

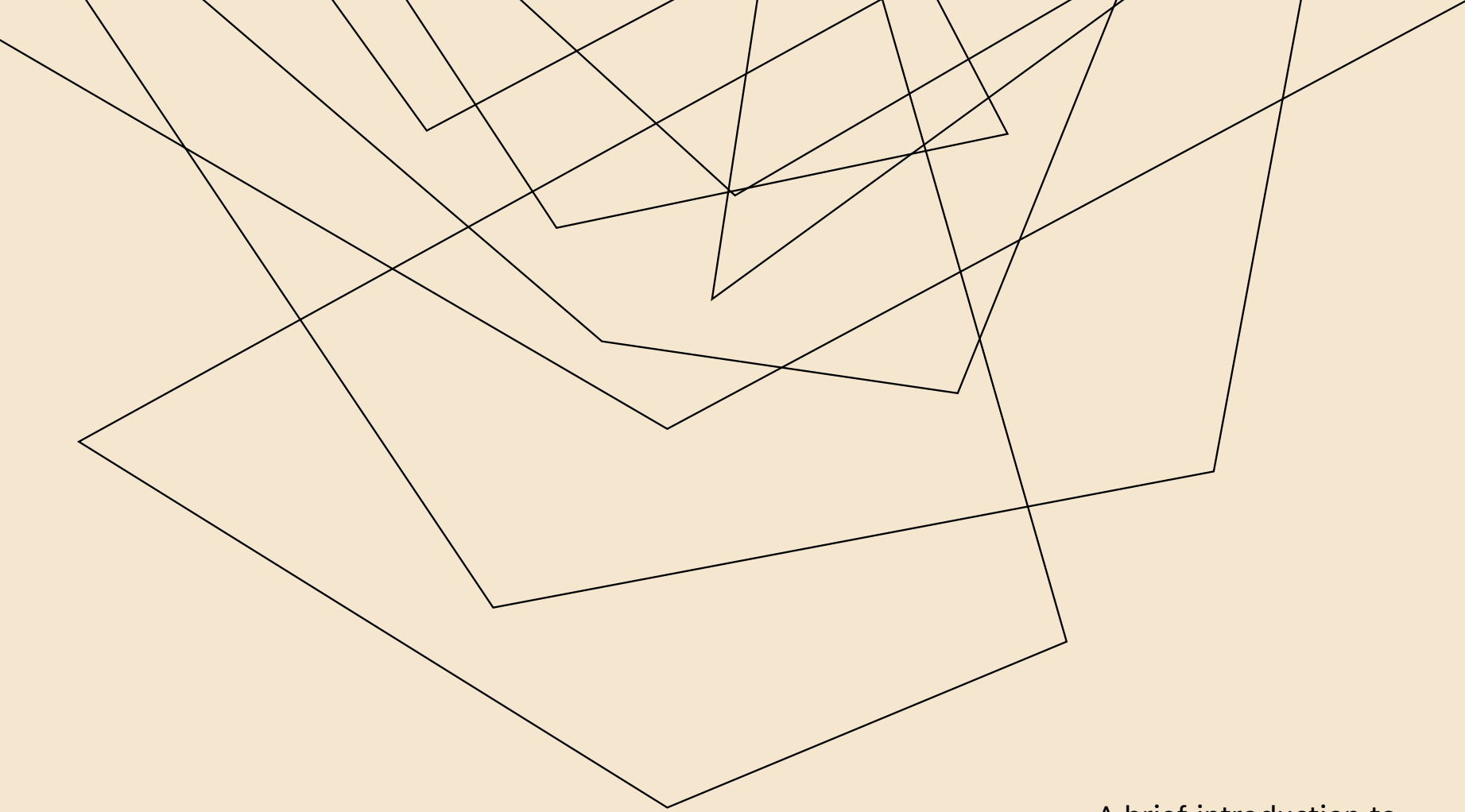


**THE FIRST BLACK AND
BROWN IN BIOETHICS
CONFERENCE 2024**

“Engaging Diversity
in Bioethics Theory
and Practice”

Tuesday 9 April 2024

BLACK AND BROWN IN
BIOETHICS



A brief introduction to

**BLACK AND BROWN IN
BIOETHICS**

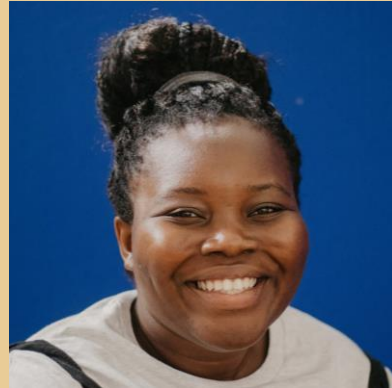


OUR TEAM



HARLEEN KAUR JOHAL

Co-Founder
PhD Candidate
University of Bristol



MATIMBA SWANA

Co-Founder
PhD Candidate
University of Bristol



KUMERI BANDARA

Co-Founder
DPhil Candidate
University of Oxford

OUR MISSION

Black and Brown in Bioethics (BBB) was launched following the realisation that there are no regular events in UK bioethics, which are led by people of colour or focus on issues affecting ethnic minorities.

Our mission is to achieve racial equity within the UK bioethics community by creating a network that expands opportunities for community engagement, promotes anti-racism, and accelerates the well-being, education, and health of all people of colour.

By upholding and championing our key values, we hope to work towards equity for people of colour within the UK bioethics community.

Inclusivity
Individuality
Collaboration
Courage
Empathy
Equity

PAST PROJECTS

PANEL

12 June 2023

–

Postgraduate Bioethics
Conference on
“Disrupting Bioethics as
a Postgraduate:
Advocacy and Activism”

WORKSHOP

22 June 2023

–

UKCEN Pre-Conference
Workshop on
“Addressing Inequity in
and through Clinical
Ethics”

WEBINAR

5 September 2023

–

“Bioethics and Global
Health: In Search of
Common Ground”

WEBINAR

1 November 2023

–

"Insights from industry:
inclusionary digital
health"

ONGOING PROJECTS

RESEARCH

Being Black and Brown in Bioethics (BBBB)

–
A qualitative study into the experiences of postgraduate researchers of colour working in UK bioethics, funded by IME.

Research

Inclusive Bioethics

–
The research project "*Inclusive bioethics: modifying methodology to transform research*" has three components: a literature review, an autoethnography, and a Delphi study, supported by EACME.

EDUCATION

Inclusive Bioethics

–
Creating a video series of educational videos on bioethics methodologies, that are not taught as part of mainstream canon, funded by IME PSC Wellcome Trust.

PODCAST

Power and Privilege in Academia

–
A limited podcast series, in conversation with Black and Brown leaders in bioethics, supported by Oxford Podcasts.

FORUM

Medical Humanities Research Forum

–
A forthcoming edited collection in BMJ Medical Humanities, on the theme of "Who is a Global Health expert: Reimagining Global Health Futures".



FOLLOW OUR WORK &
JOIN OUR MAILING LIST

bristol.ac.uk/black-brown-bioethics

CONTACT US

bbb-network@bristol.ac.uk

KEYNOTE ADDRESS 1 UNFORESEEN CHALLENGES AND GATEKEEPERS TO PROGRESS IN BIOETHICS

Sridhar Venkatapuram (King's College London)
Agomoni Ganguli-Mitra (University of Edinburgh) as Chair

Word Cloud

26 responses



ORAL ABSTRACT PRESENTATIONS (I)

Jordan A. Parsons as Chair

Should vaccination status be a consideration during secondary triage?

Isaac Jarratt Barnham - FY1, Buckinghamshire NHS Trust

The Ethics of Privacy in Charitable Crowdfunding

By Ashmita Grewal

Positionality

- Born and raised in Canada
- South Asian Ancestry



The Rise of Crowdfunding

- Campaigns can be created for oneself, on behalf of others, and for specific organizations
- Replaces relationship asymmetries between donor and recipient ⁽¹⁾





Inequities with Crowdfunding

- PRIVACY ⁽²⁾
- Should exchanging deeply personal information online to address personal circumstances be permitted?

What does privacy mean?

- Onion Analogy – the different layers represent different layers of private information ⁽³⁾
- Privacy as having control over who has access to personal aspects of oneself ⁽³⁾




Ethics of Privacy in Crowdfunding

- Having control is important for making decisions autonomously and formation of relationships, among other things ⁽³⁾
- Crowdfunding campaigners often do not have control over who views this information or how the information is passed on ⁽³⁾
- Crowdfunding campaigners are often compelled to include as many details as possible to raise funds ⁽⁴⁾



Limited Research

- No study has examined the topic of privacy related to crowdfunding from an ethical perspective to understand the tension and pressure experienced while navigating privacy related concerns
 - Our current study conducts semi-structured interviews with 30 individuals crowdfunding for health and/or housing reasons
- 




Crowdfunding Campaigners Approach to Privacy

Campaign Accessible by All

Potential Harm to Oneself or Others

Intrusive / Probing

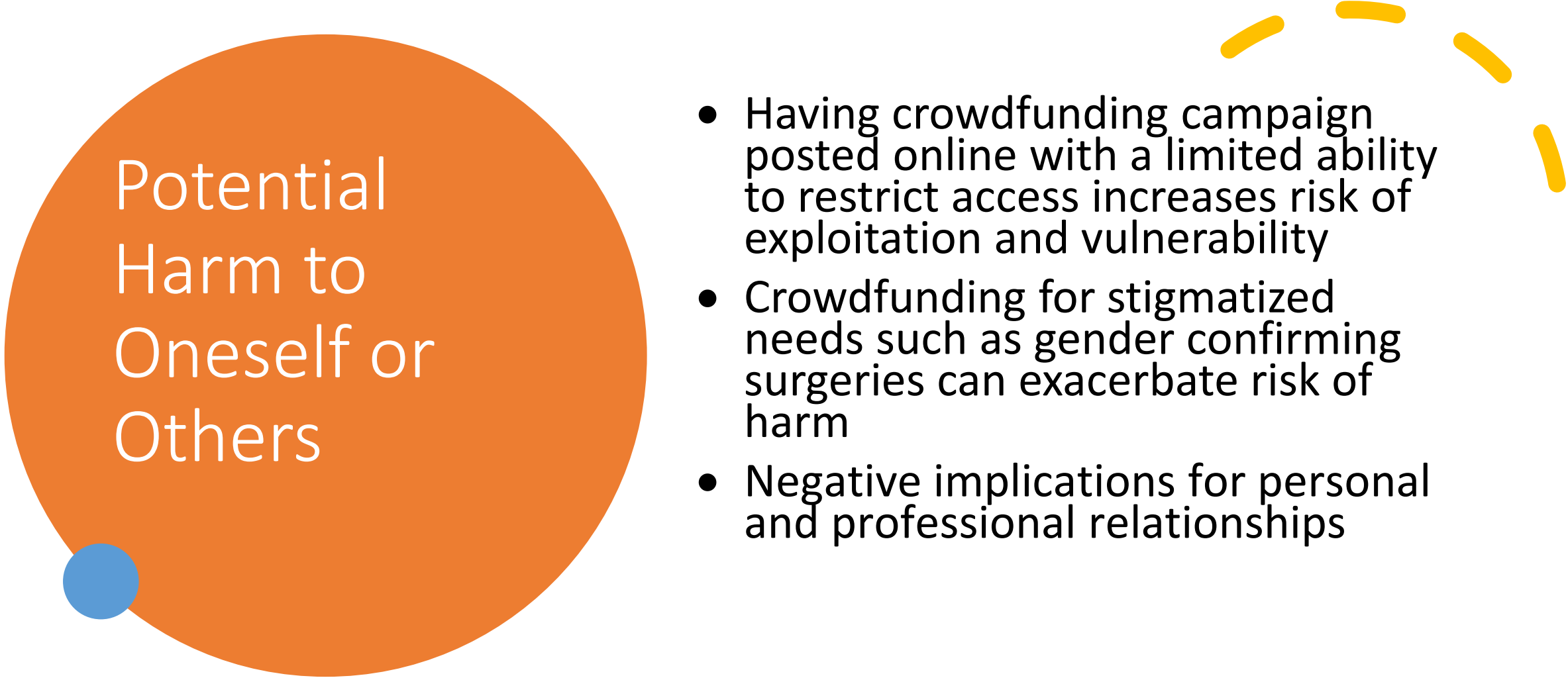
Information Collection & Sharing



“I didn't want certain people to see this. So, I was very careful on social media about making it not visible to certain people. But then being asked to do the study. It kind of made me be like, Oh, okay, interesting. Like people I don't even know can find this”



Campaign
Accessible by
All



Potential Harm to Oneself or Others


- Having crowdfunding campaign posted online with a limited ability to restrict access increases risk of exploitation and vulnerability
- Crowdfunding for stigmatized needs such as gender confirming surgeries can exacerbate risk of harm
- Negative implications for personal and professional relationships




Intrusive/ Probing

“I definitely was influenced to share more than I wanted to, because of other people...asking more questions in regard to my surgery”

- Probing people to understand their experiences, and not usually with the aim of donating.

- 
- Some participants were uncertain whether their personal information would be shared to other social media platforms, as this can create other risks.



Information
Requesting &
Information
by Platforms


Advice to Campaigners

- Be both cautious and specific
- Be informed
- Consider Uncertainties





Complexity of Concerns

- Concerns heightened for people with complex personal histories and circumstances
 - Thus, crowdfunding heightens vulnerabilities for select groups of people.
- 



Equity and Inclusion

The authors have no potential conflict
of interest to disclose.

Thank you!

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(4) Snyder, J., Mathers, A., & Crooks, V. (2016). *Fund my treatment!: A call for ethics-focused social science research into the use of crowdfunding for medical care*. 169(27–30).
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**Charles
University**

BLACK AND BROWN IN
BIOETHICS

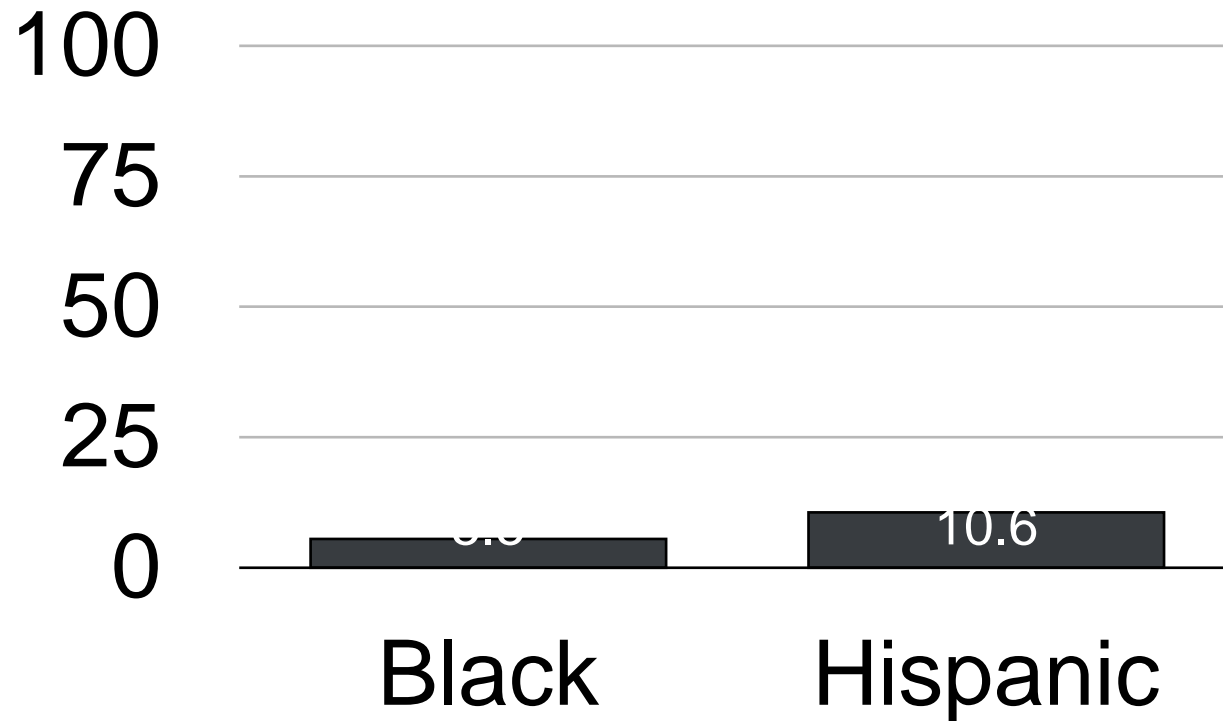
Restorative Justice Bioethics: Addressing Racial Disparities in Clinical Trials

**The First Black and Brown in Bioethics conference 2024
“Engaging Diversity in Bioethics Theory and Practice”**

Georgios Kalaitzidis, PhDc Charles University in Prague

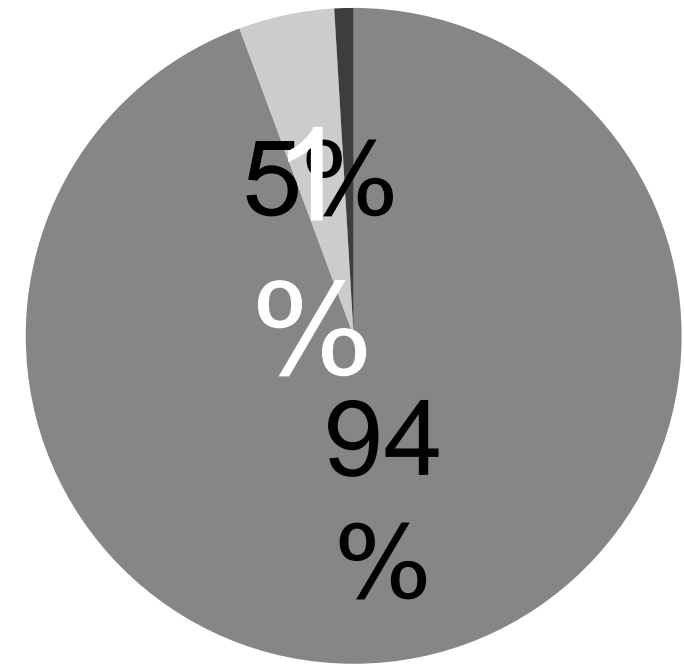
The author has no potential conflict of interest to disclose

Alarming data highlighting racial disparities in clinical trial participation:

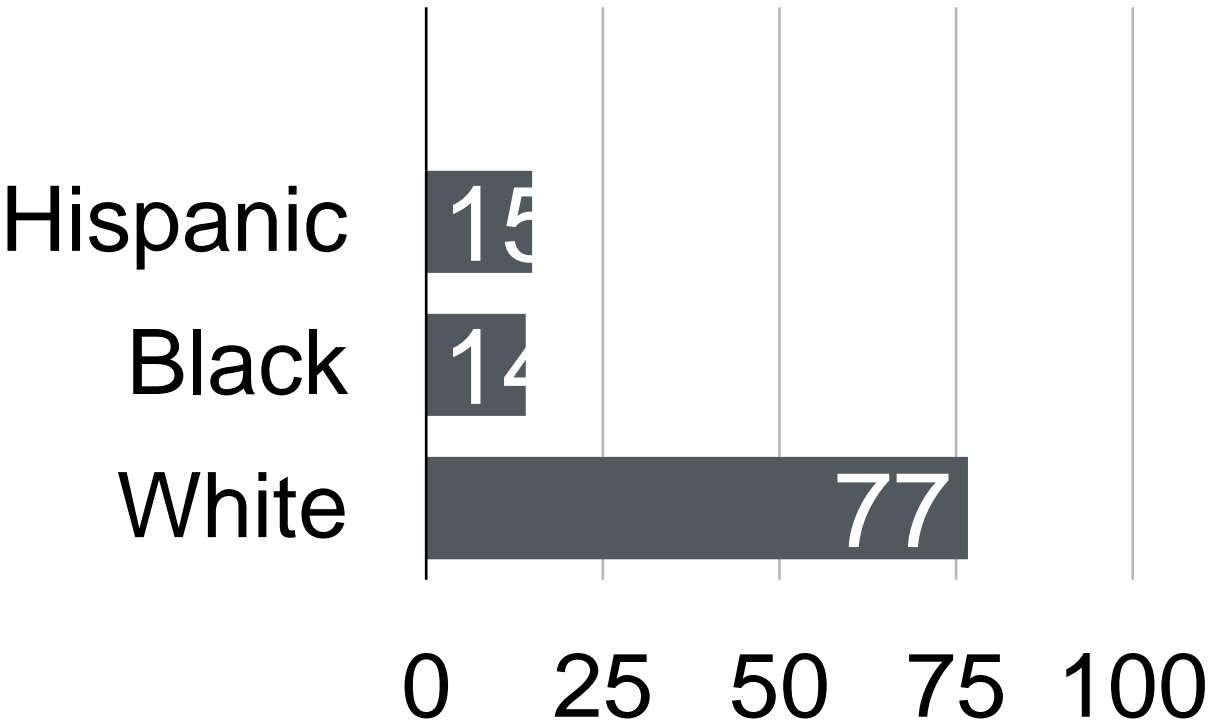


Actual vs Expected US Clinical Trial Participation of Black and Hispanic populations based on US Census data, 2020 (5.5%/13.4%, 10.6%/18.3%)

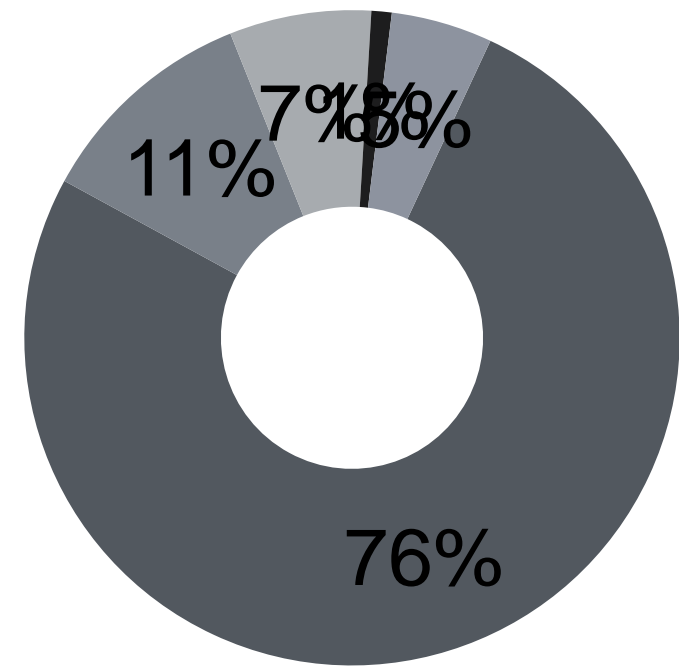
■ Total (White, Asian)



Representation of Black or African and Hispanic or Latino communities in clinical trials for chronic diseases and cancers.



