

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

**“Engaging Diversity
in Bioethics Theory
and Practice.”**



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#BBB2024

FOR MORE INFORMATION, VISIT:

bristol.ac.uk/black-brown-bioethics



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Welcome to the First Black and Brown in Bioethics Conference 2024



Welcome to the First Black and Brown in Bioethics conference 2024 “Engaging Diversity in Bioethics Theory and Practice”.

Black and Brown in Bioethics (BBB)’s mission is to achieve equity and social inclusion within the UK bioethics community. There is presently no regular event in the UK bioethics calendar concerned with issues affecting ethnic minorities or led by people of colour. The main aim of our first BBB conference is to nurture this underrepresented community in the spirit of learning, knowledge exchange, academic interaction, and driving change.

Bioethics involves a broad and interdisciplinary community of researchers including those from the humanities, social sciences, health sciences, law, healthcare professionals, computer sciences, and many more. Despite this wealth of backgrounds and expertise little or no attention is given to issues concerning race in UK Bioethics. Topics like social justice, racial justice, disability ethics, LGBTQ+ ethics, poverty ethics, and topics specific to immigrants and other marginalised group are less commonplace and often not seen as “real” bioethics.

BBB chose “Engaging Diversity in Bioethics Theory and Practice” as the theme of our first conference to counter the lack of active recognition and consideration given to meaningful engagement of diverse voices and experiences in the bioethics field.

We are very pleased to have participants in person and online from a range of disciplines and countries across Europe, Africa, Asia, and the Americas. We would like to extend our thanks to our local host, the University of Bristol for their support in the preparation of the conference. We would also like to thank the Scientific Committee of this conference, the funders for their continuing support and all the abstract contributors. We are grateful for all the support and we very much hope the conference will be a positive experience for us all.

Thank you for joining us!

*Matimba Swana, Kumeri Bandara and Harleen Kaur Johal
BBB Co-founders*

Scientific Committee members

- Gideon Cornel Msee, University of Edinburgh
- Rachel Davies, University of Bristol
- Jordan Parsons, University of Birmingham
- Vorathep (Dev) Sachdev, University of Edinburgh
- Ruach Sarangarajan, University of the Witwatersrand
- Helen Smith, University of Bristol
- Supriya Subramani, University of Sydney
- Rasita Vinay, University of Zurich

Funders

- Society of Applied Philosophy aim to promote philosophical work that has a direct bearing on areas of practical concern; please visit www.appliedphil.org
- Institute of Medical Ethics promote and support the impartial study and understanding of medical ethics and its integration into clinical practice; please visit ime-uk.org for further information
- Fabulous Minds is a youth empowerment platform that utilizes inter-generational mentorship to build confident, resilient minds; follow [fabulousmindsco](https://www.instagram.com/fabulousmindsco) on Instagram
- Inclusive Research Collective aim to promote inclusive and diverse academic environments for further information please visit inclusiverc.com/

BLACK AND BROWN IN BIOETHICS

“Black and Brown in Bioethics (BBB)” was launched in late 2022, 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. We hope to achieve this by upholding and championing our key values:

Inclusivity | Individuality | Collaboration | Courage | Equity | Empathy

Our Team



Harleen Kaur Johal
(she/her)
Co-founder,
University of Bristol



Matimba Swana
(she/her)
Co-founder,
University of Bristol



Kumeri Bandara
(she/her)
Co-founder,
University of Oxford

Our Approach

Research

- Conduct research with postgraduate and early career researchers from ethnic minority backgrounds
- Promote “inclusive” research methodologies and methods in bioethics
- Develop opportunities to create an inclusive and fair publishing system

Events

- Expand opportunities for community engagement
- Challenging prototypical discourse on race
- Promote anti-racism
- Deliver training on anti-racism

Connect with us at bristol.ac.uk/black-brown-bioethics our online home of our community, where we share all things #BBBnetwork.

Venue Information

BBB conference 2024

Lecture Theatre C44, Biomedical Sciences Building,
University of Bristol, Tankard's Close, University Walk, Bristol
BS8 1TD, United Kingdom
Virtual – Zoom

The Biomedical Sciences building is a busy hub for learning and research, built on the academic and creative output of over 430 staff members, 1400 undergraduate and about 400 postgraduate students from across the world. Registration and the conference will take place in Lecture Theatre C44.

After the hybrid conference ends, there will be an optional social for in-person delegates. The social: Comedy stand-up *Dark Humour, Medicine and Misinformation* with Muhsin Yesilada will take place in PGR Hub Room 2.22 (Bristol Doctoral College), University Of Bristol, Senate House, Tyndall Avenue, Bristol, United Kingdom.

The PGR Hub is a cross-disciplinary research collaboration space. The Hub is situated on the second floor of Senate House and is a dedicated space for postgraduate researchers to relax, work together, and attend events and training.

Biomedical Lecture Theatre C44



Main entrance - University Walk



C44 Lecture Theatre

Directions

Lecture Theatre C44 is in the Biomedical Sciences Building, University Walk. Enter the building via the main entrance, using a UCard, someone from the BBB team will be at the entrance to meet you. Proceed directly ahead and take the stairs or lift to floor C. Turn left on exiting the lift and follow the signs to C42.

Building Opening Times

07.00 – 18.00 MON - FRI

Please be ready to vacate this room before the building is due to close.

Wheelchair accessible. Most LFM rooms have a PC, display screen, and VGA laptop connector.

Means of Access into the Building

MAIN ENTRANCE - in University Walk.

- There are 7 steps to ascend at the main entrance to the building.
- There is a graded accessible access ramp from street level to the building entrance and porter reception desk.

