Engaging Health Centers in Community Based Participatory Research to Improve Health Outcomes

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Health Forum
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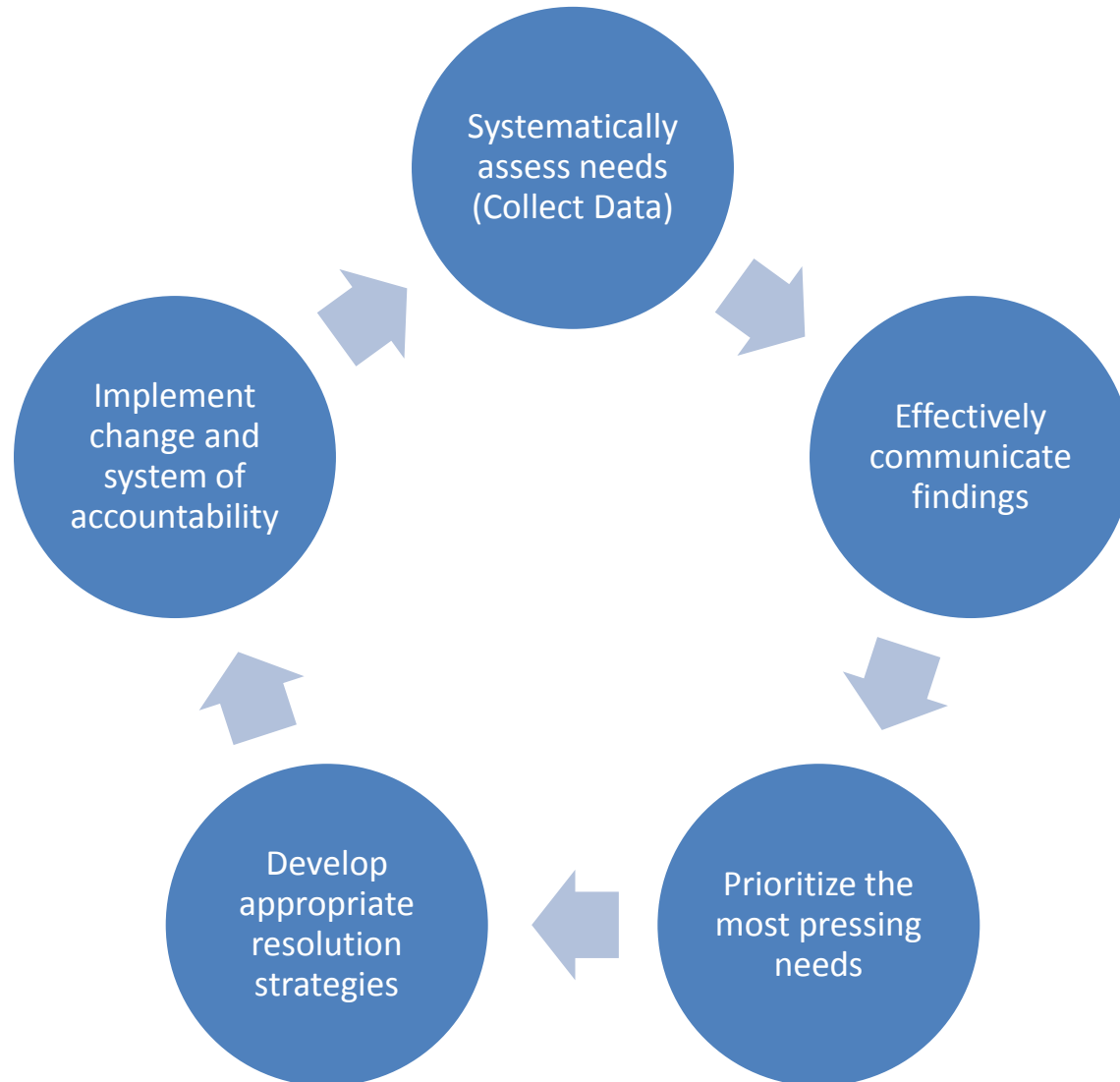Sylvia Partida

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Objectives

- Define community based participatory research and its impact on health outcomes
- Describe how community based participatory research provides patients and communities a voice in research design, conduct and use of findings
- Identify the roles of community, health care and academic partners in community based participatory research that protects patient confidentiality
- Promote the support of CBPR by boards and stakeholders at Community Health Centers to engage in research.

