Feeding Information Back to the Community and Putting Data into Practice[1]

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Thank you for opportunity to provide testimony to your subcommittee on the important issues of how communities can effectively and efficiently collect and receive data and translate those data into practice. The report *The Community as a Learning System for Health: Using Local Data to Improve Local Health* identified important questions about how communities can become learning systems for health, what resources exist or could be created to assist with this learning, and what is needed if communities are to succeed in addressing the many different kinds of health concerns that confront communities. In my testimony I would like to highlight three points:

1. The importance and challenges of taking diversity in communities into account
2. The value of more fully involving higher education institutions as a resource
3. The value of learning from community data partnerships in areas outside health and bringing these lessons into the community health arena

My testimony on these three points draws from my three decades of experience in working with communities in urban and rural areas on the challenges of using data to address local health problems. Much of this work has involved refugee and immigrant communities. Using partnerships, we have attempted to identify innovative solutions that can cost-effectively draw on the resources that community members bring to solving health problems. Below I summarize suggestions on the three points.

1. **The Challenge and Opportunities of Diversity:** As we are all well aware, American communities are becoming increasingly diverse. Across the nation— from Lewiston, Maine to Long Beach, California—communities are becoming home to refugee and immigrant families. By no means is this the only type of diversity that impacts communities, but this diversity is confronting communities with many new challenges in use of health data. Refugee and immigrant families come to communities with:
   - Different health experiences, problems, and practices
   - Different uses of language to describe health and illness
   - Differences in comfort in answering interview and survey questions, particularly when asked by strangers, government officials, or those in authority
   - Differences in customs from their home countries in how illnesses are expected to be treated
   - Differences in practices at the individual and family level related to health decision making
   - Differences in practices for developing health programs and implementing initiatives
   - Differences in previous interactions with health providers

   As many communities are now discovering, a "one size fits all" approach in diverse communities has not led to successful data collection, translation, and community use. Differences in diverse communities require innovative approaches to community data collection and usage. New efforts are targeting many elements of the data collection to program implementation continuum, such as:
   - **Solving the Problem of Data Collection Without Community Involvement:** Many refugee and immigrant communities with pressing health problems see themselves as having become targets of data collection by researchers, with little focus on how these findings will be used to address community health problems.

[1] Testimony to hearing of Privacy Subcommittee of the National Committee on Vital and Health Statistics, April 17, 2012

Some communities (Lawrence, MA, for example) have now taken steps to develop and publish their own procedures for ensuring that rigorous data are collected with community involvement and with a focus on how these data will be used to address community health problems.

- **Tackling the Problem of Confidentiality:** In many refugee and immigrant communities, people know each others' extended families and thus confidentiality and privacy are difficult to maintain when data are collected. At the same time, those who are of the community are exactly those who are the most familiar with the health problems and are more likely to organize data collection in ways that reflect a nuanced understanding of these health problems and of the interventions that might succeed. Communities are identifying effective ways to maintain confidentiality while also collecting accurate data, such as methods described at the researchethics.org website.
- **Finding Ways to Convey Results:** Once local community health data are collected, many communities are finding that reliance on written data summaries for dissemination and program development is unsuccessful. In diverse communities, many people are not literate in English or other languages. Innovative alternative approaches are needed. One example of such an approach is the use of community mapping using Geographic Information Systems (GIS). Community data on various environmental health issues (i.e., pediatric asthma) are collected. The information is given back to communities in the forms of engaging maps that show neighborhoods where the incidence of pediatric asthma vary, superimposed on census data. These maps can include key community locations (such as Buddhist temples) that help orient viewers to their neighborhoods. At community meetings, community members can be given customized maps that highlight their neighborhoods.
- **Finding Ways to Link Data with Action:** When communities are asked to become involved in using the data, new methods are often needed to make the data meaningful to communities. Reports are frequently unsuccessful in connecting to people's lives. Community partnerships are designing active community events as a way to link data and action. For example, in Lowell, Massachusetts, data about environmental health problems related to the environment were collected through community partnership teams bringing together graduate students in health and Cambodian and Laotian community leaders. Rather than rely only on written reports, community events (such as the highly successful Southeast Asian Water Festival) were created to bring the ideas to the community in a culturally-arresting manner. What has become the central cultural event in the community served as a way to communicate data and develop interventions.

