

# IRB Webinar

California Reducing Disparities Project

Asian & Pacific Islander Population

June 9, 2017



We will begin shortly.

For assistance with technology, please contact Nichole Heil:

[nheil@ssg.org](mailto:nheil@ssg.org)

213-223-0611

# Technology Housekeeping

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Participants mics are open throughout the webinar

Discussions etiquette:

- Please mute yourself! (Phone or Zoom icon)
- For multiple people in one room: use only 1 microphone & 1 speaker

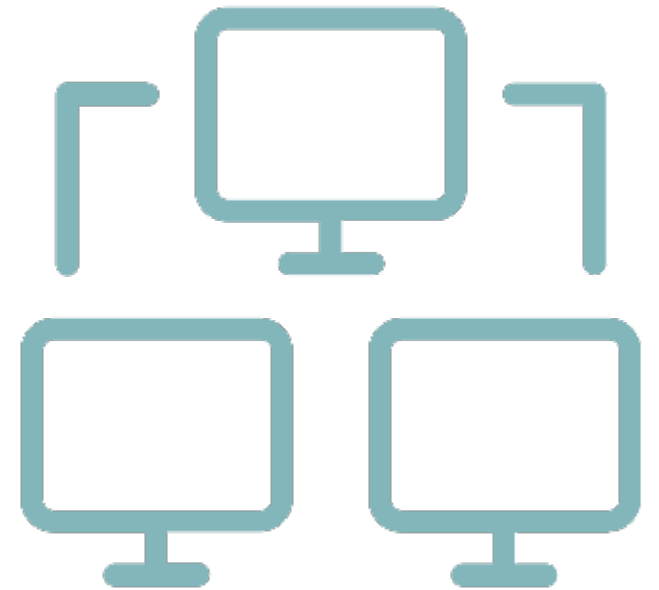
We will record webinar and share link to recording.

We will also send slides.

Contact Nichole for assistance:

[nheil@ssg.org](mailto:nheil@ssg.org)

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# Presenters

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# Purpose:

Provide information about why and when to consider IRB approval

Provide overview of SSG's Community IRB and review process

# Institutional Review Boards (IRBs)

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IRBs are independent bodies that review research activities.

The focus of IRB review is to protect the rights and wellbeing of human subjects who participate in those research activities.

The IRB is authorized to approve, require changes, or disapprove all research activities that it reviews.

## Key principles

**Respect for persons:** Individuals have the freedom to choose and act on their decisions.

**Beneficence:** Do no harm. Research should demonstrate maximum benefits and minimum harms.

**Justice:** All human subjects should be treated equally

# Seeking IRB Approval for a Project

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Review needed for research projects and/or projects that seek to generalize information beyond current program

Other considerations:

- Risk of population and data being collected (mental health data considered to be highly sensitive)
- Intent to use data for dissemination to broader audiences (beyond internal use)

Weigh priorities given timeline and capacity:

- May use first year data as evaluation only (internal use) and seek IRB approval at later date



# SSG's Community IRB

# History of SSG IRB

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Established in 2004

One of the very few community-based IRBs recognized by the [Office for Human Research Protections](#), the federal oversight body within the US Dept. of Health and Human Services

Part of an effort from Racial and Ethnic Approaches to Community Health (REACH), a project funded by the Centers for Disease Control and Prevention (CDC)

- Promoting Access to Health for Pacific Islander and Southeast Asian Women (PATH for Women)
- Health Access for Pacific Asian Seniors (HAPAS)

Resource for community researchers (not affiliated with universities) with history of working with underserved and under-represented communities

Response to growing trend of community-based participatory research projects and lack of community voice within many university IRBs

Envisioned efficient process that was rigorous but more friendly and sensitive to community-based research with less bureaucracy



# Vision for SSG's Community IRB

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Engage and educate community programs and partners on the importance of research ethics

Provide guidance for human subjects and community protections in community based participatory research (CBPR) projects

Empower community programs and partners to be equal research partners through IRB process

Give a voice to under-represented communities regarding research, especially involving human subjects

