

# Stakeholder Assessment in Community-Based Research

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# ACTRID Application Assumptions

- There are health disparities in the Appalachian region that affect all residents including minority group members.
- We do not know why.
- There is a need to improve university capacity through partnerships with communities to conduct research to determine reasons that may be unique to the region.

# Assumptions

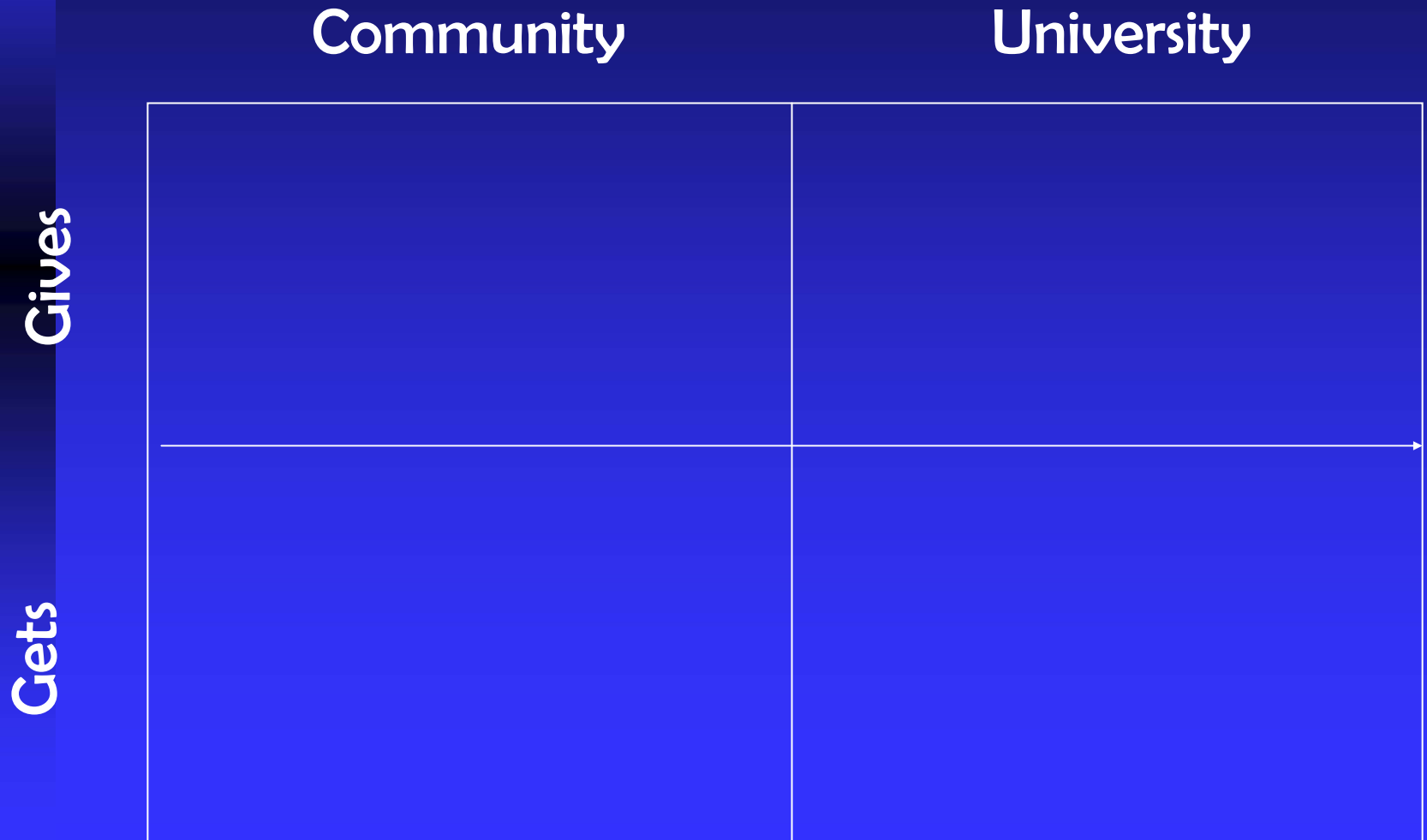
- Research is not a naturally occurring event in our region.
- This could lead to
  - ◆ Blind acceptance by communities with potential abusive relationships
  - ◆ Community rejection because of disinterest or concern over confidentiality or use of results
- Therefore it is important to recognize communities as stakeholders in research.