Problem: U.S. Farmworkers Are At Risk
due to…

- the disproportionately high frequency of injuries and illnesses associated with their work

- significant barriers to healthcare access

- lack of data to assess needs and improve the health of farmworkers and their families

Solution: Reduce Risk and Improve Farmworker Health

What Is Health Research?

- Research is a method of acquiring new knowledge

- Health research makes discoveries about how to improve health

- Health researchers collect data from
  - Patient health records and registries
  - Interviews, surveys, lab tests

Health Research Ethics:
A Checkered History

- We need new ways to build and conduct research
  - In past, research has harmed communities
  - Approaches researchers use feel like: research "on" a community not "with" a community
  - Benefit of research to communities is not usually recognized and is rarely seen as leading to change

- Distrust and reluctance to participate in research

Improved Ethics and Accountability
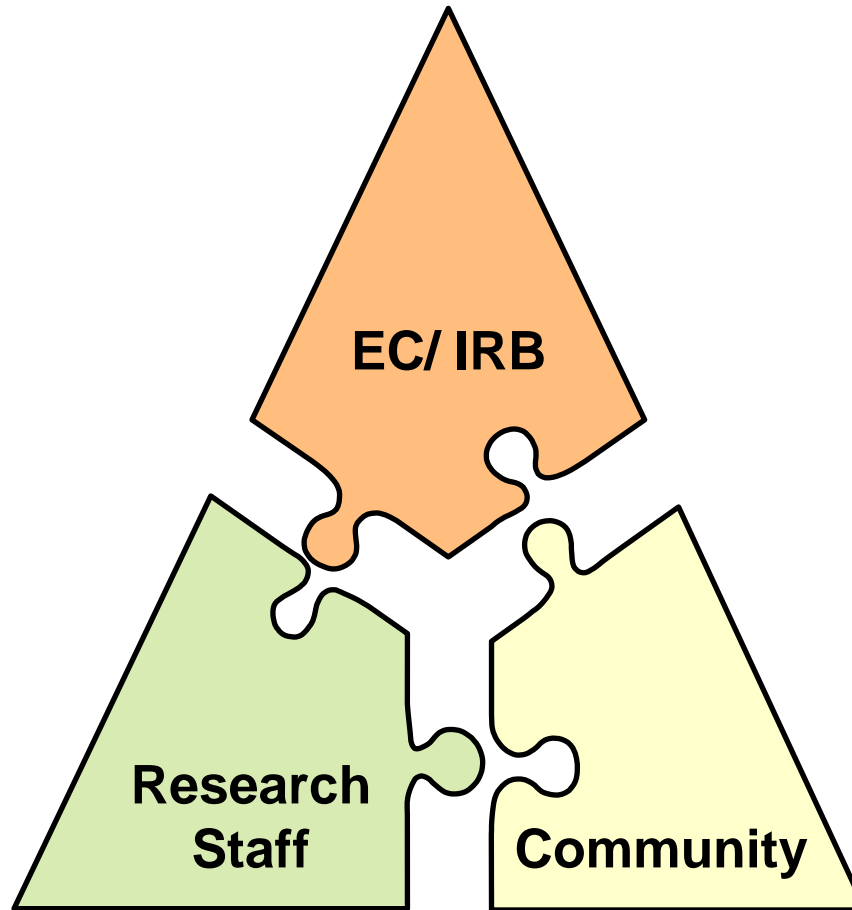## *Today's Broad Spectrum Engages the Community*

- Investigator-initiated Research
  with Institutional Review Board (IRB) Oversight to Protect Human Subjects

- Investigator-initiated Community Based Research
  with Community Partners

- Community-initiated Research

Community Based Participatory Research (CBPR)

CBRN Partners: the Model

The Community Based Research Network (CBRN) Mission

Contribute infrastructure to *improve migrant farmworker health* through. . .

