

**Lessons from a PCORI Methods Project: Innovative Strategies to Engage**

**Minority Stakeholders in Research**

**SGIM Workshop Supplementary Materials**

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Thursday 4/24/2014 (3:30-5:00PM)

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# **Evaluating Methods to Engage Minority Patients and Caregivers as Stakeholders**

## **Abstract**

### **BACKGROUND**

For patient-centered outcomes research (PCOR) to address health care decision-making effectively and authentically, patients and caregivers must serve as stakeholders. The PCORI Methodology Committee's Report prioritized research on methods to engage patients, especially from hard-to-reach or underserved groups.

### **OBJECTIVES**

This stakeholder engagement methods study has two objectives;

- 1) To conduct a mixed methods study of two widely used non-probability sampling methods to recruit minority patients and caregivers as stakeholders.
- 2) To develop and broadly disseminate an evidence-based protocol for patient stakeholder engagement that reflects the results of this mixed-methods study.

### **METHODS**

The framework for our patient stakeholder engagement study is adapted from Jeffrey's Road Map to Meaningful Engagement for business and society. Within this framework, we will compare two widely used sampling methods to recruit minority subjects from two similar communities (Frio and Karnes Counties, TX), using one method per county. In Frio, patients and caregivers will be recruited by respondent-driven sampling (RDS), a chain referral process where participants recruit others in their social network. In Karnes, purposive sampling (PS) will target recruitment based on analyzing national and local data about the community to engage stakeholders from diverse community constituencies. A community advisory board (CAB) in each county will guide stakeholder recruitment.

Our exemplar PCOR topic for stakeholder discussion is improving care options and decision making by persons with chronic low back pain (CLBP). From each county, we will recruit 65 Hispanic patients aged 40-75 with chronic musculoskeletal pain or their caregivers (total 130). They will be oriented and educated about CLBP from videotaped patient testimonials and an interactive web- and mobile app-based program. At meetings using structured group processes, stakeholders will brainstorm, rate, and categorize concepts/ideas about research addressing care and decision making about CLBP. Mixed methods analyses structured by the RE-AIM model will compare the two sampling methods regarding: 1) staff resources/time, 2) representativeness, 3) stakeholder experience, 4) concept mapping of stakeholders' concepts/ideas, and 5) ratings of potential importance and feasibility of concepts/idea on an Internet survey of representative sample of 400 Hispanic adults in Texas. We will develop and disseminate a protocol handbook summarizing our framework for patient engagement and the findings from our analysis to serve as a key resource for PCOR.