Build community capacity to do CBPR

# SSG IRB Structure

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Administered by SSG (Co-Administrators are Erica Shehane & Art Garcia from SSG's Research & Evaluation Team)

Board Members are volunteers

No fee to have project approved

Focus on Social and Behavioral Research and Community Based Participatory Research

IRB is a resource for projects referred by SSG divisions and board members

- **NOTE: All API IPPs as part of CRDP may use SSG's IRB if desired**

# SSG IRB members

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10 members

- 1 SSG program director
- 1 SSG R&E staff
- 3 community partners of SSG
- 3 academic partners (2 USC and 1 University of Connecticut)
- 2 independent consultants for community-based organizations
- All but 2 are founding members

3 alternates

Credentials of community IRB members are not mutually exclusive

- 2 of the 3 academic partners spent years working in the community running programs.
- SSG program director also has a doctorate in social work.
- All community members, regardless of academic credentials, have experience conducting CBPR.

# Example projects approved by SSG's IRB

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- ❖ Impact of services for refugees who were torture victims
- ❖ Adaptation of evidence-based program to help re-entry individuals transition back into their communities
- ❖ Adaptation of evidence-based child abuse prevention program in Korean and Cambodian community
- ❖ Identifying sustainable outcomes for minority adolescent clients in an occupational therapy program
- ❖ Effectiveness of navigation services for cancer patients in Pacific Islander community
- ❖ Effectiveness of navigation of breast health services in Hmong community
- ❖ Effectiveness of depression treatment in South LA, focusing on homeless population

# Common issues addressed by SSG's IRB

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Community involvement in all phases of research process (not just subject recruitment and data collection)

Community dissemination (not just publication in peer-reviewed journals) and data ownership

Benefits and harms to the community, not just individuals

## Informed consent

- Voluntary – subjects can still receive service even if they don't participate
- Sensitive topics: HIV/AIDS, criminal activities
- Length and format of consent form

Language (e.g. conversational and non-scientific) – translation, interpretation, verbal consent

Subject recruitment and selection

Role conflict for provider-researcher (e.g. mandated reporting, confusion to subjects, etc.)

Importance of data dissemination: not just in peer reviewed manuscripts and reports to funders, but giving back information to the communities who are involved through community forums, reports and briefs (i.e., community friendly).

# Brief Overview of SSG IRB Application Process

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1. Researcher(s) submit written application to IRB Co-Administrators by email
  - Co-Administrators work with researcher to complete application, if necessary
2. Co-Administrators send application to IRB board members, who review application to determine if project needs full review, expedited review or may be exempt.
3. If full review needed, IRB board members meet with researchers (in person or via video conference) to discuss project, clarify questions and make suggestions.
  - Board notifies researcher in meeting verbally about decision. (Usually researchers are asked to make some modifications based on discussion with board.) A written letter is sent following the meeting.
4. Co-Administrators work with researchers to make any needed changes.
  - IRB Chair and Vice Chair approve changes and make final decision
5. Co-Administrators notify researchers in writing of final board decision.
6. A final report is provided to the IRB with the completion of the project.

**Co-Administrators are available to answer questions and provide support throughout the entire process.**

NOTE: Process may vary depending on project. The timeline may also vary, though is about 2-3 months from submission of a complete application.

# Why Consider IRB Review for CRDP?

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- IRB review keeps a door open to disseminate data from CRDP more broadly
  - Even if you don't have intentions to publish or seek EBP status right now, you never know what kind of data you might have at the end of the project.
- Broader dissemination provides an opportunity to share information on underserved populations (i.e., share data with the field on populations for whom there is often very little data)
  - CRDP may be an opportunity to contribute to the field of what works for Asian and Pacific Islander mental health in diverse community settings
- If unsure now, can consider IRB review in future (i.e., for Year 2 data)



# OPEN SPACE

Discussion and Questions



# Next Steps

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API TAP team available for individual support related to IRB and other questions.

For more information about submitting a proposal to the SSG IRB, contact the API TAP team.

## Additional Resources

SWE Guidelines: pages 88-93 and Appendix 7

SSG IRB website:

[http://www.ssgresearch.org/community\\_irb](http://www.ssgresearch.org/community_irb)