- A ***National Consortium*** of Community/Migrant Health Centers
- A ***National Steering Committee***
- A ***National Advisory Committee***
- A ***National Farmworker Clinical Research Database***

CBRN Community/Migrant Health Centers & Advisory Committee

- InterCare Community Health Network, Bangor MI
- Salud Family Health Centers, Fort Lupton CO
- Finger Lakes Community Health, Penn Yan NY
- Columbia Basin Health Association, Othello WA
- Clinicas del Camino Real, Ventura CA

Health Research Responsibilities

- Protect every individual involved as a research subject or participant

- Conduct research according to the fundamental ethical principles

- Use the best possible scientific methods

- Obtain appropriate informed consent or waiver of authorization

- Respect confidentiality

Health Research Responsibilities

- Conduct research according to protocol

- Ensure compliance with all IRB requirements

- Provide assistance as agreed in the protocol

- Support long-term interests of participants/communities after the study

- Communicate the findings of the study

Community Representatives and the Dissemination of Research Findings

- Track completion of major milestones
- Help identify appropriate communication modes/media for progress and final reports to the community
- Provide feedback on drafts of progress and final reports
- Help distribute reports to interested participants and community leaders

Community-Based Participatory Research

- A partnership approach designed to addresses community concerns:
  - Equitably involves community members, organizational representatives, and academic researchers in all aspects of the research process.
  - All partners contribute expertise with shared responsibility and ownership.
  - Enhances understanding of a given phenomenon.
  - Integrates knowledge gained with action.

–Israel, Schulz, Parker, and Becker, 1998

Community-Based Participatory Research

Eight Principles:

1. Recognizes community as a unit of identity.

2. Builds on community strengths and resources.

3. Promotes collaborative and equitable partnerships.

4. Facilitates co-learning and capacity building.

–*Israel, Schulz, Parker, Becker, Allen, and Guzman, 2008*
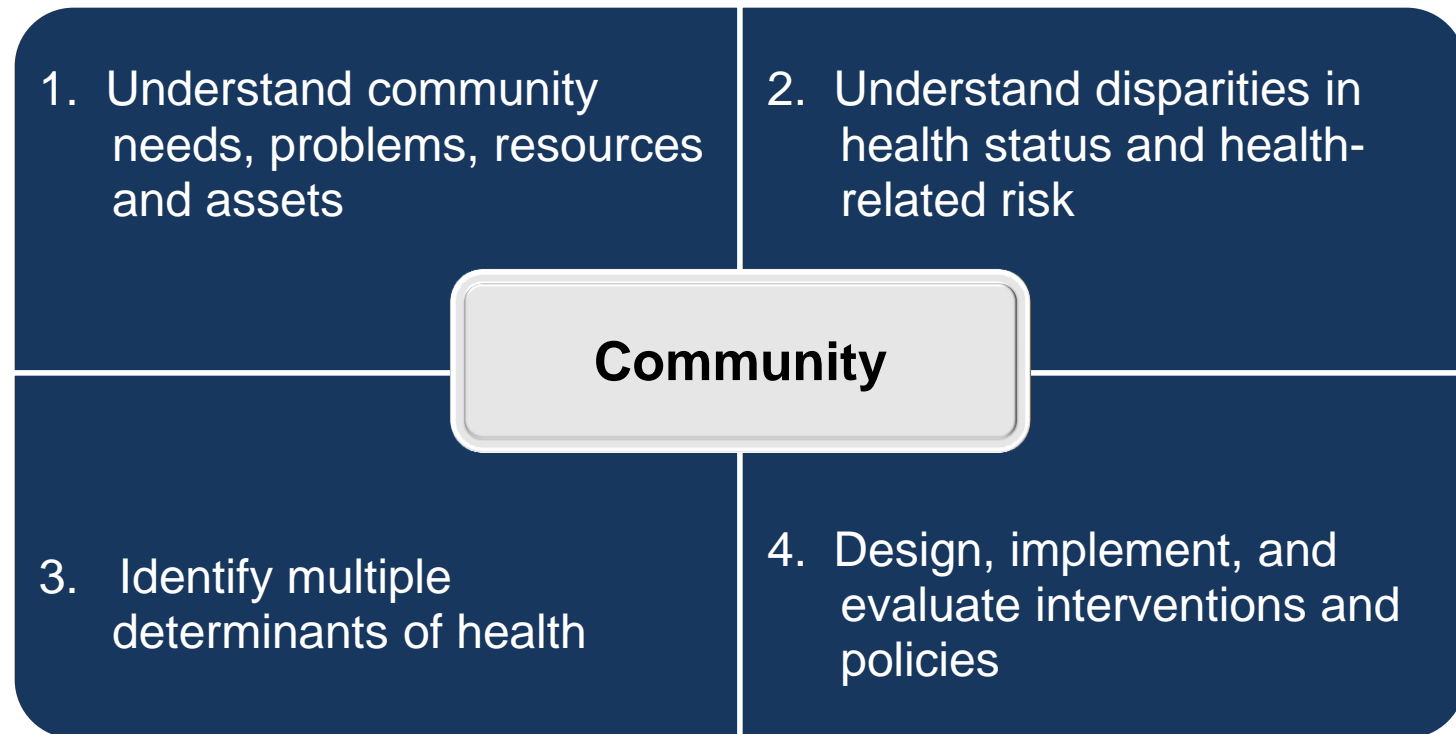
Community-Based Participatory Research

