defined) through partnerships between communities and higher educational institutions.

Website: <http://depts.washington.edu/ccph/index.html>

#### Electronic links

- [About Us](#) ^
- [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum, Appendix A](#)
- [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum, Appendix B](#)
- [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum, Appendix C](#)
- [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum, Appendix D](#)
- [CCPH - Community-Based Participatory Research](#)
- [CCPH - Links](#)
- [CCPH - Research and Evaluation Programs](#)
- [CCPH: Community-Based Participatory Research](#)
- [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum](#)

As interest in community-based participatory research (CBPR) grows, there is a growing need and demand for educational resources that help build the knowledge and skills needed to develop and sustain effective CBPR partnerships. This evidence-based curriculum is intended as a tool for community-institutional partnerships that are using or planning to use a CBPR approach to improving health. It can be used by partnerships that are just forming as well as mature partnerships.

#### Electronic copies

- Partners have agreed upon mission, values, goals, and measurable outcomes for the partnership. (summer1-f.pdf)
- The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment. (summer2-f.pdf)
- The partnership builds upon identified strengths and assets, but also addresses

## SECTION II: Organizations

- areas that need improvement. (summer3-f.pdf)
- The partnership balances power among partners and enables resources among partners to be shared. (summer4-f.pdf)
- There is clear, open and accessible communication between partners, making it an ongoing priority to listen to each need, develop a common language, and validate/clarify the meaning of terms. (summer5-f.pdf)
- Roles, norms, and processes for the partnership are established with the input and agreement of all partners. (summer6-f.pdf)
- There is feedback to, among, and from all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes. (summer7-f.pdf)
- Partners share the credit for the partnership's accomplishments. (summer8-f.pdf)
- Partnerships take time to develop and evolve over time (summer9-f.pdf)

### Notes

- There is an extensive amount of information here. Much of it is focused at the academic/research community (versus the CBO community) and is nationally oriented, but it offers a wealth of information.
- Included in a separate binder is a whole workshop at building a community-campus partnership.
- The above electronic copies can be found in the CCPH folder.

### [Community-Engaged Scholarship for Health Collaborative \(CCPH\)](#)

A project of the Community-Campus Partnerships for Health.

To foster partnerships between communities and educational institutions that build on each other's strengths and develop their roles as change agents for improving health professions education, civic responsibility and the overall health of communities. At the essence of Community-Campus Partnerships for Health are partnerships.

Partnerships between communities and higher educational institutions as a strategy for social change are gaining recognition and momentum. In their truest form, these partnerships require time and commitment and have the power to transform the individuals and institutions that are part of them. As such, partnerships are an effective tool in ultimately improving health in our communities. Despite being formed with the best of intentions, however, authentic partnerships are very difficult to achieve.

## SECTION II: Organizations

### [Institute for Community Research](#)

#### Description

The Institute for Community Research is a nonprofit organization that partners with communities in research, training, and programming to strengthen prevention, youth development, and urban heritage arts. CR's strategy of participatory action research engages the public in dialogue about issues that are of concern to them.

Participatory action research is a partnership between the affected community and researcher where the community is actively involved in all phases of the research project: defining the problem, designing the research methodology, collecting data, and analyzing and disseminating results. ICR has used participatory action research as a capacity building and prevention approach for youth and adults in the greater Hartford, CT area.

Website: <http://www.incommunityresearch.org/>

#### Electronic links

- [Home](#)

#### Notes

- The resources and materials available from this organization are sold.

## **B. Organizations with Community IRB**

### [Papa Ola Lokahi - Native Hawaiian Healthcare](#)

#### Description

To improve the health status and wellbeing of Native Hawaiians and others by advocating for, initiating and maintaining culturally appropriate strategic actions aimed at improving the physical, mental and spiritual health of Native Hawaiians and their 'ohana (families) and empowering them to determine their own destinies.

Website: <http://www.papaolalokahi.org/>

#### Electronic links

- [Home page](#)
- [Research – Institution Review Board](#)
- [Health Resources](#)
- [Opportunities](#)

#### Electronic copies

- Mental Health: Culture, Race & Ethnicity
- National Healthcare Disparities Report. US DHHS Agency for Healthcare Research and Quality. July 2003.

## SECTION II: Organizations

- Asian Americans and Pacific Islanders addressing health disparities: opportunities for building a healthier America. 2003
- Race, Ethnicity and Healthcare. Kaiser Family Foundation. March 2005
- Health Disparities among Americans. Out of Many, One. 2004.
- Paoakalani Declaration. 2005

### Notes

- Organization has strong focus on IRB process and instituted a “Community IRB.”
- Website is well organized and contains much information regarding funding and health resources.

### [Southeast Community Research Center](#)

#### Description

The SCRC is established to promote, facilitate, and conduct participatory and community-based research throughout the Southeastern United States. Founded on the campus of Morehouse College, and through the efforts of community-based organizations such as Project South, the Southeast Community Research Center maintains the spirit of Historically Black Colleges and Universities (HBCU) and community-driven decision making to improve the quality of life for all under-served populations regardless of race, ethnicity, class, national origin, gender or sexual orientation, with the goal of nurturing effective democratic processes and building strong communities. Community-Based Participatory Research is a collaborative approach to research involving researchers, and initiated and directed by the community members who are most impacted by the issue.

#### Website:

[http://www.cbpr.org/index.php?option=com\\_content&task=view&id=87&Itemid=65](http://www.cbpr.org/index.php?option=com_content&task=view&id=87&Itemid=65)

#### Electronic links

- [Home > Mission Approach](#)
- [New Tools New Visions](#) ^
- [Community IRBs](#)

#### Notes

- The pages are not so easy to read when printed but organization seems well structured.
- In particular this CBO has developed a Community IRB. The link is included in bookmarks because language is concise and comprehensive (reflects much of what literature and other CBO says).

## SECTION II: Organizations

### [Southcentral Foundation](#)

#### Description

Southcentral Foundation (SCF) is an Alaska Native-owned healthcare organization serving Alaska Native and American Indian people living in Anchorage , the Mat-Su Valley , and 60 rural villages in the Anchorage Service Unit.

Website: <http://www.southcentralfoundation.com/aboutscf.cfm>

#### Electronic links

- [Home page](#)
- [Research](#)
  - Section I: About the Research Webpage
  - Section II: What is Health Research?
  - Section III: Study Participants
  - Section IV: Alaska Native People Leading Health Research
  - Section V: Tribal Ownership of Research
    - Southcentral Foundation Research Approval Process
  - Section VI: Health Research at Southcentral Foundation
  - Glossary

#### Electronic copies

- Section V: Tribal Ownership of Research
  - I want to know more about research oversight. (flow-chart\_1) ^
  - SCF Guidelines for Researchers
  - Application for approval of abstracts by Southcentral Foundation
  - Application for approval of manuscripts by Southcentral Foundation
  - Application for approval of research proposals by Southcentral Foundation
  - Application for approval of student research by Southcentral Foundation
  - Maori Health Committee-Health Research Council of New Zealand (guides\_maori.pdf)
- Section VI: Health Research at Southcentral Foundation
  - Smith Research with arctic 2006.pdf
  - Witmer Heart Disease prevention 2004.pdf
  - Stefanich Development adaption 2005.pdf
  - Pierce bulger Nutaqsiivik 2001.pdf
  - Livingston Results of a General 2007.pdf
  - Wood Tribal Connections 2003.pdf
  - Jonas M Finding adolescents 2007.pdf
  - Bell Immunogenicity of an 2007.pdf

#### Notes:

- Information included is basic but demonstrates how CBO involves and keeps focus of research at community level.

## SECTION II: Organizations

- Includes a “glossary” of research terms.

