Resource List for Conference Call Series on Institutional Review Boards (IRBs) and Ethical Issues in Research

If you have recommended resources to add to this list, please email them to CCPH graduate research assistant Jessica Grignon at jgrignon@u.washington.edu

Call #6: IRB Reform: Changing Policy and Practice to Protect Communities

Selected articles:


Call #5: Beyond the University IRB: Understanding Alternative Models for Human Protection, Part II: Creating an Independent Community IRB — When is it Right for You?

Selected articles on community IRBs and building community research capacity:

• Colwell-Chanthaphonh C. Self-governance, self-representation, self-determination and the questions of research ethics--commentary on "Protecting the Navajo People through tribal regulation of research". Sci Eng Ethics. 2006 Jul;12(3):508-10.
• Oneha MF; Beckham S. Re-examining community based research protocols. Pacific Public Health 2.11:1;2004.
• Schrag B. Research with groups: group rights, group consent, and collaborative research commentary on "Protecting the Navajo People through tribal regulation of research". Sci Eng Ethics. 2006 Jul;12(3):511-21.

Selected examples of independent community IRBs:
• Orange County Asian and Pacific Islander Community Alliance: http://www.ocapica.org in collaboration with Special Services for Groups: http://www.ssgmain.org/
  o About the IRB: http://www.eberp.org/publications/newsletters/2006/page_17.php
• Waianae Coast Comprehensive Health Center: http://www.wcchc.com/
• Papa Ola Lokahi: http://www.papaolalokahi.org
• Navajo Nation Human Research Review Board: http://www.nnhrrb.navajo.org/

Call # 4 – Beyond the University IRB: Understanding Alternative Models for Human Protection, Part I: Supplementing the IRB for Community Protection with a Community Advisory Board

Selected Articles on community advisory boards or similar entities:
• Gilbert SG. Supplementing the traditional institutional review board with an environmental health and community review board. Environ Health Perspect. 2006 Oct;114(10):1626-9.

Organizations with Supplementary Models of Protections:
• Kanahawke Schools Diabetes Prevention Project, Community Advisory Board: http://www.ksdpp.org/whatcab.html
• University of Pittsburgh Center for Minority Health, Community Research Advisory Board (CRAB): http://www.cmh.pitt.edu/research_crab.asp
  o CRAB guidelines: http://www.cmh.pitt.edu/pdf/crabguidlines_dates.pdf
• Yakima Valley Farm Workers’ Clinic, Community Advisory Board: http://www.farmworkerhealth.org/newsletters/10934vol6_Newsletter.pdf
• Access Alliance: Multicultural Community Health Center: http://www.accessalliance.ca/index.php?option=com_content&task=view&id=37&Itemid=56
• University of California San Francisco, Positive Health Program Community Advisory Board: http://www.communityconsortium.org/about/about_cab.html
• HIV/AIDS research network community advisory boards: http://www.thebody.com/content/policy/art4866.html

Call # 3 – Community-Based Participatory Research (CBPR) Proposals and the Human Subjects Review Process: Methods for Working with University IRBs

Selected Articles on IRB Review and Community-based Participatory Research or Participatory Action Research:

Call # 2 – Highlighting the Importance of the Nonaffiliated (Community) IRB Member

Resources for Non-affiliated/Non-Scientific Community IRB Members:
• Citizens for Responsible Care and Research’s listing of IRBs registered with the Office for Human Research Protections. Available at: http://www.circare.org/info/researchbythenumbers1.htm
• Research Advocacy Network is a non profit organization working to bring together all participants in the medical research process with the focus on education, support and connecting patient advocates with the research community to improve patient care. To learn more about the network and how to get involved, please visit: http://www.researchadvocacy.org/about/index.php

Recent Past Conferences and Presentations on Community IRB Members
• PRIM&R’s educational session on recruitment and retention of non-affiliated members. Available at: http://www.primr.org/education/2006_Webinar/overview_webinar06.htm
• Southeast Community Research Center & Tuskegee University Center for Bioethics in Research and Health Care presented a workshop in 2003 entitled, “Science By the People: Promoting Community Participation on Institutional Review Boards” Description available at: http://www.cbpr.org/index.php?option=com_content&task=view&id=18

Selected Articles on Community IRB Members:
• Bauer PE. A few simple truths about your community IRB members. IRB. 2001 Jan-Feb;23(1):7-8.
Regulations on IRB Membership:

Call #1 - What is an Institutional Review Board (IRB) and What Purpose does it Serve?

Code of Federal Regulations:
• Title 45 Public Welfare, Department of Health and Human Services, Part 46 Protection of Human Subjects: www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm

Historical Events & Ethical Codes:
• Nuremberg Code: www.hhs.gov/ohrp/references/nurcode.htm
• Declaration of Helsinki: www.wma.net/e/policy/b3.htm
• Belmont Report: http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.htm

Educational Materials & Resources on IRBs:
• Research Ethics and IRB Resources for Tribes and Researchers – by Aberdeen Area Tribal Chairmen’s Health Board: http://www.aatchb.org/epi/docs/ResearchEthics.htm

Relevant Websites:
• Community-Campus Partnerships for Health (CCPH) Ethics & IRBs Links Page: http://depts.washington.edu/ccph/links.html#Ethics
• Department of Health and Human Services, Office of Human Research Protections: http://www.dhhs.gov/ohrp/
• Tuskegee University National Center for Bioethics in Research and Health Care: www.tuskegee.edu/bioethics
• Public Responsibility in Medicine and Research (PRIM&R): www.primr.org