## **Links to Project Materials**

Patient Video: <http://youtu.be/gJ536Z-6loQ>

Provider Video: <http://youtu.be/HOBZI2m63qw>

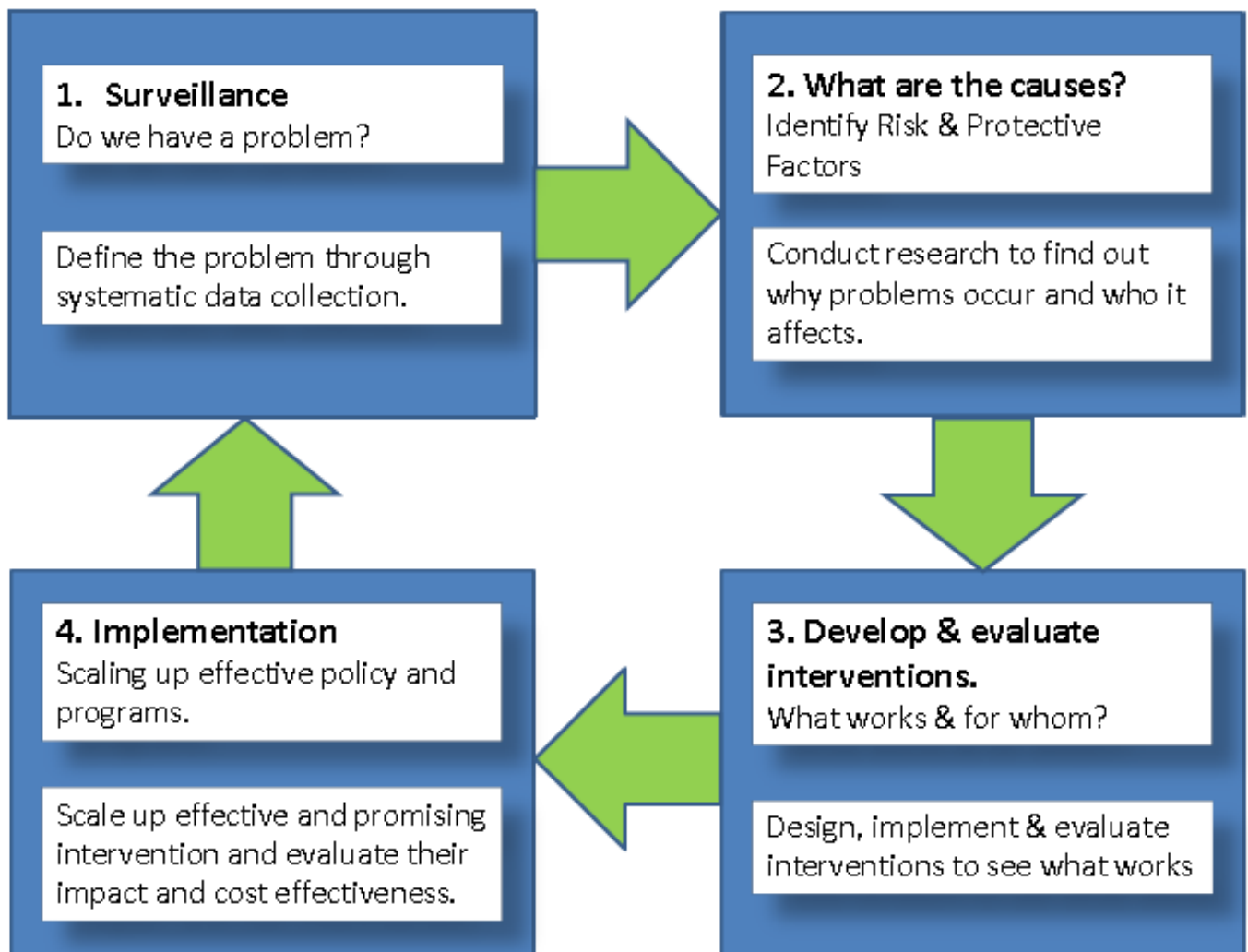
Jeffery's Road Map to Meaningful Engagement:

<http://www.som.cranfield.ac.uk/som/dinamic-content/media/CR%20Stakeholder.pdf>

Asset Mapping Toolkit:

<http://hdanielsduncanconsulting.org/pdfs/Asset%20Mapping%20Toolkit.pdf>

## WHO Public Health Approach



WHO Regional Committee for Europe resolution. EUR/RC55/R9 Prevention of injuries in the WHO European Region. Copenhagen, WHO Regional Office for Europe, 2005. <http://www.euro.who.int/en/home>, accessed March 2013).

## Key Points from Recent Publications about Minority/Low-Income Recruitment Strategies

Key themes relevant to low income, minority subject recruitment strategies from selected recent publications:

- A. Establish a trusting community-academic partnership, study the community – locally visible site for project and a community advisory board
  - a. References: 2, 5
- B. Employ recruiters from the same community/cultural background reviewing messages with the community to be sure culturally appropriate; minority (“cultural insider”) investigators
  - a. References; 1, 2, 3, 5
- C. Recruitment in subjects’ preferred language
  - a. References: ALL
- D. Active recruitment in community settings
  - a. References: 1, 2, 3
- E. Recruitment through relatives and friends
  - a. References 1, 2, 3
- F. Informational workshops/multiple personal contacts to about the topic; improved communication about concordance between community goals and motivations and investigators’ goals and motivations
  - a. References 1, 2, 3, 5
- G. Value for community and/or family (altruism)
  - a. References 3, 4
- H. Personal gain in knowledge or health care
  - a. Reference 4
- I. Supportive staff
  - a. Reference 1, 4
- J. Convenient safe location with support for children if needed
  - a. Reference: 3, 4
- K. Compensation
  - a. Reference: 4
- L. Informed consent process – low literacy, explained well, balanced, time to review
  - a. Reference: 4
- M. Long-term committmenet
  - a. Reference: 5

### Annotated References

1) *de la Torre A, Sadeghi B, Green RD, Kaiser LL, Flores YG, Jackson CF, Shaikh U, Whent L, Schaefer SE Niños Sanos, Familia Sana: Mexican immigrant study protocol for a multifaceted CBPR intervention to combat childhood obesity in two rural California towns. BMC Public Health. 2013 Oct 31;13:1033. PMID: 24172250*

- a. Suggested recruitment settings:
  - (1) door-to-door recruitment
  - (2) meet and greet events,
  - (3) one-on-one/personal networks,
  - (4) school events (back to school nights, child pick up drop off intervals), (5) parent teacher meetings,
  - (6) open market or *remate* informational booths,
  - (7) community events (e.g., Day of the Dead, Red Ribbon Week),

