

(C20) Populations on the Edge

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John A. Guidry, Amy Ahrens Terpstra**

November 15, 2016 11:15 AM – 12:30 PM

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**2016 Advancing Ethical
Research Conference**
November 13-16 • Anaheim, CA



Disclosure: Cynthia A. Gómez

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

Disclosure: John A. Guidry

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professional/financial relationship(s)
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Disclosure: Amy Ahrens Terpstra

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Learning Objectives

1. Be able to identify special research-related ethical considerations related to people experiencing homelessness, people who use substances, and LGBTQ-identified individuals
2. Be equipped with a framework for identifying study populations with vulnerabilities beyond those addressed by federal regulations
3. Be able to apply the framework and special considerations to other potentially vulnerable populations beyond those discussed

Cynthia A. Gómez



Cynthia A. Gómez is the founding director of the Health Equity Institute at San Francisco State University. She previously served as co-director of the Center for AIDS Prevention Studies at the University of California at San Francisco and has been a leading scientist in HIV prevention research since 1991. Cynthia has been a health policy advisor for over 20 years. She was served on the Presidential Advisory Council on HIV/AIDS under both WJ Clinton and GW Bush administrations. She is a member of the PRIM&R Board of Directors.

John Guidry



Dr. John A. Guidry, PhD, is a consultant to community health organizations across the United States. He provides services in grant writing, evaluation, strategic planning, community research, and IRB development and is also an Adjunct Professor with New York University's College of Global Public Health. He has published numerous peer-reviewed articles and two books on social movements and community engagement. He hails from New Orleans and has lived in Brooklyn since 2004.

Amy Ahrens Terpstra



Amy Ahrens Terpstra is a social worker turned researcher. In her current role as Senior Partnership Director at the United Way of Salt Lake, she convenes, facilitates, and helps build collective action among partners to improve specific, measurable outcomes at a population level. For 11 years prior to that, she led the research and evaluation services at Heartland Alliance's Social IMPACT Research Center, conducting community-based applied research. Amy has a Master's in Social Work degree from the University of Illinois at Chicago.

UNDERSTANDING VULNERABILITY BEYOND THE REGS

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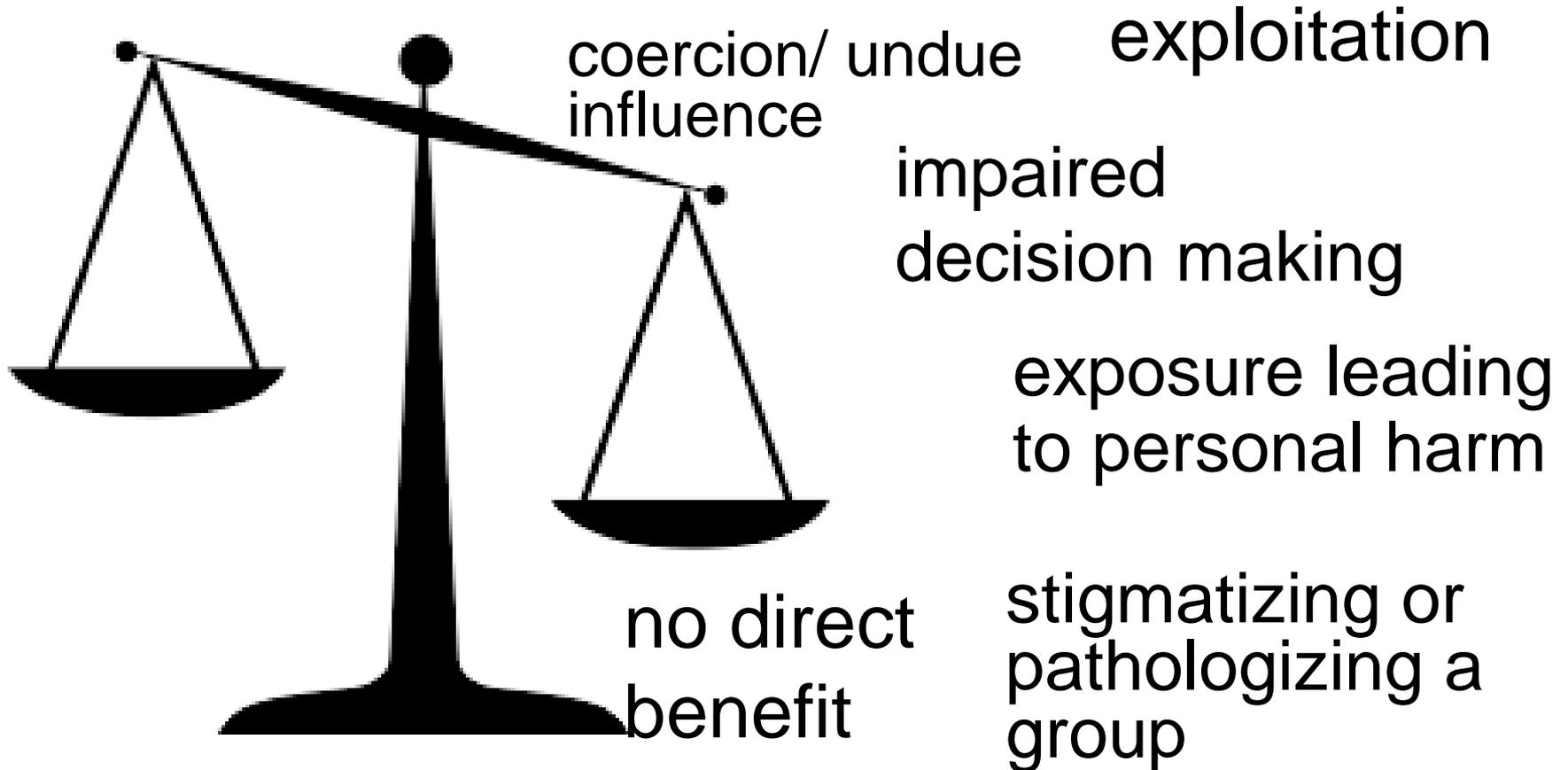
§46.107 IRB membership