## SECTION II: Organizations

### [Northern Plains Tribal Epidemiology Center \(NPTEC\)](#)

#### Description

Aberdeen Area Tribal Chairmen's Health Board Mission: To provide leadership, technical assistance, support, and advocacy to Northern Plains tribal nations and communities in order to eliminate the disparities in health that currently exist for tribal people of the area.

Resolving the severe health disparities that exist for the tribal people of this area will require a coordinated approach, including a partnership between the eighteen sovereign Indian tribes of the area, NPTEC, Indian Health Service (IHS), other federal and state agencies, and the academic health institutions of the area. As a tribally operated program, NPTEC will have a unique trust relationship with the tribes of the area. This trust relationship will allow NPTEC to collaborate with federal and academic entities for Indian-specific health projects to produce a far greater effect than could be achieved by any entity alone.

Website: <http://www.aatchb.org/epi/index.htm>

#### Electronic links

- [Home](#)
- [Home > Research Ethics Resources](#)

#### Electronic copies

- AATCHB Research Ethics
  - NPTEC Guidelines for researchers (Same as can be found in binder)^
  - ResearchEthics

#### Notes

- In the "Research ethics and IRB Resource page," there are many helpful links to documents such as templates for building IRBs, meeting agendas, etc. These may be helpful when at the point of involving community members.

## SECTION II: Organizations

### [Witness for Wellness](#)

#### Description

The Witness for Wellness project is a community-led, multi-stakeholder, academic-community partnership aimed at developing community-based approaches to improve health outcomes for depression in minority communities. We hope to develop strategies for talking about and dealing with depression, increasing awareness and recognition of depression, improving options for care, and addressing issues that can lead to and/or result from depression. To do so, we will utilize a community-based model for stimulating change developed by Healthy African American Families (HAAF). At the center of HAAF's collaborative model are community work groups that engage diverse stakeholders around a particular health issue.

Website: <http://www.witness4wellness.org/>

#### Electronic links

- [Home page](#)
- Wellness Council
  - [Collaborative Agreement](#) ^
- [Workgroup: Supporting Wellness](#) ^
  - [Workplan](#) ^
- [Workgroup: Building Wellness](#) ^
  - [Workplan](#) ^
- [Workgroup: Talking Wellness](#) ^
  - [Workplan](#) ^

#### Electronic copies

#### Notes

- Collaborative Agreement is included. Much of the literature suggests that one important component of collaborative work is a Memo of Understanding. This is an example of theirs.
- Workplans demonstrate how organization structured their work. This may be very helpful during planning process.

### [Powderhorn Phillips Cultural Wellness Center](#)

#### Description

Healthy Powderhorn, funded in 1994 by the Allina Foundation, worked to bring groups of residents and health care workers together to identify and seek solutions to issues that have an impact on the total community's health status. Over a thousand people were organized over a two-year period. These voices stated that loss of connection to culture

## SECTION II: Organizations

and community underlies many diseases.

Website: <http://www.ppcwc.org/>

Electronic links

Notes

- Local organization that is developing a community IRB.
- I spoke with Janice Barbee from this organization and she was very willing to discuss history of process and the issues they have faced.

### C. Organizations/projects based at University

#### [National Center for Cultural Competence \(NCCC\)](#)

Description

Georgetown University, Center for Child and Human Development

The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health care and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.

Website: <http://www.ncccurrericula.info/public/C18.html>

Electronic links

- [Home](#)
- [Modules > Public Health in a Multicultural Environment](#)

Notes

- This organization/program belongs in the “University Based Programs/Organizations” as it is housed Georgetown University.
- Modules are focused on academic side of research, i.e. how to conduct public health in a multicultural environment, but it provides good language and frameworks.

#### [Community Health Scholars Program](#)

University of Michigan, School of Public Health

Supported by a grant from the W.K. Kellogg Foundation

The goal of the Community Health Scholars program (CHSP) is to increase the number of faculty at health professional schools, with an emphasis on schools of public health, who possess the capacity to carry out community-based participatory research and

## SECTION II: Organizations

teaching and who understand determinants of community health and how to build the capacity of communities, health-related agencies and academic centers to function as equal partners in community-based research, service and education.

Community-Based Participatory Research (CBPR) in health is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.

### [Institute for Women's Health](#)

Virginia Commonwealth University

The mission of the VCU Institute for Women's Health is to improve the health of women through health education, research, clinical care, outreach and leadership development and to bring these diverse activities under a single umbrella, create synergy within VCU, and foster coordinated alliances with the greater community. Community-Based Participatory Research (CBPR) is an approach to health and environmental research meant to increase the value of studies for both researchers and the communities being studied. CBPR creates bridges between scientists and communities, through the use of shared knowledge and valuable experiences.

### [Policy Research Action Group \(PRAG\)](#)

Loyola University, University of Chicago

Founded in 1989, PRAG is a consortium of community-based and community-focused nonprofit organizations and urban universities which currently include Chicago State University, DePaul University, Loyola University of Chicago, National-Louis University, and University of Illinois, Chicago.

For nearly 15 years, PRAG has played a catalytic role that has helped change the research landscape and transform a relationship that was either adversarial or non-existent to one that is engaged and productive. Today, there are hundreds of community/university collaborations across the country, even around the world. Visitors from England, El Salvador, and even Australia, have come to Chicago to consult with PRAG about its approach.

### [Asset-Based Community Development Institute](#)

## SECTION II: Organizations

Northwestern University Institute for Policy Research Community Development Program

The Asset-Based Community Development Institute (ABCD), established in 1995 by the Community Development Program at Northwestern University's Institute for Policy Research, is built upon three decades of community development research by John Kretzmann and John L. McKnight.

The ABCD Institute spreads its findings on capacity-building community development in two ways: (1) through extensive and substantial interactions with community builders, and (2) by producing practical resources and tools for community builders to identify, nurture, and mobilize neighborhood assets.

### [Center for Collaborative Action Research](#)

Pepperdine University, Graduate School of Education and Psychology

The Center for Collaborative Action Research links educators, researchers, and community members with the goal of creating deep understanding of educational problems in the school context and to encourage evidence-based reasoning to solve these problems. The Center shares collaborative action research projects and supports the development of "knowledge-building" communities. The goal is to share what others are doing to reinvigorate their workplace with the capacity to reflect and adapt to evolving needs.

A year-long Action Research Project forms the centerpiece of the work of students to earn a Master of Arts degree in Educational Technology from Pepperdine University. In this blended face-to-face/online program, the study is directed to helping the students understand this process of progressive problem solving in contexts that are important to them. The program requires a final exhibition and online publication of action research outcomes. The CCAR site showcases the best of these publications as a way to illustrate the way in which this form of inquiry can change not only the person but their context. The program uses distance communication technology to take the learning from the university and seat it in the everyday practices of the students.

The translation of theory to practice is not something that happens after the students leave the university, but rather happens every day as the students take on challenges that are important to them. This process of "taking the university to work" is one of the less celebrated but extremely valuable affordances of online learning. CCAR is based at Pepperdine University in the Graduate School of Education and Psychology under the direction of Margaret Riel, Ph.D and with leadership from the first Associate Director, Karen Elinich and the able assistance of the 2007-2008 Editorial Board.

## SECTION II: Organizations

### [The Center for the Health Professions](#)

University of California, San Francisco

Our mission is to assist health care professionals, health professions schools, care delivery organizations and public policy makers respond to the challenges of educating and managing a health care workforce capable of improving the health and well being of people and their communities.

As an active part of one of the nation's leading academic health centers, the Center for the Health Professions at the University of California, San Francisco focuses its efforts on understanding the challenges faced by the health care workforce and developing programs and resources that assist in making successful transitions to the emergent health care systems.