Clinical Trial participation based on 29 US-based clinical trials, initiated between January 2017 and October 2022.

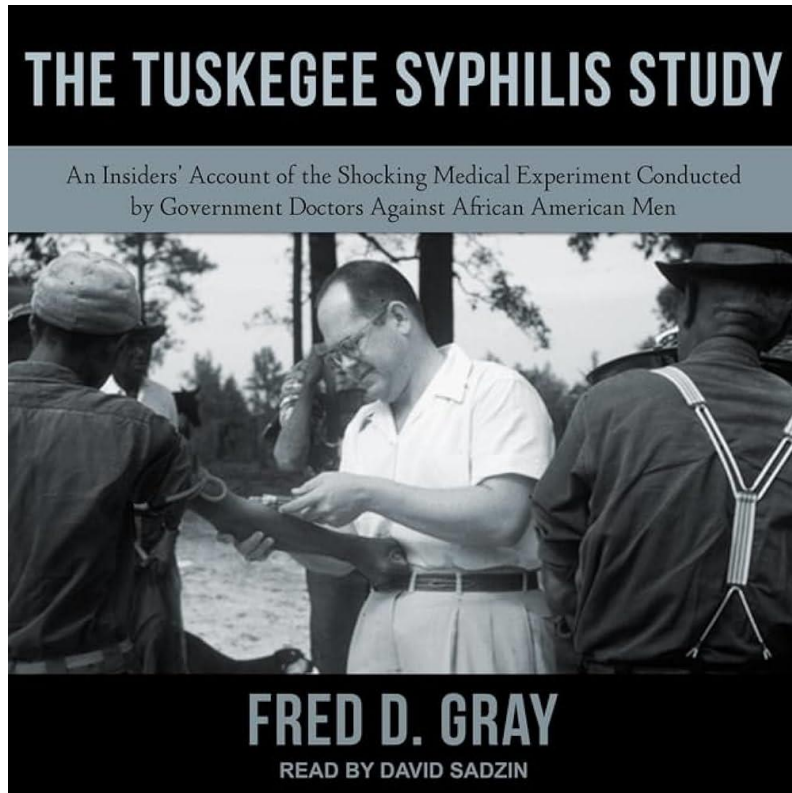


White

2020 analysis of global clinical trial participation conducted by the FDA

The historical context of racial disparities in clinical trials

Key events and periods



The Tuskegee Syphilis Study (1932-1972)



Thalidomide Trials (1950s-1960s)



Health Care Disparities and Cancer Clinical Trials

Historically Inadequate Inclusion in Cancer Trials.



FDA Drug Approval Disparities.



Socioeconomic Barriers

The Restorative Justice Bioethics (RJB) Framework

01

Acknowledging
Historical Context



02

Engaging and
empowering affected
communities in
research process



03

Reparative actions
based on distributive
justice



RJB's fundamental values and principles

- Justice
- Equity
- Respect for Autonomy
- Solidarity
- Accountability
- Community empowerment
- Beneficence & Non-maleficence

Conclusion

- The Restorative Justice Bioethics (RJB) framework emerges as a beacon of hope in the field of clinical research, offering a unique and holistic approach to address the longstanding racial disparities in clinical trial participation
- Through a combination of acknowledgment, engagement, and reparative actions, RJB not only sheds light on the systemic barriers but also actively works towards disassembling them.
- As we strive towards a future where equitable healthcare access is not just an ideal but a reality, RJB stands as a testament to our collective commitment to justice, equity, and community empowerment.
- By embracing the principles of RJB and implementing them in our research practices, we take a crucial step towards fostering a research ecosystem that truly serves all individuals, regardless of their race or ethnicity.

A faint, light gray background pattern of interconnected nodes and lines, resembling a network or constellation diagram, is visible across the entire slide.

**Thank You
For Your Attention!**



EXPLORING KNOWLEDGE, BELIEFS, AND ATTITUDES IN DATA-DRIVEN HEALTH RESEARCH IN KENYA

Black and Brown in Bioethics conference 2024 “Engaging Diversity in Bioethics Theory and Practice”.

PRESENTED BY: MERCURY SHITINDO

Authors: M Shitindo, B Odero, G Samuel, O Ndiaye



Agenda

3	<ul style="list-style-type: none">• Background of the Study
4	<ul style="list-style-type: none">• Problem Statement
5	<ul style="list-style-type: none">• Framework
6	<ul style="list-style-type: none">• Methodology
7	<ul style="list-style-type: none">• Findings

BACKGROUND OF THE STUDY

- Data and artificial intelligence (AI) are burgeoning global commodities, with Africa poised to contribute significantly to the data revolution.
- A recent Google and International Finance Corporation report estimates Africa's digital economy could contribute \$180 billion by 2025.
- However, data-driven technologies have notable environmental impacts, including carbon emissions and mineral extraction, with health implications.



BACKGROUND OF THE STUDY

- Data-driven research encompasses various fields and is often associated with promising benefits, yet it has environmental impacts.
- These impacts include carbon emissions, mineral extraction, and e-waste, posing significant health risks, especially in low-to-middle-income countries.
- Despite growing awareness, there's a notable gap in ethics literature addressing digital sustainability, particularly in African research contexts.



PROBLEM STATEMENT

Briefly elaborate on what you want to discuss.



Scope of the study

a qualitative exploration within Kenya, focusing on individuals actively engaged in data-driven health research, utilizing purposive sampling and semi-structured interviews to understand their perspectives on environmental impacts, with a methodological emphasis on data collection and analysis to inform future research initiatives and ethical frameworks in African contexts.

Relevance of the study

potential to inform ethical frameworks, promote environmental awareness, mitigate risks, foster collaboration, and contribute to global sustainability goals in data-driven health research within African contexts such as Kenya.

Research Questions

What are the knowledge, beliefs, and attitudes of Kenyan researchers conducting data-driven health research, or those managing or funding this research, about the environmental impacts of such research and the need to consider them in a

FRAMEWORK

Overview	Proponents
<ol style="list-style-type: none">1. Research Ethics Frameworks2. Sustainability3. Environmental Ethics4. Stakeholder Theory5. Qualitative Research Methodology6. Sustainable Development Goals	<ol style="list-style-type: none">1. Principles of research ethics, which emphasize the importance of considering ethical implications in research practices, including environmental impacts.2. The concept of sustainability underpins the research, highlighting the need to balance social, economic, and environmental factors to ensure long-term well-being and resource stewardship.3. Emphasizing the moral responsibility to protect the environment and minimize harm to ecosystems and human health.4. Acknowledgment of diverse stakeholders involved in data-driven health research, including researchers, funding bodies, industry partners, and policymakers, and seeks to understand their perspectives on environmental impacts.5. Emphasizing in-depth exploration and understanding of participants' knowledge, beliefs, and attitudes

FRAMEWORK

THEMES

1. Awareness and Understanding
2. Challenges and Considerations
3. Policy and Institutional Frameworks
4. Technological Solutions
5. Community Engagement

1. The importance of integrating environmental sustainability into research practices.
2. The need for interdisciplinary collaboration to address environmental challenges.
3. The role of policies, regulations, and technological innovations in promoting sustainability.
4. The significance of community engagement and education in fostering a

METHODOLOGY

Qualitative Methods, Exploratory

The research methods employed by the researchers encompass a diverse array of qualitative techniques aimed at comprehensive data collection and analysis. They utilized qualitative data collection methods such as interviews, surveys, and audio recordings, coupled with transcription and half-surveys featuring open-ended questions. The researchers also engaged in exploratory data analysis to uncover relationships within datasets and relied on secondary data from databases for additional insights. Institutional policies guided data sharing

KEY TAKEAWAYS



AWARENESS AND UNDERSTANDING

- Importance of environmental sustainability,
- "So environment sustainability is ensuring that the environment we are living in is better... making sure that the land, the environment is clean, it's not polluted."
- Need for managing resources in a fair and environmentally friendly way,
- "In my own research in the day today's world of online working... Just creating an environment where you are optimizing resources."
- The responsibility aspect of sustainability,
- "Something that is sustainable has got an element of responsibility... making sure that something is perpetual."



PERCEPTIONS AND ATTITUDES OF RESEARCHERS

- Not perceive environmental considerations as integral to the research process, particularly in health research where the focus is primarily on improving health outcomes.
- "In the realm of health research, there's often a prioritization of health outcomes over environmental impacts. The environmental dimension is often overlooked."
- a disconnect between the perceived intrinsic value of health research and its environmental impacts, leading to the dismissal or neglect of environmental concerns.
- the definition and evaluation of 'value' in health research, especially regarding the trade-offs between health benefits and environmental risks.
- "There's a fundamental question about what we consider valuable in health research. Should we prioritize health outcomes at the expense of environmental degradation? It's a complex ethical dilemma.



RESEARCH ETHICS AND CONSIDERATIONS

- Current research ethics frameworks in Africa often prioritize human research subjects over longer-term environmental and health consequences.
- There is a need to bridge the gap between research ethics and environmental sustainability, particularly in the context of data-driven research.
- "Our research ethics frameworks have historically focused on human subjects, but there's a growing recognition of the need to expand these frameworks to include environmental considerations."
- "We need to integrate environmental considerations into our research ethics discourse. It's not just about human subjects; it's about the broader impact of our research on the environment."



THANK YOU

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Framing the debate: Race-based requests in medicine

Presented by **Peter D. Young**

Peter.young@ethox.ox.ac.uk

9 April 2024

Black and Brown in Bioethics Conference

Agenda for this talk

- **Johns Hopkins Hospital policy about race-based requests**
- **Reasons behind race-based requests**
- **Race-based requests in an emergency situation**
- **Deliberation as a way forward?**

JHH policy on race-based requests circa 2017



- Race-based requests are not fulfilled under any circumstances.
- This includes emergency situations.

Reasons for race-based requests

- **Acceptable reasons for race-based requests**
- **Skills based-requests**
- **Unacceptable reasons for race-based requests**



¹ London School of Paediatrics

² Department of Sociology, University of Cambridge

³ Ethox Center, University of Oxford

⁴ Cardiff University School of Medicine, Cardiff, UK

⁵ Royal Aberdeen Children's Hospital

Cite this as: *BMJ* 2021;375:n3067

<http://dx.doi.org/10.1136/bmj.n3067>

Published: 13 December 2021

Addressing racist parents in a paediatric setting: the nuance of zero tolerance policies

Healthcare professionals need clearer guidance on responding to racism in paediatric settings, argue Zeshan Qureshi and colleagues

Zeshan Qureshi,^{1,2} Mehrunisha Suleman,³ Alexandra Richards,⁴ Julian Sheather,⁴ Hugh Bishop⁵

Everyone has a right to healthcare, but on occasion this can conflict with the right of healthcare professionals to dignity in the workplace. One example is when a patient refuses the care of a healthcare professional on the grounds of race. This is an experience that many doctors from an ethnic minority background have faced: in one US study, 23% of ethnic minority doctors reported that a patient had directly refused their care due to their race.¹ The Medical Workforce Race Equality Standard in the UK also reported that 34.4% of doctors in training from an ethnic minority background had experienced “bullying or abuse from patients, relatives, or the public” in the past year, including racist abuse.²

When an adult seeks care for themselves, it can be argued that although access to healthcare is a right, it comes with responsibilities. If these are breached by imposing racial conditionality on receiving care, healthcare professionals and organisations can refuse to treat them, as recently stated by the UK government and other professional bodies.^{3,4} Exceptions may apply for people who are critically unwell or those with a cognitive disorder, but otherwise the importance of respecting staff dignity is imperative.

development and healthcare encounters can be an opportunity to challenge racist narratives that children may have been exposed to previously.⁵

Paediatricians also have a professional obligation to consider all child protection issues. Given its negative effects on children, extreme, overt racist behaviour, particularly when associated with violence and aggression, may give rise to such concerns. A parent or guardian that denies their child access to medical treatment based on the ethnicity of the available healthcare professional may meet UK and other legal definitions of committing neglect.^{6,7}

However, there may be occasions where a parent's racism is less explicit or definable, for example, demanding a doctor who speaks better English, making it harder to label as a child protection issue. And, even if a parent explicitly has a racial preference, if they are still able to privately arrange timely and appropriate assessments so that their child's health is not compromised, it would not constitute neglect. That said, any racism is morally unacceptable and being around racist individuals—termed vicarious racism—may have other negative impacts on children.^{8,9}

Qureshi et al. 2021

“In a case where a child requires urgent medical attention, however, this must take priority. Protecting the health of a severely unwell child may require temporary accommodation of a parent’s racist preferences...”

Framing the debate: race-based requests in medicine

Leading scholars have argued that when a healthcare professional and patient's race align, a provider can speak better to certain beliefs, religious practices, and cultural norms of their patients. There are also subtler, yet equally important, benefits of having your provider look like you, including patient-compliance as well as the potential for less polarising power dynamics in the provider-patient relationship. But not all reasons for race-based requests should be accepted, especially where they are based on discriminatory attitudes. In what follows, I hope to show that requests for race-based concordance is a complicated area of medicine, and it is one that is not easily dealt with through formalised policies. Instead, well-reasoned judgements by the care team through a deliberative process, that begin with ethical frameworks, might provide a more fruitful way forward.

Acceptable forms of race-based requests



Red game pieces and one black game piece on white surface. Credit: Markus Spiske on Unsplash.

dietary considerations (these are not attributes physicians are born with, but skills they develop throughout their lives

grounded in the wrong reasons. Assigning physicians to a patient solely because of skin colour sets

Reasons against race-based requests in an emergency

Major harms affecting the child's health outcomes:

- Not assigning the best physician for each job poses a safety risk
- Disrupting the workflow of a team could potentially lead to worse outcomes

Reasons against race-based requests in an emergency

Other additional harms:

- The discriminatory effects of these requests lead to outcomes that do not allow healthcare professionals to flourish in their work environments
- Other parents knowing that race-based requests are being honoured, and therefore, many more individuals might attempt to make racist requests in emergency situations.

Deliberation as a way forward

- Quershi et al's piece and my piece are somewhat in agreement in that deliberation might be the way forward. Those authors suggest:

“Responding to racism from a child's parents should involve balancing three factors...”

Deliberative frameworks

- Four-quadrant approach
- Four principles of bioethical ethics

Problem with deliberation

- When we open up questions to deliberation, there must be a judge. Are we ok with clinicians being the judge of these matters? (some clinicians might get it wrong)
- Is there more benefit to top-down policies like the one seen at Johns Hopkins Hospital?

