

Creating Partnerships to Improve Health: An Overview of Community-based Participatory Research.

Debbie Salas-Lopez MD, MPH

Lehigh Valley Health Network, debbie.salas-lopez@lvhn.org

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Creating Partnerships to Improve Health: An Overview of Community-based Participatory Research

Debbie Salas-Lopez, MD, MPH, FACP
Chief, Division of General Internal Medicine
Vice Chair of Medicine

Overview

- Community based participatory research and its appropriate use
- Culture, cultural competency, impact on clinical practice
- Case Examples relevant to researchers working with diverse populations
- Ethical issues important to the conduct and dissemination of research

Community Based Participatory Research

- Community based research that directly involves the community in every aspect
- Provides an opportunity for input as partners, not just subjects
- Uses the knowledge of the community to understand health problems and then design activities to improve health
- Connects community members directly with how the research is done and what comes out of it.

Community Based Participatory Research

Provides direct benefits from the results of the research to the community that participated in the study



Community members are also involved in getting the word out about the research and promoting the use of the findings

Why Research Had to Change

- In traditional research, the community is not actively involved in designing the project.
- Often, when these projects run into problems – for example, the project took too long or costs too much money- community members, who gave their time and energy were left without information or findings that could benefit the community.
- Over time, the community became less involved.

**“To Be Effective, Researchers
Need Feedback from the
Community”**

“You can’t fix people, you have to
work with people”

Community Participatory Research “An Engaged Institution”

- The Kellogg Commission Report asks that we “organize our outreach, service, and research into “engagement.”
- Engagement refers to institutions that design research, to become *even more* sympathetically and productively involved with their communities, however community may be defined.
- Embedded in the engagement “ideal” is a commitment to sharing and reciprocity – two-way streets.

Defining the “Engaged Institution”

- 1. Responsiveness. We need to ask ourselves periodically if we are listening to the communities, regions, and states we serve.
- 2. Respect for partners. The purpose of engagement is not to provide the institution’s superior expertise to the community, but to encourage joint academic-community definitions of problems, solutions, and definitions of success.
- 3. Academic neutrality. Of necessity, some of our engagement activities will involve contentious issues.
- 4. Accessibility. Our institutions are confusing to outsiders. We need to find ways to help inexperienced potential partners negotiate this complex structure so that what we have to offer is more readily available.

Defining the 'Engaged Institution'

- 5. Integration. Our institutions need to find ways to integrate the service mission with their responsibilities for developing intellectual capital, financial growth, and research.
- 6. Coordination. A corollary to integration, the coordination issue involves making sure the left hand knows what the right hand is doing.
- 7. Resource partnerships. Engagement is not free – it costs. The most obvious costs are those associated with the time and effort of staff. But they also include program costs and must take into account the limitations of the institution.

Future of Community Based Participatory Research

- Provides for a better understanding of the growing needs of our communities for clinical care, education, and research.
- Can only be done if we work in true partnerships including financial rewards and educational gains for our community partners
- Will be the **only** approach for research in the near future.

Q: What will we need to know about CBPR to be successful?

A: Know your Community!

Community

- Not just a collection of houses; it is a “sociological construct.”
- There may be communities within larger communities.
- Communities have social and cultural components.

What do we mean by Culture?

Refers to the unifying beliefs of any group of people of similar religion, values, attitudes, ritual practices, family structures, language, and/or mode of social organization

What does being Culturally Competent mean?

“The ability of systems to provide care to patients with diverse values, beliefs and behaviors including tailoring services (research) to meet patients’ social, cultural, and linguistic needs.”

The Commonwealth Fund. New York, NY, 2002

How can we be more Culturally aware?

Cultural awareness is the deliberate, cognitive process in which health care providers become appreciative and sensitive to the values, beliefs, lifeways, practices, and problem solving strategies of a patient's culture.

Cultural Skill

Cultural skill is the ability to collect relevant cultural data regarding patients' health histories

Case Example

- Patient is African-American and has been in the New Jersey area for four years. She is originally from Georgia.
- She was depressed and concerned since this was the fourth time she had been hospitalized in the last year.

Case Example

- Patient was found to be extremely anemic – multiple work-ups were negative and was approached for a clinical trial.
- She first wanted answers to why she was always found to be anemic and still had no clear diagnosis.
- Patient was asked, “What is a day in your life like?”

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Case Example

- A 42 year old Peruvian woman was referred for uncontrolled hypertension and headaches.
- She had been to 4 other physicians and was on multiple medications without significant improvement.

Cat Claw

the bark of a tree that
grows in the Andes
Mountains
used for many
conditions



Andes Mountain Range



Q: Why is this important for Research?

A: It provides better quality of care and
better quality of research

Quality Research

- Researchers who know their community well:
- Are prepared to work with every aspect of the community in an ethical manner.
- Understand the cultural and social aspects such as literacy levels, language preference.

Language: National Facts and Figures

- Approximately 14% (32 million) of the US population speaks a language other than English at home.
- Immigration patterns have changed so that 15% are European, 37% Asian, and 44% are of Latino Countries.
- Foreign born population now over 28 million – Latinos currently the largest minority in the nation.

Inadequate Communication

- Greater risk of hospital admissions.
- Higher resource utilization for diagnostic testing.
- Longer medical stays.
- Potential for patient misunderstanding of diagnoses, medications, and follow up.

Inadequate Communication

- Greater risk of disease complications.
- Increased risk of drug complications.
- Significant threat to patient safety.
- Compromises high quality of care and research.
- Lower patient satisfaction.

Using Interpreters in Research

- Promotes accurate diagnoses.
- Reduces medical errors.
- Increases compliance / adherence.
- Facilitates patient-provider understanding.
- Improves access to care.
- Promotes informed consent.
- Increases satisfaction and trust.
- Promotes equality.

Other Sociocultural Aspects

- Level of acculturation of subjects.
- Within group differences of ethnic groups.
- Response bias to healthcare providers.
- Health literacy levels.
- Many social determinants of health.

For Present Day Researchers

"Not everything that can be counted counts, and not everything that counts can be counted."

Albert Einstein