### [Community Research Institutional Review Board \(CRIRB\)](#)

Michigan State University, Human Research Protection Program

The Community Research Institutional Review Board was developed by MSU and its community partners and is one of three IRBs operated by MSU. The CRIRB reviews multi-community projects, those that will be performed at two or more sites, including East Lansing/Lansing and projects which require expertise in community-based research. The CRIRB has great expertise in clinical and community-based research and a diversity of topical expertise among individual members.

Once approved by the CRIRB, each participating institution provides concurrence to allow the project to be performed at their site, and all review and changes will occur at the CRIRB level. While the CRIRB is operated by MSU, its members include representatives from the participating IRBs around the state which are affiliated with MSU. Participating IRBs list the CRIRB as one of the authorized IRBs on their FWA and sign authorization agreements between the two organizations.

As part of MSU's Human Research Protection Program, CRIRB is fully accredited through the Association for the Accreditation of Human Research Protection Programs (AAHRPP). MSU also provides IRB education for investigators and IRB members and Chairs from all participating institutions through annual conferences, online training and other educational programs.

## SECTION II: Organizations

### **D. Organizations based in MN with focus on Health & Health Disparities**

Includes organizations working with Immigrant & Refugee communities focused on health issues. [This is not a comprehensive list.]

#### [West Side Community Health Services Home](#)

Our Mission: Caring for the Health of Diverse Communities

We strive to ensure that everyone has access to high quality, affordable health care, to actively engage patients in their own health care, and to respect the traditions of those we serve. We strive to improve the health of our region for the benefit of all.

Founded in 1972, West Side Community Health Services is one of the largest and most established community health care organizations. Few organizations serve so many sectors of the population so sensitively and effectively – improving the health of our region for the benefit of all. West Side Community Health Services (WSCHS) provides comprehensive health care and social services with bilingual/bicultural staff on a sliding fee scale.

Services include primary, specialty, preventive, urgent care, complementary, pharmacy, dental, OB/GYN, mental health, social and wrap-around services such as child care, transportation and assistance with health plan enrollment. We are proud to serve over 35,000 patients each year.

We serve the diverse St. Paul metro area community -- particularly the Latino and Hmong populations, St. Paul public housing residents, people in the homeless population, and adolescents in a service area that includes a significant portion of the City of St. Paul and Ramsey County.

#### [MN Dept Human Services](#)

The Minnesota Department of Human Services helps people meet their basic needs by providing or administering health care coverage, economic assistance, and a variety of services for children, people with disabilities and older Minnesotans.

#### [Minnesota Department of Health](#)

#### [Ramsey County PH Home](#)

#### [State Health Access Data Assistance Center at the University of Minnesota](#)

The State Health Access Data Assistance Center (SHADAC) is state-level health policy analysis and research center at the University of Minnesota School of Public Health. SHADAC's affiliated faculty and staff conduct a variety of research and consultation projects for state and federal agencies. It was founded in 2000 with principal funding

## SECTION II: Organizations

from The Robert Wood Johnson Foundation.

### **E. Organizations based in MN with focus Immigrants & Refugees**

Organizations based in Minnesota which serve the Immigrant & Refugee communities.  
[This is not a comprehensive list.]

#### [New American Community Services](#)

Our objective is to assess the health priorities of African immigrant and refugee communities in Minnesota. Our work in this area began as a member of the Minnesota Participatory Research Partnership (PRP). The overarching goal is to develop and apply participatory research and intervention planning processes that fully engage African communities in creating knowledge and strategies for improving their health. We seek to respectfully bridge knowledge in African communities with resources in academic and governmental agencies. NACS programs continuously build on its research in the African immigrant community. The results of our research lead to community health outreach programs for African immigrants.

#### [Hispanic Advocacy and Community Empowerment through Research \(HACER\)](#)

Hispanic Advocacy and Community Empowerment through Research (HACER) is a nonprofit, community-based research organization that originated in 1988 as a collaborative effort between Ramsey County Human Services, Chicanos Latinos Unidos en Servicio (CLUES), and Metropolitan State University to address the lack of information about Latinos and Latino issues in Minnesota's public discourse.

HACER is housed within the University of Minnesota's Center for Urban and Regional Affairs (CURA). Our Mission HACER's mission, is to provide the Minnesota Latino community the ability to create and control information about itself in order to affect institutional decisions and public policy. HACER identifies research needs and delivers quality research products that strengthen the Latino communities of Minnesota. We do so through collaborative research efforts that are timely, methodologically sound and culturally appropriate.

HACER engages in partnerships with community members to inform policy around immigration, education, public health, housing, criminal justice, social welfare, employment and income disparities, public safety, community development, migrant work, and demographic change. HACER also facilitates cooperation among agencies that serve the Latino community, and evaluates government and nonprofit programs that target Latinos in the state.

#### [Lafamilia Guidance Center Inc.](#)

## SECTION II: Organizations

La Familia Guidance Center, Inc. was established in 1995 to provide culturally competent mental health social services in order to enhance the quality of life for Chicano/Latino youth and families. The Multicultural Mental Health Clinic is a rule 29 mental health clinic serving culturally-specific needs of communities of color. It includes:

- \* La Familia Guidance Center, Inc.
- \* Lao Family Community of Minnesota, Inc.
- \* Thad Wilderson & Associates
- \* United Cambodian Association of Minnesota

### [Neighborhood House](#)

Vision: Be the community-building resource for an increasingly diverse Minnesota. Building doorways of opportunity for vibrant, diverse communities. We do this in partnership with individuals, families, and organizations by:

- \* Meeting essential human needs
- \* Facilitating active participation in community life
- \* Providing access to additional community resources and programs

### [Hmong American Partnership](#)

Hmong American Partnership (HAP) was founded in 1990 as a Hmong community-based organization that would draw equally on the strengths of the Hmong culture and those of other American communities.

HAP's mission is: to help Hmong grow deep roots in America while preserving the strength of our culture. In its first thirteen years, the agency has grown from a small organization focused on basic refugee resettlement issues to an established provider of comprehensive, culturally appropriate social services.

HAP is one of the largest Hmong refugee agencies in the U.S., and now works with Hmong families not only as refugees but as both permanent residents of the U.S. and contributing members of the larger community.

HAP's goals are to: 1. assist Hmong adults in gaining English language and job skills, and finding and retaining employment; 2. prevent Hmong youth involvement in drugs and crime, while helping to improve their academic achievement; 3. help Hmong parents increase their confidence and ability to communicate with their children; 4. educate health professionals, community leaders, and the broader Hmong community on disparities of access and understanding mental health; and, 5. play a leadership role in community and economic development, which will be furthered by the new facility (Hmong American Center) on St. Paul's East Side neighborhood.

### [Center for Victims of Torture](#)

## SECTION II: Organizations

The Center for Victims of Torture (CVT) has a list of agencies servicing refugees and immigrants in the state of Minnesota.

### [Minnesota Department of Health](#)

The Minnesota Department of Health has a list of agencies and reports focused on the immigrant and refugee communities.

## **F. Organizations – general**

### [Access Alliance](#)

#### Description

Access Alliance works to promote health and well-being and improve access to services for immigrants and refugees in Toronto by addressing medical, social, economic and environmental issues.

Access Alliance was established in 1989 with four ethno-cultural communities coming together to create the Centre in response to their identification of significant barriers to services for immigrants and refugees.

In 2000 Access Alliance started re-defining its mandate by undertaking ongoing needs assessments and looking at its role within the sector of immigrant and refugee serving agencies and other community health centres in Toronto. At that time, the Board of Directors directed the organization to prioritize “the most disadvantaged” immigrants and refugees. Since then Access Alliance has developed indicators of disadvantages to help us define those immigrant and refugee groups who face the most barriers to services.

### [Seattle Partners for Healthy Communities](#)

Seattle Partners works to improve the health and quality of life of urban, disadvantaged Seattle communities by promoting activities which are effective in preventing disease, promoting healthy behaviors and environments, and influencing the underlying social factors that affect health such as education, income, housing and economic development.

