



Partnering with Communities in Survey Design, Implementation and Dissemination

Kathleen Thiede Call, Ph.D.

AAPOR, Anaheim CA

May 19, 2007

Supported by a grant from the Minnesota Department of Human Services



Problems: Disparities and Mistrust

- Understanding, eliminating disparities is a national priority
 - Progress in reducing disparities is slow
- Survey research used to monitor nature and sources of disparities
- Community most affected by disparities often suspicious of research, including survey research
 - Lack of utility, application, action



Solution: Community “Involvement” in Research

“Community-based participatory research in public health is a *collaborative* approach to research that equitably involves...

community members, organizational representatives, and researchers in all aspects of the research process.” (Israel et al., 2000)

Academic
Research

Community
Based



3

From Theory to Practice

“Barriers to care among Minnesota Health Care Program enrollees”

- Creation and implementation of statewide survey of program (e.g., Medicaid) enrollees stratified by race/ethnicity
- **Data:** Outcomes of participatory process using meeting minutes, progress reports, observations of team members, debriefing survey at end of project

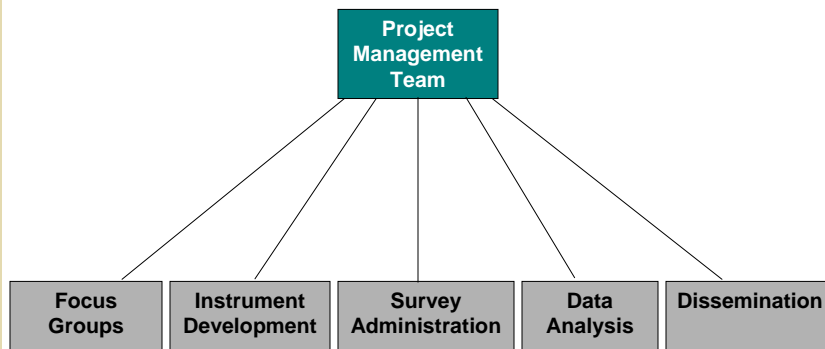


4

Participatory Components of Disparities Project

- Resource distribution to enhance equity
 - Although limited, budget supported academic and community researchers
 - Set up subcontracts to minimize ICR to university, ensure timely payments to community researchers
- Administrative structure to balance power
 - Project Management Team and subcommittees
 - Consensus decision making where possible (80% comfortable rule)
- Communication intentional, inclusive
 - Monthly meetings of PMT, weekly meetings of subcommittees, overlapping membership
 - Communication via telephone, e-mail

Organizational Structure of Research Team



Constraints Created by Project Timeline

Background research	Jan-Feb 03
Focus groups	Feb 03
Sample drawn	Feb 03
Instrument development	Feb-June 03
Survey translation	June 03
Data collection	July-Sep 03
Data cleaning, weighting	Sep 03
Data analysis/reporting	Sep-Nov 03
Final report submitted	Dec 03



7

Survey Development

- **Mixed mode survey administration:**
 - English only for mail version
 - Translated for telephone follow-up: English, Spanish, Somali, Hmong
 - Face page included instructions in all 4 languages and phone numbers for those wishing to complete phone survey
- English survey created by full mono- and bi-lingual PMT
- Focus groups informed survey content – not as much as some would have liked
 - Essential to have clear project goals



8

Survey Content Expanded

- Sources of preventive care (turn to for help to keep from getting sick)
 - Expanded response categories beyond doctor or clinic
 - Spiritual or traditional healer, shaman
 - Chiropractor
 - Acupuncturist or herbalist
 - Beliefs: “To what extent do you agree or disagree with the following statement: There is little doctors can do to keep you from getting sick?”
- Discrimination
 - Addition of class-oriented item-- Being enrolled in a Minnesota Health Care Program such as Medicaid, Medical Assistance or MinnesotaCare
- Barriers
 - Worry about going to the doctor or clinic for a check-up because you might get bad news
- Confidence in providers– afraid their provider:
 - may not do enough to find out what is really wrong
 - may deliver care that makes them feel worse
 - tell them they have an illness they do not really have
 - fail to find an illness they do have



9

Conceptual Equivalence and Translation Quality

- Bi-lingual members participation in design of English survey ensured conceptual equivalence and quality of translation
- Two major problems in all 3 languages:
- Translations too literal
 - Spanish: “Indian Health Center” word for “Indian” that could be confused with “from India” instead of American Indian
 - Hmong: “tus kws kho mob” (the one who cures diseases) instead of “doctor” which is term used
 - Errors
 - Spanish back translation yielded “*It could be said...*” instead of “*Would you say...*” [response options]. For example “In general, how would you rate your overall health? *Would you say* it is excellent, very good, good, fair or poor?”
 - Hmong language-- multiple ways of saying “Yes/No” and the response code selected must correspond to the question asked. Sometimes instead of using “Yes/No” the equivalent of “I believe/do not believe,” or “can do/cannot do,” (Pab, Txhawj, Ua Tau, Mus, etc) is more appropriate.
 - Somali translation yielded inappropriately “loaded” phrasing of questions or simply did not capture meaning of question.



10

Survey Administration

- Bi-lingual PMT members participated in recruitment, hiring, training and monitoring of interviewers
 - A first for the survey center
- Sample drawn February
- Survey fielded April – July 2003
 - Delayed entry in urban American Indian community
- Initial mailing to 9,350 enrollees
 - De-duplication at household level
 - All ages, with parent responding for sampled child



11

Response and Cooperation Rates (overall response rate 54% AAPOR RR4)

Stratum	Target	Completes			Lower response rate	Lower Coop. rate
		Mail	Phone	Mail + Phone		
SRS	1400	1379	477	1856	63.0%	84.6%
American Indian	600	338	190	528	42.9%	80.7%
African American	600	354	227	581	46.7%	78.0%
Hispanic/Latino	600	324	339	663	54.5%	85.0%
Hmong	600	585	112	697	56.5%	70.3%
Somali	600	304	324	628	50.4%	75.0%

Total of 4,953 surveys completed



12

Dissemination and Potential for Impact

- Translation budget eliminated culturally relevant dissemination funds
- Continuing saga...
 - Medica “closing the loop” grant 2005-06
 - Community dialogue
 - Radio spots
 - American Indian and Latino newspapers
 - Community–Provider Forum: “Working Together to Achieve Results: Implementing Community Recommendations to Reduce Healthcare Barriers in Minnesota”
 - Third forum met April 27, 2007



13

Summary of Value Added Through Community Partnership

- Mail survey in English only (cost savings)
- Instrument design
 - Content of survey expanded
 - Accessible wording
 - Increased conceptual equivalence
- Quality of translations
- Quality of interviewing
 - Hiring and training of interviewers; resources for additional projects
- Relevance of interpretation, recommendations and dissemination



14

Lessons Learned in Two Areas

- Participatory process
 - Lose a little....gain a lot
 - Mistakes are the most important part
 - Conflict happens
 - Intentional communication allows us to build relationships, partnerships and most importantly TRUST
 - Sharing power challenges everyone
 - *Forward momentum* can help counter personal politics
 - Process is as important as product
- Survey research and policy community
 - No need to compromise methodological rigor
 - Improved quality and serves larger purpose—ownership and application of results versus subjects of research