Nov 12th, 9:00 AM - 9:45 AM

**What if Black Lives MEANINGFULLY Mattered in Research?**

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Black Lives Matter in Research

A Look at Inequalities in Research and Research Methodologies

Thursday
November 12, 2020
9 a.m. to 2 p.m.

FREE REGISTRATION
THANKS & ACKNOWLEDGEMENTS!

- Conference Organizers: Hila Berger, Amy Krenzer, & Denise O’Shea
- Dr. Jason M. Williams
  - The Democratizing Knowledge Andrew Carnegie Mellon Fellowship
- The Members and Research Affiliates of The Bronx Community Research Review Board Inc.
- Past, Present, & Future Black Feminist Organizers, Ethicists and Epistemologists
The views and opinions expressed in this discussion, about what it would mean for ALL Black Lives to **MEANINGFULLY** Matter in research, are my own and do not necessarily reflect the official policy or position of Bronx Community College &/or The Bronx Community Research Review Board Inc.

All claims included in this presentation are based on extensive interdisciplinary literature reviews, interviews with qualitative researchers, vast experience conducting community research review, and over 10 years of consultation work to participatory action and community engaged research projects.

The presenter deliberately refuses conceptualizations of ethicality rooted in ideological neutrality. However, the views and research therein are not intended to malign any: group of peoples, religion, ethnic group, club, organization, company, individual, or anyone or anything.
WHAT IF BLACK LIVES ACTUALLY MATTERED IN RESEARCH?: INSIGHTS FROM UNAPOLOGETIC BLACK FEMINIST P.A.R.

DR. MONIQUE A. GUISHARD (SHE/HER/HERS)
Associate Professor of Psychology, Bronx Community College Chair, The Bronx Community Research Review Board
Cite Black Women.
• Corbie-Smith, G., Thomas, S.B., & St. George, D.M. (2002). Distrust, race, and research. *Archives of Internal Medicine, 162*(21), 2458-2464.
#CITEBLACKWOMXN!


I went to a talk about a community research review board newly active in the Bronx...
“Ethics are pedagogies of practice. IRBs are institutional apparatuses that regulate a particular form of ethical conduct, a form that may be no longer workable in a transdisciplinary, global and postcolonial world.”
(Denzin, 2008 p. 1)

#SayTheirNames
#BetseyAnarchaLucy
The Relf Sisters
Forty-seven years ago, two Alabama sisters, 12 and 14, sued a federally funded clinic after they were sterilized without consent in 1973.
KENNEDY KRIEGER LEAD PAINT STUDY

- A study conducted by Johns Hopkins Kennedy Krieger Institute (KKI) in poor neighborhoods in Baltimore, MD during the 1990s.

- Lead paint poisoning of children was an epidemic in the 1990s.

- This study wanted to compare different degrees of lead paint abatement. Poor families were recruited to move into homes that were only partially abated.
POLL QUESTION #1

HOW MANY BLACK FOLX WERE ON THE BELMONT COMMISSION?

A. 0
B. 1
C. 2
D. I don't know

I WAS ALSO IN MY FEELING BECAUSE HE DIDN'T KNOW RESEARCH ETHICS HISTORY!
THE MEMBERS OF THE BELMONT COMMISSION (1979)

- Kenneth John Ryan, M.D., Chairman, Chief of Staff, Boston Hospital for Women.
- Joseph V. Brady, Ph.D., Professor of Behavioral Biology, Johns Hopkins University.
- Robert E. Cooke, M.D., President, Medical College of Pennsylvania.
- Dorothy I. Height, President, National Council of Negro Women, Inc.
- Albert R. Jonsen, Ph.D., Associate Professor of Bioethics, University of California at San Francisco.
- Patricia King, J.D., Associate Professor of Law, Georgetown University Law Center.
- Karen Lebacqz, Ph.D., Associate Professor of Christian Ethics, Pacific School of Religion.
- David W. Louisell, J.D., Professor of Law, University of California at Berkeley.
- Donald W. Seldin, M.D., Professor and Chairman, Department of Internal Medicine, University of Texas at Dallas.
- Eliot Stellar, Ph.D., Provost of the University and Professor of Physiological Psychology, University of Pennsylvania.
Dorothy I. Height, MA

Patricia A. King, JD

SOURCE: The Harvard Crimson

Source: David Kohl / AP

THE MEMBERS OF THE BELMONT COMMISSION (1979)
June 30, 2004
Belmont Oral History Project

Interviewer: Dr. Bernard A Schwetz, D.V.M., Ph.D., Director, Office for Human Research Protections
“Though important efforts to introduce context and social justice concerns into bioethical thought have been made, much still remains to be done. The challenge that bioethics and health law face in confronting race is formidable and substantial. Characterizing differences in terms of race is only the beginning, it is important to go beyond merely describing and defining the perspectives of racial groups in order to engage directly and to transform the core norms, values and practices of bioethics. Confronting race is critical in uncovering the ways we interpret human similarity and human difference, hierarchies, and power in the practice of medicine and research.”