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LUNCH & POSTER VIEWING

12:30 – 13:15

FIRESIDE CHAT REFLECTIONS ON ROLES AND CAREERS IN ACADEMIA

Anna Dowrick (University of Oxford) & Tanvi Rai (University of Oxford)
Princess Banda (University of Oxford) as Chair



ORAL ABSTRACT PRESENTATIONS (II)

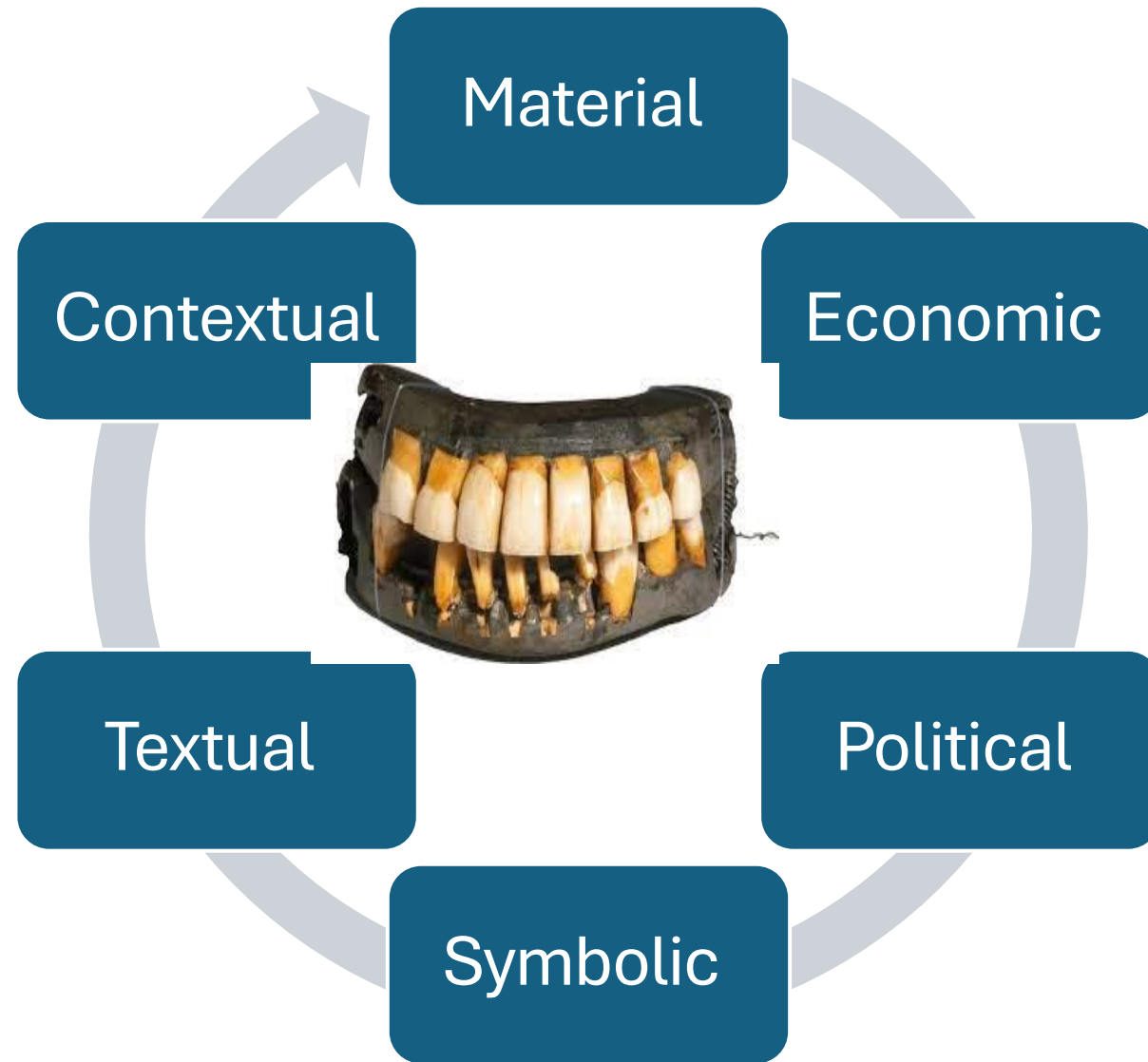
Kumeri Bandara as Chair

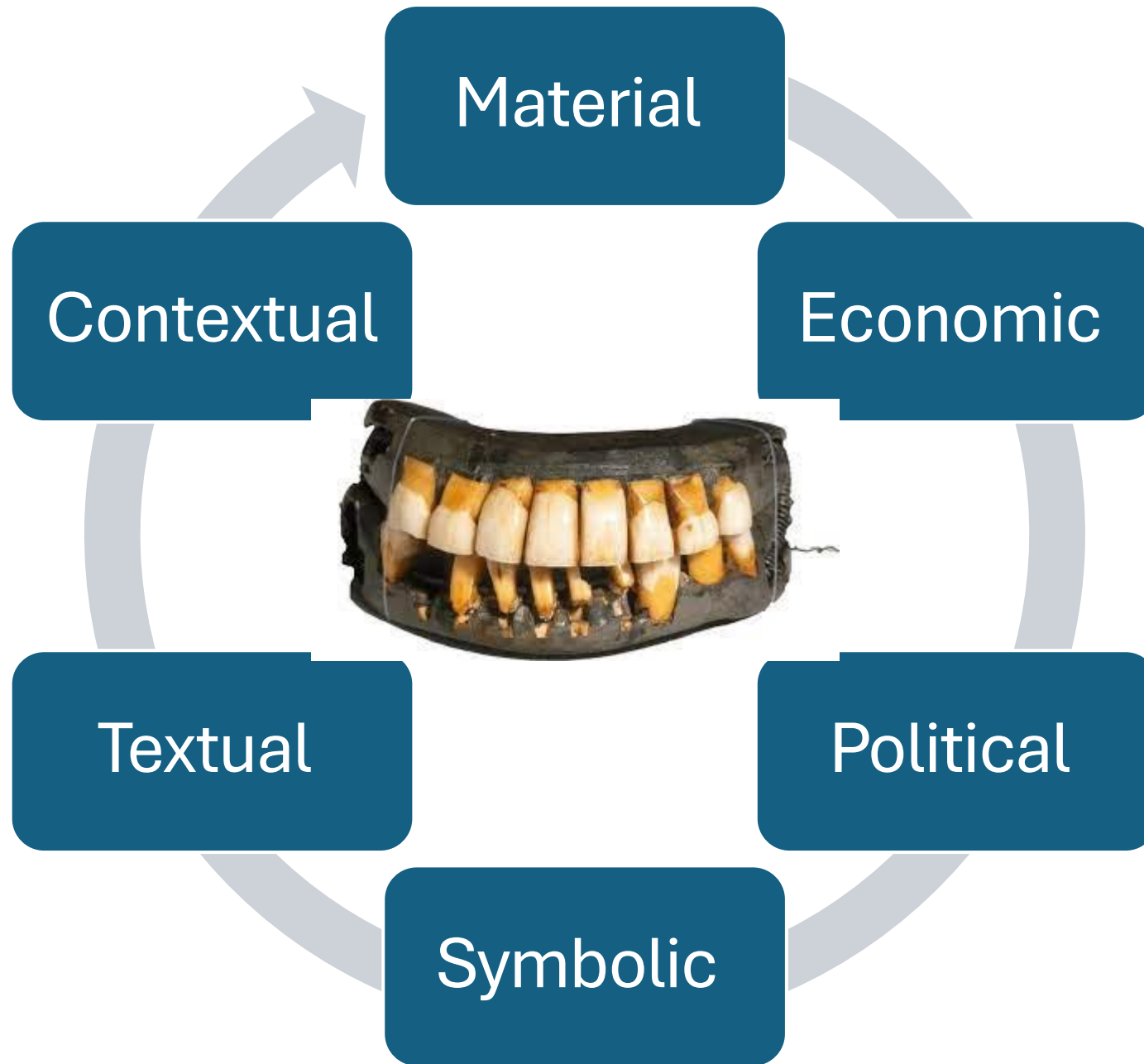


A Critical Retelling of Dental Ethics Told Through "George Washington's Complete Denture"

Eleanor Fleming, University of Maryland at Baltimore and Patricia Neville, University of Bristol

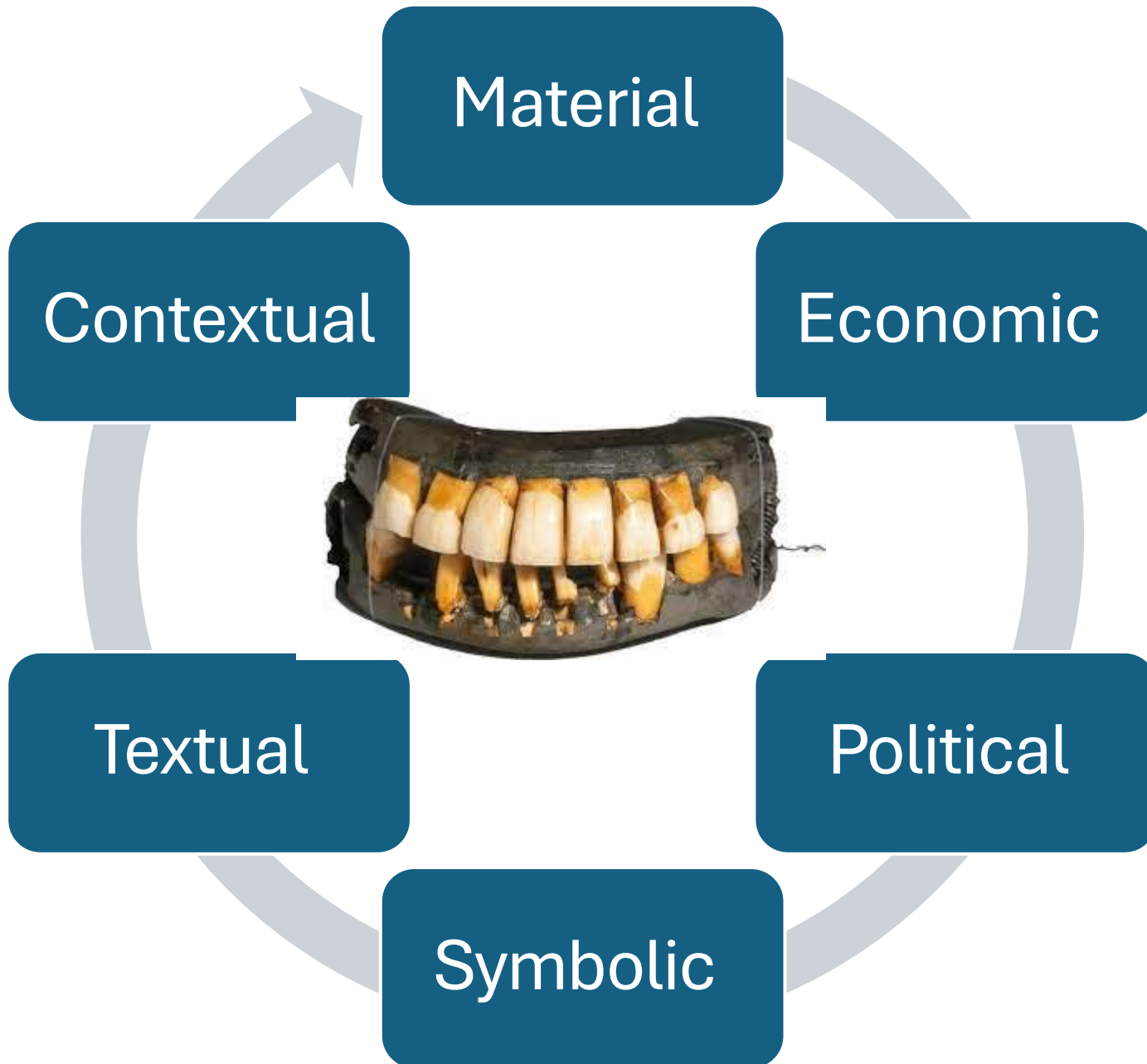
Analysing George Washington's dentures using the 'implosion method'





Material: made of bone, hippopotamus ivory, human teeth, lead, brass screws, gold metal wire. Materials are byproducts of the extractive industry of colonialism and the Atlantic slave trade

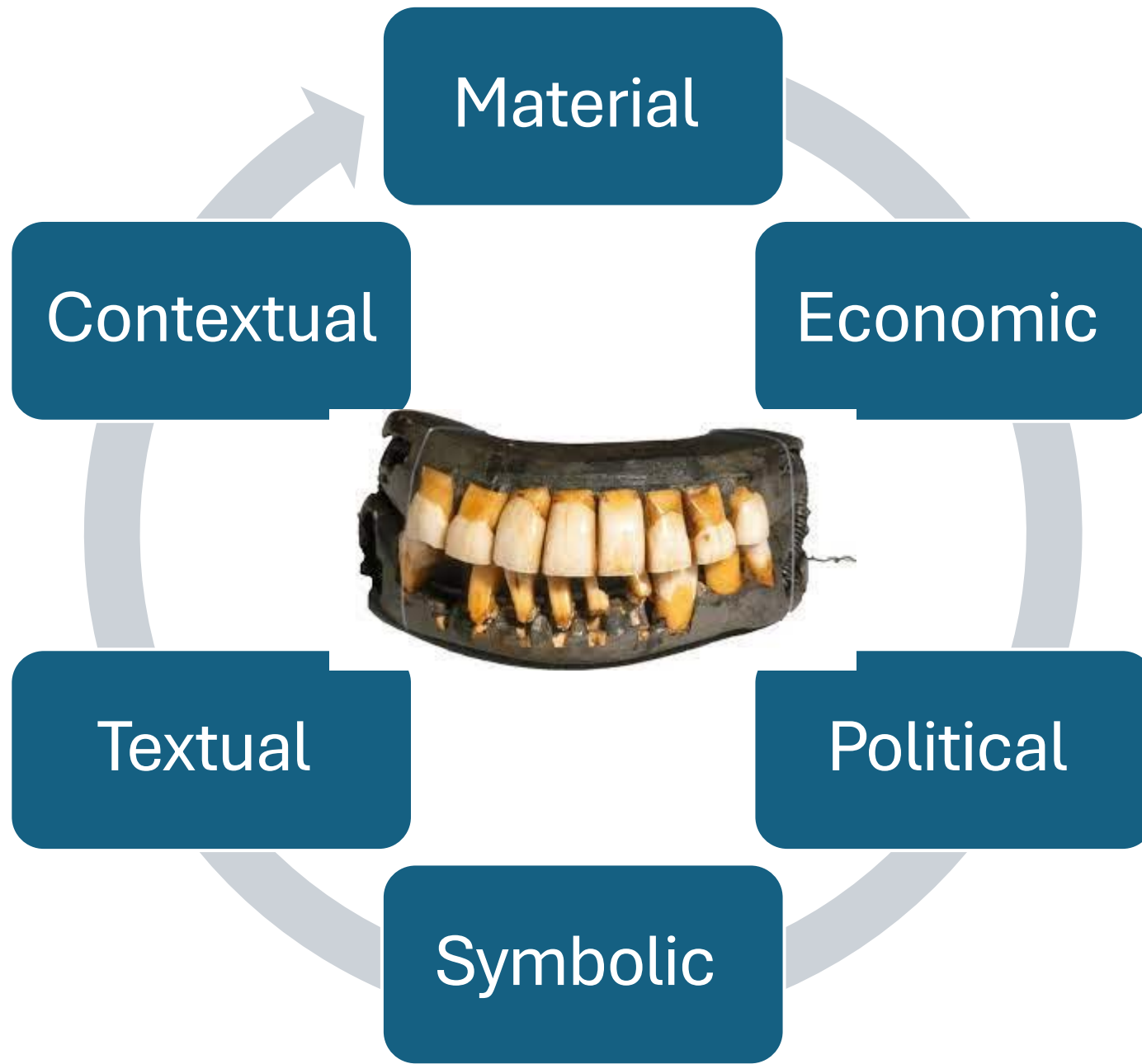
Qs: whose teeth were used? One person or multiple people? How were the teeth extracted and fabricated into the denture? Who created the denture?



Economic: These dentures are facilitated by and the outcome of racial capitalism and its extractive ideology

- Trade in human teeth
- Trade in human beings in the Atlantic slave trade
- Ivory trade links
- Gold mining

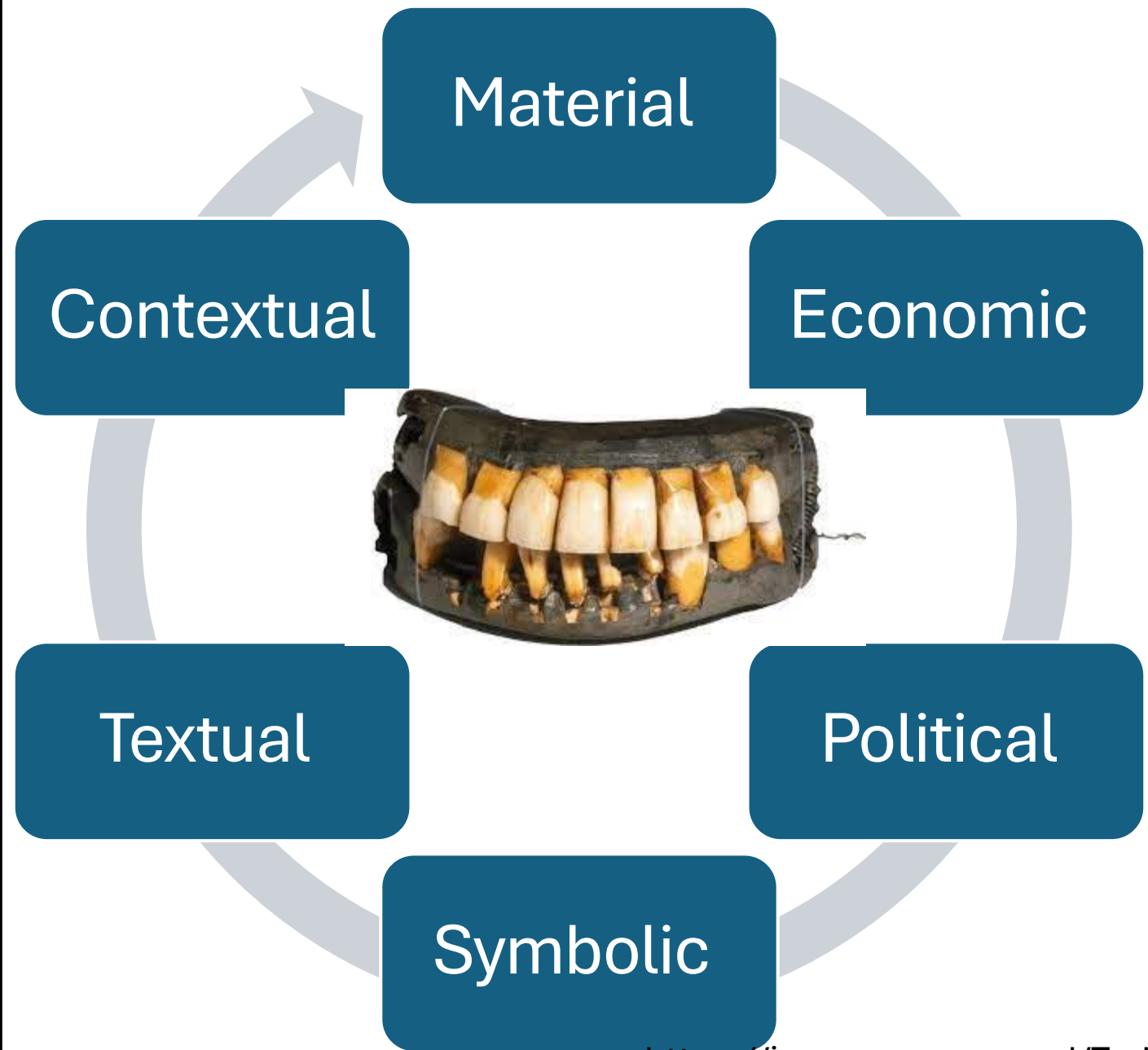
Q. What would be the cost of producing such a set of dentures?
Who typically could afford this dental object in 18th USA?



