(C20) Populations on the Edge

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Disclosure: Cynthia A. Gómez

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Disclosure: John A. Guidry

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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.
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 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
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

- Coercion/ undue influence
- Impaired decision making
- Exposure leading to personal harm
- No direct benefit
- Stigmatizing or pathologizing a group
- Exploitation
Individual AND Community Harm
Types of Communities

Community of Interest

Community of Place
Belmont Report Principles

- Respect
- Community
- Justice
- Beneficence
Domains of Vulnerability & Resiliency

- social
- medical/health
- economic
- cognitive
- institutional/deferential

Maslow’s Hierarchy of Needs

- Biological and physiological
- Safety
- Love and belongingness
- Esteem
- Cognitive
- Aesthetic
- Self-actualization
- Transcendence
HOMELESSNESS & SUBSTANCE USE
What’s the Problem?

https://commons.wikimedia.org/wiki/File:Homeless_Man.jpg
What’s the Harm?

https://commons.wikimedia.org/wiki/File:Photograph_of_Mrs._Reagan_speaking_at_a_%22Just_Say_No%22_Rally_in_Los_Angeles_-_NARA_-_198584.jpg
Research with or about LGBTQ individuals

creating new knowledge with a complex community
What is the Problem?
What is the Problem?

HEALTH WATCH

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

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 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
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

http://fenwayhealth.org/

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 …
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?
THE FRIDAY AFTERNOON
IRB PHONE CALL
OTHER DISCUSSION & SESSION NAMING
Thank you!!