COMMUNITY ENGAGEMENT IN RESEARCH

PREPARED BY: KATHRYN SMITH, CIP

OBJECTIVES:

- AAHRPP impact
- Definitions
- Reviewer Responsibilities
- Resources

AAHRPP IMPACT

AAHRPP IMPACT:

 Site visitors found IRB reviewers were not aware of "additional considerations for reviewing research that involved community members in the research process, including the design and implementation of research and the dissemination of results."

 Education and training provided for IRB members/reviewers to satisfy this standard.



DEFINITIONS:

- Community-Based Qualitative Research:
 - Research conducted engaging people on their own territory, using a variety of data collection methods, in the form of textural descriptions of human experience rather than numbers, to understand the cultural values of the community under study.
 - Used to explore public health problems, design programs and policies, and evaluate effectiveness.

Community:

• The notion of community is flexible, and may be bound by geography, defined socially or culturally, or by economic status or disorder.

Taken from "Protecting Study Volunteers in Research: A Manual for Investigative Sites"

EXAMPLE:

- An asthma researcher who wanted to test whether a drug usually associated with cholesterol regulation was effective in reducing severe asthma.
 - Community Engagement: How do asthma patients view study recruitment materials and potential barriers to participation in clinical trials?

REVIEWER RESPONSIBILITIES

REVIEWER RESPONSIBILITIES:

Protocol Template

- Question 21: Community-Based Participatory Research
 - Describe involvement of the community in the design and conduct of the research.
 - Note: "Community-based Participatory Research" is a collaborative approach to research that
 equitably involves all partners in the research process and recognizes the unique strengths
 that each brings. Community-based Participatory Research begins with a research topic of
 importance to the community, has the aim of combining knowledge with action and achieving
 social change to improve health outcomes and eliminate health disparities.

REVIEWER RESPONSIBILITIES:

Things to take into account:

- Maintain confidentiality of the community
 - Waiver of documentation of consent or a Certificate of Confidentiality
- Study methods
- Disenfranchised and/or vulnerable populations

REVIEWER RESPONSIBILITIES:

Things to take into account:

- Dissemination of study findings
 - Goal is to render accounts that present an empathetic understanding of the study community's circumstances and the logic that informs decision making and actions.
 - Avoid promoting stereotypes or stigmatizing individuals/communities.

RESOURCES

RESOURCES

- CTSC Community Engagement
 - http://www.ucdmc.ucdavis.edu/ctsc/area/engagement/index.html
 - Community Review Board
 - Research and Education Community Advisory Board (RECAB)
 - UC Davis Center for Reducing Health Disparities
- Include in letters of action, if applicable

PROGRAM EVALUATION

• This process will be evaluated by our RCI Analyst in 6-9 months (based on volume) to ensure all procedures are being followed, and to make any changes, as necessary.

Questions or Comments

Kathryn Smith, CIP kamsmith@ucdavis.edu 916-703-9162 or 530-304-8051

Dan Redline, BA, CCRP, CIP dredline@ucdavis.edu 916-703-9157 or 916-425-2152

Cindy Gates, JD, RN, CIP cmgates@ucdavis.edu 916-703-9154