Political: these dentures have been inserted into the American nationalist discourse and its 'myth' because of its association with the body of the 'Founding father' of America

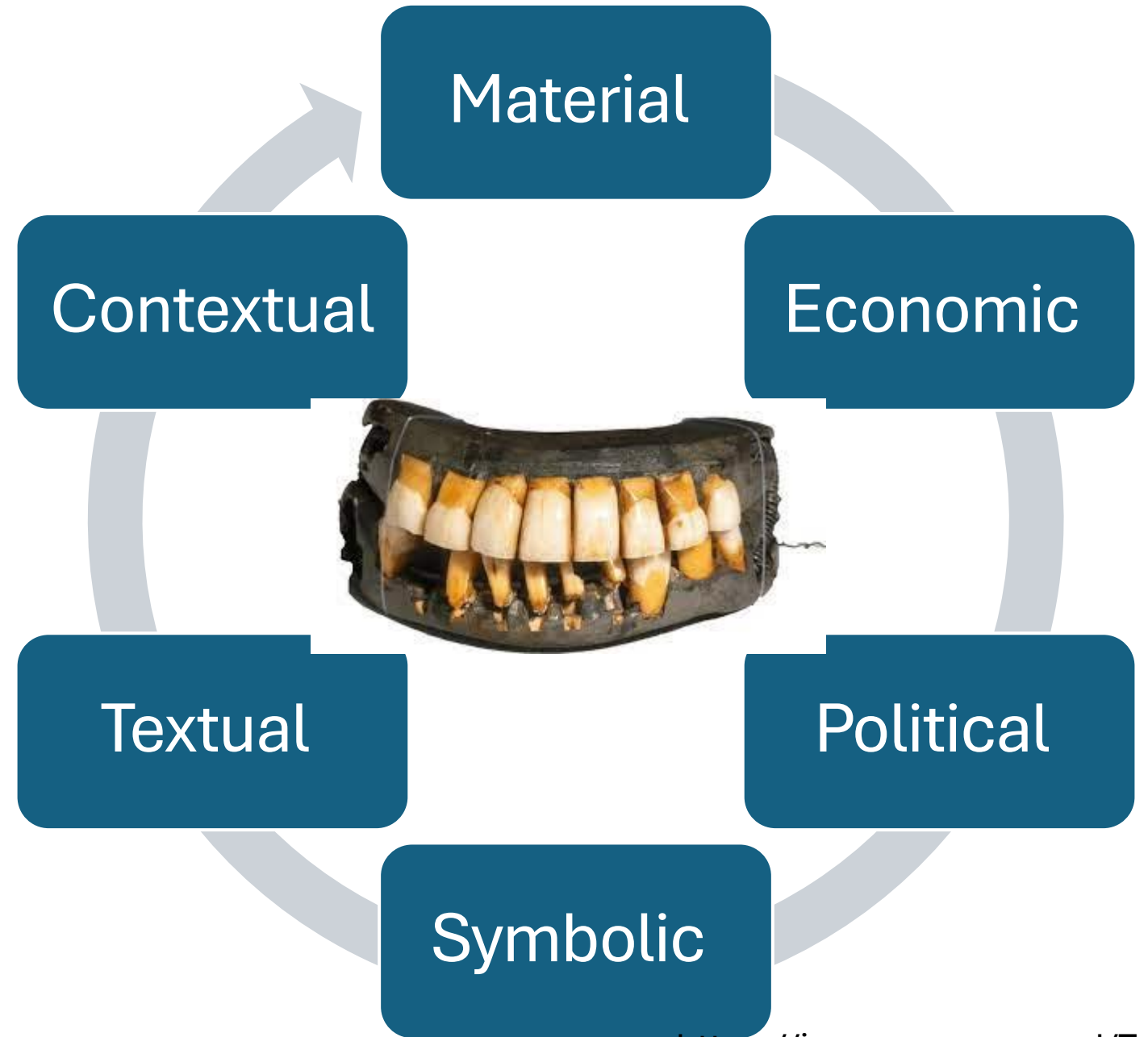
Symbolic: There are multiple and overlapping symbolic dimensions to GW's denture. These can include:

- Recognising dentures as an emblem of the innovation and skills of early US dentistry
- Associated with the ideals of progress and self-determination as encoded in the struggle for independence from English colonisers
- Ideology of being dentonate/edentulist and its ability to confer 'gentleman' status on GW
- Marker of GW's social status and wealth

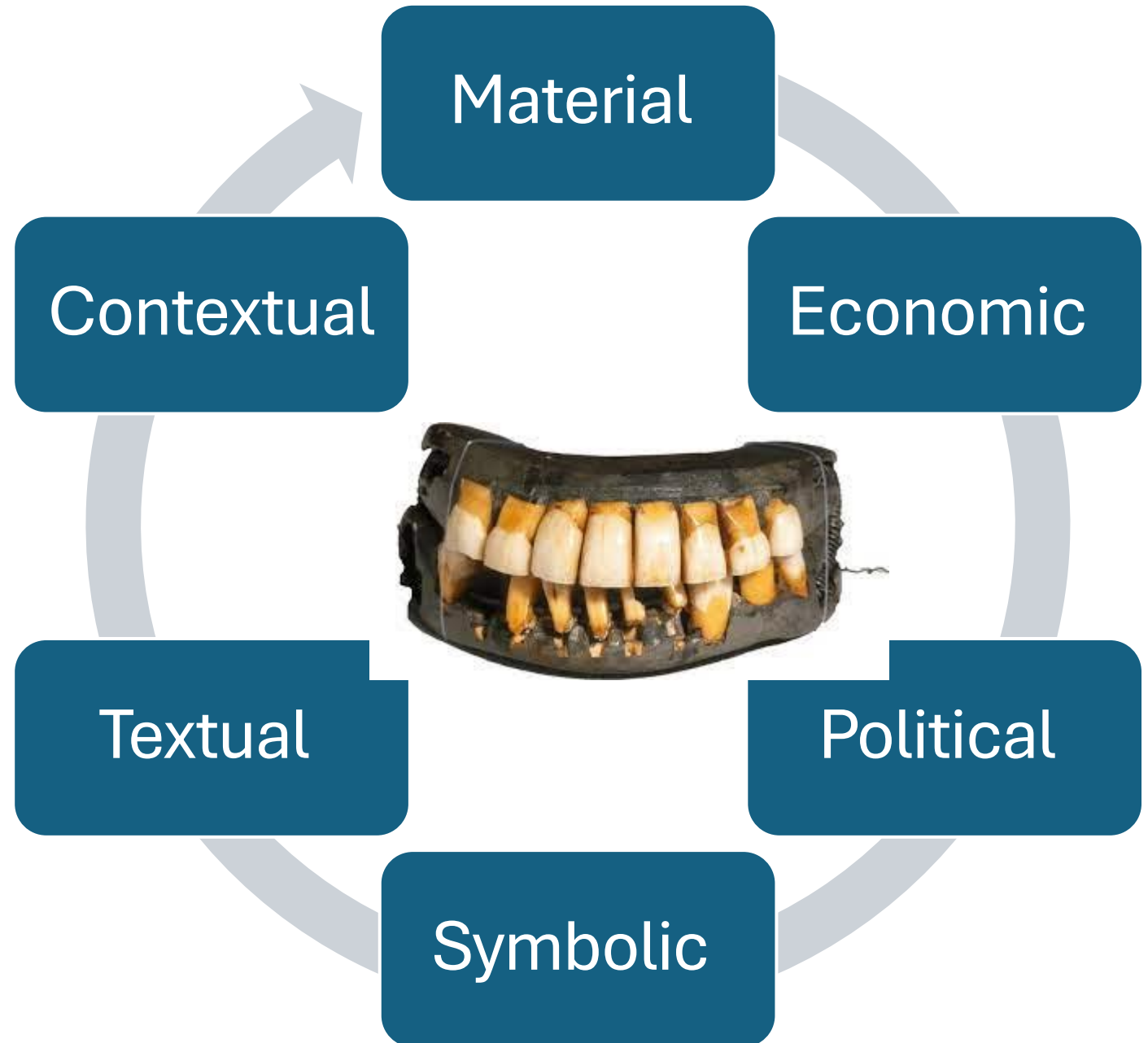


Textual:
What is the
role/purpose of Mount
Vernon
Museum? (where the
dental object is on
display)

How are they
displayed? Are they
displayed as part of a
dental collection or as
a personal possession
of GW?



Contextual:
When and in what ways(e.g. Media form) is the image of GW's dentures circulated?
Are there certain times of the year that this object become more newsworthy or salient?
Why? Why not?



Abolition in Medicine or Abolition of Medicine?: Exploring Carcerality in Biomedical Contexts

Black and Brown in Bioethics Conference
Tuesday, April 9th, 2024

Whitney V. Cabey MD, MSHP, MA

Center for Urban Bioethics

Lewis Katz School of Medicine at Temple University

Philadelphia, PA, USA



Lewis Katz School of Medicine

Conflicts of Interest

I have no conflicts of interest to disclose

Goals



Abolitionist frameworks applicability to healthcare



The current landscape of abolition in medicine



Envisioning emancipatory futures towards abolition of medicine

Positionality & Identity

(or, how I came to fully embrace abolition)

- Roots in community organizing and reproductive justice
- Emergency physician in Philadelphia, PA
 - Epicenter of the American opioid epidemic
 - Highly impacted by endemic and entrenched structural violence
- Appointed at Temple University's Center for Urban Bioethics
 - Urban bioethics centers the experiences of the diverse, disparate and dense spaces
 - Emphasizes solidarity, agency and social justice as expansions of traditional bioethics principles
 - Commits to community engagement as process and praxis

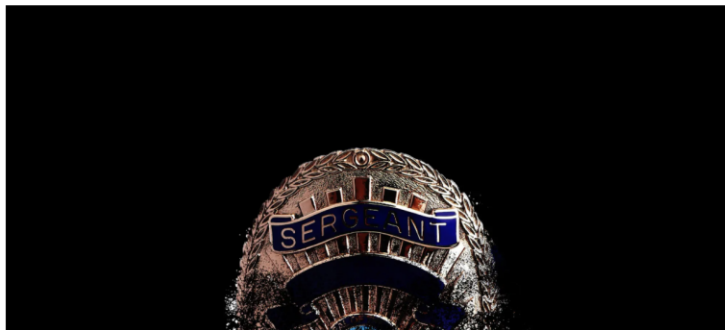
A reckoning and an awakening

OPINION

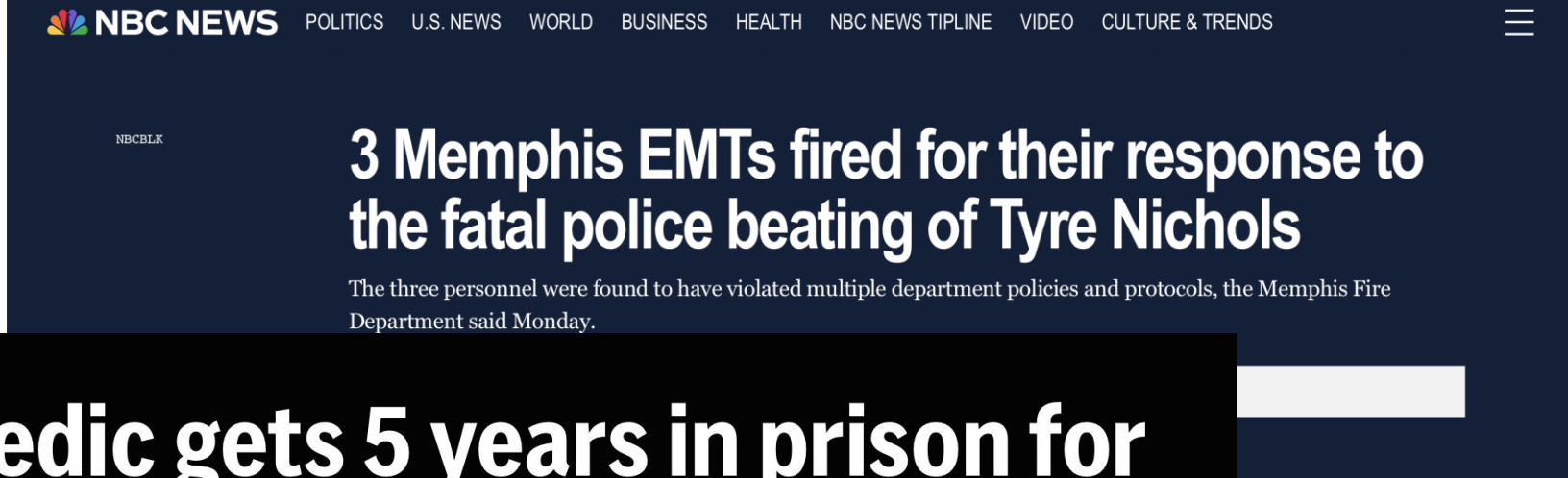
Yes, We Mean Literally Abolish the Police

Because reform won't happen.

June 12, 2020



“I think it’s us. We’re the villains.”



U.S. NEWS

Paramedic gets 5 years in prison for Elijah McClain’s death in rare case against medical responders

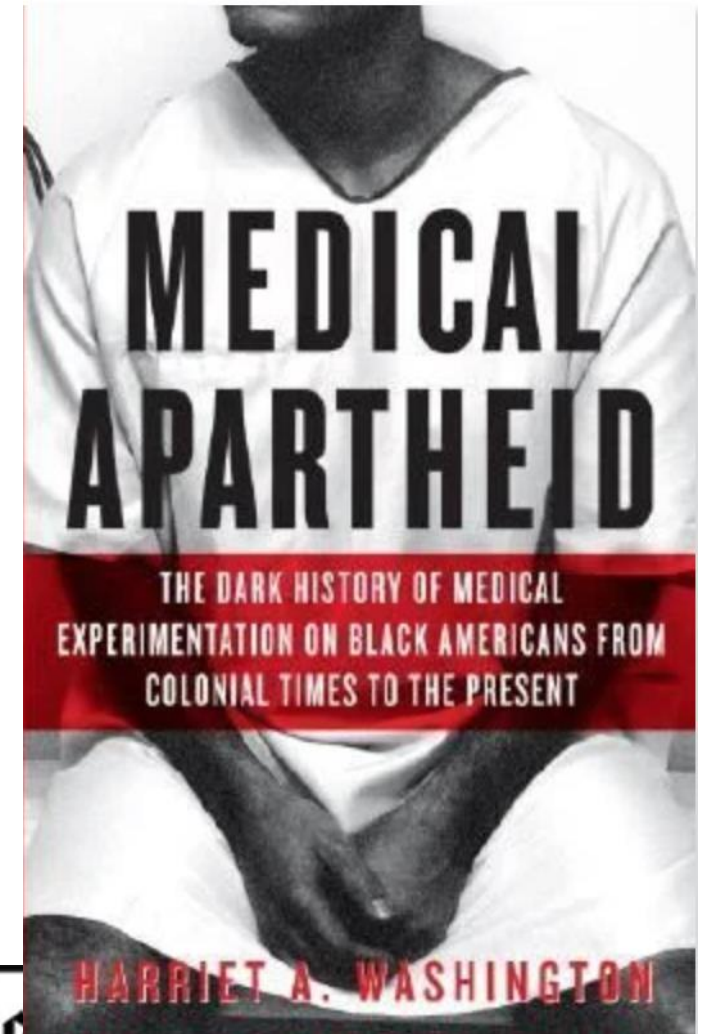
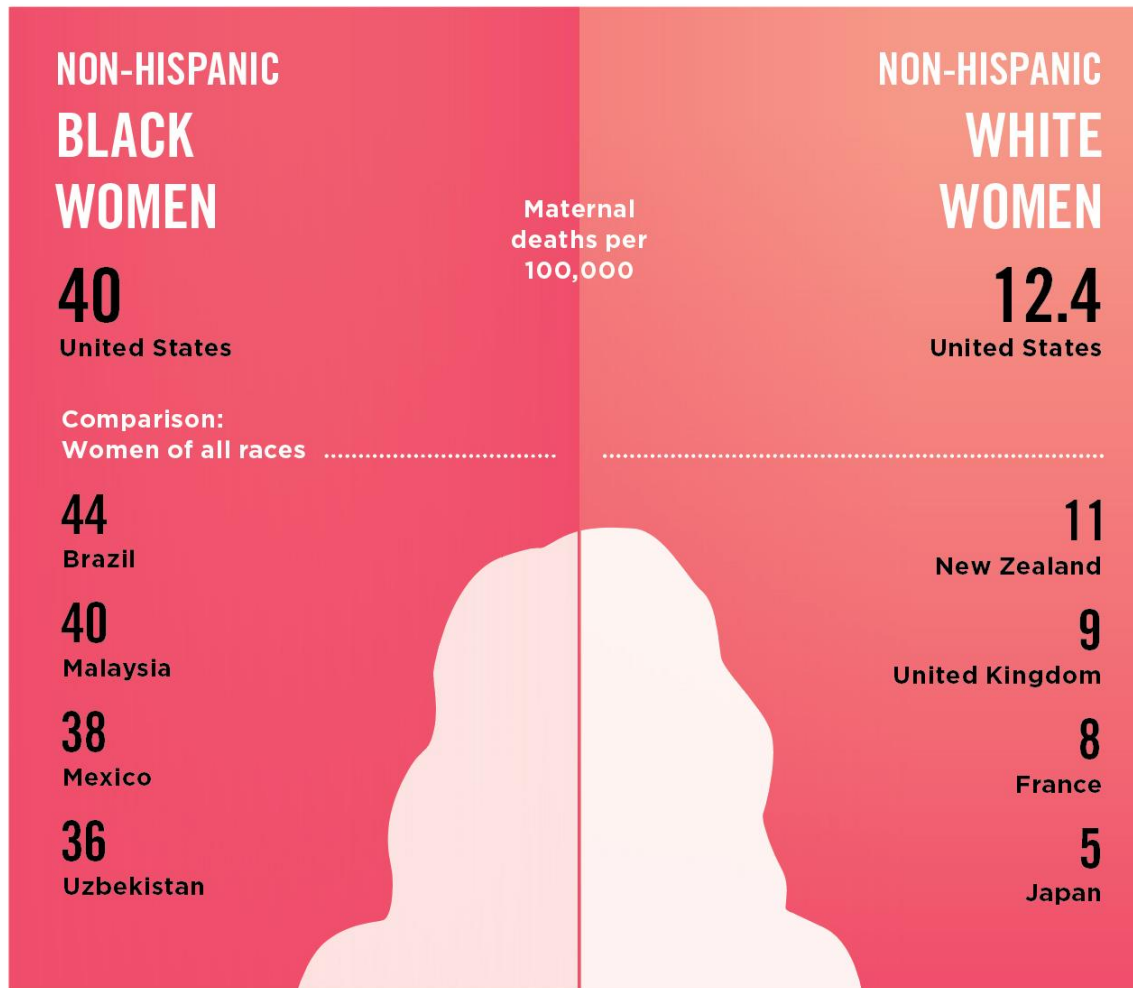


Andrea Dezsö

MORTALITY GAP FOR U.S. MOMS

In the U.S., black women who are expecting or who are new mothers die at rates similar to those of the same women in lower-income countries, while the maternal mortality rate for white U.S. mothers more closely resembles rates in more affluent nations.

Sources: U.S. ratios (2011-2013): CDC Pregnancy Mortality Surveillance System; Global ratios (2015): UNICEF



The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For | have serious doubts about the

...abolitionist are, simply put, those beings who look out upon their time and say, “No”.

- Mumia Abu Jamal

Abolition is a verb...

- The act of officially ending or stopping something.
 - Miriam-Webster Dictionary
- The ending of a law, a system, or an institution.
 - Oxford Dictionary
- An invitation into finding new answers to the problem of harm and into building new ways to prevent harm in the first place
 - Derecka Purnell

...and a declarative position

- “Enough is enough”
- Abolition is necessary when no other option seems reasonable, ethical, or moral
- Abolition is necessary when the purpose of the structure or institution is to withhold liberty, **measured by its outcomes not its ideals**



Healthcare fails to achieve health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

– Constitution of the World Health Organization

The purpose of healthcare is to maintain the political economy of disease

by Jeff Voigt WG85

March 2, 2017

HEALTH CARE

SHARE: [f](#) [X](#) [in](#)

Joe Biden's Cancer Moonshot

The former vice president teams up with Penn and Wharton to pursue an aggressive health care initiative and search for a cure.



