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 #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:

- 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:

- Special Service for Groups (http://www.ssgmain.org/) and the Orange County Asian Pacific Islander Community Alliance (http://www.ocapica.org) co-founded and developed a community-based Institutional Review Board (IRB) in Los Angeles, California. A broad
group of community-based organizations and community leaders support the IRB and serve in several capacities, such as IRB members.


- Waianae Coast Comprehensive Health Center: http://www.wcchc.com/

- Papa Ola Lokahi: http://www.papaolalokahi.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:


Organizations with Supplementary Models of Protections:
• Kanhawake 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:
• 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:

Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical Dilemmas in Community-Based
Apr 10.

Khanlou N and Peter E. Participatory action research: considerations for ethical review. Social

Malone RE et al. “It’s like Tuskegee in reverse”: A case study of ethical tensions in institutional
review board review of community-based participatory research. American Journal of Public

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

Resources for Non-affiliated/Non-Scientific Community IRB Members:
• The Community IRB Member: Neighbor and Partner, U.S. Department of Energy website:
  http://www.orau.gov/communityirb/default.htm. Join their listserv at:
  http://www.orau.gov/communityirb/listserv.htm
• Research Ethics Training Curriculum for Community Representatives, Family Health
  International. Available at:
• 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

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:


Historical Events & Ethical Codes:

- Nuremberg Code: www.hhs.gov/ohrp/references/nurcode.htm
- Declaration of Helsinki: www.wma.net/e/policy/b3.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