### [SINAI Urban Health Institute](#)

The mission of the Sinai Urban Health Institute (SUHI) is to identify and create effective approaches that improve the health of urban communities. A major component of the Institute’s work involves examining the impact of social issues, such as poverty, on health. SUHI is a diverse group of epidemiologists, research assistants, and health educators involved in social epidemiology, program evaluation, teaching and consulting.

## SECTION II: Organizations

Founded in 2000 as part of the Sinai Health System, SUHI's mission is grounded in the belief that in order to serve our neighbors well, we need to understand not just the "patients" who enter our doors but the entire community as well.

### [Research for Action](#)

Through research and action, Research for Action seeks to improve the education opportunities and outcomes of urban youth by strengthening public schools and enriching the civic and community dialogue about public education. We share our research with educators, parent and community leaders, students, and policy makers with the goals of building a shared critique of educational inequality and strategizing about school reform that is socially just.

RFA is a Philadelphia-based, non-profit organization engaged in education research and evaluation. Founded in 1992, RFA works with public school districts, educational institutions, and community organizations to improve the educational opportunities for those traditionally disadvantaged by race/ethnicity, class, gender, language/cultural difference, and ability/disability. Research for Action was founded by women who aimed to connect their social activism, feminist beliefs, and professional practice as education researchers.

Basic tenets for RFA's approach to evaluation emerge from feminist theory. Research for Action (RFA) employs multidisciplinary, rigorous research, diverse teams, and feedback that challenge stakeholders and researchers to interrogate assumptions and listen to multiple voices. We share our research with educators, parent and community leaders, students, and policy makers in order to build a shared critique of educational inequality and school reform that is socially just.

Through reciprocal relationships with these stakeholders, we expand knowledge, foster collaboration, and provoke public dialogue at local, state, and national levels to promote equity, organizational learning, democratic participation, and accountability for school improvement.

### [Community Based Collaboratives Research Consortium \(CBCRC\)](#)

The Community Based Collaboratives Research Consortium (CBCRC) is a national network comprised of researchers, mediators and facilitators, government agencies, community and environmental groups and others who are seeking to understand and assess collaborative efforts involving natural resource issues and community development.

### [DOE: Community IRB](#)

Community IRB members, so critical to the protection of human subjects, are a nationwide resource that needs to be acknowledged and strengthened. To that end, the goal of

## SECTION II: Organizations

this website is to:

### [National Center on Minority Health and Health Disparities \(NCMHD\)](#)

The mission of the National Center on Minority Health and Health Disparities (NCMHD) is to promote minority health and to lead, coordinate, support, and assess the NIH effort to reduce and ultimately eliminate health disparities. In this effort NCMHD will conduct and support basic, clinical, social, and behavioral research, promote research infrastructure and training, foster emerging programs, disseminate information, and reach out to minority and other health disparity communities.

### [Collaborative Solutions for Healthy Communities by Tom Wolff and Associates](#)

(Consultants) Tom Wolff & Associates have the tools and resources necessary to mobilize the power of collaborative processes in your community or organization. These processes are the key to addressing the critical challenges that confront our communities, our states and our nation today. Through collaborations and coalitions, individuals, organizations and communities become empowered to impact the world around them.

### [Center for Cultural Understanding and Change at The Field Museum](#)

The Center for Cultural Understanding and Change (CCUC) at The Field Museum uses problem-solving anthropological research to identify and catalyze strengths and assets of communities in Chicago and beyond.

## SECTION III: Resources

The following section includes additional resources that may be helpful at different stages of the process. It includes the following subcategories:

- A. Databases
- B. Journals
- C. Tool Kits
- D. Universities/ Public Health Program
- E. Foundations/Funding
- F. Publication Lists/Reference Lists

### **A. Databases**

#### [APHA: Health Disparities Database](#)

The Health Disparities Community Solutions Database is sponsored by the American Public Health Association and the United Health Foundation. This historical database contains projects and interventions that have been submitted by members of the public health community since 2003. Some of the programs are still in existence, while others have been discontinued. APHA has decided to continue to list all programs that were submitted, in order to provide a learning tool for future health disparities initiatives.

#### [Finding Answers Intervention Research \(FAIR\) Database](#)

The FAIR Database contains 206 journal article summaries from a systematic review of racial and ethnic health disparities interventions published as a Special Supplement to the October 2007 issue of Medical Care Research and Review. Systematic literature reviews were conducted for the following health topics and intervention strategies: cardiovascular disease (CVD), depression, diabetes mellitus, breast cancer, cultural leverage and pay-for-performance incentives. The FAIR Database was designed to provide a customized list of interventions that match a user's interest in the following areas: health topic, racial/ethnic population, organizational setting, and intervention strategy.

#### [National Institutes of Health \(NIH\) - The NIH Almanac - NCMHD](#)

NIH Almanac data on the National Center on Minority Health and Health Disparities

### **B. Journals**

#### [Johns Hopkins University Press | Journals | Progress in Community Health Partnerships: Research, Education, and Action](#)

The mission of the Journal is to facilitate dissemination of programs that use community partnerships to improve public health, to promote progress in the methods of research and

### SECTION III: Resources

education involving community health partnerships, and to stimulate action that will improve the health of people in communities. Communities, as defined by the Journal, may be based on geography, shared interests, or social networks.

The Journal is dedicated to supporting the work of community health partnerships that involve ongoing collaboration between community representatives and academic or governmental partners. This area of research and evaluation may be referred to as community-based participatory research (CBPR).

The W. K. Kellogg Foundation defines CBPR as a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.

#### [EHP Online: Home of Environmental Health Perspectives](#)

Environmental Health Perspectives (EHP) is a monthly journal of peer-reviewed research and news on the impact of the environment on human health. EHP content is free online and available in print issues through paid subscription., Environmental Health Information Service, EHP Online, Environmental Health Perspectives, National Institute Of Environmental Health Sciences, EHIS, EHP, NIEHS, environmental health, toxicology, cancer, environmental medicine, scientific journal, environmental health news, toxocology database, environmental health sciences, toxicogenomics

#### [PubMed Central](#)

PubMed Central (PMC) is the U.S. National Library of Medicine's digital archive of life sciences journal literature.

### **C. Tool kits**

#### [CCUC: Participatory Action Research](#)

A Practical Introduction to Participatory Action Research for communities and scholars.

#### [Community Partnerships ToolKit](#)

This is a Tool Kit for building and maintaining partnerships to strengthen communities. It starts with people getting involved and using better information. Each of the tools drives home a critical message learned about partnerships. Success takes time and commitment—picking the right tools, sharpening them with experience and eventually learning how to master the tools.

## SECTION III: Resources

### [Tri-Ethnic Center: Community Readiness Model](#)

The Community Readiness Model is an innovative method for assessing the level of readiness of a community to develop and implement prevention programming. It can be used as both a research tool to assess distribution of levels of readiness across a group of communities or as a tool to guide prevention efforts at the individual community level.

### [Research Ethics Tip Guide](#)

Ways of doing research are dramatically changing. Conducting research used to be considered only a scientist's privilege; now research is being seen as the community's business as well. There is an increasing awareness of the importance of being respectful to the rights of participants not only as individuals and also as members of a community that may be affected by research.

