Engaging Health Centers in Community Based Participatory Research to Improve Health Outcomes
Community Based Research Network (CBRN) Team

**Academic Health Center**

[UTHealth](http://www.uthealth.edu)

*Multiple PI*

**Ed Hendrikson**

**Multiple PI**

**Sharon Cooper**

Co-Investigators
Deborah del Junco
Melissa Valerio
Kristi Whitworth

**Graduate Assistants**
Christina Socias,
Nicole Henry, Alex Zottarelli

**Community Based Research Network (CBRN) Team**

**Multiple PI**

**Bobbi Ryder**

Community Research Associate
Co-Investigator
Sylvia Partida

**Multiple PI**

**Eva Shipp**

**Consultant**
Jeff Levin
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

Systematically assess needs (Collect Data)

Effectively communicate findings

Prioritize the most pressing needs

Develop appropriate resolution strategies

Implement change and system of accountability
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

- EC/IRB
- Research Staff
- Community
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?

1. Understand community needs, problems, resources and assets
2. Understand disparities in health status and health-related risk
3. Identify multiple determinants of health
4. Design, implement, and evaluate interventions and policies

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:

- Goals
- Language
- Experiences
- Beliefs
- Interests
- Values
- Problems
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

- Enhancing the quality and transparency of health research
  [http://www.equator-network.org](http://www.equator-network.org)

- Public Responsibility In Medicine & Research

- Belmont Report educational video (key research ethics history)
  [http://www.youtube.com/watch?v=W7sfIA1dIGQ](http://www.youtube.com/watch?v=W7sfIA1dIGQ)