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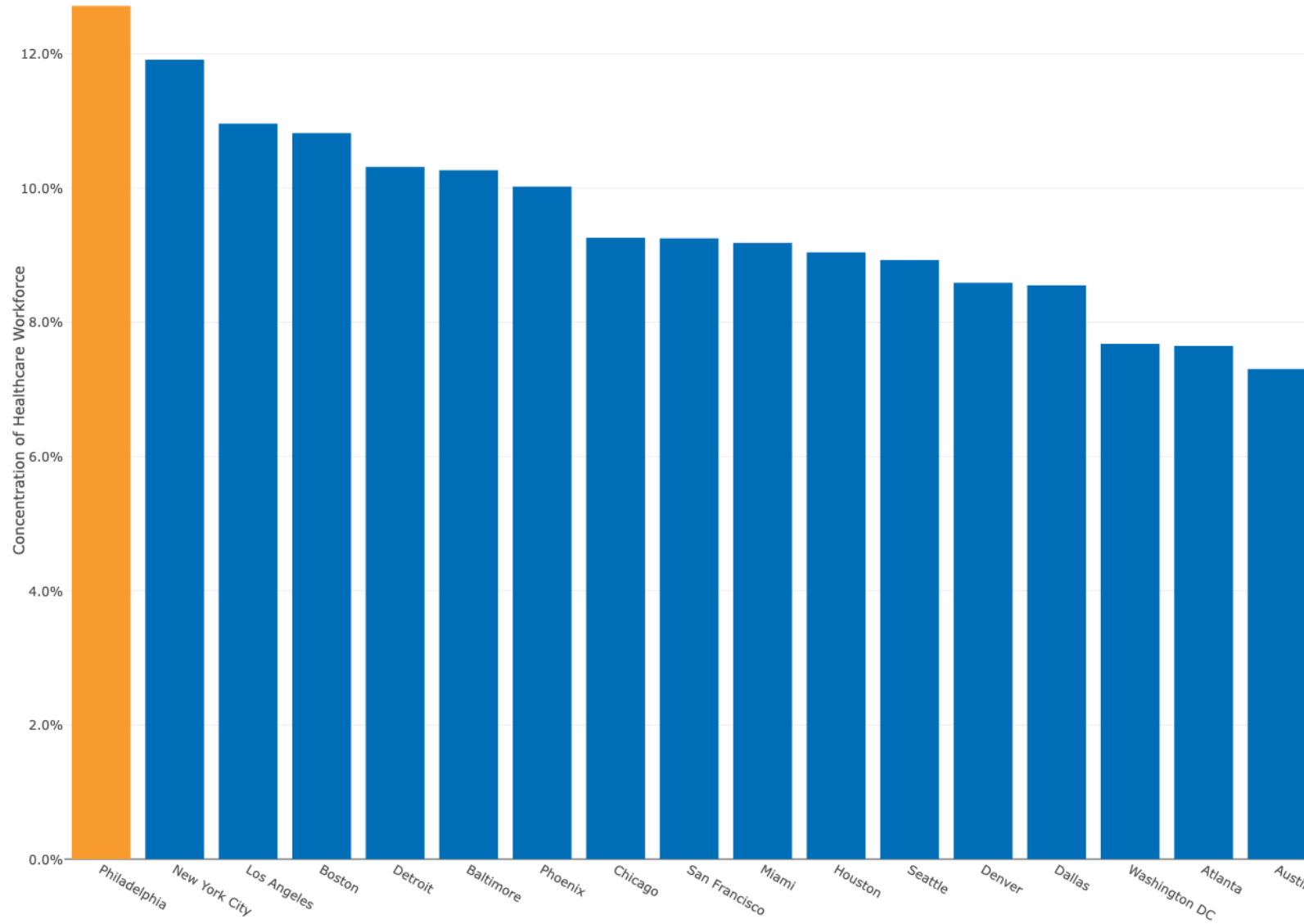
Lung Center

800-TEMPLE-MED Schedule Appointment

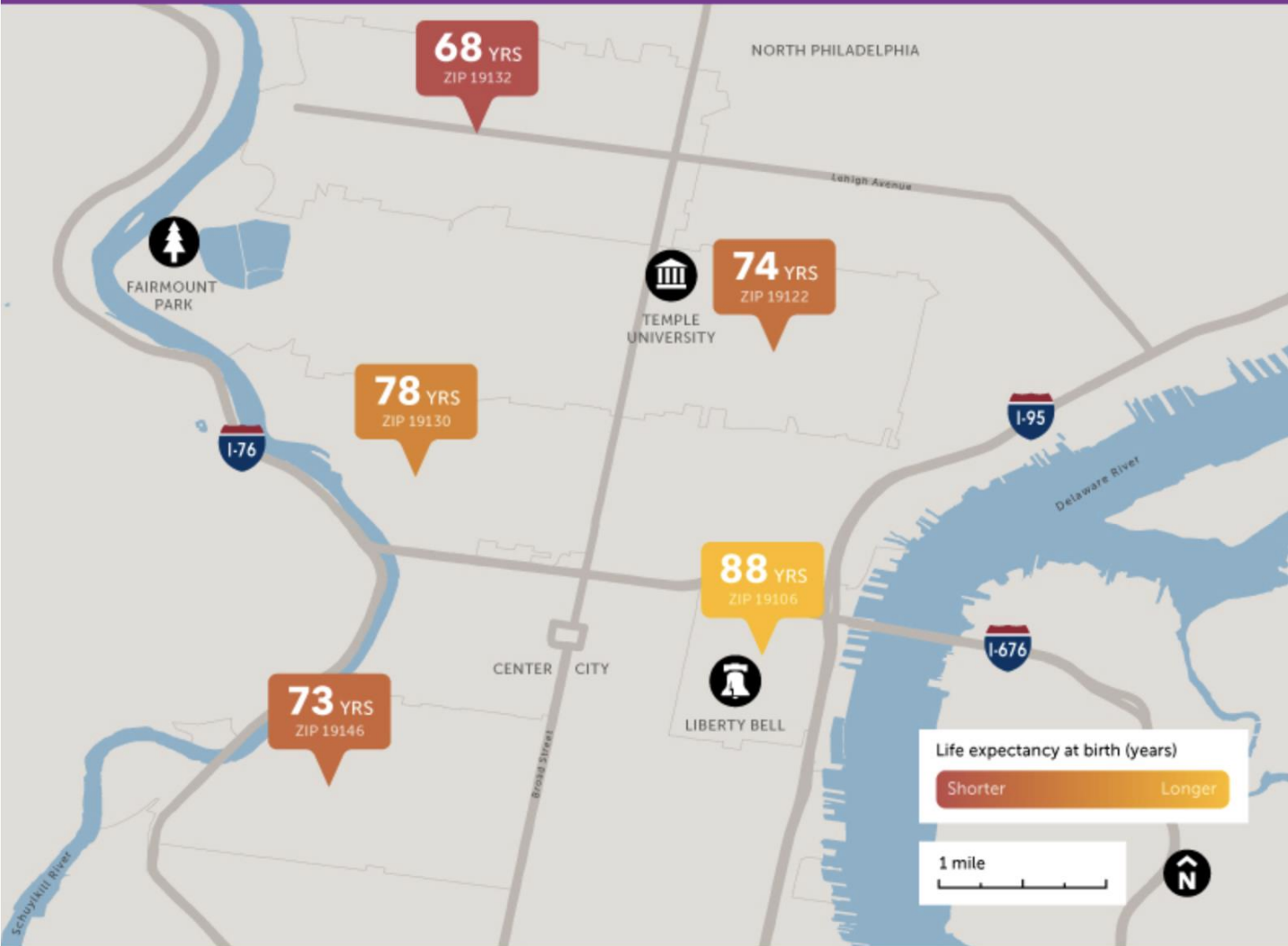
Doctors Locations Patient Care Research & Clinical Trials For Physicians About



Healthcare Workforce Concentrations Across Major Metropolitan Areas



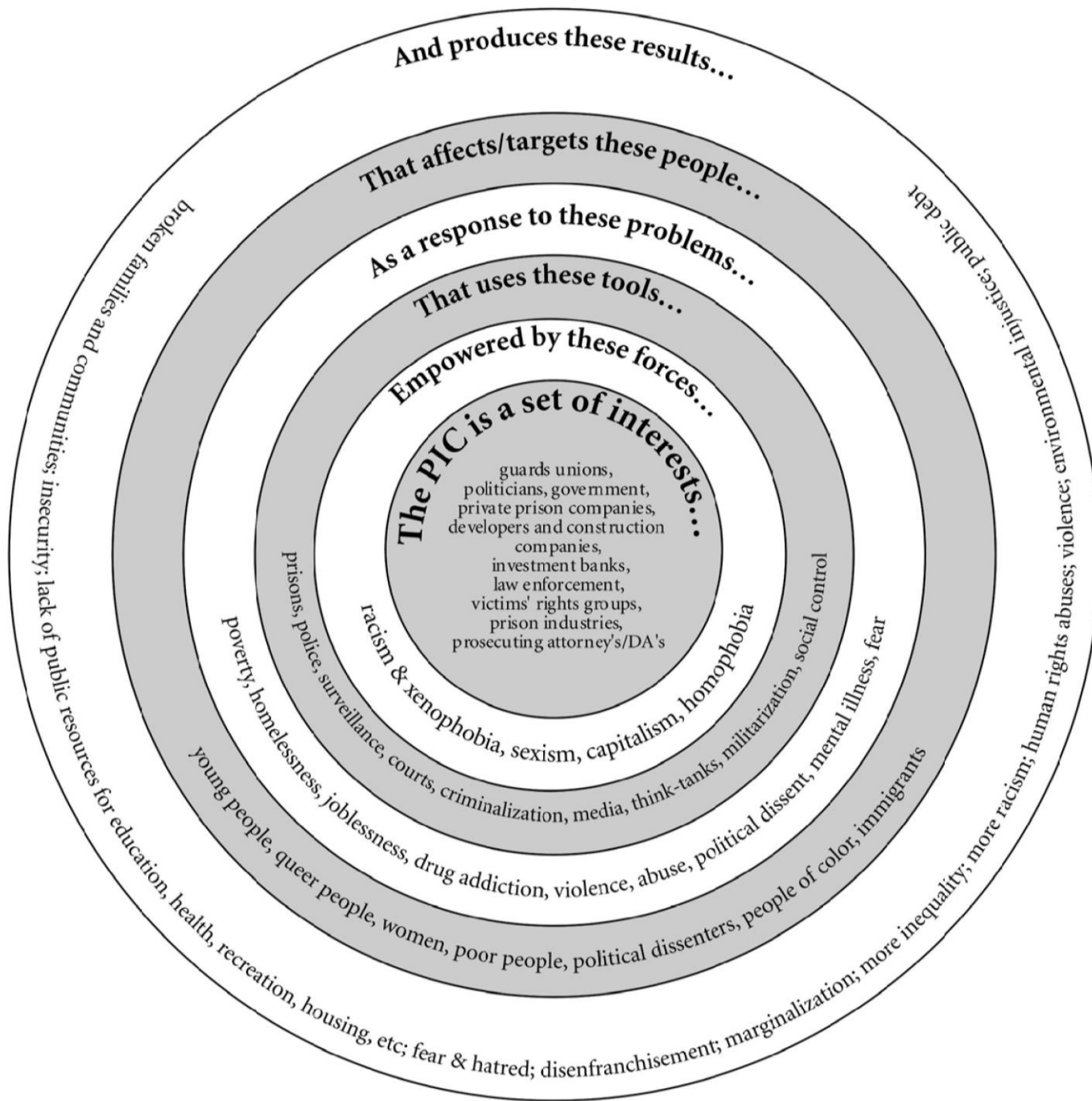
Short Distances to Large Gaps in Health



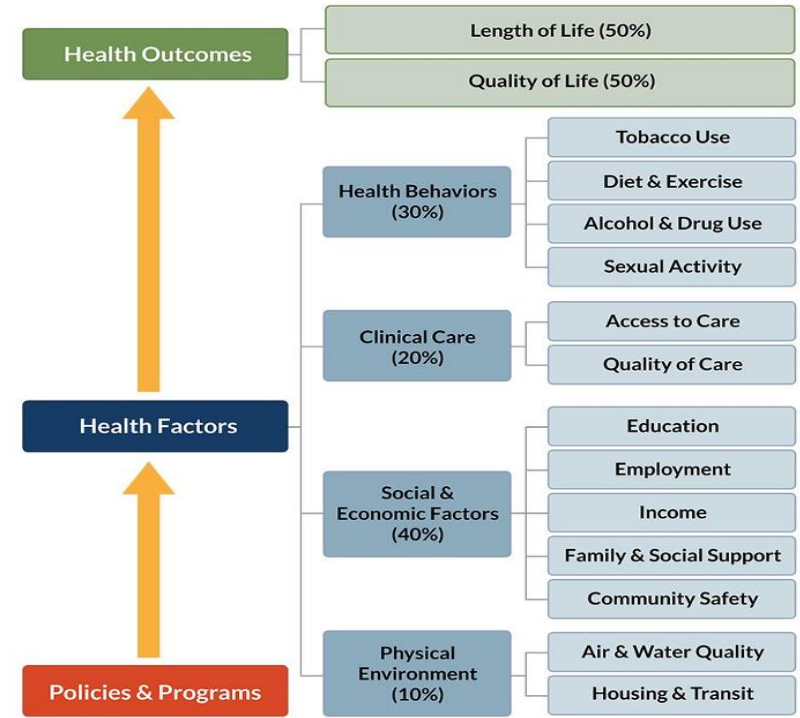
Healthcare fails to achieve health just as prisons and policing fail to achieve public safety



What if health disparities are the feature, not the bug?



The **prison industrial complex (PIC)** is a term we use to describe the **overlapping interests** of government and industry that **use surveillance, policing, and imprisonment** as solutions to **economic, social and political problems**. – Critical Resistance

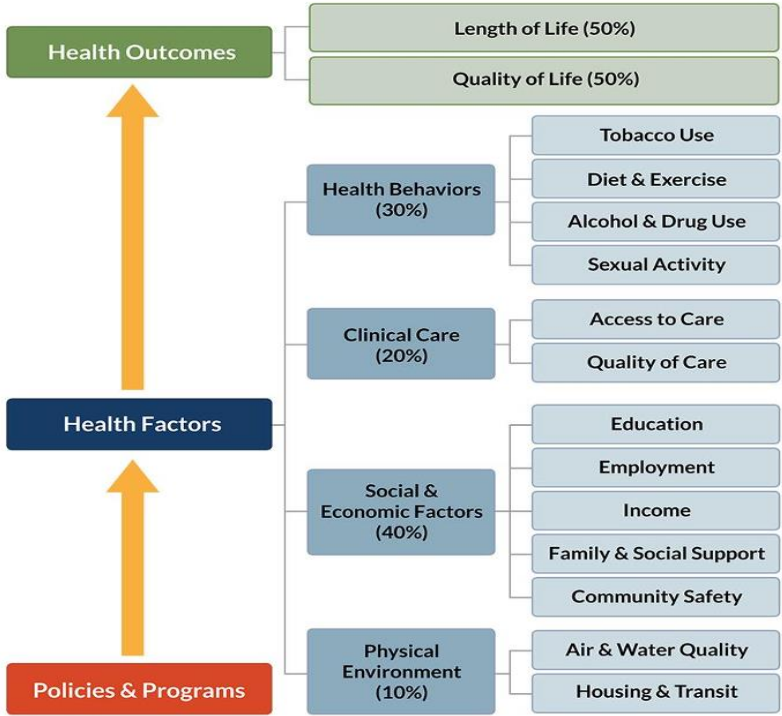
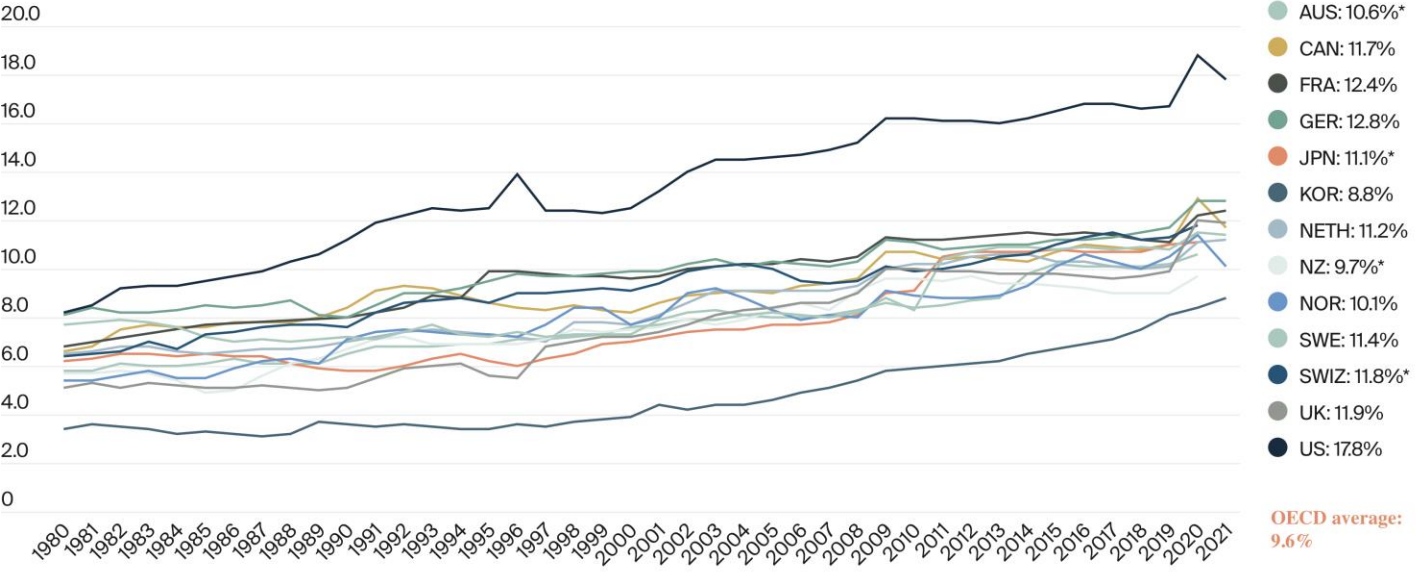


County Health Rankings model © 2016 UWPHI

We would benefit from spending more time investigating, interrogating and dismantling, the medical industrial complex

The U.S. is a world outlier when it comes to health care spending.

Percent of GDP spent on health, 1980–2021*



County Health Rankings model © 2016 UWPHI

Modern bioethics is a reformist reform, but it doesn't have to be

- From the extreme injustices of Tuskegee, WWII, etc. bureaucratic strategies were developed that function similarly to police reforms (like body cameras).
- This has not shifted the foundation of medicine away from the roots of systemic violence that made the injustices possible.
- We all continue to engage (willingly and unwillingly) in the cycle of incremental inaction that academic bioethics offers us.
- While it is important that we do the work that we currently do (as harm reduction) it is also possible that we are feeding the beast

What questions might a non reformist bioethics pose?

- What should healthcare “be”?
 - Start with the assumption that we’re not the right people to do the work
 - Determine what should we divest or remove from healthcare
- How does the remaining field/discipline reconcile and remove its anti-liberatory orientation?
- What is the most direct route to change? Hint: it’s not “more study is needed”.
- What is the academic and community capacity for more radical change? (And how do we build the capacity that is needed?)

Let us embrace the revolutionary framework of abolition

- Conditional on the understanding that some things cannot be fixed or reformed
- Oriented to both the radical future and the radical now
- Intrinsically linked to a liberatory creative imaginary

To address both the carceral logic in healthcare and the carceral logic of healthcare



Another Voice

The Problem Is Not (Merely) *Mass* Incarceration: Incarceration as a Bioethical Crisis and Abolition as a Moral Obligation

Jennifer Elyse James

First published: 22 December 2023 | <https://doi.org/10.1002/hast.1542>

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PERSPECTIVES | THE ART OF MEDICINE | VOLUME 396, ISSUE 10245, P158-159, JULY 18, 2020 [Download Full Issue](#)

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Abolition medicine

Yoshiko Iwai • Zahra H Khan • Sayantani DasGupta

Published: July 18, 2020 • DOI: [https://doi.org/10.1016/S0140-6736\(20\)31566-X](https://doi.org/10.1016/S0140-6736(20)31566-X) Check for updates

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Who do you serve, who do you protect? Doctors and nurses are not soldiers. Antibiotics are not bombs, hospitals are not the front lines, hard-working medical trainees are not “gunners”, and neither disease nor patients are “the enemy”. Militarised language valorises aggression and violence in medical training and the clinical encounter while obfuscating the loyalties of health workers who serve and protect individuals and communities in need.

Narrative medicine, and the broader health humanities, is

[Request your institutional access to this journal](#)

To address both the carceral logic in healthcare and the carceral logic of healthcare

AMA Journal of Ethics®

January 2024, Volume 26, Number 1: EXXX-XXX

MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

What Might It Mean to Embrace Emancipatory Pedagogy in Medical Education?

Whitney V. Cabey, MD, MSHP, Nicolle K. Strand, JD, MBE, MPH, and Erin Marshall, MSS, LSW





THE AMERICAN JOURNAL OF BIOETHICS
2024, VOL. 24, NO. 5, 27–30
<https://doi.org/10.1080/15265161.2024.2327306>



OPEN PEER COMMENTARIES



Revive and Respect: Using Structural Competency and Humility to Reframe Discussions of Decision-Making Capacity

Whitney Cabey , Olivia Duffield, Brendan Hart, Sam Stern and Brian Tuohy 

Center for Urban Bioethics, Lewis Katz School of Medicine at Temple University

We have more work to do!