## **D. Universities/Public Health Programs**

[Harvard School of Public Health \(HSPH\)](#)

[UC Berkeley School of Public Health](#)

[Johns Hopkins Bloomberg School of Public Health](#)

[University of Michigan School of Public Health](#)

[Tulane University School of Public Health and Tropical Medicine](#)

[University of Iowa- College of Public Health - Community and Behavioral Health](#)

[University of Florida, School of Nursing](#)

[UMN - School of Public Health](#)

[UMN Health Disparities Working Group](#)

[University of Washington School of Public Health and Community Medicine](#)

[UCLA School of Public Health](#)

[Association of Schools of Public Health \(ASPH\)](#)

[University of Arkansas for Medical Sciences, College of Public Health](#)

[NYU Medical Center \(NYU Hospitals / NYU School of Medicine\)](#)

## **E. Foundations/Funding**

[Otto Bremer Foundation](#)

[Amherst H. Wilder Foundation](#)

## SECTION III: Resources

### [W.K. Kellogg Foundation](#)

### [National Institutes of Health \(NIH\)](#)

### [Northwest Health Foundation \(NWHF\) - Community-Based Participatory Research](#)

The mission of the Northwest Health Foundation is to advance, support and promote the health of the people of Oregon and southwest Washington. Community-based participatory research (CBPR) takes place in community settings and equitably involves community and academic partners in the planning, design, implementation, and evaluation phases of research — recognizing the unique strengths that each partner brings to the process. CBPR combines knowledge with action to effect social change, including the improvement of health and the elimination of health disparities.

### [Office of University Partnerships \(OUP\)](#)

The Office of University Partnerships (OUP) facilitates the formation of campus-community partnerships through sharing information about community partnership development, in general, and about OUP's various funded programs. Our Web site provides many helpful resources, including funding, research, news, events, technical assistance, and highlights of campus-community activities nationwide. OUP is committed to helping colleges and universities join with their neighbors to address urban problems—partnerships that enable students, faculty, and neighborhood organizations to work together to revitalize the economy, generate jobs, and rebuild healthy communities.

### [The Robert Wood Johnson Foundation \(RWJF\)](#)

The Robert Wood Johnson Foundation seeks to improve the health and health care of all Americans. RWJF focuses on the pressing health and health care issues facing our country. The Foundation works with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful and timely change.

### [Prevention Research Centers - PRC](#)

Prevention Research Centers, A network of academic researchers, public health agencies, and community members that conducts applied research in disease prevention and control.

### [Community Campus Partnership for Health](#)

A listing of announcements for funding opportunities that we believe would be of interest to our members and other stakeholders. Announcements are listed by deadline and are updated every two weeks.

## SECTION III: Resources

[Laidlaw Foundation](#)

[Greater Twin Cities United Way](#)

[Blue Cross and Blue Shield of Minnesota](#)

Blue Cross and Blue Shield of Minnesota offers individual and group health plans. Worldwide coverage, extensive networks, prescription drug coverage, leading health improvement programs, more.

[Office for Extramural Research > Grants Web Site](#)

OER Home Page - Grants Web Site - NIH Office of Extramural Research (OER) web site with NIH Medical and Behavioral Research Grant Policies, Guidelines and Funding Opportunities.

[The Minneapolis Foundation](#)

### **F. Publication Lists/Reference Lists**

[Detroit URC > Publications](#)

Publications and Presentations list

[Community Projects/Research - College of Public Health - University of Arkansas for Medical Sciences - Where Medicine Lives](#)

University of Arkansas, College of Public Health, Office of Community-Based Public Health CBPH/CBPR Resources List

[Southeast Community Research Center](#)

CBPR Case Studies

[Institute for Community Research](#)

ICR Publication List

[National Institute of Environmental Health Sciences](#)

Grantees: Environmental Justice and Community-Based Participatory Research

[DOE: Community IRB](#)

Helpful Websites

## SECTION III: Resources

### [The Center for the Health Professions](#)

Links & Resources

### [Action Research Reference List](#)

Action research, sometimes called "practitioner research," is a reflective investigation of a personal interest, problem or challenge. The process begins with the development of questions, which may be answered by the collection of data. Action implies that the practitioner will be acting as the collector of data, the analyst, and the interpreter of results.

### [Community-Based Research Network](#)

This website is part of the National Community-Based Research Networking Initiative, which is being managed through by Princeton University's Community-Based Learning Initiative and the Bonner Foundation with funding support from the Corporation for National and Community Service.

### [Participatory Research at McGill](#)

PRAM Participatory Research Toolkit

### [Turning Point - Collaborating for a New Century in Public Health](#)

Turning Point, started in 1997, was an initiative of The Robert Wood Johnson Foundation and the W.K. Kellogg Foundation. Its mission was to transform and strengthen the public health system in the United States by making it more community-based and collaborative. The initial idea for Turning Point came from the foundations' concerns about the capacity of the public health system to respond to emerging challenges in public health, specifically the system's capacity to work with people from many sectors to improve the health status of all people in a community.

## APPENDIX A: Documents from Organizations

The following items have been taken from various organizations websites. These documents were made available to the public. They have been included here due to their resourcefulness.

Included:

- Southcentral Foundation Research Approval Process
  - Southcentral Foundation has implemented a Community IRB
- Northern Plains Tribal Epidemiology Center/Aberdeen Area Tribal Health Board Research ethics and Institution Review Board Resources for Tribes and Researchers
  - NPTEC/AATCHB has implemented a Community IRB
  - This document offers links to a number of templates to be used by community organizations during the Community IRB process (these may also prove helpful during the CBPR process), such as NPTEC Guidelines for Researchers or Sample Protocols (Protocols and Consent Forms).
  - The document is broken into the two sections: Resources for Tribes and Resources for Researcher.
  - Documents in this section include PowerPoints, Word, PDFs and links to webpages. While all of these are informative in some way, with little time, I recommend focusing on the Word documents.
  - The Resources for Tribes is broken into further subsections:
    - Foundations in Research Ethics
    - Tools to Review Research Protocols:
      - The documents in this section focus on what the community should be aware of and consider when engaging with researchers in a project.
      - While not useful initially, they may be insightful when discussion operating norms or establishing principles.
      - They may also prove useful in educating community members about types of documents or agreements that can be made between the community and the researcher.
      - Documents to check out:
        - **Research Review Checklist: Tribal Research (Word)**
        - **Research Review Checklist: IRB review (Word)**
        - **Research Review Checklist: IRB Review (Word)**

## APPENDIX A: Documents from Organizations

- Tools to Build a Tribal or TCU IRB
  - This section focuses on how to build a Community IRB
  - Again, perhaps not helpful during the discussion stage of developing a CBPR partnership, but some documents may prove useful when working with community members to educate about what rights community members could recommend.
    - **Sample Tribal “IRB” Polices and Procedures**
- Additional Tools and Templates
- References and Interesting Reading
- Witness For Wellness Documents:
  - Wellness Council (included to provide quick overview of project/organization)
  - Witness for Wellness DRAFT Collaboration Agreement
    - This is an example of a Memorandum of Understanding developed during a CBPR partnership. It includes CBPR principles designed by the partnership, delineated Rights, Conflicts, and Responsibilities section, and description of Project Design.
  - “Supporting Wellness” workgroup description and workplan
  - “Building Wellness” workgroup description and workplan
  - “Talking Wellness” workgroup description and workplan
    - Each workplan includes: Action Plan, Methodology, Timeline, and Participants.
    - Each workplan explains “Component” and “Goal” it is aligned with in the project.
- Southeast Community Research Center “New Tools New Visions”
  - Includes helpful image of relationship between stakeholders, with the Resource Hub at the center. The Resource Hub is parallel to “The Institute.”
- Community-Campus Partnerships for Health About Us webpage
  - Our Mission and Values includes informative language and values and beliefs
  - The Principles of Good Community-campus Partnerships is example of CBPR Principles adopted by organization. Each principle is further explained in a document (these have been printed and are included in a separate binder).

## APPENDIX B: Literature Cited with Abstract and Key Words

### Literature Cited

- \*\* Aaron KF and Stryer D. 2003. Moving from rhetoric to evidence-based action in health care. *Journal of General Internal Medicine* 18: 589-591.