There has always been a relationship between...

Black Feminism(s) & Black Women's Organizing

&

Research Ethics in the United States
Black lives have always mattered.
“If white academics in particular forget this all too pertinent and ever-unfolding United States history and operate in a race- and power-evasive manner in our construction of bioethical theories, knowledge, methods, and policies, we risk reproducing white privilege and supremacy in our own cultural practice. That is why I am arguing that we need to be more vigilant and self-reflective regarding our production of knowledge and our cultural practice within the largely racially homogenous (i.e., Caucasian) zone of bioethics in the United States. Such vigilance will enable us to enter into a more complex, dynamic, and historically situated analysis of our own positionings—particularly as white academics in bioethics—in a racially hierarchical society.”

“Even when the racism, ethnocentrism, and sexism in haunting key events have been acknowledged, they have usually been treated as a layer of extra insult added onto the more fundamental harm (depriving the generic research subject of the chance to give genuine consent for instance). At most, bioethics have called for treating people of Color as whites are treated, or women as men. What is missing is a bioethics analysis that places race, ethnicity, and gender at the center and delves into the significance of difference.”

IN WHAT WAYS DOES WHITE NORMATIVITY & ANTI-BLACKNESS SHOW UP IN ETHICS REVIEW?

SEE ALSO

- Klitzman R. Institutional review board community members: who are they, what do they do, and whom do they represent?. *Acad Med*. 2012;87(7):975-981.
IN TOO MANY WAYS!!!

I cannot stress enough how important representation is ...

If I wanted a white savior, I’d watch Sandra Bullock in The Blindside.
The lack of representation of non-white, dis/abled, LGBT+ persons within IRB boards

The onus of diversity is often thrust on the community members who are outnumbered & out jargoned.

Presumptions about the purpose and theories of change in research.

Research is not a benevolent enterprise. It ALWAYS involves commodification & appropriation.

Research as a transaction, involving infrequent encounters between strangers.

It is (or should be) RELATIONAL, REFLEXIVE, & RESPONSIVE.

The decision to consent/participate as an individual one. Participation as only impacting persons who provided consent.

Many of us make these decisions relying on input/consultation with others. Black folx not seen as agentic; capable of engaging beyond passive participation.
White normativity shows up, in research, too many ways!!!

5. Reliance on whitestream ethical theories/perspectives/practices particularly around justice.

6. Narrow conceptualizations of risks & benefits to participation in research. Preoccupation with ethics of procedures & intent, which are not necessarily demonstrable ethics.

7. Persistent refusal to engage with non-whitestream, critical race, emancipatory, liberatory, qualitative approaches to research & ethics review practiced by racialized, minoritized, and marginalized scholars.
Research ethics training/education is comprised of incomplete histories of the ways that research has historically been (and continues to be) a site of trauma, exploitation, commodification, and humiliation for Black peoples.

It does not adequately address the ways academic research is complicit in sustaining settler colonialism & white imperialist capitalist patriarchy:
- Vaccines for whom?
- Helicopter/Parachute/Mosquito Research
- Damage centered inquiry/Deficit theorizing

It CENTERS IRBs as the arbiters of ethics. Encourages research down, but not research up power asymmetries.
POLL QUESTION #2

HOW DOES YOUR LOCAL IRB HANDLE/REVIEW COMMUNITY ENGAGED AND/OR PARTICIPATORY ACTION RESEARCH PROJECTS?

A. I don't know.
B. The projects are usually exempt(ed) or expedited.
C. It rigorously reviews them.
D. We don't get many submissions to tell.
I’m going to be #unapologetic and share that IRBs and researchers can learn much about meaningfully holding space for #blacklivesmatter-ing in research from BFPAR, CRRBS, & CERBS.
CERA taught us about what BlackLivesMatter-ing in research looks like.
Black Feminist Participatory Action Research (BFPAR) is an unapologetical continuum of approaches to participatory inquiry and action between Black scholars and Black communities. BFPAR actively engages, produces, and conducts research in service of empowering and improving the plight of Black peoples. Its methodologies are diverse; it can aim to produce new shared knowledge, but also includes secondary data and archival analyses, because new research is not always the intervention that is needed (Guishard, 2018; Guishard & Tuck, 2013; Tuck & Guishard, 2014; Tuck & Yang, 2014).
More on Black Feminist P.A.R.