- (8) religious organizations, and
  - (9) community health fairs.
  - b. Challenge - Lack of space in the community so project staff use space available from local organizations such as churches and the community center.
- 2) Farquhar S, de Jesus Gonzalez C, Hall J, Samples J, Ventura S, Sanchez V, Shadbeh N J  
*Recruiting and Retaining Indigenous Farmworker Participants. Immigr Minor Health. 2013 Jun 4. [Epub ahead of print]. PMID: 24172250*
- a. Recruitment strategies included:
    - (1) consulting with indigenous relatives and friends about potentially eligible workers that they know,
    - (2) consulting with members of the Community Advisory Committees, that were formed as a way to gather farmworker input,
    - (3) meeting with indigenous leaders from hometown associations in countries of origin,
    - (4) talking with community partners, interpreter training participants, and former participants in other projects,
    - (5) contacting current participants to see if they knew additional eligible workers.
  - b. Challenges - Techniques that did not yield many participants included an ad on local Spanish-language station and door-to-door knocking, time consuming and not very effective.  
 Developing trust very slow - the multiple recruitment sites and strategies
- 3) Yancey AK, Ortega AN, Kumanyika SK. *Effective recruitment and retention of minority research participants. Annu Rev Public Health. 2006;27:1-28. PMID: 16533107.*
- a. Major barriers to recruitment that, if addressed appropriately, facilitate recruitment:
    - (1) distrust toward and perceptions of the scientific and medical community, particularly among African Americans;
    - (2) local recruitment sites (churches);
    - (3) lack of knowledge and perceptions of prospective participants;
    - (4) prospective participant psychosocial issues such as self-efficacy, depressiveness, distress, hostility, social support; and readiness to change;
    - (5) study incentives and logistics;
    - (6) community involvement;
    - (7) participant beliefs, e.g., religiosity;
    - (8) cultural adaptations or targeting.
  - b. Facilitator - Utility of community involvement by project staff or using community-based organizations as intermediaries was nearly universally cited as critical
- 4) Kost RG, Lee LM, Yessis J, Coller BS, Henderson DK; *Research Participant Perception Survey Focus Group Subcommittee. Assessing research participants' perceptions of their clinical research experiences. Clin Transl Sci. 2011 Dec;4(6):403-13. PMID: 22212221.*
- a. Selected points – key reasons for participation from focus groups of mostly Whites and African Americans  
 Main incentives by order of priority
    - 1) Altruism
    - 2) Study topic relevant to the individual's health or the health of family/friends
    - 3) Anticipated learning about science, research or health topics from participation
    - 4) Access to new therapies
    - 5) Financial compensation
    - 6) Free healthcare
    - 7) Researchers enrolled as research participants
    - 8) Family influence
    - 9) Commitment to volunteerism
    - 10) Previous positive experience with investigator/staff

5) Greiner KA, Friedman DB, Adams SA, et al. *Effective recruitment strategies and community-based participatory research: community networks program centers' recruitment in cancer prevention studies. Cancer Epidemiol Biomarkers Prev. 2014 Mar;23(3):416-23. PMID: 24609851.*

a. All studies emphasized the following principles:

- 1) define and recognize the community as a distinct identity,
- 2) build on the unique strengths and resources within entity,
- 3) facilitate collaborative, equitable partnerships in all research phases in a manner consistent with equitable sharing of power to reduce social inequalities,
- 4) engage communities in learning and capacity building,
- 5) achieve the balance between generating data and intervening in a way that is mutually beneficial to both the community and academic partners,
- 6) focus on the local relevance of public health problems and a recognition of multiple determinants of health,
- 7) develop systems in a cyclical and iterative manner,
- 8) put in place plans to disseminate results to all those involved,
- 9) commit to long-term process related to sustainability

6) George S, Duran N, Norris K. *A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Pub Health. 2014 Feb;104(2):e16-31. PMID: 24328648.*

a. Priority list of barriers from systematic review of 44 studies:

- 1) Mistrust (esp African Americans);
- 2) Competing demands; time and financial constraints
- 3) Unintended outcomes
- 4) Poor access to information – including language barriers, misperceived risk
- 5) Stigma
- 6) Health insurance companies – from disclosure of disease
- 7) Legal status

