



Community Consultation and Ethically Responsible Mental Health Research with Populations of Color

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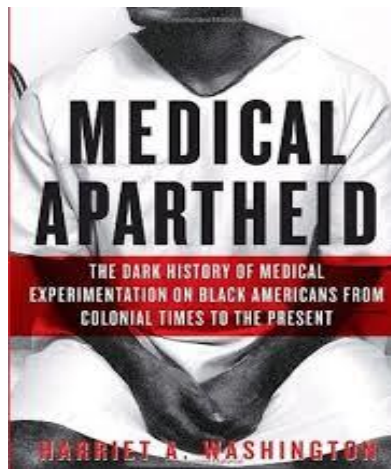


TRUE OR FALSE?

PEOPLE OF COLOR
DON'T LIKE TO
PARTICIPATE IN
RESEARCH

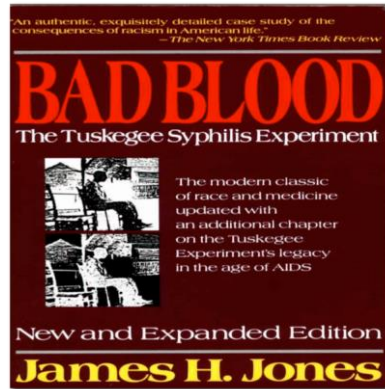
- I thought it [survey] was good. I'm glad you chose me to take the survey. I will be ~~very interested in another one very soon,~~ thank you.
- To tell you the truth, I love it and appreciate your effort on helping us black young men. Keep up the good work.
- I really think that it's a really good survey for young black men. I really enjoyed engaging in taking this survey. I highly appreciate it.
- The survey was very interesting and will be a great deal of information that will better many communities.

History of Mistreatment in Medical Research

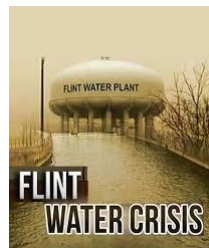


History of Mistreatment in Medical Research

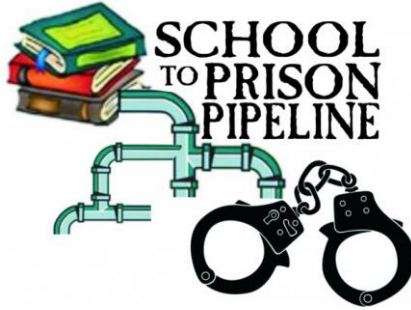
- ❑ Guatemala syphilis study (1946-1948)
- ❑ Jewish Chronic Disease Hospital Study (1963)
- ❑ Human radiation experiments (1940s-1960s)
- ❑ PHS syphilis study, aka "Tuskegee" (1932-1972)



Discontent with Current Conditions/Policy



Negative Experiences with Education/Academia



Ethics

□ Ethics

- The branch of philosophy that deals with morality.
 - concerned with distinguishing between right and wrong human actions

□ Bioethics

- The discipline dealing with the ethical implications of biological and behavioral health and its applications especially in medicine and healthcare

Codifying BioEthics

- Nuremberg Code (1949)
- Helsinki Code (WMA, 1964, 2013)
- National Research Act (1974)
- 45 CFR 46
- Belmont Report (1979)



APA Ethics Code

- APA's first ethics code developed in 1953
 - 10 updates, most recent in 2010
 - Current code has
 - 5 principles
 - 10 general standards
 - 88 enforceable standards

APA Ethics Code

- Five Principles
- Principle A: Beneficence and Non-maleficence
 - Benefit; Do no harm
- Principle B: Fidelity and Responsibility
 - Relationships of trust; Professional and scientific responsibility
- Principle C: Integrity
 - Accuracy, honesty, truthfulness
- Principle D: Justice
 - Access to fairness and justice for all
- Principle E: Respect for People's Rights and Dignity
 - Respect dignity and worth, rights to privacy, confidentiality, and self-determination.