- Acknowledging the impact of mass incarceration and the specific health needs of those ensnared by the prison industrial complex
- Acknowledging the reality of police brutality
- Uncovering carceral logic in healthcare spaces
 - Collaboration with policing
 - Cooptation of medicine and providers
 - Carceral mimics in specific contexts
 - Incarcerated citizens obtaining healthcare in community settings
 - Institutionalization and behavioral health care
- Defining an emancipatory healthcare, creating a praxis
- Preparing healthcare to participate in the upstream work of other abolition movements

Reading List

Books

- *Abolition. Feminism. Now.* Meiners et al, 2022
- *Torn Apart.* Dorothy Roberts, 2022

Podcasts

- “Ruth Wilson Gilmore Makes the Case for Abolition” [Intercepted](#), 2020.

Articles

- Toward Abolition Medicine. *AMA Journal of Ethics*. Mar, 2022.
- Abolition Medicine. Iwai, et al. *The Lancet*, 2020.

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- Voight, Jeff. Joe Biden's Cancer Moonshot. Wharton Magazine. March 2, 2017.

Questions?

Thank you!

whitney.cabey@temple.edu

The screenshot shows the website for the Lewis Katz School of Medicine Center for Urban Bioethics. The header includes the Temple University logo and name, a search bar for the medical school, and a navigation menu with links for Faculty Directory, Admissions, Alumni, Giving, Contact, Resources, and Temple Health. The main navigation bar lists: About, People, Educational Programs, Research Programs, Community Programs, Contact, and Support Us. The central image is a photograph of a city skyline with a brick building in the foreground. The footer contains the Temple University logo and name, contact information for the Lewis Katz School of Medicine (Medical Education & Research Building, 3500 N. Broad St., Philadelphia, PA 19140), important links (Give Now, Careers, Dean's Office, News, Events, Maps & Directions), and social media icons for Facebook, Twitter, LinkedIn, YouTube, and Instagram.

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f t in y i

Eugenics Revisited: A Critical Examination of its Historical Roots and Contemporary Implications in the Era of CRISPR

RIGOBEL AZANWI, MDIV., MBE, PH.D(C)

BLACK AND BROWN IN BIOETHICS

CONFERENCE APRIL 9, 2024

UNIVERSITY OF BRISTOL

BLACK AND BROWN IN
BIOETHICS



Disclosures

Conflicts of interest: None

Presentation Outline

- Overview of Eugenics
- Nazi Germany
- CRISPR-Cas9
- Bioethical Discuss
- Limitation

Methods

- Google Scholar
- PubMed
- Key words
 - Eugenics
 - The Holocaust and Eugenics
 - CRISPR-Cas9
 - CRISPR Risk

Definition of Concepts

- Eugenics
- CRISPR-Cas9

Historical Context of Eugenics

- German Physician Johan Blumenbach
- Enlightenment
 - Scottish David Hume
 - German Immanuel Kant
- French Arthur Gobineau
- English Charles Darwin

Nazi Germany

- Eugene Fischer
 - Biologist German and Jew distinction
 - Jew exceptional abilities
- Fritz Lenz
 - First professor of racial hygiene
 - Interiority of Jewish exceptionality
- Hitler's Germany
 - Origin of Aryan ideal
 - Madison Grant

CRISPR-Cas9

- What is gene editing?
 - Correction
 - mutation
- CRISPR advantage
 - High accuracy
 - Easy handling
 - Relative low cost compared to previous technologies

Process

- In vivo
- Ex vivo
- Somatic cells vs. Germline cells

CRISPR for Sickle Cell Disease

- What is SCD?
 - CRISPR Promise
 - Concerns

Eugenics/Holocaust Ideologies & CRISPR

- Superior/Elite Race
- Unfit/better breeding
- Undesirable traits
- Racial hygiene

Bioethical Discourse

- Power of the unconscious
- Bias
- Objectivity and Relative relevance

Some limitations

- Consensus challenge
- Enforceability

Conclusions and Future Directions

- Eugenics/ Holocaust and similar atrocities education
- Incorporation of Eugenics in decision-making framework
 - What are we doing?
 - Why are we doing it?
 - Is it ethical?
 - Who is it meant for?
 - How will they get it?

THANK YOU

- Email for complete references or other questions
- Rigobel.Azanwi@kcl.ac.uk

A photograph of three healthcare workers in blue scrubs and white face masks walking down a hospital hallway. The worker on the left is a Black man, the one in the middle is a Black woman, and the one on the right is a white man. They are all wearing stethoscopes and ID badges. A metal gurney is visible on the left side of the frame.

Addressing Health Inequalities Within Healthcare Through the Lens of Intersectionality

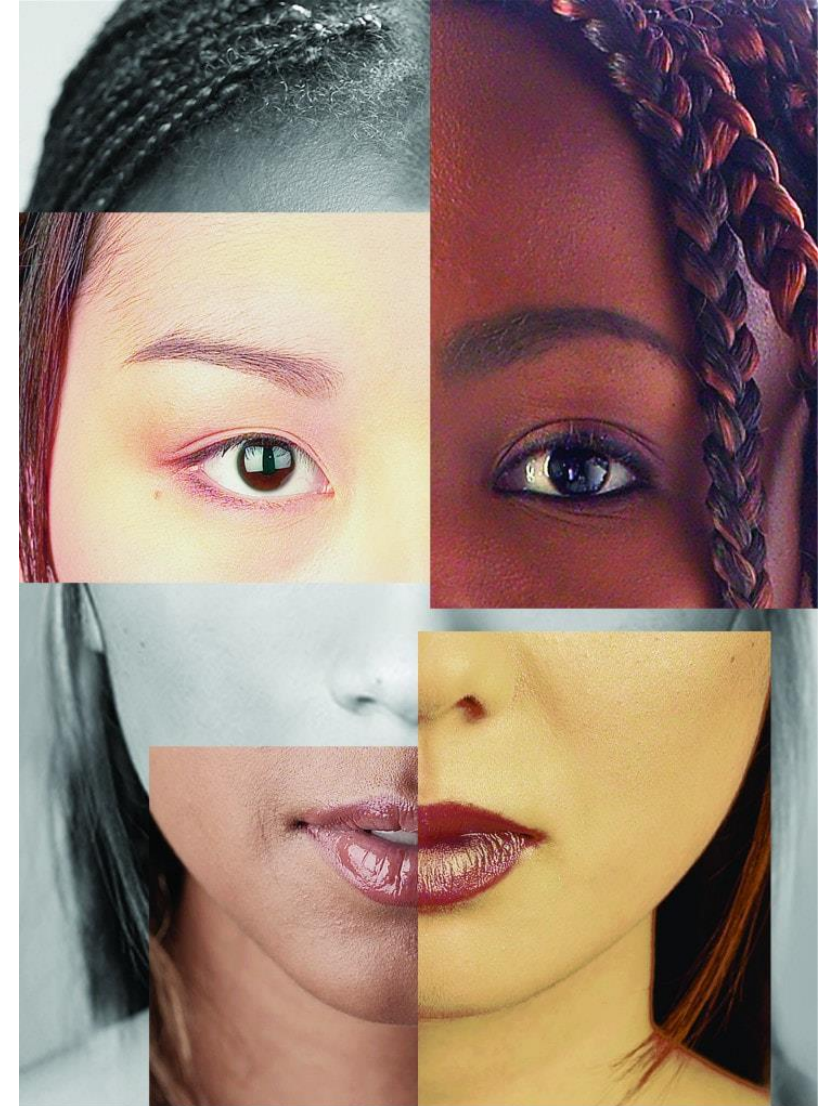
MELISSA RAJALINGAM

SUPERVISOR: DR PETER WEST-ORAM



Race

- Social construct. Based on skin colour to secure racial hegemony.
- Race has no biological distinction or genetic basis.



(Bulmer et al., 1999; Gramsci and Buttigieg, 1996; Thomas C. Holt, 2000).



Intersectionality

- Intersectionality is the interconnected nature of social categorizations such as race, class, and gender applicable to a given individual or group, which creates overlapping systems of discrimination or disadvantage.

(Crenshaw, 1989; Samra and Hankivsky, 2021).



Health inequalities and Covid-19

- Ethnic minorities were more than twice as at risk of death from COVID-19 (Nafilyan et al., 2021; Public Health England, 2020; Williamson et al., 2020).
- 95% of the doctors who died of COVID-19 were of ethnic minority groups (Keith Cooper, 2022).
- Ethnic minorities represent 21% of the NHS workforce and yet account for 63% of staff fatalities (Razai et al., 2021).

ETHNIC HEALTH INEQUALITIES IN THE UK



BLACK WOMEN ARE

4x MORE LIKELY THAN WHITE

women to **DIE** in **PREGNANCY** or childbirth in the UK.

Ref: <https://bit.ly/3ihDwcN>



SOUTH ASIAN & BLACK PEOPLE ARE

2-4x MORE LIKELY TO DEVELOP

Type 2 diabetes than white people.

Ref: <https://bit.ly/3ulDy88>



IN BRITAIN, SOUTH ASIANS HAVE A

40% HIGHER DEATH RATE

from **CHD** than the general population.

Ref: <https://bit.ly/3iifo9V>



IN THE UK, AFRICAN-CARIBBEAN MEN ARE UP TO

3x

more likely to **DEVELOP PROSTATE CANCER** than white men of the same age.

Ref: <https://bit.ly/39KWqEs>



ACROSS THE COUNTRY, FEWER THAN

5% OF BLOOD DONORS

are from **BLACK AND MINORITY ETHNIC** communities.

Ref: <https://bit.ly/3ulg17r>



BLACK AND MINORITY ETHNIC PEOPLE HAVE UP TO

2x

the mortality risk from **COVID-19** than people from a **WHITE BRITISH BACKGROUND**.

Ref: <https://bit.ly/3EzS2Qd>



BLACK AFRICAN AND BLACK CARIBBEAN PEOPLE ARE OVER

8x

more likely to be subjected to **COMMUNITY TREATMENT ORDERS** than White people.

Ref: <https://bit.ly/3zK5lJL>



ESTIMATES OF DISABILITY-FREE LIFE EXPECTANCY ARE

10 YEARS

LOWER FOR **BANGLADESHI MEN** living in England compared to their White British counterparts.

Ref: <https://bit.ly/3urjmit>



24% OF ALL DEATHS IN ENGLAND & WALES, IN 2019,

were caused by **CARDIO VASCULAR DISEASE** in Black and minority ethnic groups.

Ref: <https://bit.ly/3CYz22P>

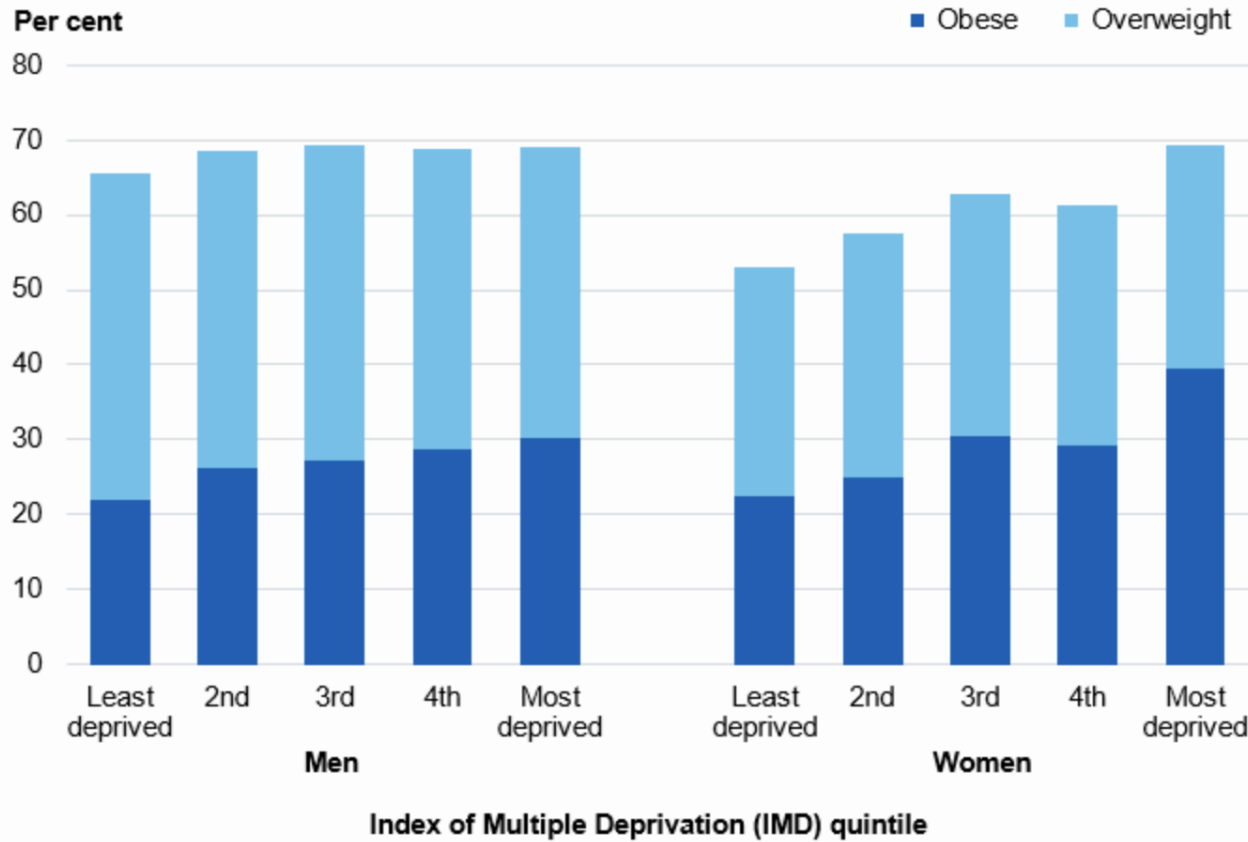


CONSENT RATES FOR ORGAN DONATION ARE AT

42%

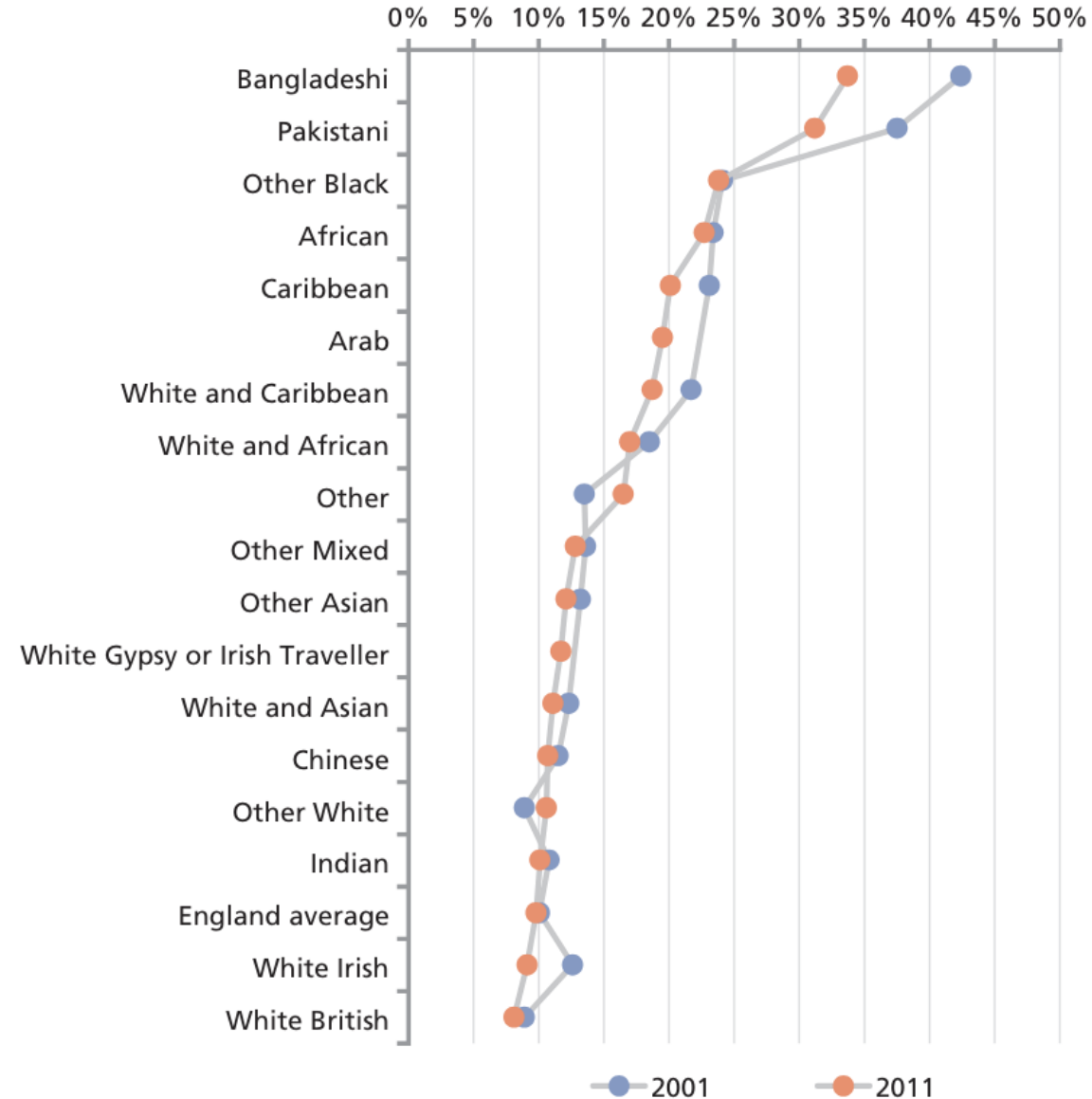
for Black and minority ethnic communities and **71% FOR WHITE ELIGIBLE DONORS**.

Ref: <https://bit.ly/3ogH3fm>



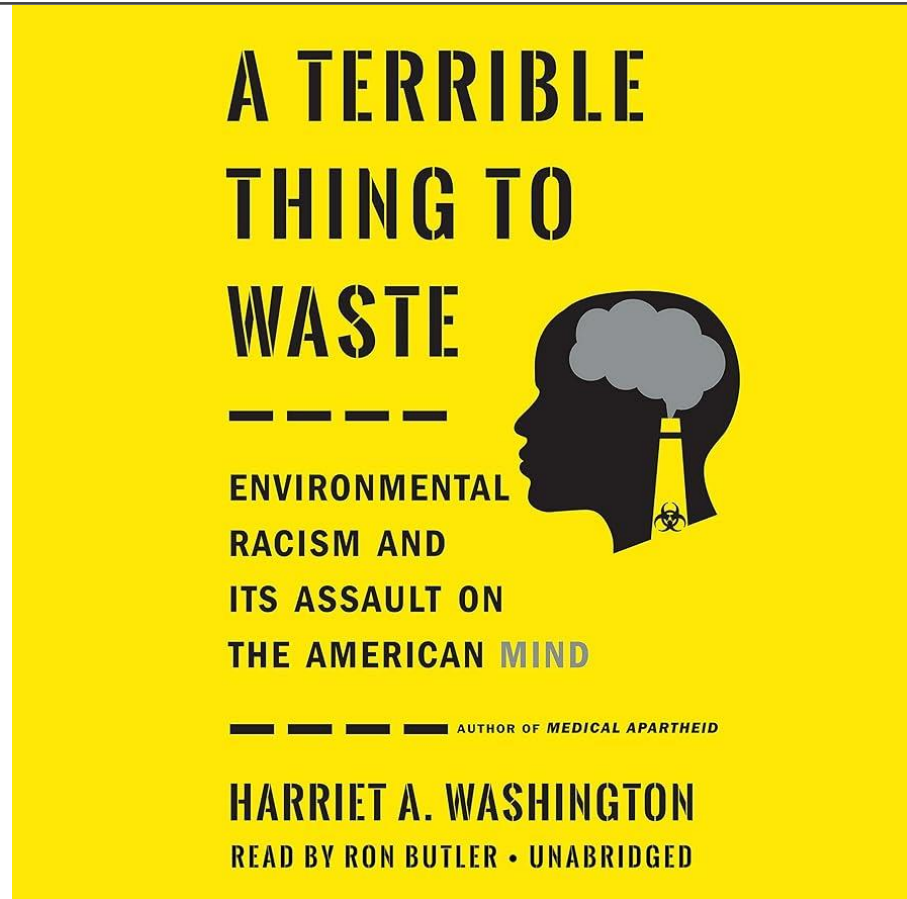
Prevalence of overweight and obesity in adults in deprived areas (“NHS and National Statistics, 2019; Health Survey for England 2018 Overweight and obesity in adults and children,” n.d.).

