

Community Institutional Review Boards

**Conference Call Series on Institutional Review Boards
and Ethical Issues in Research**

Co-sponsored by

*Community-Campus Partnerships for Health & Tuskegee University National
Center for Bioethics in Research and Health Care*

May 24, 2007

Jacqueline H. Tran, MPH

**Orange County Asian and Pacific Islander
Community Alliance**

Eric C. Wat, MA

Special Service for Groups

Background on SSG

- Special Service for Groups, Inc. (SSG) was established in 1952
- Mission statement: *“SSG is a non-profit organization dedicated to providing community-based solutions to the social and economic issues facing those in greatest need. SSG has evolved into a model organization which is designed to provide service to diverse groups with maximum efficiency and impact. This is achieved by developing and managing programs which serve our many communities by encouraging their involvement and self-sufficiency. SSG believes that the needs of groups and individuals cross traditional ethnic, racial, and other cultural boundaries. SSG serves as a bridge between people with common needs to identify ways to pool resources for the greatest good of all.”*
- SSG has over 23 programs and three affiliate organizations in Los Angeles, Orange County, and San Francisco
- Contact Information:
Telephone: (213) 553-1800
Website: www.ssgmain.org

Background on OCAPICA

- Orange County Asian and Pacific Islander Community Alliance (OCAPICA) was established in 1997
- Mission statement: *“To build a healthier and stronger community by enhancing the well-being of Asians and Pacific Islanders through inclusive partnerships in the areas of service, education, advocacy, organizing, and research. OCAPICA conducts numerous programs in the areas of health, education, youth and policy. OCAPICA and SSG partner together on various collaborative initiatives and projects. SSG is proud to be part of this union and currently provides various fiscal and technical assistance services.”*
- Contact Information:
Telephone: (714) 636-9095
Website: www.ocapica.org

Why was the Community IRB started?

- Part of an effort on a nationally-funded CDC project
- History of research projects
- Growing trend of community-based participatory research projects (with or without university partners)
- Experience with university IRBs
- Community was lacking from university IRBs
- Multiple university IRBs with minimal community representation

How was the Community IRB started?

- Initiation by the CDC REACH 2010 – Promoting Access to Health for Pacific Islander and Southeast Asian Women (PATH for Women) project
- Support of leadership
- Dedicated staff person and intern
- A year's work in research and development
- Developed policies and procedures
 - IRB application, review, and renewal forms (and associated forms, as appropriate)
 - Meeting protocols
 - Review guidelines
 - Training tools for IRB members and organizational programs

When did the Community IRB start?

- Initiated in 2004
- Reviewed and approved by US DHHS OHRP
- Official IRB number and seal
- Recruitment from organizations and community leaders for IRB members
- Training of IRB members
- Renewal in 2007

What is the purpose of the Community IRB?

- Provide guidance for human subjects protections
- Engage and educate community programs and partners on the importance of IRBs
- Empower community programs and partners in the IRB process
- Empower community programs and partners to be equal research partners
- Give a voice to under-represented communities regarding research, especially involving human subjects
- Build capacity

How does the Community IRB function?

- Accepts IRB applications on a quarterly basis for review
- Provides application and forms to interested projects
- Currently an internal review board for SSG programs, affiliated organizations, and community partners
- Requires a report at year-end
- Reviews renewal requests

How is the Community IRB maintained?

- Roles and Responsibilities
 - Maintain record of all applications
 - Document all processes of the IRB
 - Coordinate application review requests
 - Communicate with IRB application contact person for materials and review process
 - Provide workshops and TA on research design, methodology and human subjects protection
- Structure
 - Staff person who coordinates all efforts and requests
 - Support provided by Special Service for Groups
 - In-kind support of efforts, meetings costs, etc.
 - Volunteer participation by IRB members

How is the Community IRB maintained? (cont'd)

- Case Load
 - On average, 3 applications per year (not including renewals)
 - Looking at expanding; requests have been made by external organizations
- IRB Renewal
 - Not burdensome to applicants
- Recruitment of Members
 - Initially recruited diverse members from the organization and affiliated community members
 - Will review terms and ask for recommendations from the current Board and groups that have submitted applications

What are the benefits to the community?

- Community owns the data; SSG does not have any ownership
- SSG serves as a conduit to provide oversight on human protections
- Community organizations and members become more aware of the IRB process
- Empowerment of communities' role in the IRB process

What are the benefits to the community? (Cont'd)

- Sharing of best practices, research methods and tools, and solutions to common challenges
- Benefits from the research process (beyond research findings)
- Conflict resolution

What are the projects that have been approved by the Community IRB?

- Assessment of Southeast Asian families to support young children
- Impact of services for refugees who are torture victims
- Adaptation of evidence-based child abuse prevention program in Korean and Cambodian communities
- Identification of sustainable outcomes for minority adolescent clients in a occupational therapy program

What are the projects that have been approved by the Community IRB? (Cont'd)

- Assessment of Pacific Islander communities to reduce cancer disparities
- Adaptation of evidence-based programs to help re-entry individuals transition back into their communities
- Assessment of LGBT South Asian community and their health needs
- Exploration of Southeast Asian women's navigation of breast health services

What are some common issues addressed by the Community IRB?

- Informed consent
 - Voluntary – subjects can still receive service even if they don't participate
 - Sensitive topics: HIV/AIDS, criminal activities
 - Contact people and information
 - Length and format of consent form
 - Data use and dissemination
- Language (e.g. conversational and non-scientific) – translation, interpretation, verbal consent

What are some common issues addressed by the Community IRB? (Cont'd)

- Subject recruitment and selection (e.g. experimental design)
- Role conflict for provider/researcher (e.g. mandated reporting, confusion to subjects)

How and when to start a Community IRB?

- Review and assess the resources in the community
- Review and assess the resources to develop, conduct and maintain the IRB
- Work with existing resources to improve status quo

Resources

- Sieber, Joan E. Planning Ethically Responsible Research: A Guide for Students and Internal Review Boards. Applied Social Research Methods Series, Volume 31. SAGE Publications 1992 Newbury, CA.
- US DHSS Office of Human Research Protections & Belmont Report at <http://www.hhs.gov/ohrp/>

Thank you!

- Contact Information

Jacqueline H. Tran, MPH
Program Manager – OCAPICA
12900 Garden Grove Blvd.,
Suite 214A
Garden Grove, CA 92843
Telephone: (714) 636-9095
Email: jtran@ocapica.org

Eric C. Wat, MA
Data Manager – SSG/Census
Data and GIS
605 W. Olympic Blvd., Suite
600
Los Angeles, CA 90015
Telephone: (213) 553-1820
Email: ewat@ssgmain.org