Abstract: Participatory approaches to research are well established in environmental and public health and other non-health-related field. Their role in understanding and improving health care, however, has been quite limited. While there is some skepticism about the value and validity of participant/subject involvement in research, there is the growing consensus that strategies that aim to make change should include the active involvement of stakeholders, including communities and patients. This editorial presents a brief overview of CBPR and its role in improving health and health care, discusses why CBPR has failed to attract more support, and finally outlines action needed to advance CBPR.

- \*\* Blumenthal DS. 2006. A community coalition board creates a set of values for community-based research. *Centers for Disease Control and Prevention newsletter*.

Abstract BACKGROUND: Researchers generally agree that communities should participate in the community-based research process, but neither a universally accepted approach to community participation nor a set of guiding principles exists. CONTEXT: The Morehouse School of Medicine Prevention Research Center was established in 1999 with the support of a grant from the Centers for Disease Control and Prevention. Its partners include a low-income, predominantly African-American community, six public agencies, and two other academic institutions. A Community Coalition board was established to represent the partners. The majority of the board is community members; it serves in a governance rather than an advisory capacity; with the community acting as the senior partner in interactions with the medical school, the agencies, and other academic institutions. METHODS: The Community Coalition Board developed a set of research priorities and a set of 10 community values, or principles, to guide research. A board committee reviews each protocol to ensure they uphold values. CONSEQUENCES: The Community Coalition board has been using the values since 1999, and in this article we describe its experience. After an initial period that included some disagreements between researchers and community members on the board, relationships have been good, and protocols have been approved with only minor changes. INTERPRETATION: Although the established community values reflect universally acknowledged principles of research ethics, they also address local concerns. An equal partnership between community members and researchers is most beneficial if the partners can agree on a set of values to govern research.

## APPENDIX B: Literature Cited with Abstract and Key Words

Corburn J. 2002. Combining community-based research and local knowledge to confront asthma and subsistence-farming hazards in Greenpoint/Williamsburg, Brooklyn, New York. *Environmental Health Perspectives* 110 (suppl 2): 241-248.

Abstract: Activists in the environmental justice movement are challenging expert-driven scientific research by taking the research process into their own hands and speaking for themselves by defining, analyzing, and prescribing solution for the environmental health hazards confronting communities of the poor and people of color. I highlight the work of El Puente and The Watchperson Project – two community-based organizations in the Greenpoint/Williamsburg neighborhood in Brooklyn, New York, that have engaged in community-based participatory research (CBPR) to address asthma and risks from subsistence-fish diet. The CBPR process aims to engage community members as equal partners alongside scientists in problem definition, information collection, and data analysis – all geared toward locally relevant action for social change. In the first case I highlight how El Puente has organized residents to conduct a series of asthma health surveys and tapped into local knowledge of the Latino population to understand potential asthma triggers and to devise culturally relevant health interventions. In a second case I follow The Watchperson Project and their work surveying subsistence anglers and note how the community-gathered information contributed key data inputs for the U.S. Environmental Protection Agency Cumulative Exposure Project in the neighborhood. In each case I review the processes each organization used to conduct CBPR, some of their findings, and the local knowledge they gathered, all of which were crucial for understanding and addressing local environmental health issues. I conclude with some observations about the benefits and limits of CBPR for helping scientists and communities pursue environmental justice.

Key words: asthma, community health, community-based participatory research, cumulative exposure assessment, El Puente, environmental justice, local knowledge, subsistence fishing, The Watchperson Project,

\*\*\* Edgren KK, Parker EA, Israel BA, Lewis TC, Salias MA, Robins TG, and Hill YR. 2005. Community involvement in the conduct of a health education intervention and research project: Community Action Against Asthma. *Health Promotion Practice* 6 (3): 263-269.

Abstract: There is a need for more guidance on how to implement community-based participatory research, particularly on the roles of community members, throughout the process. This article focuses on how a Steering Committee, composed of representatives from community-based organization, a local health department, an integrated health care system, and academia from the University of Michigan: Community Action Against Asthma. In addition, this article focuses on the role of community members as data collectors, examining a variety of

# The Institute for Immigrant and Refugee Health & Wellness

## Resource List

### APPENDIX B: Literature Cited with Abstract and Key Words

sophisticated data collection roles. A description and analysis of how community members shaped and participated in the project, the lessons learned, and recommendation for practitioners are also presented.

Key words: community-based participatory research; health intervention; asthma; community involvement; collaborative research; partnership; data collection

Fowles ER. 2007. Collaborative methodologies for advancing the health of underserved women. *Family Community Health* 30(suppl 1): S53-S63.

Abstract: Collaborative methodologies that incorporate local community members offer a unique approach to conducting women's health research. These approaches actively seek to mobilize community resources to solve healthcare problems and may be effectively implemented, accepted, and sustained. Understanding differences among collaborative methodologies is needed to assist the researcher in selecting the strategy that is most consistent with the study purpose and setting. The purpose of this article is to discuss the processes involved in these methodologies and the role of the researcher and the research community and compare how these methodologies differ in identifying and evaluating healthcare outcomes for underserved women.

Key words: behavior change, collaborative methods, community-based participatory research, positive deviance, women's health

\*\*\*\* Giachello AL, Arrom JO, Davis M, Sayad JV, Ramirez D, Nandi C, and Ramos C. 2003. Reducing diabetes health disparities through community-based participatory action research: the Chicago Southeast Diabetes Community Action Coalition. *Public Health Reports* 118: 309-323.

Abstract: To address disproportionately high rates of diabetes morbidity and mortality in some of Chicago's medically underserved minority neighborhoods, a group of community residents, medical and social service providers, and a local university founded the Chicago Southeast Diabetes Community Action Coalition, a Centers for Disease Control and Prevention REACH 2010 Initiative. A community-based participatory action research model guided coalition activities from conceptualization through implementation. Capacity building activities included training on: diabetes, coalition building, research methods, and action planning. Other activities sought to increase coalition members' understanding of the social causes and potential solutions for health disparities related to diabetes. Trained coalition members conducted epidemiologic analyses, focus groups, a telephone survey, and a community inventory. All coalition members participated in decisions. The participatory process led to increased awareness of the complexities of diabetes in the community and to a state of readiness for social action. Data documented disparities in diabetes. The participatory action research approach (a) encouraged key stakeholders outside of the health sector to participate (e.g., business sector, church groups); (b) permitted an examination of

# The Institute for Immigrant and Refugee Health & Wellness

## Resource List

### APPENDIX B: Literature Cited with Abstract and Key Words

the sociopolitical context affecting the health of the community; (c) provided an opportunity to focus on preventing the onset of diabetes and its complication; (d) increased understanding of the importance of community research in catalyzing social action aimed at community and systems change and change among change agents.

- \*\*\* Gilbert SG. 2006. Supplementing the traditional institutional review board with an environmental health and community review board. *Environmental Health Perspectives* 114: 1626-1629.

**Abstract:** **BACKGROUND:** Community-based research often involves additional ethical, legal, and social considerations beyond those of the specific individuals involved in the study. The traditional institutional review board (IRB) typically focuses on protecting the rights and ensuring the safety of the individuals involved. For projects involving community members, IRBs should be more sensitive to issues related to the broader community concerns. **OBJECTIVES:** The objective of this article is to discuss the concept of community-based participatory research and the shortcomings of the traditional IRBs in dealing with ethical issues associated with broader community concerns such as implications for family members, neighborhood groups, and local businesses. I examine the rationale and benefits for expanding the roles and responsibilities of review boards related to community-based issues. **DISCUSSION:** I propose the development of environmental health and community review boards (EHCRBs) that combine the fundamental responsibilities and ethical concept of the traditional review boards with an expanded ethical construct of dignity, veracity, sustainability, and justice, with an added emphasis on community. **CONCLUSIONS:** Only by acknowledging the needs of and working with the community can we ensure ethically based and socially responsible research. An EHCRB will allow researchers and community members to more fully address their mutual interest in conducting scientific, ethical, and socially responsible research.