# Principles of Community-Based Participatory Research

- Recognize community as unit of identity
- Build on community issues, strengths and resources using broad definition of health
- Facilitate collaborative long term partnerships in all phases of research
- Integrate knowledge and actions of all partners
- Promote co-learning and empowerment process to address social inequalities
- Involve cyclical and iterative process
- Share findings with all partners

Israel presentation at ETSU, 2001

# Creating Stakeholder Interest: The ETSU Give-Get Model for Community Partnerships



# Community panel: Defining stakeholders and identifying their interests

- Issues in “representing ” a community
- What are your interests as an individual or member of a community regarding research?
- How can research be perceived to help or hurt communities like your own?

**After intent of research is  
established and negotiated...**

**Language and process become the  
biggest stumbling blocks**

# Your definitions of health literacy

And related health issues that result  
because of health literacy issues

# Health Literacy

- The ability to read, understand and act on health care information
- Does your patient/client understand what you are telling them?
- Inadequate health literacy skills may reduce an individual's ability to:
  - Access and navigate health care system
  - Make appropriate health care decisions
  - Appropriately act on health information

Claudette Dalton, UVA School of Medicine

# Community panel

- Examples of issues arising from health literacy issues in my community
- How can health literacy impact research?
- What can researchers do in recognizing health literacy to improve permission and participation?

# Low literacy skills have been linked to

- Hospitalizations
- Poor patient understanding
- Poor treatment compliance
- Underutilization of care and screening
- Advanced disease presentation
- Poor health outcomes

# Inadequate health literacy skills may reduce an individual's ability to

- Access and navigate health care system
- Make appropriate health care decisions
- Appropriately act on health information rural areas, especially in the South, have greater burden of low literacy
- Low literacy may impact use of cancer screening or cause a delay in obtaining appropriate care
- Knowledge of cancer screening and early detection is often imparted through written materials and physician interaction
- Patients with low literacy skills may not being able to:
  - a) read cancer materials
  - b) comprehend physician instructions
  - c) ask questions to physician

# Types of issues

- Functional (visual, hearing, neurological)
- Sensory/physical
- Cultural/language
- Psychological
- Computational

# Assessment Methods

Different methods to conduct research in community settings

# Community Assessment Methods

## Secondary Data Analysis

Collecting statistical indicators from published reports. Statistics are then interpreted to determine prevalence, characteristics, and implications of problem.

- +Reliable for generalizing events and behavior
- +Accepted indicators with associated events
- +Data is comparable with other communities and state
- +Less subject to question
- Reliability dependent on comprehensiveness of data
- Cannot assume cause and effect relationship
- Data available for collective groups, sometimes not specific enough

# Community Assessment Methods

## The Classical Approach

Using a panel of experts to gain insight concerning an issue. Experts may include representatives who interact with issue and have community wide view.

- + Gains varied viewpoints
- + Primary factors may be uncovered
- + Completed in short period of time
- Findings are intuitive, may not be statistically based
- Reliability of experts might be questions
- Information not generalizable

# Community Assessment Methods

Using standardized techniques to gain information directly by interviews, studies and surveying through questionnaires and observations.

## Primary Source Data

- + Information sought directly
- + Gain great specificity on individuals and communities
- + Information on users' perspectives about issues
- All the criticisms of survey research
- Expensive and time consuming
- Legalities of consent information

# Community Assessment Methods

## Community Meeting Approach

Accepting testimony about issues through public meetings in community.

Generally need to assure findings will be used for action.

- + Consumes little actual time
- + Excellent if issue is important at the time
- + Testimony usually varied and voluntary
- Subject to prevailing political overtones
- Sometimes emotional and special interests can dominate
- “Legwork” required to plan and recruit participation

# Community Assessment Methods

## Individual Case Study

Following one case through service system to gain information about issue, cause and effectiveness of services. Can be done retrospectively or prospectively.

- + Gains personal perspectives
- + Identifies breakdowns and misunderstandings
- + Information affective, not typically analytical
- + Identifies contributing and precipitating factors
- Questions about objectivity can be raised
- Confidentiality and ethical questions
- Results least generalizable

# Community Assessment Methods

## In-depth Agency Analysis

Viewing issues from perspective of major service provider. Use flow charts to show causes of issue, patterns of services and referral.

- + Identifies provider labels for problems and services
- + Identifies stress points in system
- + Identifies degree of cooperation among providers
- Information about one provider agency, not total system
- Quality seldom measured
- Results dependent on completeness and accuracy of provider records

# To begin research in my community, pay attention to...

## The Do's

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## The Don'ts

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