

Presentation to VCU's IRB Panels, Spring 2013

Community-Engaged Research

Valerie Holton, Ph.D., LCSW
 Director for Community-Engaged Research
 VCU Division of Community Engagement
vholton@vcu.edu

Michelle Stickler, DEd, CIP
 Executive Director
 VCU Office of Research Subjects Protections
mstickler@vcu.edu

Goals

- Learn more about VCU's commitment to community-engaged research (CEnR)
- Learn more about CEnR designs and methods
- Review ethical considerations and the role of the IRB

VCU Quest for Distinction 2011-2017

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Theme IV: Become a national model for community engagement and regional impact.

- Expand community engaged scholarship and service learning.
- Create university-community partnerships with a focus on the key targeted areas of:
 - K-12 Education
 - Access to Health
 - Economic Development
 - Sustainability
- Provide strategic leadership in addressing sustainability challenges through curricular and service innovations and green facilities and operations



Faculty P&T Policies and Procedures

2012 Proposed Revisions

Descriptions were added to the general criteria for evaluation of faculty (2.1):

- Expansion of the description for demonstrated *continuing scholarship and professional growth* including: language describing independent scholarship and/or collaborative research that leads to the creation of new knowledge or creative expression; forms of scholarship; and a description of community-engaged research
- Expansion of the description for *quality teaching* including: demonstrating that students learn; a commitment to classroom instruction; inclusion of advising, availability to students as components of teaching; and community-engaged teaching
- Expansion of the description of demonstrated *performance in service* including: engaging in the application of learning and discovery to improve the human condition and support the public good at home and abroad; and community-engaged service

A National Model for Community Engagement and Regional Impact

RECOGNIZED AS A COMMUNITY-ENGAGED INSTITUTION BY THE CARNEGIE FOUNDATION

PRESIDENT'S HIGHER EDUCATION SERVICE HONOR ROLL MEMBER




RECIPIENT OF CTSA GRANT



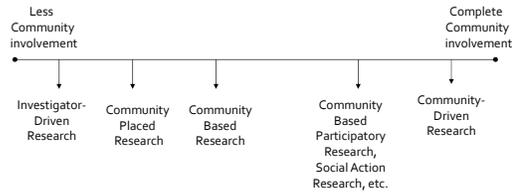
Community-Engaged Research

An Overview

Community-Engaged Research is ...

- A collaborative process between the researcher and community partner that creates and disseminates knowledge and creative expression with the goal of contributing to the discipline and strengthening the well-being of the community.
- Community-engaged research (CEnR) identifies the assets of all stakeholders and incorporates them in the design and conduct of the different phases of the research process.

CEnR Continuum



Key Strategies of CEnR

- Active engagement and shared decision-making of community members, academic researchers and funders
- Integrated sources of knowledge (e.g., formal & informal)
- Iterative data collection and analysis using multiple methods (e.g., qualitative and quantitative)
- Use of multiple channels for knowledge dissemination
- Achievement of common goals: social change, improved health and well-being

A Comparison

| | Traditional Research | Community Research |
|--|---|--|
| Goal of research | Advance knowledge | Betterment of community |
| Source of research question | Theoretical work | Community-identified problem |
| Designer of research | Trained researcher | Trained researcher & community |
| Role of researcher | Outside expert | Collaborator, learner |
| Role of community | Subject of study | Collaborator, learner |
| Relationship of researcher to participants | Short-term, task-oriented, detached | Long-term, multifaceted, connected |
| Value of research | Acceptance by peers (e.g., publication) | Contribution to community change |
| Ownership of data | Academic researcher | Community |
| Means of dissemination | Academic conference, journal | Any and all forums, media, meetings, community |

(Strand K, et al. 2003)

Ethical Considerations

The IRB's Role

IRB Purview

- CEnR often involves non-research and research activities:
 - Networking
 - Team building
 - Education
- Be aware of what is research and what is not. Don't overstep boundaries of IRB oversight.

Overlapping Roles

- Community members may play dual roles – investigator and participant
 - Consent for investigator role?
 - Consent for participant role?
- Compensation issues
 - Separate payment for work as investigator from payment for study participation
 - Separation enables expectations for payment based on “employment”

Review of Risk

- Usually minimal risk research, but still be cognizant of where potential risks lie and how to minimize:
 - Potential risks to whom – individual, group, community?
 - Don't over-reach on risk: consider “probability and magnitude of anticipated harm or discomfort” (45 CFR 46.102)
 - Ask for input from the community if necessary to determine risks

Fluid Study Design

- Often linear or phased development based on overall study objectives
 - Build in phases of IRB approval (e.g., start with overall description and 1st phase; amend to add next phase)
 - Consider splitting out sub-projects that could qualify as exempt review where most modifications do not require IRB amendment

Required H.S. Training

- CITI may not be the best model for community researchers
- Consider alternatives:
 - CIRTification
 - Investigator developed training – specific to roles and responsibilities
 - IRB should review and approve

Privacy and Security Challenges

- What are the expectations for privacy among the community individuals, group?
 - It may not be possible to offer “private” options for all aspects of study participation. Be flexible and “hear” the investigator/community perspective.
- Data security issues
 - How will data be transferred from community to investigator?
 - Where will data be stored?

Ethical Issues Summary

- Determine IRB purview
- Identify roles and responsibilities of all players
- Be flexible and open to new ideas
- Build flexibility into the research plan
- Maintain open lines of communication with investigators and community (as appropriate)

Next Steps

Questions Added to IRB Application

Is there at least one community partner* involved in the proposed study? Yes/No

*A community partner is an individual or organization that is not affiliated with VCU or VCU Health Systems (e.g. VA Health Systems, a non profit or NGO, a business) but who is engaged with VCU or VCU Health Systems in this proposed study.

If yes ...

Please provide the following details about each community partner. If there are more than 5 community partners, please provide the following information on the 5 most significant community partners. If a community partner is a collaboration of multiple partners, please indicate the name of the larger collaboration and the zip code or country of the location where the majority of the research is taking place.

- Name of the organization
- Zip code or Country of the organization

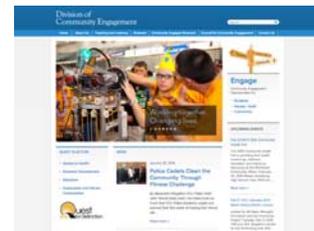
Questions Added to IRB Application (cont)

Which of the three statements below best describes the role of the community partner in the study?

1. Community partners only provide access to study subjects or project sites. They are not involved with study design, subject recruitment, data collection, or data analysis.
2. Community partners do not make decisions about the study design or conduct, but provide guidance to the researcher about the study design, subject recruitment, data collection, or data analysis.
3. Community partners make decisions with the researcher(s) about the study's research activities and/or help conduct those activities (i.e. study design, subject recruitment, data collection, and/or data analysis).

Khodyakov, D., Stockdale, S., Jones, A., Mango, J., Jones, F., & Lizaola, E. (2012). On measuring community participation in research. *Health Education & Behavior*, XX(X), 1-9.

For more information ...



<http://www.community.vcu.edu>