Deprivation and health outcomes



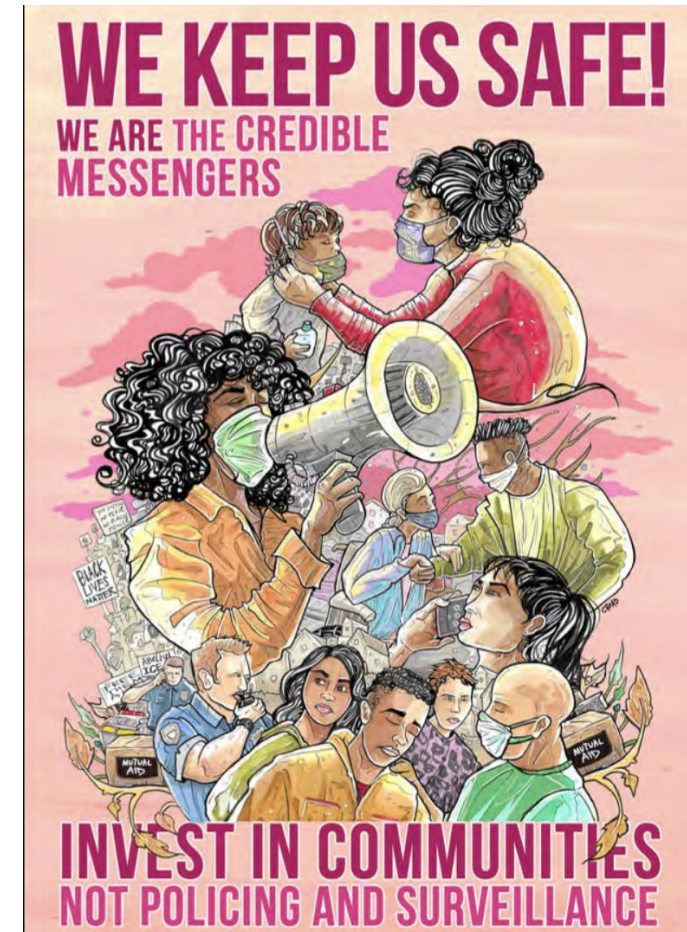
Ethnic minority groups were more likely to live in deprived neighbourhoods in 2001 and 2011 based on census data (Stephen Jivraj and Omar Khan, 2013)

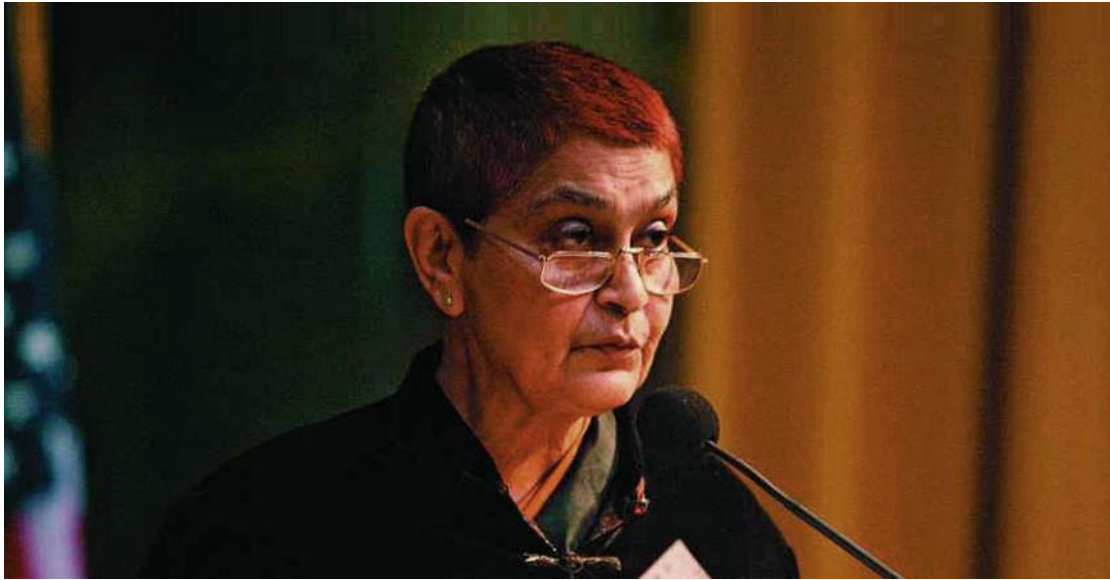
Environmental factors



Public health policy during the pandemic

- Front facing work
- “luxury nature of stay-at-home orders”
- Blame rhetoric





Autonomy and representation

Ethnicity and Type 2 diabetes risk

The **South Asian** population living in the UK are up to **6 times** more likely to develop Type 2 diabetes than that of the white population.

People of **African and African-Caribbean** descent are **3 times** more likely to have type 2 diabetes than the white population.



Impact of implicit bias in healthcare

Disparities in Pain Management

Opioid Medications



LONG BONE FRACTURES

Retrospective study of 115 ED patients with confirmed long-bone fractures.

RACIAL BIAS AND OPIOIDS

White patients were more likely to receive opioid analgesics than non-white patients (70% vs 50%).



PEDIATRIC PATIENTS

Pediatric patients were more likely to receive acetaminophen compared to adult or geriatric patients.



PAIN SCALES DON'T HELP

Patient self-report of pain score had no impact on the type of analgesic administered.



Culturally sensitive advice



Working together, listening to people



Building the picture on diabetes in ethnic communities

10.1% of Sandwell adult population are registered as having diabetes.

People of **African, African Caribbean and South Asian (Indian, Bangladeshi and Pakistani)** ethnicity have a higher risk of developing diabetes than white people and at a younger age.



Are health, care and support services meeting needs?

South Asian communities: What are people saying?

Food

Sharing food is part of the culture of families and communities. There can be high levels of carbohydrates in cultural meals. South Asian traditional celebrations may include sweet treats. **“There is an emotional attachment to certain traditional foods, especially in older generations who migrated to the UK.”**

اَرْدُو

Diabetes awareness

Low understanding of the condition and health risks. “Diabetes” not a recognised word in some cultures “sugar in blood” understood.

پنجابی
پنجابى

“No interpreter at my G.P. Practice to explain diabetes. I felt rushed through.”

Information

Not enough information provided. Need more culturally appropriate, reliable information, including in other languages.



Diabetes education

Low referral and uptake to diabetes courses. Often do not reflect and resonate with cultural aspects, not personalised.

Desi Diabetes run South Asian focused courses including in Punjabi.

“Diabetes information in video and more of local classes would help.”



Support

Health conditions may sometimes be hidden or not spoken about. A need to encourage diabetes conversations and awareness raising within families across the generations and in communities.

Being active

Family responsibilities can mean less time available to manage individual health and wellbeing needs. Community activity -cultural needs.



Help build the picture, get involved to improve services.

**“THE SINGLE STORY
CREATES STEREOTYPES,
AND THE PROBLEM WITH
STEREOTYPES IS NOT
THAT THEY ARE UNTRUE,
BUT THAT THEY ARE
INCOMPLETE. THEY MAKE
ONE STORY BECOME THE
ONLY STORY.”**

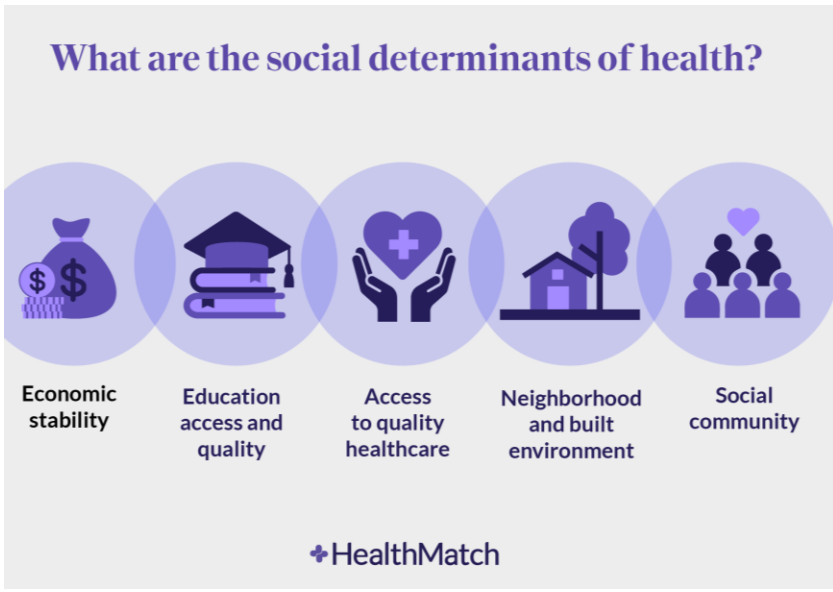
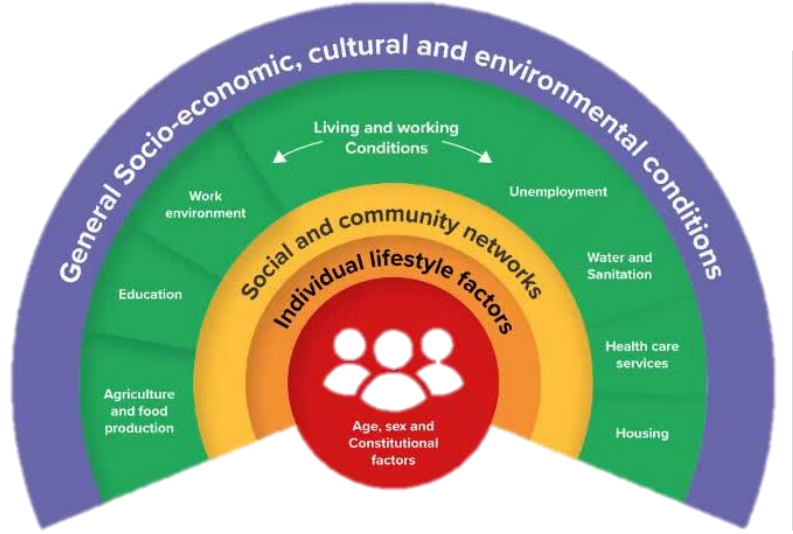
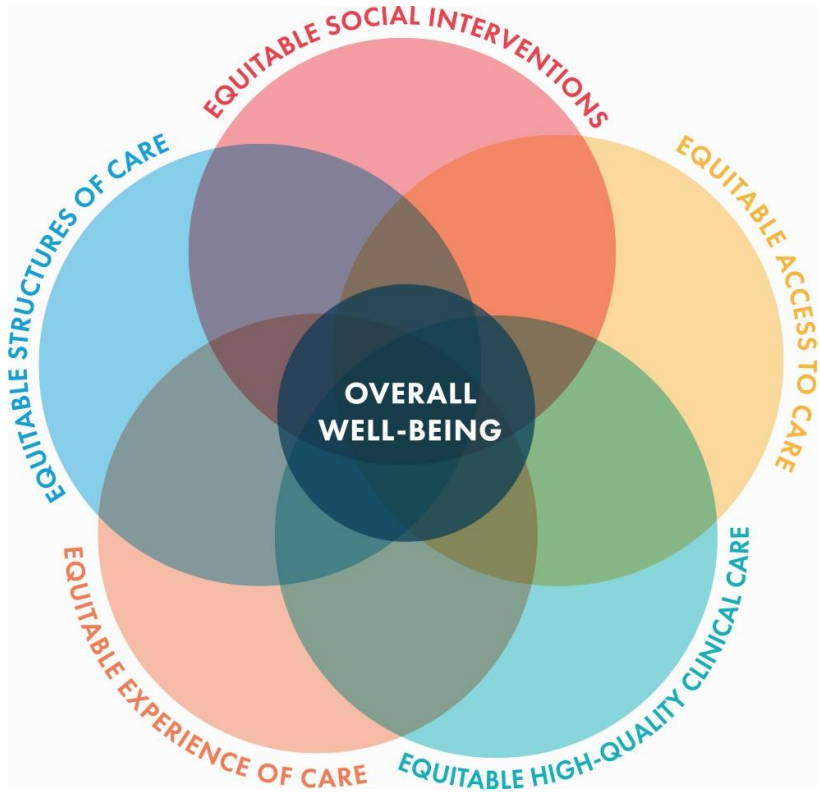
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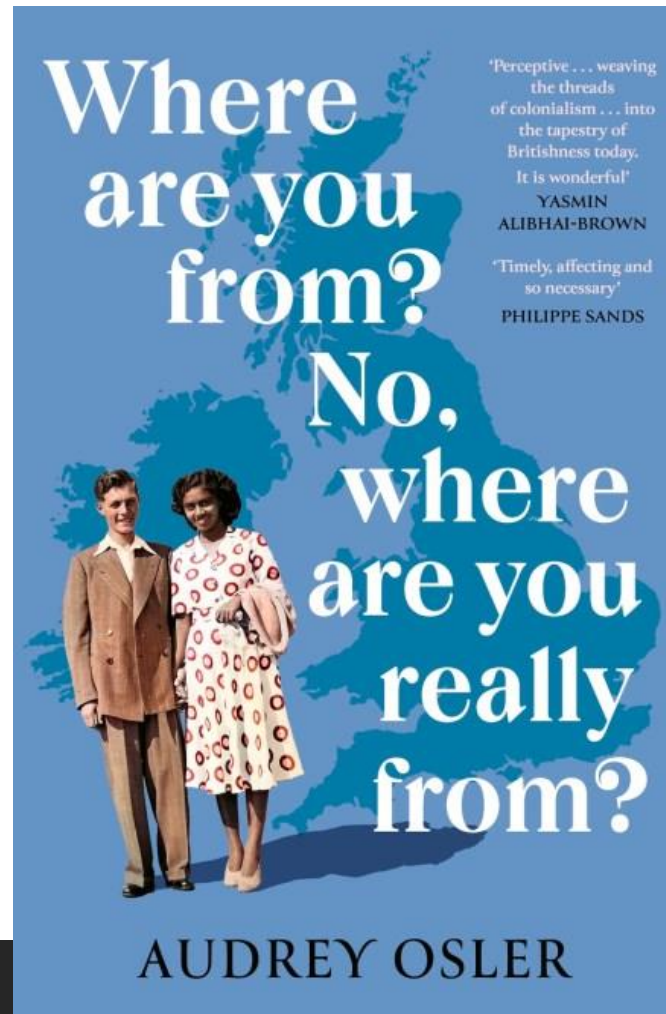
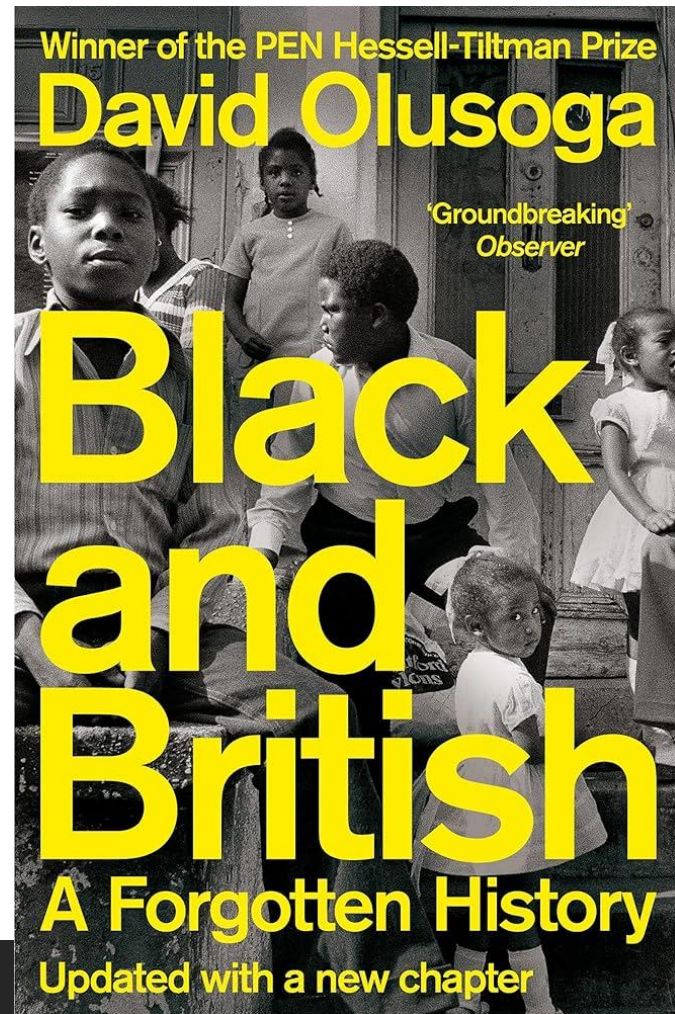
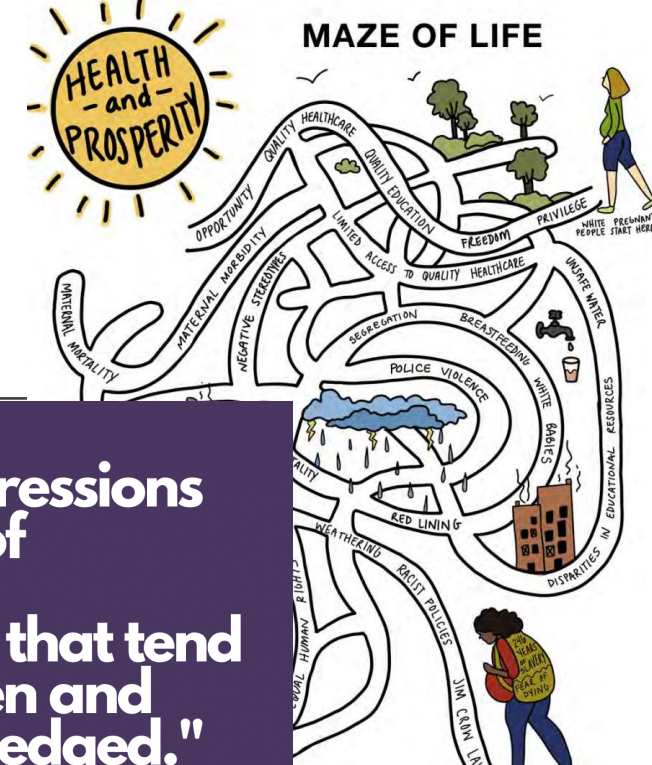
Courtesy of the John D. and Catherine T. MacArthur Foun

(Adichie, 2009).



Determinants of health

Culminative stressors



"Microaggressions are forms of everyday oppression that tend to go unseen and unacknowledged."
MAKING SENSE OF MICROAGGRESIONS



“MONUMENTAL.”