- The IRB shall be sufficiently qualified through the experience and expertise of its members, and the **diversity of the members**, including consideration of race, gender, and cultural backgrounds and **sensitivity** to such issues as **community attitudes**, to promote respect for its advice and counsel in **safeguarding the rights and welfare** of human subjects.

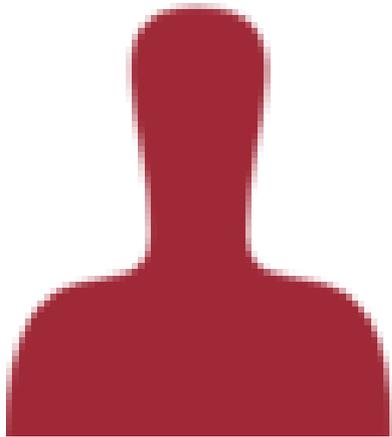
§46.111(a)(2): Criteria for IRB approval of research

- Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and **the importance of the knowledge** that may reasonably be expected to result.
- The IRB should not consider possible **long-range effects of applying knowledge** gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility.

Tipping the 'Risk for Harm' Scale



Individual AND Community Harm



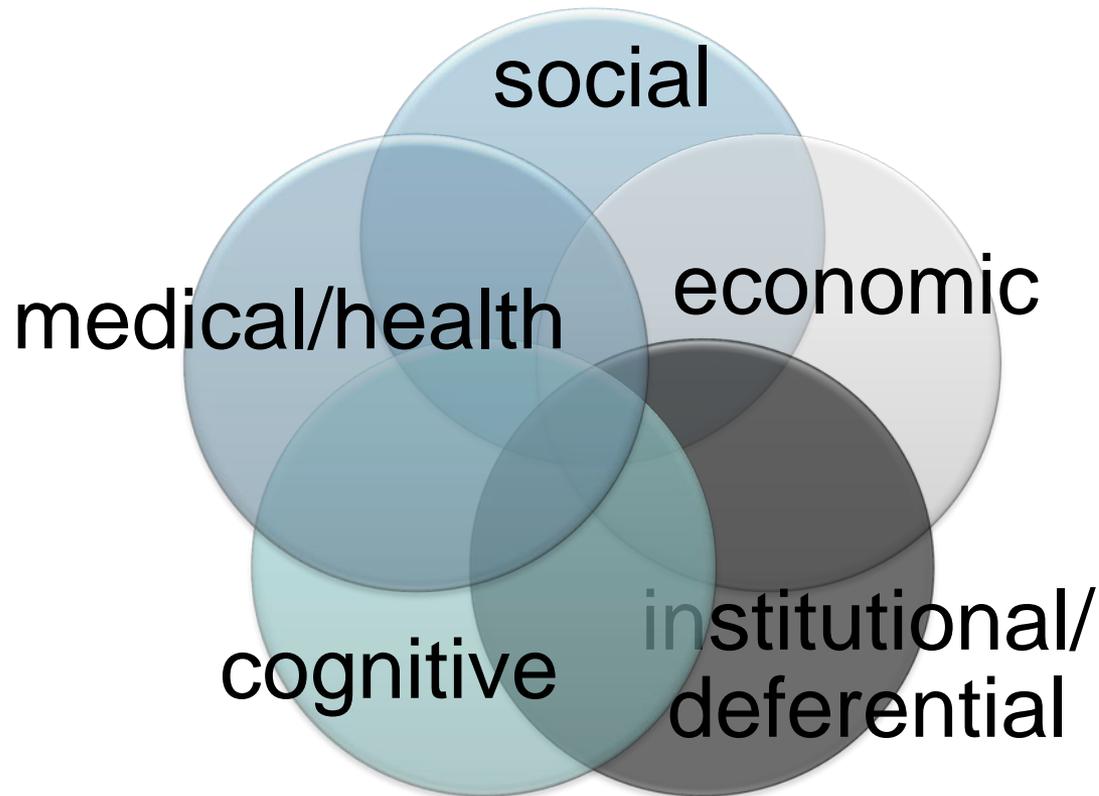
Types of Communities



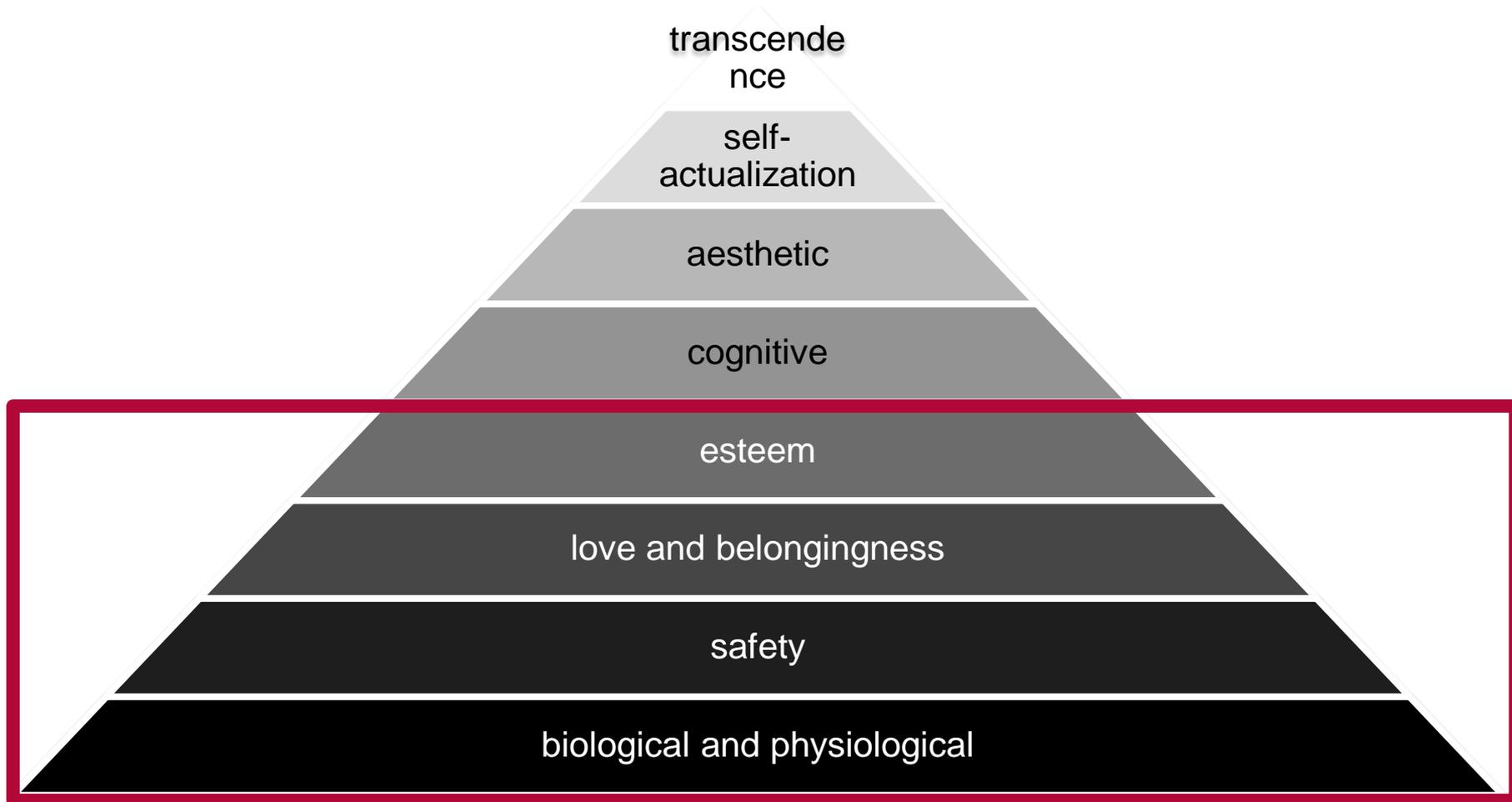
Belmont Report Principles



Domains of Vulnerability & Resiliency



Maslow's Hierarchy of Needs



HOMELESSNESS & SUBSTANCE USE

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What's the Problem?



What's the Harm?



Research with or about LGBTQ individuals

creating new knowledge with a
complex community

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What is the Problem?



What is the Problem?



Search Queerty



HEALTH WATCH

STUDY: Nearly 50% Of Gay Men Using Hook-Up Apps Engage In Unprotected Sex

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Email

Comments (15)

A new study by New York's non-profit **Community Healthcare Network** of gay and bisexual men who utilized social apps such as Grindr, Scruff, Manhunt and Growlr found that nearly 50% admitted to barebacking.