- BFPAR does not frame Black people as researchable objects to be classified and surveilled.
- It instead reflects on the racist, sexist, ableist history of research on Black bodies (and other bodies) and endeavors to empower participants through research.
- BFPAR recognizes the ways settler colonialism and white supremacist capitalistic hetero-patriarchy continue to shape research.
- However, it dares to imagine that research can be used as a tool to connect us together; wielded to advocate for social justice; and used to document our: private inequalities, shared hardships, histories activism/resistance, and desires.
BFPAR HAS TAUGHT TO CONDUCT RESEARCH IN WAYS THAT LOVE ALL BLACK PEOPLE

The ethics that guide our work.

We are committed to facilitating a safe space in which all CERA participants feel their abilities, race, ethnicity, language, sexualities, age, gender, lived experience(s), etc., are honored and respected.

CERA is founded on LOVE, love of our neighbors (of all ages, all hues, and backgrounds), concern for their needs, passion to change racism and exploitation of us in research. We DO NOT have space for HATEFULNESS within the community we are trying to grow. If you are accepted we will ask you to commit to checking us and each other for:

ABLEISM
AGEISM
ANTI-IMMIGRANT HATE
FATPHOBIA
HOMOPHOBIA
ISLAMOPHOBIA
RACISM
SEXISM
TRANSPHOBIA
OR any other kind of HATEFULNESS.
RESERVE TIME
to develop shared aims, timeline, and expectations.

ENGAGE WITH PROFESSIONAL HUMILITY...
respectfully engage experiential knowledge and organize before inserting your research expertise.

SHARE EVERYTHING
the burdens, benefits, and products of your collaboration.

ANTICIPATE
disagreements; work through them with MOUs, MOAs, and project mediators. Do not gloss over differences in ethics and values. They will fester and erode trust.

SUSTAIN TRANSPARENCY
commit to demonstrating partnership ethics by sharing plans, sharing decisions, and constantly checking in with each other.

RETURN RESULTS
to wide audiences, to folks most impacted in multiple mediums.
The Bronx Community Research Review Board Inc. advocates for Bronx Residents by engaging researchers and communities, to assure culturally appropriate research practices that are fair, ethical, and will demonstrably address: health equity, well-being, social, and environmental justice in the borough we call home.
My momma and the BxCRRB said not to let you in, because you look like exploitative researchers! We don’t need more of all y’all in the Bronx. 👋

You wish you was from the Bronx at that moment?
WITH RADICAL LOVE FOR OUR NEIGHBORS, OUR AIDS ARE TO:

- TRANSFORM the culture of health research in our borough (from top-down to bottom-up) by increasing the power of those who are researched.
- PROTECT the health of the Bronx through community engagement, our research review process, and promoting the return of research findings back to impacted persons and communities.
- INSIST on the shared ownership of the benefits and products of research.
- PROVIDE **healing-centered education to Bronx patients AND researchers, through our Community Engaged Research Academy (CERA).
What are YOUR research questions?
What questions do your community partners NEED answered?
How are you incorporating MULTIPLE RESEARCH METHODS?
MULTIPLE EPISTEMES, ONTOLOGIES, & HERMENEUTICS?
What is off-limits and sacred?
Beyond your university IRB, have you developed an MOU?
An MOA? Have you been TRUTHFUL about your time, promises, and vulnerability?
Do you have evaluative allies?
What is your plan to shareback findings?
To adjourn the project?
POLL QUESTION #3

WHAT DOES #BLACKLIVESMATTER-ING IN RESEARCH MEAN TO YOU?

A. A diversity and inclusion project within IRBs.
B. Updating research ethics education modules to include excluded histories.
C. Requiring graduate and undergrad programs to address anti-Blackness in research.
D. Increasing funding opportunities for Black academicians and CBOs.
E. Establishing and sustaining independent Community-IRBs, CRRBs, & CERBs staffed by Black folx.
F. All of the above and more.
G. None of the above.

PHOTO BY GAYATRI MALHOTRA
THANK YOU!

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