APA Ethics Code

- Ten General Standards
 - Standard 1: Resolving Ethical Issues
 - Standard 2: Competence
 - Standard 3: Human Relations
 - Standard 4: Privacy and Confidentiality
 - Standard 5: Advertising and Other Public Statements
 - Standard 6: Record Keeping and Fees
 - Standard 7: Education and Training
 - **Standard 8: Research and Publication**
 - Standard 9: Assessment
 - Standard 10: Therapy

Standard 8: Research and Publication

- 8.01 Institutional Approval
- 8.02 Informed Consent to Research
- 8.03 Informed Consent for Recording Voices and Images in Research
- 8.04 Client/Patient, Student, and Subordinate Research Participants
- 8.05 Dispensing with Informed Consent for Research
- 8.06 Offering Inducements for Research Participation
- 8.07 Deception in Research
- 8.08 Debriefing
- 8.09 Humane Care and Use of Animals in Research
- 8.10 Reporting Research Results
- 8.11 Plagiarism
- 8.12 Publication Credit
- 8.13 Duplicate Publication of Data
- 8.14 Sharing Research Data for Verification
- 8.15 Reviewers

Ethical Issues in Research

- The research community relies heavily upon self-regulation.
 - Universities and government agencies have established Institutional Review Boards (IRBs) to deal with ethical and procedural questions regarding human and animal research.
 - Principle Investigators develop appropriate guidelines for designing and conducting research

Ethical Issues in Research

- The conduct of scientific research involves two general categories:
 - 1) scientific misconduct, such as falsification of data, plagiarism, and undeserved credit.
 - 2) protect research participants against undue risk.

Scientific Misconduct

LaCour & Green (2014) Data Forgery

- UCLA political science graduate student Michael LaCour and Columbia University political science professor Donald Green.
- Article was published in Science in December 2014, and retracted in May 2015
- The data in the study forged by LaCour.

Scientific Misconduct



- ❑ **Ellen Roche Johns Hopkins (2001)**
- ❑ The cause of Roche's death was almost certainly a drug that she inhaled so that doctors could test a theory on how asthma occurs.
- ❑ The chief researcher missed literature reports of safety problems published in the 1950s.
- ❑ The IRB at JHU failed to press the researcher hard for more safety data, even though the drug had not been approved by the FDA.
- ❑ When Roche developed a cough and shortness of breath, the researcher discounted the symptoms and never alerted the review board.

Scientific Misconduct

- ❑ Other forms of scientific misconduct
 - Plagiarism
 - Going outside of expertise
 - Misuse of data
 - Underserved credit/Omission of authorship

DATA SHARING AGREEMENT

This document describes an agreement between the Principal Investigator responsible for the research (PI), and the collaborating investigator or trainee named below (CI). In this agreement, the CI signs on behalf of her/himself, but this agreement extends to constrain the activities and behavior of research assistants, research fellows, or other members of the research staff working with the shared data. The PI agrees to share the data under the following conditions:

1. The CI agrees to receive a dataset from which all linking identifiers have been removed, except for an encrypted identifier that the PI or other designated staff member can use to make a linkage back to the original identifiers.
2. The CI agrees to send the dataset back to the PI upon completion of the work, and agrees not to share the dataset with others, unless obtaining prior approval of the PI.
3. The CI agrees to maintain confidentiality and privacy safeguards that the PI created as part of this protocol. This includes working under the aegis of the PI and the federal Certificates of Confidentiality issued to the PI.
4. The CI agrees to provide the PI with a copy of data analyses and abstracts or manuscripts prepared for review and either presentation or publication, giving ample time for PI-level review of the material and checking of its conformity and accuracy in relation to characteristics of the original sample and data. When appropriate, the PI may designate 1-2 co-authors who have been responsible for important elements of the proposed research, and who merit inclusion as co-authors in any publications derived from the shared data.
5. The CI agrees to the boundary conditions of the original proposal under which data sharing was requested (concept sheet form). That is, the CI will not re-specify the proposed response variables, nor the proposed covariates, without prior approval of the PI.
6. The CI agrees to acknowledge support of the pertinent grant award as part of the published acknowledgments section for any paper produced with data shared under this agreement, as well as sharing. The PI will supply this information prior to data dissemination.
7. The PI reserves the right to re-assign the proposed scope of work to another CI or to herself, if the proposed work has not been completed and accepted for publication within 12 months of the initiation of this agreement, unless there is an advance agreement for a mutually acceptable extension of this agreement.