Dr. Freddy Molano, Assistant Vice President of HIV Programs and Services at CHN, and Renato Barucco, CHN's Transgender Program Manager, surveyed 725 participants on four main areas: perspectives on HIV/AIDS; perspectives on unprotected anal intercourse; HIV/AIDS knowledge; and, in an optional section, the reasons behind risk-taking behaviors during intercourse.



What is the Harm?

Stigmatizes

Pathologizes

Reinforces prejudice

Prevents resources from
coming to light

How Gay Became a Medical Problem

- Historically shunned
- Medicalized in 19th Century
- Pathologized in the 20th Century
- Early research—*all male*—validates homosexuality as both normative and as pathological: Evelyn Hooker and Irving Beiber
- Pathology – and bad science – become the norm

AIDS changed things (for some people)

- Much of what we know about gay men and transgender women comes from medical and health studies of illness and the community's attempts to deal with it.
- HIV crowds out other research and other work with LGBTQ communities.

AIDS

AIDS changed things (for some people).

Much of what we know about gay men and transgender women comes in large part from medical and health studies of illness and the community's attempts to deal with it.

Some Big Questions

- What do we do when “otherness” defines what we know about a community or a group of people?
- When is otherness diversity – and when is it vulnerability?
- How do we break the cycle of pathology?

IDEAS FOR MINIMIZING VULNERABILITIES AND MAXIMIZING RESILIENCY

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Change the Question



- Juan Battle and team
CUNY Graduate Center
- ~5,000 LGBTQ persons of color, national
- Purpose: to document and celebrate the experiences

Translate research into practice



- Caitlyn Ryan & Rafael Diaz, 2002
- <http://familyproject.sfsu.edu/>