Eight Principles:

5. Balances research and action for mutual benefit of all partners.

6. Focuses on determinants of health from a local standpoint within ecological approach.

7. Disseminates findings to all partners and involves them in the dissemination process.

8. Promotes long-term process and commitment to sustainability.

–*Israel, Schulz, Parker, Becker, Allen, and Guzman, 2008*

Community-Based Participatory Research

What can CBPR do for communities?

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1. Understand community needs, problems, resources and assets

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2. Understand disparities in health status and health-related risk

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Community

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3. Identify multiple determinants of health

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4. Design, implement, and evaluate interventions and policies

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Israel, Schulz, et al., Detroit Community Academic Urban Research Center

Community-Based Participatory Research

Community engagement in:

- Pinpointing the problem to be studied

- Discussion of the research design decisions

- Determining if an intervention or policy change component is to be included

- Designing the intervention/policy change

- Co-authors of papers/make presentations

- Distribution and use of the results

Community-Based Participatory Research

Ways a CBPR approach gets off the ground?

- May grow out of a prior collaboration

- Identified common interest or issue

- Funding opportunity

- Initiated by a community or academic partner

✋ *Assess the appropriateness of CBPR for the issue and the community*

Community-Based Participatory Research

What does a community using a CBPR approach look like? Usually something in common:

Language

GOALS

Experiences

Problems

Beliefs

Interests

VALUES

Community-Based Participatory Research

Building a Partnership

- Selecting partners and understanding roles

- Guidelines for developing & facilitating partnership

- Selecting health issues

- Identifying community assets

- Supporting partnership infrastructure for sustainability

Time and commitment

Community-Based Participatory Research

Building a Partnership

- Define community and who represents the community

- Start small, involve a few highly regarded community-based organizations

- Involve diverse set of partners representative of communities involved and serving

Community-Based Participatory Research

Identifying Priorities – Establish Criteria for Selecting Health Issue

- Does the community recognize and feel the issue is significant and will work to address it?

- Does the partnership have expertise in this area? If not, should the partnership bring in a new partner?

- Would the partnership be able to engage in activities to promote change?

- Will the issue help move the community toward its overall vision of a healthy community?

Community-Based Participatory Research

Research

- Plan and conduct rigorous research
- Terminology and partnering to improve research

Dissemination

- Distribution of research findings to community and other audiences

Translation

- Use of key findings to develop future research studies, interventions and policies
- Improving clinic practices and advancing understanding of health needs of communities

Engagement in research to promote health outcomes

- Approaches for the design and conduct of more appropriate research should:
  - Address ethical standards
  - Incorporate IRB reviews and processes
  - Build partnerships around CBPR
  - Commitment to dissemination and translation of findings

Community Based Participatory Research and Health Outcomes

- Examples of projects that work:
  - The Community Health and Social Services (CHASS) Center, Inc. – Detroit, MI
  - type 2 diabetes education
  - Community Health Workers
  - Walking groups and fitness
  - Consent forms and Institutional Review Boards
  - Data collection, analysis and reporting

Community Based Participatory Research and Health Outcomes

- CBRN and health outcomes:
  - Collaborating to improve health systems
  - Delivery and priority to address most important community needs
  - Building capacity and partnerships
  - Sustainable changes – patient portals and EHRs

Additional Resources

- **For CBRN questions or to volunteer and get more involved**
  Contact: Firstname Lastname
  Email: **Phone:**
  Address:
- Family Health International, Research Ethics Training
http://www.fhi360.org/sites/all//libraries/webpages/fhi-retc2/index.html
- Enhancing the quality and transparency of health research
http://www.equator-network.org
- Public Responsibility In Medicine & Research
http://www.primr.org/
- Belmont Report educational video (key research ethics history)
http://www.youtube.com/watch?v=W7sfIA1dIGQ