Principal Investigator:

Collaborating Investigator/Trainee:

Date: _____

Date: _____



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Respect in Research

- Protecting participant autonomy
 - Right to refuse participation in research
 - Disclose nature of research
 - Informed consent

Respect in Research

- What issues have seen/heard about in mental health research with populations of color in terms of disclosure of the nature of research, informed consent and right to refuse participation?



Exercise

- Discuss in pairs
- What are two ways you can improve your informed consent procedures?
- What is one idea you have to make your informed consent format easier to comprehend?

Beneficence in Research

- Maximizing good outcomes for science and research participants
- Avoiding or minimizing unnecessary risk

Beneficence in Research

- Avoiding or Minimizing Risk
- Risk level is compared to “minimal risk” as defined by the federal regulations:
 - Minimal risk is the probability and magnitude of harm or discomfort anticipated in the research are **not greater than those ordinarily encountered in daily life** or during the performance of routine physical or psychological examinations or tests (45.CFR.46.102(i)).
- Greater than minimal risk studies require full committee review, while minimal risk studies may be eligible for expedited review or exempt certification.



Beneficence in Research

- Greater-than-minimal-risk examples
 - A psychological or behavioral intervention study involving individuals with serious mental health disorders includes treatments that have a reasonable possibility of exacerbating distressful or maladaptive psychological or behavioral symptoms (including self-harm).
 - The potential for physical harm associated research participation of victims of interpersonal violence.



Beneficence in Research

- Examples of Vulnerable populations
 - Children
 - Pregnant Women
 - Incarcerated
 - Persons from economically or socially disenfranchised groups
 - Persons with Undocumented Status
 - Individuals with mental health disorders
 - Individuals engaged in illegal activities (e.g., substance use)

Beneficence in Research

Table. Kinds of Harms Identified in the Belmont Report

Kind of Harm	Illustrations
Psychological	Boredom, anxiety, embarrassment, depression, or exacerbation of a psychological condition
Physical	High blood pressure, sexual dysfunction, death, or exacerbation of a physical condition
Legal	Legal fines or imprisonment
Economic	Lost time at work or medical bills
Social	Stigmatization, harm to reputation, or harm to relationships

Beneficence in Research

- Things to consider
 - Risk to whom? Individual, community, population
 - How risk is defined?
 - 'Daily Life'
 - Omission from research literature is also a risk/harm



Exercise

- Discuss in pairs
- List three risks involved in your area of research?
 - Psychological, Medical/Physical, Legal, Economic, Social.
- What are two ways you can minimize harm from these risks?

Justice in Research

- Carefully considered research procedures (including cultural, contextual factors)
- Fair administration of procedures and/or research
- Balanced distribution of costs and benefits

Justice in Research

- “Fairness and Equality”
 - Distribution of scarce resources
 - Who gets what treatment?
 - Burdens and benefits of new or experimental treatments distributed equally among all groups

Justice in Research

- Limited codes or regulations related to this principle
- Communities often left without tangible benefits



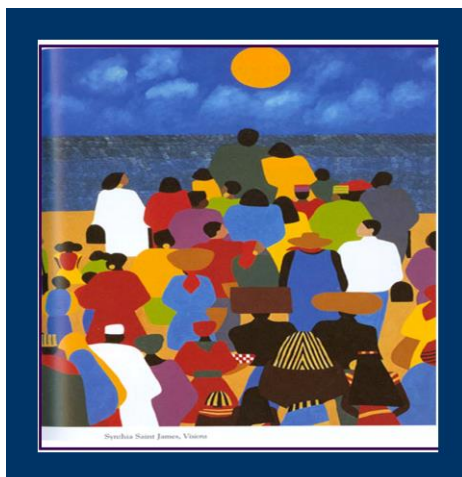
Exercise

- Discuss in pairs

- What are two contextual factors (historic/contemporary) that might impact burden vs. benefit of your research with the populations you serve?
- What can you do to balance the distribution?