—Ibram X. Kendi, author of *Stamped from the Beginning*

Weathering

The

EXTRAORDINARY STRESS

of ORDINARY LIFE in an

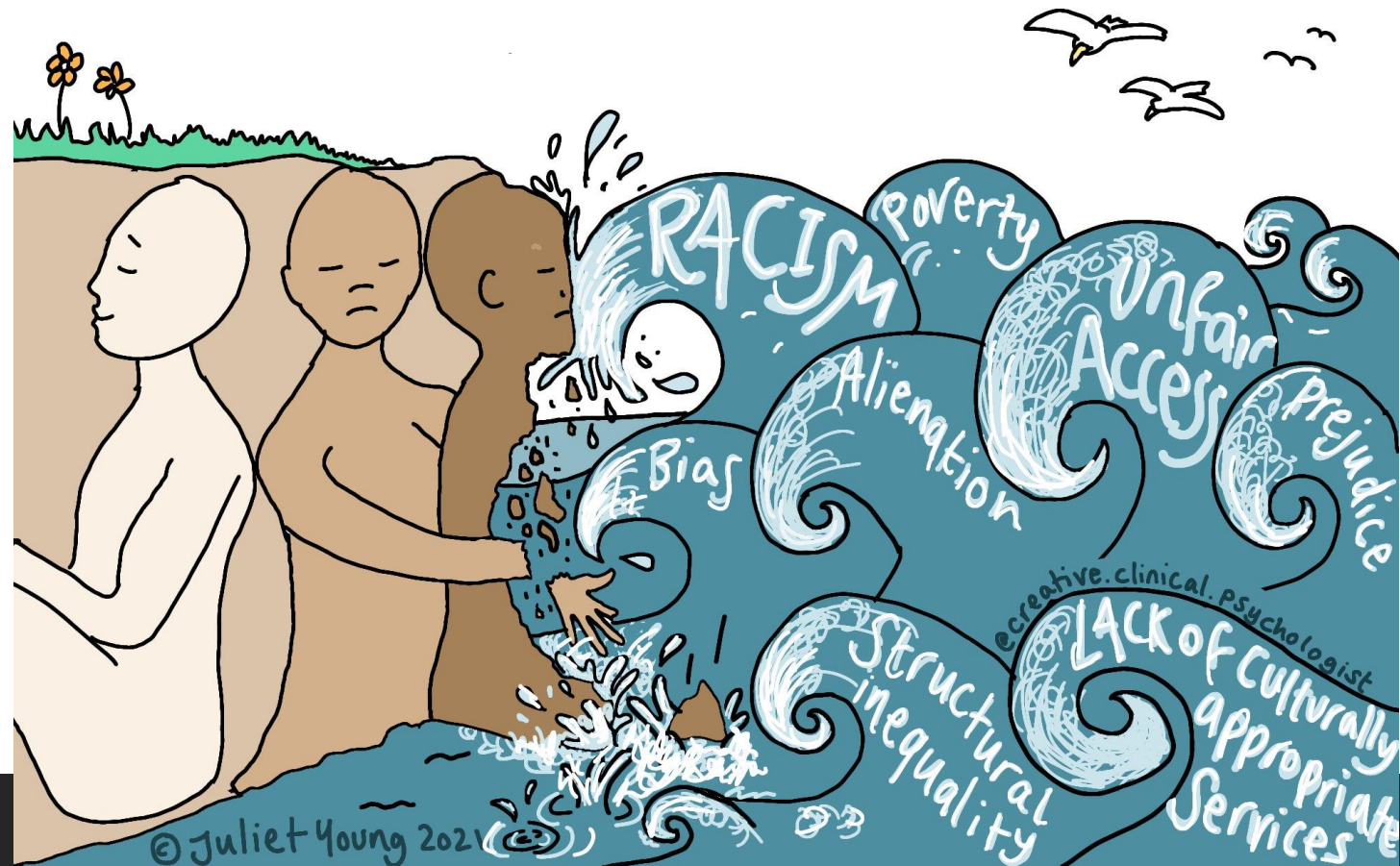
UNJUST SOCIETY

Arline T. Geronimus

The Weathering Hypothesis

(Geronimus, 1992)

Chronic exposure to socioeconomic disadvantage, marginalisation and discrimination leads to early health deterioration.



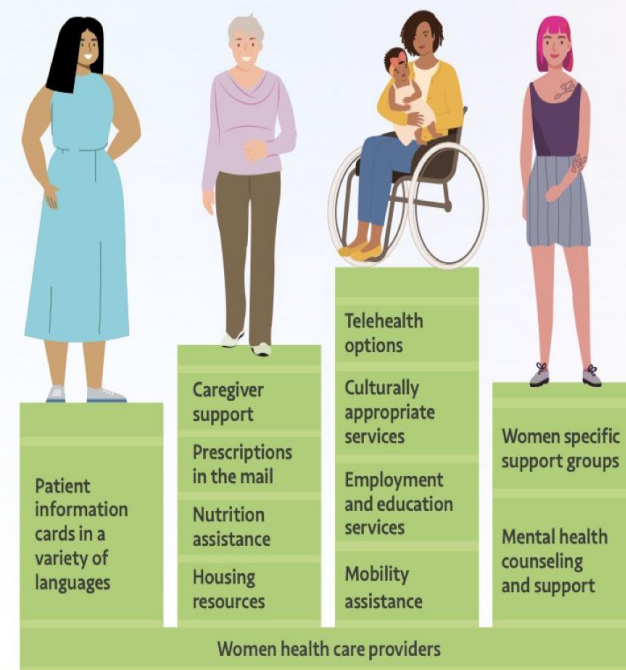


What is Health Equity?

Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health. Achieving this requires ongoing societal efforts to:

- Address historical and contemporary injustices;
- Overcome economic, social, and other obstacles to health and health care; and
- Eliminate preventable health disparities

HEALTH EQUITY IS CARE THAT FITS YOUR NEEDS





Thank you

Dr Peter West-Oram,
Brighton and Sussex
Medical School

For more information please
email:

r.rajalingam1@uni.bsms.ac.uk



POWER AND PRIVILEGE IN ACADEMIA PODCAST



SPRING '24
BLACK AND BROWN
IN BIOETHICS

HOSTED



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KEYNOTE ADDRESS 2 IMPLEMENTING INCLUSIVE BIOETHICS IN POLICY AND PRACTICE

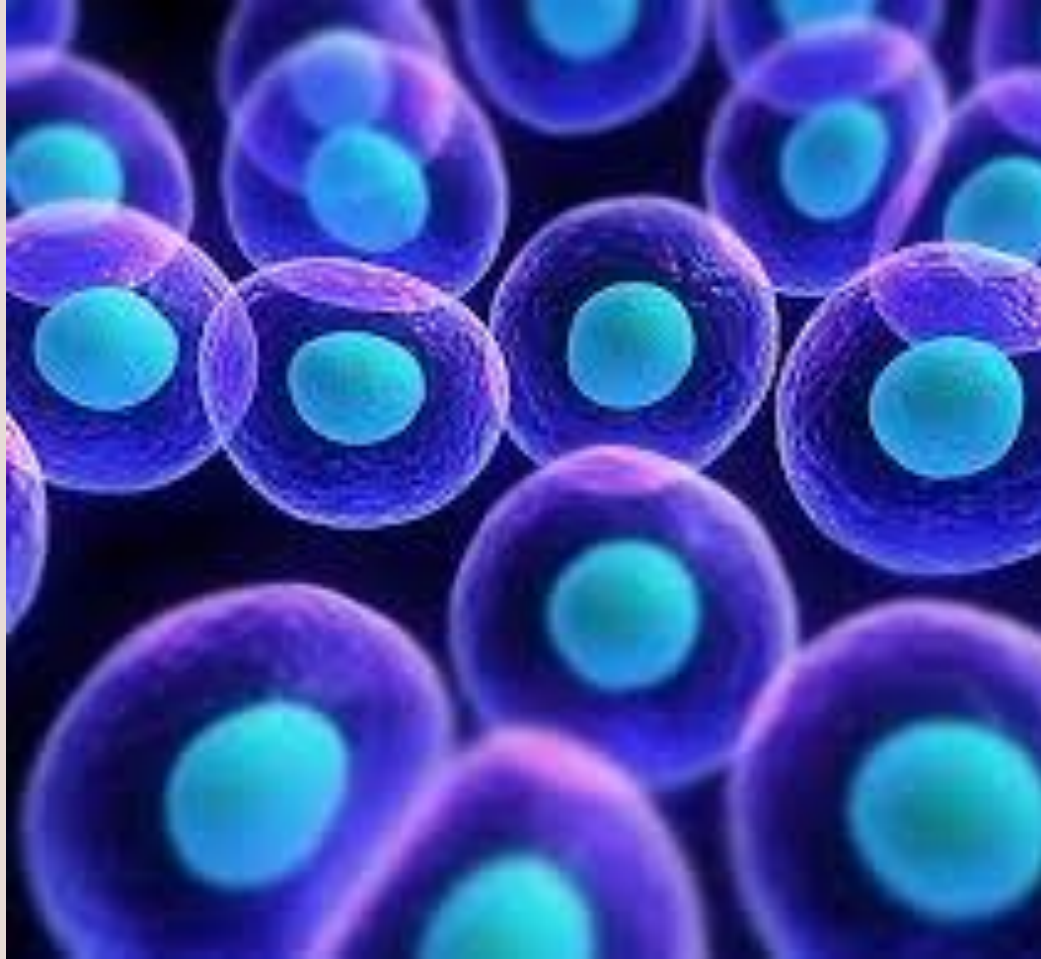
Rita D'Alton-Harrison (Royal Holloway, University of London)
Jonathan Ives (University of Bristol) as Chair



Implementing Inclusive Bioethics in Policy and Practice

Professor Rita D'Alton-Harrison





Challenging Bioethics

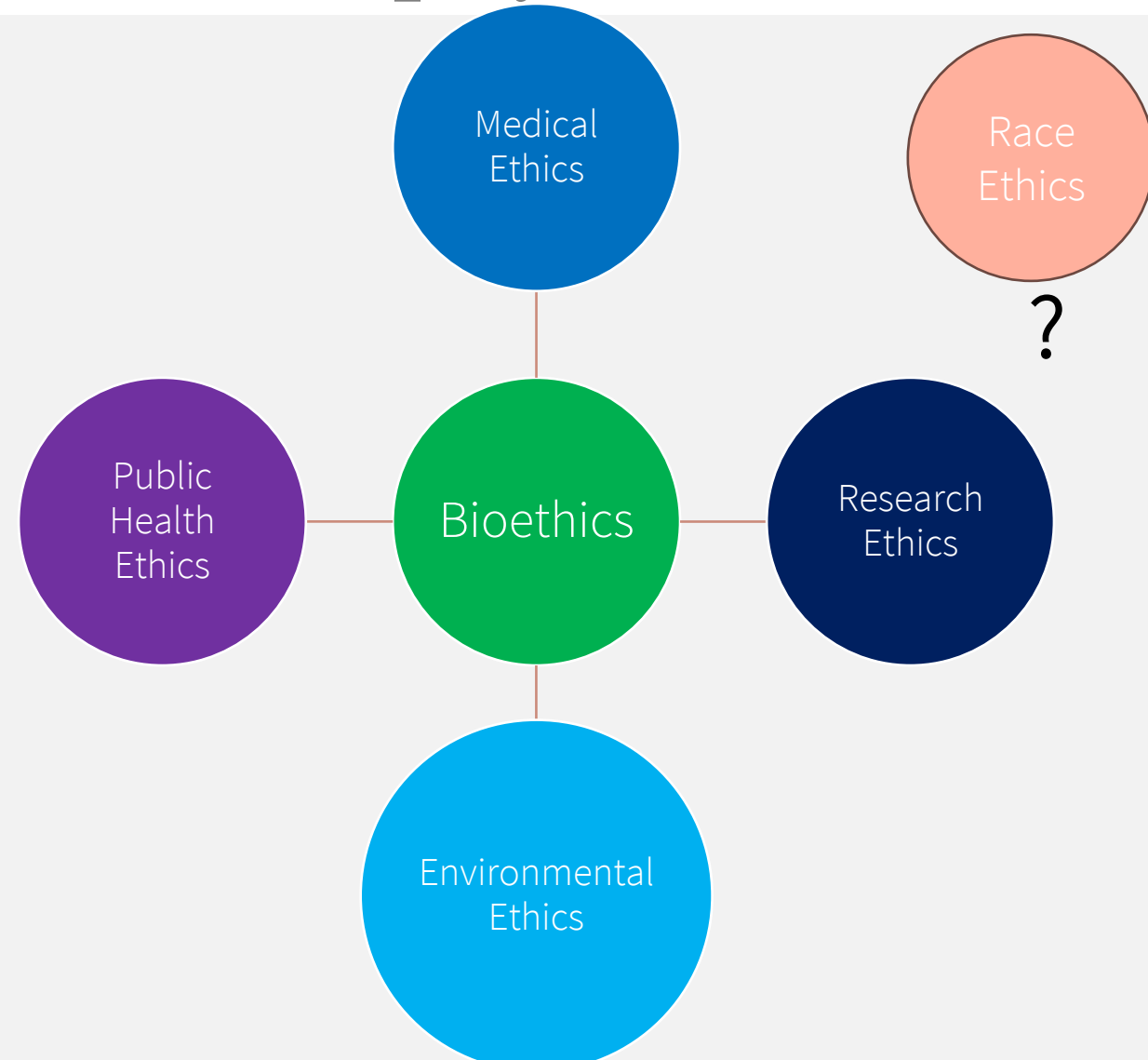
- “Bioethics ... does not lend itself to being mobilized on behalf of catalyzing social or institutional transformations.”

(John Hoberman, 2016)

- “...the thinker must think for truth not for fame.”

(WEB Du Bois, 1903)

How Diverse is the Philosophy?



Because Means To Become

Progressive Bioethics

Because

- **Discrimination** and **Bias** in Mainstream Research Methods
- **Lack of Inclusion** on Editorial Boards in Leading Journals and Funding Bodies
- **Structural Discrimination** in Healthcare Systems
- **Mistreatment** of Black and Brown Medical Staff
- **Unethical** Research on Black and Brown Participants

Become

- *Inclusive* Research Design Principles
- *Incorporate* Non-Western Philosophies
- *Utilise* Moral Traditions and Local Cultures
 - *Embrace* Structural Theories of Justice

Progress

- Learn from Lived Experiences of Researchers/Participants from Minoritized Backgrounds
- Foster Inclusive Relationships Between Medical Professionals and Patients
- Improve Healthcare Data Collection
- Decolonise the Healthcare Curriculum

Inclusive Policy and Practice

Moving Beyond
Consent &
Autonomy As
Absolute Signifiers

Dispelling Suspicion
and Modelling
Change With
Institutional &
Government
Support

Engaging With the
History, Culture
and Religion of
Race





Rebirthing Bioethics

- Moving to a ‘Joyful Polycrisis’
- Researching the ‘Cultural Receptors’
- Shifting bioethics into Spatial Inclusivity
- Learning a new set of behaviours in research, policy and practice

POWER AND PRIVILEGE IN ACADEMIA PODCAST



SPRING '24
BLACK AND BROWN
IN BIOETHICS

HOSTED



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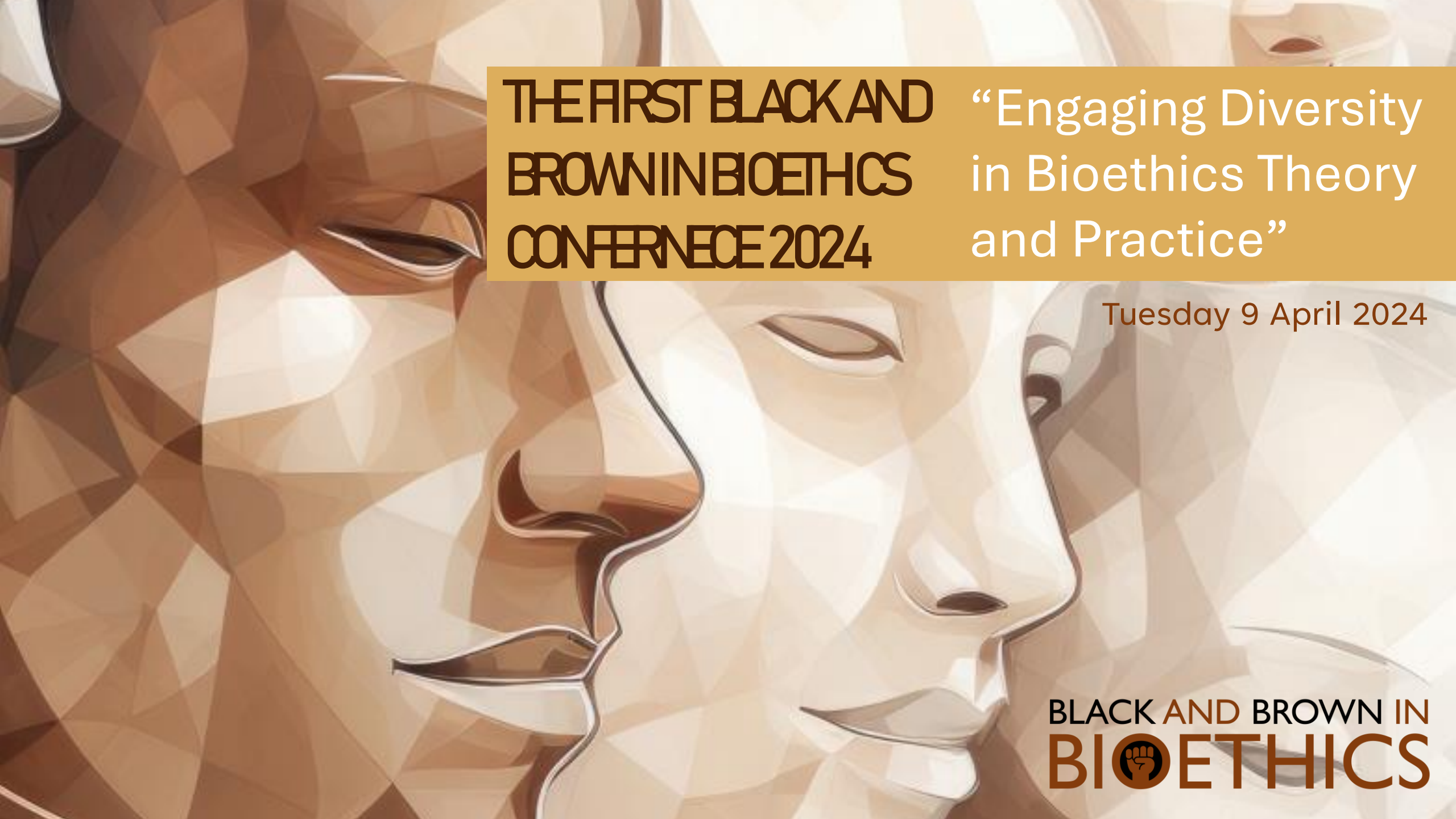
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PANEL DISCUSSION
**SHAPING THE FUTURE OF BIOETHICS:
TABOOS, UNCERTAINTY AND HOPE**

Alya Khan (London Metropolitan University), Jose Lingna Nafafe
(University of Bristol) & Mavis Machirori (Ada Lovelace Institute)
Rachael Goberman-Hill (University of Bristol) as Chair

PRIZE ANNOUNCEMENTS

Eve Kamau (Fabulous Minds Founder & Senior Director at Thermo Fishier Scientific)



**THE FIRST BLACK AND
BROWN IN BIOETHICS
CONFERENCE 2024**

“Engaging Diversity
in Bioethics Theory
and Practice”

Tuesday 9 April 2024

BLACK AND BROWN IN
BIOETHICS

THANK YOU!

Scientific Committee

Gideon Cornel Msee

Rachel Davies

Jordan Parsons

Vorathep (Dev) Sachdev

Ruach Sarangarajan

Helen Smith

Supriya Subramani

Rasita Vinay

Funders

Society of Applied Philosophy

Institute of Medical Ethics

Fabulous Minds

Inclusive Research Collective

Volunteers

Shyamli Suneesh

Helen Smith

Faiq Habash

Khulud Alharthi

Contributors

Speakers

Chairs

Oral presenters

Poster presenters

Attendees

In-person attendees

Online attendees

Supporters

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University of Bristol

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