**Key words:** autonomy, bioethics, community-based participatory research, dignity, environmental justice, institutional review board, justice, sustainability, veracity.

- \*\*\* Israel BA, Parker EA, Rowe Z, Salvatore A, Minkler M, López J, Butz A, Mosley A, Coates L, Lambert G, Potito PA, Brenner B, Rivera M, Romero H, Thompson B, Coronado G, Halstead S. 2005 Community-based participatory research: lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. *Environmental Health Perspectives* Oct;113(10):1463-71.

**Abstract:** Over the past several decades there has been growing evidence of the increase in incidence rates, morbidity, and mortality for a number of health problems experienced by children. The causation and aggravation of these

## APPENDIX B: Literature Cited with Abstract and Key Words

problems are complex and multifactorial. The burden of these health problems and environmental exposures is borne disproportionately by children from low-income communities and communities of color. Researchers and funding institutions have called for increased attention to the complex issues that affect the health of children living in marginalized communities--and communities more broadly--and have suggested greater community involvement in processes that shape research and intervention approaches, for example, through community-based participatory research (CBPR) partnerships among academic, health services, public health, and community-based organizations. Centers for Children's Environmental Health and Disease Prevention Research (Children's Centers) funded by the National Institute of Environmental Health Sciences and U.S. Environmental Protection Agency were required to include a CBPR project. The purpose of this article is to provide a definition and set of CBPR principles, to describe the rationale for and major benefits of using this approach, to draw on the experiences of six of the Children's Centers in using CBPR, and to provide lessons learned and recommendations for how to successfully establish and maintain CBPR partnerships aimed at enhancing our understanding and addressing the multiple determinants of children's health.

Key words: children's health, collaborative research, community-based participatory research, partnership.

\*\*\*\* Israel BA, Lichtenstein R, Lantz P, McGranaghan R, Allen A, Guzman R, Softley D, and Maciak B. 2001. The Detroit Community-Academic Urban Research Center: Development, Implementation, and Evaluation. *Journal of Public Health Management Practice* 7(5): 1-19.

Abstract: There is increasing research evidence that stressors in the social and physical environment (e.g., poverty, inadequate housing, air pollution, and racism) are associated with poor health outcomes. Given the complex set of determinants of health status, the disproportionate burden of disease experiences within marginalized communities, and the limited effectiveness of traditional prevention research, particularly within community of color, there have been growing calls for more comprehensive and participatory approaches to public health research and practice. The purpose of this articles is to describe and analyze the process of establishing, implementing, and evaluating the Detroit Community-Academic Urban Research Center (URC), a community-based participatory research (CBPR) partnership involving community-based organizations, a local health department, academia, and an integrated health care system. Lessons learned and recommendations for creating effective CBPR partnerships are presented.

Key words: community-based participatory research, participatory action research, prevention research, social determinants of health, urban health.

# The Institute for Immigrant and Refugee Health & Wellness

## Resource List

### APPENDIX B: Literature Cited with Abstract and Key Words

\*\*\*\* Israel BA, Schulz AJ, Parker EA, and Becker AB. 1998. Review of community-based research: assessing partnership approaches to improve public health. *Annual Review of Public Health* 19:173-202.

Abstract: Community-based research in public health focuses on social, structure, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to benefit the community involved. This review provides a synthesis of key principles of community-based research, examines its place within the context of different scientific paradigms, discusses rationales for its use, and explores major challenges and facilitating factors and their implications for conducting effective community-based research aimed at improving the public's health.

Key words: community-centered research, participatory action research, participatory research, collaborative research, public health partnerships.

\*\* Kagawa-Singer M, Tanjasiri SP, Foo MA, Nguyen TN, Tran J, and Valdez A. 2006. Breast and cervical cancer control among Pacific Islander and Southeast Asian women: participatory action research strategies for baseline data collection in California. *Journal of Cancer Education* 21(1 suppl): S53-S60.

Abstract: **BACKGROUND.** No data exists on the breast and cervical cancer screening practices among Cambodian, Laotian, Thai, and Tongan women. In this article, we describe the efforts required to conduct a baseline survey among these non-English-speaking women using the participatory action research (PAR) approach. **METHODS.** We tailored small population sampling techniques to each of the populations in partnership with Community Health Outreach workers. **RESULTS.** A total of 1825 surveys were successfully conducted in 8 communities. **CONCLUSION:** PAR and the culturally based techniques used to conduct the survey proved successful in maintaining scientific rigor, developing true community-researcher partnership, and achieving over 90% participation.

Lindsey E and McGuinness L. 1998. Significant elements of a community involvement in participatory action research: evidence from a community project. *Journal of Advanced Nursing* 28(5): 1106-1114.

Abstract: Participatory action research (PAR) has been heralded as an important research methodology to address issues of research relevance, community involvement, democracy, emancipation and liberation. Increasingly, nurse researchers are turning to PAR as a method of choice. Although nursing interest in PAR is expanding little is known about how to successfully involve the community in research. This article attends to this dearth of information by presenting the results of a study investigating the significant elements of community involvement in PAR. Through the use of qualitative research

## APPENDIX B: Literature Cited with Abstract and Key Words

methods, five themes emerged that describe the community participation process: (a) planning for participation, (b) the structural component of community participation, (c) living the philosophy, (d) enhancing the credibility, and (e) the type of leadership required to facilitate community participation. It is hoped that by sharing these results others may consider the knowledge gleaned from this project as they plan and process with the challenges and rewards inherent in PAR.

Key words: community participation, community involvement, participatory action research, nursing research.

Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, and Twohig PL. 1999. Participatory research maximizes community and lay involvement. *BMJ* 319: 774-778.

Abstract: The knowledge, expertise, and resources of the involved community are often key to successful research. Three primary features of participatory research include collaboration, mutual education, and acting on results developed from research question that are relevant to the community. Participatory research is based on a mutually respectful partnership between researchers and communities. Partnerships are strengthened by joint development of research agreements for the design, implementation, analysis, and dissemination of results. Results of participatory research both have local applicability and are transferable to other communities.

Key words: community, participatory research, collaboration, partnership.

Matsunaga DS, Enos R, Gotay CC, Banner RO, DeCambra H, Hammond OW, Hedlund N, Ilaban EK, Issell BF, and Tsark JA. 1996. Participatory research in a native Hawaiian community: the Wai'anae Cancer Research Project. *Cancer* 78(7): 1582-1586.

Abstract: **BACKGROUND:** Community participation was a key component of a cancer control research project in a Native Hawaiian community. This project tested the effectiveness of a culturally appropriate intervention as a means of increasing breast and cervical cancer screening practices among Native Hawaiian women on the Wai'anae Coast of the island of O'ahu. **METHODS:** The Wai'anae Cancer Research project was community driven, with Native Hawaiian community representatives involved in all phases of the project, from grant proposal development to data interpretation. A community health center administered the grant award from the National Cancer Institute. The policy-making steering committee included community representatives, health professionals, and researchers to balance community and scientific quality standards. A factor in the project's success was continuous involvement over 7 years by a core of community representatives and professional staff. **RESULTS:** More than 500 women participated in the intervention, and outcome measures indicated that there was a community wide impact on cancer-related knowledge,

## APPENDIX B: Literature Cited with Abstract and Key Words

attitudes, and behaviors. Important contributions of the project also included research capabilities, and dissemination of findings to other communities and researchers. **CONCLUSION:** Community participation in all phases of the research was essential in generating community acceptance and resulted in an innovative and effective intervention. This participatory research project has left the community richer in knowledge, skills, experience, confidence, and resources. These qualities provide a strong foundation for building future programs and research.