- Research, training, assessment, resources models

Build community-based institutions



THE FENWAY INSTITUTE

<http://fenwayhealth.org/>



About Us

Meet Center leadership
and staff

Programs & Services

Learn how we work to
improve trans health

<http://transhealth.ucsf.edu/>

But, Who Makes the Rules?

- Common rule provides no answer.
- LGBTQ community?
- Roles of researchers ...
- Roles of community members ...

Cultural shift ...

What IRBs Can Do

Check for risk related to vulnerabilities and mitigating resiliency at each step of research process



What IRBs Can Do

- Make IRB proactive and helpful
- Check for credentials and training of entire research team, not just PI
- Consider changes to IRB forms
- Conduct site visits/check-ins for certain studies
- Encourage more participation from people with lived experience in certain studies and/or to review certain studies

What We All Can Do

Stigma: Know it, see it, believe it.

Resilience: Look for it, find it.

Intentional: Just because it's good science doesn't mean it's good for people.

Reciprocity: What does this work give to the people who it's about?

A vintage yellow rotary telephone is shown against a plain white background. The phone is oriented vertically, with its handset on the left and its base on the right. A white rectangular text box is superimposed over the center of the phone. The text inside the box is in a bold, blue, sans-serif font. The telephone's keypad is visible, showing numbers 3 through 9, along with letters associated with each number (BC, MNO, UV, WXY). The handset is connected to the base by a yellow coiled cord.

THE FRIDAY AFTERNOON IRB PHONE CALL

OTHER DISCUSSION & SESSION NAMING

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Thank you!!

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