2. **Looking to Higher Education Institutions as a Maturing Resource:** One of the continuing struggles communities face is finding new resources for tackling health problems. Yet, as a result of changes now taking place in higher education, new resources at universities are becoming more available. More and more faculty at higher education institutions of all kinds (community college, four year, comprehensive, and research-intensive universities) have begun to look for ways that their teaching, research, and outreach might incorporate partnerships with local communities. Commissions such as the *Kellogg Commission on Land Grant Universities* are recommending these higher education changes, and national organizations such as *Community Campus Partnerships for Health (ccph.info)* are developing detailed guidelines for this kind of work. Just a few examples of the opportunities that exist include:
   - **Connecting community need for data collection with faculty interest in seeing that their students learn good data skills:** More and more faculty who teach classes that involve data are looking to partner with groups who can provide data collection and analysis opportunities. The faculty goal is to have students work with real data that expose students to the kind of complexities they will likely encounter outside the classroom. This "win-win" situation is beginning to provide opportunities for communities to have resources and students to learn in more effective ways.

- **Looking beyond university health disciplines:** Some communities are starting to recognize that important university resources go well beyond health faculty and students. Communities are looking to programs in communication, community psychology, computer science, economics, program evaluation, and sociology, for example, for help in designing and implementing data collection and reporting strategies that can directly translate into new policies and practices.
- **Looking at thesis and dissertation opportunities:** Communities are increasingly realizing that if they can set up partnerships with faculty, there are opportunities for ensuring that thesis and dissertations carried out by honors undergraduates and graduate students can be organized to provide data that will be useful to communities. Many higher education institutions have begun incorporating a focus on interdisciplinary research that communities are finding helpful in ensuring that data collection is carried out that has direct policy implications and can be used by communities to develop and evaluate programs.
- **Assisting with the development of community repositories of knowledge:** Campuses are starting to realize that they need to know more about how communities develop and maintain the data used for decision making. Faculty are starting to look at ways they can contribute to community repositories and avoid having findings end up solely in academic journals that are accessed largely by scholars. Because academic journals focus on achieving significance to ensure publication, new researchers often repeat the same research in a community without being aware that previous unpublished studies have been done. The result is frustration on the part of community members and little progress in solving community health problems. New approaches are being developed that attend to how communities organize their knowledge and how these repositories could be better used to ensure that data collection is needed and will assist with programs development.
- **Developing partnership approaches.** An approach undertaken by U.S. Housing and Urban Development's Office of University Partnerships has impacted numerous campuses and is providing the impetus for change in higher ed institutions. The HUD program was aimed at mobilizing the underused capacity on campuses as anchor institutions to help solve community problems. Programs such as HUD's are leading to changes that emphasize partnership approaches, co-production of knowledge, and greater application of research. Syracuse University, Portland State University, Memphis State University, and University of Maine are just a few examples of higher ed institutions at which new approaches to partnership can provide opportunities for communities to enter into data partnerships that help solve community problems.

3. **The Importance of Learning from Work in Fields Outside of Health:** In addition to the health field, many other areas are rapidly advancing the knowledge base for solving the problems of community data collection, use, and analysis. Attending to these partnership lessons could serve as a low cost way for health fields to devise effective strategies. Just two of the many examples of such areas include:
   - **Citizen Science:** Researchers and policy makers around the country have begun enlisting community members to gather data on problems where time series data are otherwise expensive and labor intensive to collect (e.g., changes in marine environments, changes in avian distribution). What is now termed citizen science has anticipated and addressed problems of data quality, data control, and data usage. The extensive literature on citizen science addresses a range of issues and problems and provides detailed information that could be quite helpful in community health arenas.
   - **Sustainability Science:** The National Science Foundation, the National Academies of Science, and other entities have become increasingly concerned with questions of how scientists and communities can co-produce knowledge so as to ensure that data are rigorous, useful, and answer policy questions. The issues addressed in the growing body of research on sustainability science parallel many of the issues in the health arena with regard to community uses of data. The Sustainability Science work offers models that could be very instructive to the health arena.