Key words: culture, ethnic groups, community health services, health promotion, breast neoplasms, cervic neoplasms.

Minkler M. 2004. Ethical challenges for the “outside” research in community-based participatory research. *Health Educ Behav* 31:684-697.

Abstract: Although community-based participatory research (CBPR) shares many of the core values of health education and related fields, the outside researcher embracing this approach to inquiry frequently is confronted with thorny ethical challenges. Following a brief review of the conceptual and historical roots of CBPR, Kelly’s ecological principles for community-based research and Jones’s three-tiered framework for understanding racism are introduced as useful frameworks for helping explore several key challenges. These are (a) achieving a true “community-driven” agenda; (b) insider-outsider tensions; (c) real and perceived racism; (d) the limitations of “participation”; and (e) issues involving the sharing, ownership, and use of findings for action. Case studies are used in an initial exploration of these topics. Green et al.’s guidelines for appraising CBPR projects then are highlighted as an important tool for helping CBPR partners better address the challenging ethical issues often inherent in this approach.

Key words: community-based participatory research; research ethics; community partnerships.

\*\*\*\* Parker EA, Israel BA, Williams M, Brakefield-Caldwell W, Lewis T C, Robins T, Ramirez E, Rowe A, and Keeler G. 2003. Community Action Against Asthma. *Journal of General Internal Medicine* 18: 558-567.

Abstract: **BACKGROUND:** Community Action Against Asthma (CAAA) is a community-based participatory research (CBPR) project that assesses the effects of outdoor and indoor air quality on exacerbation of asthma in children, and tests household- and neighborhood-level interventions to reduce exposure to environmental asthma triggers. Representatives of community-based organizations, academia, an integrated health system, and the local health department work in partnership on CAAA’s Steering Committee (SC) to design and implement the project. **OBJECTIVE:** To conduct a process evaluation of the CAAA community-academic partnership. **DESIGN:** In-depth interviews

The Institute for Immigrant and Refugee Health & Wellness  
Resource List

APPENDIX B: Literature Cited with Abstract and Key Words

containing open-ended questions were conducted with SC members. Analysis included established methods for qualitative data, including focused coding and constant comparison methods. **SETTING:** Community setting in Detroit, Michigan. **PARTICIPANTS:** Twenty-three members of the CAAA SC. **MEASUREMENTS:** Common themes identified by SC members relating to the partnership's ability to achieve project goals and the successes and challenges facing the partnership itself. **MAIN RESULTS:** Identified partnership accomplishments included: successful implementation of a complex project, identification of children with previously undiagnosed asthma, and diverse participation and community influence in SC decisions. Challenges included ensuring all partners' influence in decision-making, the need to adjust to “a different way of doing things” in CBPR, constraints and costs of doing CBPR felt by all partners, ongoing need for communication and maintaining trust, and balancing the needs of science and the community through intervention. **CONCLUSIONS:** CBPR can enhance and facilitate basic research, but care must be given to trust issues, governance issues, organizational culture, and costs of participation for all organizations involved.

Key words: community-based participatory research; asthma; partnership; process evaluation.

Pothukuchi K. 2005. Building community infrastructure for healthy communities: evaluating action research components of an urban health research programme. *Planning, Practice & Research* 20(2): 127-146.

*Roussel AE, Fan NL, and Fulmer E. 2002. Identifying characteristics of successful researcher/community-based organization collaboration in the development of behavioral interventions to prevent HIV infection (Task order no. 0621-26). Prepared for the Centers for Disease Control and Prevention.*

\*\*\* Schell LW, Ravenscroft J, Cole M, Jacobs A, Newman J, and Akwesasne Task Force on the Environment. 2005. *Environmental Health Perspectives* 113 (12): 1826-1832.

Abstract: In this article we describe a research partnership between the Akwesasne Mohawk Nation and scientists at the University at Albany, State University of New York, initiated to address community and scientific concerns regarding environmental contamination and its health consequences (thyroid hormone function, social adjustment, and school functioning). The investigation focuses on cultural inputs into health disparities. It employs a risk-focusing model of biocultural interaction: behaviors expressing cultural identity and values allocate or focus risk, in this instance the risk of toxicant exposure, which alters health status through the effects of toxicants. As culturally based behaviors and activities fulfill a key role in the model, accurate assessment of subtle cultural and behavioral variables is required and best accomplished through integration of

## APPENDIX B: Literature Cited with Abstract and Key Words

local expert knowledge from the community. As a partnership project, the investigation recognizes the cultural and socioeconomic impacts of research in small communities beyond the production of scientific knowledge. The components of sustainable partnerships are discussed, including strategies that helped promote equity between the partners such as hiring community members as key personnel, integrating local expertise into research design, and developing a local Community Outreach and Education Program. Although challenges arose during the design and implementation of the research project, a collaborative approach has benefited the community and facilitated research.

Key words: adolescents, Akwesasne Mohawk Nation, community-based participatory research, health disparities, Native American, partnership research, polychlorinated biphenyls.

\*\*\* Seifer SD. 2006. Building and sustaining community-institutional partnerships for prevention research: findings from a national collaborative. *Journal of Urban Health* 83: 989-1003.

Abstract The Examining Community-Institutional Partnerships for Prevention Research Project began in October 2002 with funding from the Centers for Disease Control and Prevention Research Center Program Office through a cooperative agreement between the Association of Schools of Public Health and the CDC. The three-year project aimed to synthesize knowledge about community-institutional partnerships for prevention research and to build community and institutional capacity for participatory research. These ten organizations collaborated on the project because they were all involved in community-institutional partnerships for prevention research, had access to research and evaluation data on these partnerships, and believed that the shared learning and action that would result through a collaborative effort could significantly advance collective knowledge about partnerships and lead to substantive capacity-building responses: the Community Health Scholars Program, Community-Based Public Health Caucus of the American Public Health Association, Community-Campus Partnerships for Health, Detroit Community-Academic Urban Research Center, Harlem Health Promotion Center, National Community Committee of the CDC Prevention Research Centers Program, New York Urban Research Center, Seattle Partners for Healthy Communities, Yale-Griffin Prevention Research Center and the Wellesley Institute. This paper reports on the project's findings, including common characteristics of successful partnerships and recommendations for strengthening emerging and established partnerships.

Key words: Community-academic partnerships, Community-based participatory research, Partnership, Prevention

Seifer, SD and Maurana CA. Developing and sustaining community-campus

The Institute for Immigrant and Refugee Health & Wellness  
Resource List

APPENDIX B: Literature Cited with Abstract and Key Words

partnerships: putting principles into practice. Workshop publication.

\*\*\*\* Tanjasiri SP, Kagawa-Singer M, Nguyen T, Foo MA. 2002. Collaborative research as an essential component for addressing cancer disparities among southeast Asian and Pacific Islander women. *Health Promotion Practice* 3 (2): 144-154.

Abstract: A fundamental component of community-based health promotion efforts to eliminate disparities is the mobilization of community involvement to address not only individual but also systemic and political causes of inequalities in health. The participatory action research (PAR) paradigm is well suited to address these multilevel inequalities in research and evaluation experiences by many ethnic and racial communities. In this article, a case study of a project to reduce health disparities in breast and cervical cancer among seven Southeast Asian and Pacific Islander communities in Southern California is presented. The authors applied a PAR framework to the process of needs assessment and program planning to understand and address the complex and multilevel factors that contribute to the problem of disparate breast and cervical cancer screening rates in these communities. Finally, the authors describe the lessons that were learned about how to promote collaborative research as an essential element in the design of projects and studies to address ethnic disparities in health outcomes for breast and cervical cancer.