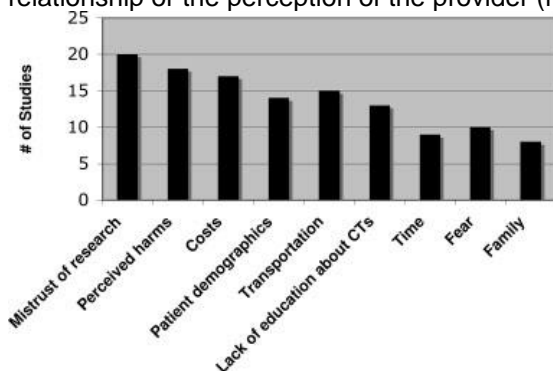
b. Priority list of facilitators

- 1) Cultural congruence of research staff, cultural and language
- 2) Benefits – mild monetary incentive, free health care, free food, education about disease
- 3) Altruism including advancing medical knowledge
- 4) Convenience of participation – employer support to take time off to attend appointments, childcare, and transportation provisions.
- 5) Low risk – regarding discomfort or invasiveness

7) Ford JG, Howerton MW, Lai GY, et al. *Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. Cancer. 2008 Jan 15;112(2):228-42. PMID: 18008363.*

Barriers to enrollment in clinical trials from 45 studies

Qualitatively, the most frequently reported barriers to acceptance of participation were mistrust of research and the medical system (n 5/ 20 studies), direct and indirect costs of participation (n 5 /17 studies), transportation (n 5 /14 studies), time commitment (n 5/ 10 studies), fear (n 5/ 9 studies), family considerations (n 5/ 8 studies), and factors related to the patient-provider relationship or the perception of the provider (n 5/ 10 studies).



**Results of Asset Mapping of Two Counties (Karnes and Frio, Texas)**

<b><u>Race/Ethnicity</u></b>	<b><u>% in Karnes</u></b>	<b><u>% in Frio</u></b>	<b><u>% in TX</u></b>
White alone	88.2%	92.1%	80.6%
Black or African American alone	9.9%	3.9%	12.3%
American Indian and Alaska Native alone	1.0%	0.8%	1.0%
Asian alone	0.3%	2.3%	4.2%
Native Hawaiian and Other Pacific Islander alone	-	-	0.1%
Two or More Races	0.6%	0.9%	1.7%
Hispanic or Latino	50.5%	78.3%	38.2%
White alone, not Hispanic or Latino	39.4%	15.8	44.5%

**Educational Attainment**

	<b><u>Karnes County Estimate</u></b>	<b><u>Pearsall County Estimate</u></b>
Population 25 years and over	10,401	10,787
Less than 9th grade	12.8%	18.4%
9th to 12th grade, no diploma	16.1%	18.8%
High school graduate (includes equivalency)	36.1%	32.8%
Some college, no degree	18.4%	18.9%
Associate's degree	6.1%	2.8%
Bachelor's degree	7.7%	6.0%
Graduate or professional degree	2.8%	2.2%
Percent high school graduate or higher	71.1%	62.8%
Percent bachelor's degree or higher	10.5%	8.2%

**Websites used to gather demographic data:**

[http://www.city-data.com/county/Frio\\_County-TX.html](http://www.city-data.com/county/Frio_County-TX.html); <http://quickfacts.census.gov/qfd/states/48/48163.html>; <http://www.co.frio.tx.us/>;  
[http://www.city-data.com/county/Karnes\\_County-TX.html](http://www.city-data.com/county/Karnes_County-TX.html); <http://quickfacts.census.gov/qfd/states/48/48255.html>; <http://www.co.karnes.tx.us/>



### Economic Characteristics

	Frio County		Karnes County	
<b>OCCUPATION</b>				
Civilian employed population 16 years and over	6,299	6,299	4,768	4,768
Management, business, science, and arts occupations	1,045	16.6%	1,443	30.3%
Service occupations	1,880	29.8%	902	18.9%
Sales and office occupations	1,578	25.1%	1,160	24.3%
Natural resources, construction, and maintenance occupations	993	15.8%	674	14.1%
Production, transportation, and material moving occupations	803	12.7%	589	12.4%
<b>INDUSTRY</b>				
Civilian employed population 16 years and over	6,299	6,299	4,768	4,768
Agriculture, forestry, fishing and hunting, and mining	648	10.3%	451	9.5%
Construction	602	9.6%	384	8.1%
Manufacturing	79	1.3%	297	6.2%
Wholesale trade	158	2.5%	75	1.6%
Retail trade	900	14.3%	573	12.0%
Transportation and warehousing, and utilities	451	7.2%	278	5.8%
Information	0	0.0%	28	0.6%
Finance and insurance, and real estate and rental and leasing	190	3.0%	275	5.8%
Professional, scientific, and management, and administrative and waste management services	543	8.6%	216	4.5%
Educational services, and health care and social assistance	1,245	19.8%	1,175	24.6%
Arts, entertainment, and recreation, and accommodation and food services	519	8.2%	302	6.3%
Other services, except public administration	120	1.9%	211	4.4%
Public administration	844	13.4%	503	10.5%
<b>CLASS OF WORKER</b>				
Civilian employed population 16 years and over	6,299	6,299	4,768	4,768
Private wage and salary workers	4,475	71.0%	3,108	65.2%
Government workers	1,366	21.7%	1,284	26.9%
Self-employed in own not incorporated business workers	446	7.1%	370	7.8%
Unpaid Family Members	12	0.2%	6	0.1%