Community Consultation



**Help
Community Understand
Benefits of
Mental Health Research**

Community Consultation



Create lay friendly workshops about research

- Present to recruitment sites
- Present to potential participants
- Present at community events

**Learn from Community
About Most Pressing
Research Questions**



Community Consultation

- Hold town hall meeting to introduce self and prior work
- Let attendees share interests, concerns, ideas
- Discuss research process and overall goals
 - No direct ask (e.g., no discussion of specific projects/recruitment)
- Collect contact information
- Stay in touch (listserv, fb group)



**Have Community
Inform Ethical
Decision -Making**



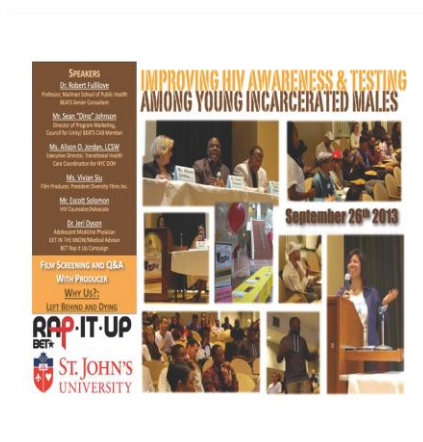
Community Consultation

- BEATS study results found high level of concurrent sexual relationships and descriptions of many acts of criminal behavior
 - Engage with community stakeholders about how to disseminate information in a factual manner while respecting concerns
 - Think of potential issues ahead of time, particularly questions during presentations (e.g., sex while in prison stereotype)



**Provide Community
with
Research Findings**

Community Consultation



Black girls are using drugs to feel good cause they don't feel good about themselves

By Dr. Seyatta A. Wallace

—Black girls will steal your boyfriend— Black girls are loud and have an attitude—

These are among the statements highlighted in my research which was recently published in the article "Gold Diggers, Video Vixens, and Jezebels: Stereotype Images and Substance Use Among Urban African American Girls" in the *Journal of Women's Health*. The federally funded study included African American adolescent girls (ages 10-15). I was very alarmed by the findings and felt a scientific article buried in the halls of academe was not doing justice to the important information found in the report.

Almost half of the girls agreed with statements such as:

- Straightened hair looks better than natural hair
- Black girls are loud and have an attitude
- Having long hair gives you a better appearance
- Black girls are mad and ready to fight

Almost a quarter of the girls agreed with statements like:

- Black girls are gold diggers
- Black girls use sex to get what they want
- It's important to have good hair

Findings from the study showed that girls who agreed with these types of statements were most likely to use drugs. Teens that use drugs at such an early age are at risk for many other issues including school dropout, early sexual activity, violent behavior, STD/HIV and involvement in the criminal justice system.

The findings are a call for us to pay attention. It shows us that some of our girls are buying into the negative stereotypes they may be seeing in the media/popular culture or their surroundings about Black girls/women. It underscores that Black girls are getting a message that what they look like counts and for some of them this means believing having darker skin and/or kinky hair counts less.

We need to ask ourselves as a community, where are our girls hearing or seeing these messages? In what ways are those messages being validated and reinforced? Are we doing a good job of helping them navigate the messages they are observing? Are we speaking up about the need for more balanced images?

So what can we do? Here are several tips to help Black girls through these difficult issues:

Community Consultation

- Community consultation is a 'living and breathing' partnership with each group providing different expertise.
- In the end, as PI you are the final decision-maker.



Exercise

□ Discuss in pairs

- What are three ethically related concerns of members of the communities you conduct research?
- What are two ideas you have for consulting with your communities about your ethical decision-making?

TRUE OR FALSE?

**PEOPLE OF COLOR
DON'T LIKE TO
PARTICIPATE IN
RESEARCH**





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