



TUSKEGEE
UNIVERSITY

*National Center for Bioethics
in Research and Health Care*



**Community-Campus
Partnerships for Health**
Transforming Communities & Higher Education



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 # 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:

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.

Khanlou N and Peter E. Participatory action research: considerations for ethical review. *Social Science & Medicine.* 2005; 60: 2333-2340.

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 Health.* 2006; 96(11): 1914-1919.

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.ornl.gov/communityirb/default.htm>. Join their listserv at: <http://www.ornl.gov/communityirb/listserv.htm>
- Research Ethics Training Curriculum for Community Representatives, Family Health International. Available at: <http://www.fhi.org/en/RH/Training/trainmat/ethicscurr/retccr.htm>
- 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

- Public Responsibility in Medicine and Research (PRIM&R) pre-conference workshop in 2006 entitled, “What does It Mean to Represent the Community?” Description available at: http://www.primr.org/education/2006_HRPP/Community_Participation.pdf
- 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:

- Anderson EE. A qualitative study of non-affiliated, non-scientist institutional review board members. *Account Res.* 2006 Apr-Jun;13(2):135-55.
- Bauer PE. A few simple truths about your community IRB members. *IRB.* 2001 Jan-Feb;23(1):7-8.
- De Vries R, Forsberg CP. Who decides? A look at ethics committee membership. *HEC Forum.* 2002 Sep;14(3):252-8.
- Sengupta S, Lo B. The roles and experiences of nonaffiliated and non-scientist members of institutional review boards. *Acad Med.* 2003 Feb;78(2):212-8.

Regulations on IRB Membership

- Code of Federal Regulations, Title 45 Public Welfare, Department of Health and Human Services, Part 46 Protection of Human Subjects. SubPart 46.107 IRB Membership: <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.107>

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
- U.S. Public Health Service Syphilis Study background: <http://www.tuskegee.edu/Global/story.asp?S=1207512>
- Belmont Report: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.htm>
- Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.* New York: Doubleday, 2007.

Educational Materials & Resources on IRBs:

- Office for Human Research Protections IRB Guidebook: http://www.dhhs.gov/ohrp/irb/irb_guidebook.htm
- Public Responsibility in Medicine and Research (PRIM&R) offers a course called IRB 101sm: http://www.primr.org/education/2007_IRB_FUND/overview_FUND_0207.html

- 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>
- IRB: Ethics & Human Research Journal Available at:
<http://www.thehastingscenter.org/publications/irb/irb.asp>

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