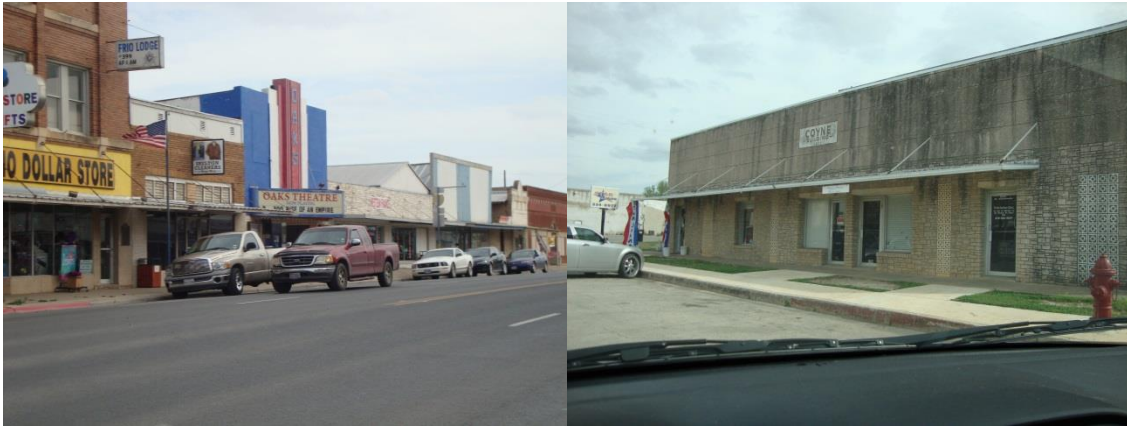
Website used to gather data on workforce:

[http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_12\\_5YR\\_DP03&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_5YR_DP03&prodType=table)

**Windshield Survey of Two Counties**

<b>Assets</b>	<b>Total in Karnes</b>	<b>Total in Pearsall</b>
Churches	11	7
Colleges/Universities	0	0
Elderly Care Facilities	3	2
Police Department	1	1
Fire Department	1	1
Animal Hospital	1	1
Nursing/Rehab Center	2	2
Hospitals and Clinics	4	16
Mental Health Facilities	0	0
Library	1	1
Schools	5	5
Transportation	0	0
State	9	10
City	1	4
Local	1	1
Federal Government Agency	2	1
Economic Development (Farm Bureau)	1	1
Military Facility	0	0
SBA	0	0
State Education Agency	0	0
Telecommunications	1	1
Small and Large Business	48	157
Finance	7	11
Food Services (Restaurants)	4	15
Citizens groups/clubs	3	4
Radio/TV Agencies	1	1
Newspaper	1	1
Non-profit Organizations	1	2
Utility Companies	2	1
Park and Rec facilities	1	3
Real Estate Agency	3	2
Waste Management facilities	0	0
Chamber of Commerce	1	1
Historic/Arts Council groups	1	1
Council for Cultural Affairs	0	0
Tourism	3	7
City Council	1	1
Museums	1	1
Entertainment	0	1

**Photographs of Two Counties**  
***Frio County***



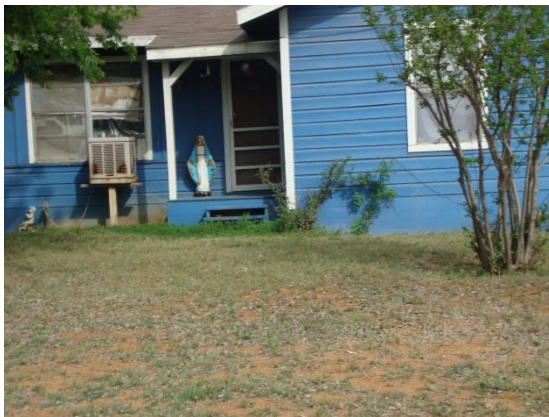
**Downtown Pearsall, TX**



**Pearsall Pioneer Park**



**First United Methodist Church**



**Residential Area Pearsall, TX**

**Karnes County**



**Residential Area**



**Local Dance Hall**



**Downtown Karnes City, TX**



**Eagle Ford Shale Site**