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The IRB/REB Curriculum on Ethical Considerations in Community-Engaged Research
Community-Campus Partnerships for Health

Mission

To promote health (broadly defined) through partnerships between communities and higher educational institutions
Mission

Promoting equity and justice in health and health care for African American and other underserved populations.
Community-Engaged Research (CEnR)

- Community Based Participatory Research (CBPR) is one type of CEnR
- CEnR the term used by the NIH’s Clinical Translational Science Awards (CTSA)
Terminology

- REB Canadian Research Ethics Board
Why Do Community-Engaged Research?

Health interventions have often not been as effective as they could be...

- Not tailored to the concerns & cultures of participants
- Rarely include participants in all aspects of intervention design, implementation & evaluation
- Focused narrowly on individual behavior change with less attention to broader social & structural issues
The Community-Engaged Research Continuum

Top-down Consultation Collaboration Partnership
None ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ ⏰ A Lot
Community engagement Community Engagement

Conventional research CBPR

References: Winer and Ray, Anucha
CCPH’s CBPR & Research Ethics Program

- 2007 Call Series “Ensuring Community-Level Research Protections”*
- CEnR & Ethics Listserv
- Oct 2008 --JERHRE Theme Issue -
- National Study, “Understanding Community-Based Processes for Research Ethics Review”
- **IRB-REB Curriculum on Community-Engaged Research***

*co-sponsored with Tuskegee Bioethics Center
Why an IRB/REB Curriculum?

- Top recommendation from Call Series
- The practice of CEnR is growing
- Community-engaged researchers report IRB/REB review as a barrier to CEnR
- Most IRBs don’t assess community-level ethical concerns
Curriculum Development Process

- Late 2007 Call for volunteers
- January 2008 Writing group convened & Advisory & Review Group assembled
- Objectives, format and group process developed
- January 2009 draft material evaluated
- 2009 Reorganized into 3 modules and revised
- December 2009 two day meeting at Tuskegee National Bioethics Center
- 2010 Revisions
Bridge knowledge gap between IRB/REB members and researchers in the area of CEnR

Create a shared understanding of CEnR and the ethical issues that can arise in conducting CEnR

Ensure that community-level research protections are explicitly and adequately addressed in the research ethics review process
Audience

- Administrators and members of IRBs and REBs
- United States and Canada
Curriculum Objectives

- Describe the rationale, principles, methods, risks and benefits of CEnR
- Identify ethical considerations that commonly arise in CEnR
- Provide tools and case studies that will help reviewers recognize, analyze and address ethical considerations that arise in CEnR
Intended Outcomes

- Understand what CEnR is and is not
- Articulate ethical issues that arise in CEnR
- Conduct informed ethics reviews of CEnR
Curriculum Components

- Introduction/Overview
- Module 1: Definitions and Rationale
- Module 2: Ethical Frameworks and Issues in Community-Engaged Research
- Module 3: Ethical Review of Community-Engaged Research Protocols
Module Components

- Learning objectives
- Key concepts (main text)
- Case studies and training exercises that illustrate key concepts & foster critical thinking
- Citations and recommended resources
- Quiz questions & answers (for CITI course credit)
Module 1 Learning Objectives

- Describe principles of a community-engaged research approach
- Describe different concepts of “community”
- List ways that researchers’ roles are different in CEnR compared to conventional research
- Summarize ways that research can benefit from collaboration among researchers and community partners
Module 2 Learning Objectives

- Examine how the regulatory framework that applies to human subjects research applies to CEnR

- Describe the ethical considerations of CEnR re: informed consent, participant privacy and confidentiality, data ownership and risk/benefit analysis

- Explain the importance of using an emergent design in CEnR
Module 3 Learning Objectives

- Identify measures to increase diverse representation of community members on IRBs/REBs
- Identify & appraise measures to maximize the CEnR expertise of all IRB/REB members
- Identify & evaluate measures to modify existing IRB/REB structures, policies and review processes to ensure ethical considerations for CEnR
Curriculum Delivery Options

- Scheduled and/or customized workshops on campuses and at conferences
- Online individually or in groups
- As a resource for discussing/planning how to restructure IRB/REB forms, policies, and practices to apply to CEnR protocols
Curriculum Next Steps

- Draft is currently under peer-review
- Will be Pilot tested & revised
- Curriculum release in Summer 2010
- Conference workshops and IRB trainings beginning in Fall 2010
- Produce as on-line modules
How You Can Get Involved

Let CCPH know--

- of any cases or innovations that we could include in the curriculum
- if you’re interested in on-site training
- what other resources would be helpful

Send CCPH your email to receive a notice when the curriculum is released
Tap into CCPH Resources
www.ccph.info

- CCPH conference, May 12-15, 2010 in Portland, OR
- Pre-conference workshops on CEnR ethics, Roadmap to CEnR Funding at NIH
- Online Reports & Toolkits
- Developing & Sustaining CEnR Partnerships
- Electronic Discussion Groups
How to Cite this Presentation

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*A Canadian committee and a review/advisory committee provide additional input