Virtual tour can be accessed online

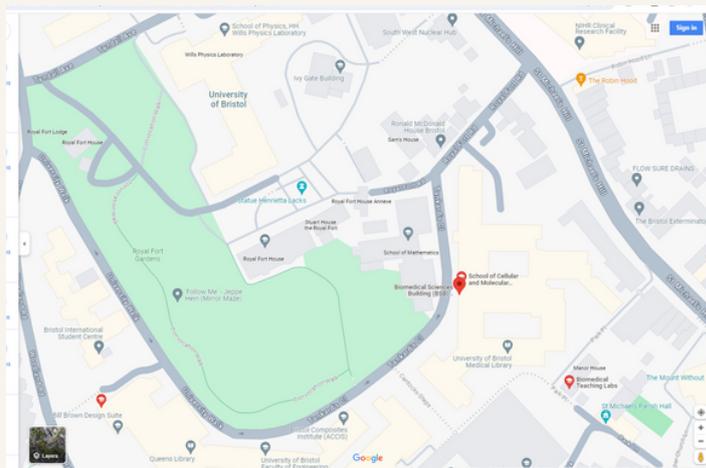
<https://www.bristol.ac.uk/virtual-tour/?s=pano2020#s=pano2020>

Reception

- There is a high level of security because of the nature of some of the processes within the building. Visitors are met and escorted. They sign in and out.
- There is a porter manned desk at the front entrance of the Medical Sciences Building.
- There is adequate room for manoeuvre of wheelchairs and part of the reception desk is at wheelchair height.
- There are U card enabled barriers which span the front entrance – a section of two gates by the porters desk can be opened by the porters so that wheelchairs entering the building from the accessible entrance ramp can pass through into the building at level D.
- On open days, for public access lectures or on other occasions when the U card security access is deactivated, then the wider barriers can be left open.
- A loop system is in place for hearing impaired visitors or staff.
- Any visitor with a visual impairment will be assisted as necessary.
- Lift and Stair Access will be available
- The Main Building is served by eight staircases and 5 lifts (dual use - passengers and goods).
- The Main building entrance is on Level D.

Toilets

Accessible toilets are available on the entrance floor (D floor) and also on other floor levels in the building including adjacent to the Medical Library entrance. There is signage and a plan on each floor in the Main building indicating their location.



PGR Hub Room 2.22

Directions

The Hub is located on Level 2 of Senate House, 5 Tyndall Avenue. Access is by Ucard. Someone from the BBB team will be at the entrance to meet you.

Access

- Wheelchair accessible.
- There is level access to the service.
- There is not a hearing assistance system.
- This venue does play background music.
- Music is played in the office area.
- The lighting levels are moderate to good.
- More detailed access information for Senate House Study Centre is on AccessAble - <https://www.accessable.co.uk/>.

Building Opening times

Monday - Friday 8am - 9pm
Please be ready to vacate this room before the building is due to close.

Toilets

Accessible toilet facilities are available. There is pictorial and written text signage on or near the toilet door. This accessible toilet is approximately 4m (4yd 1ft) from the main building lift. This accessible toilet is located on first floor, to right as you exit lift. There is level access to this accessible toilet. This is by lift.



Main entrance - Tyndall Ave



Open plan PGR Hub - main space



Room 2.22

Conference Programme

10:00	Registration, coffee & networking [in-person delegates]	
10:45	Welcome and housekeeping [hybrid conference begins]	BBB co-founders
11:00	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
11:30	<p>Oral Abstract Presentations</p> <p>Isaac Jarratt-Barnham (University of Oxford, UK) – <i>Should vaccination status be a consideration during secondary triage?</i></p> <p>Ashmita Grewal (Simon Fraser University, Canada) – <i>“Privacy is a Privilege” – A Thematic Analysis of Crowdfunding Campaigner’s Concerns and Advice</i></p> <p>Georgios Kalaitzidis (Charles University, Prague) - <i>Restorative Justice Bioethics: Addressing Racial Disparities in Clinical Trials</i></p> <p>Mercury Shitindo (African Bioethics Network) - <i>Exploring Knowledge, Beliefs, and Attitudes of Individuals in Data-Driven Health Research in Kenya</i></p> <p>Fred Yao Gbagbo (University of Education, Winneba, Ghana) - <i>My Illegal Abortion Regrets': An Ethical Analysis of a woman’s abortion experiences in Ghana</i></p> <p>Peter Young (University of Oxford, UK) - <i>Using deliberative process to resolve race-based requests in medicine</i></p>	Scientific committee - Jordan Parsons (University of Birmingham) as Chair
12:30	Lunch and chaired poster abstract viewing	Scientific committee - Harleen Kaur Johal (BBB co-founder) as Chair
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
13:45	<p>Oral Abstract Presentations</p> <p>Patricia Neville (University of Bristol, UK) & Eleanor Fleming (University of Maryland, USA) - <i>A Critical Retelling of Dental Ethics Told Through “George Washington’s Complete Denture”</i></p> <p>Whitney Cabey (Temple University, USA) – <i>Abolition in Medicine or Abolition of Medicine?: Exploring Carcerality in Biomedical Contexts</i></p> <p>Rigobel (Rigo) Azanwi (King’s College London, UK) - <i>Eugenics Revisited: A Critical Examination of its Historical Roots and Contemporary Implications in the Era of CRISPR</i></p> <p>Faith Fletcher (Baylor College of Medicine, USA) - <i>Expanding the Reproductive Bioethics Canon: An Urgent Appeal to Prioritize African American Women in the United States</i></p> <p>Melissa Rajalingam (Brighton and Sussex Medical School, UK) - <i>Addressing Health Inequalities Within Healthcare Through the Lens of Intersectionality</i></p>	Scientific committee - Kumeri Bandara (BBB co-founder) as Chair
14:45	Tea and coffee break and poster abstract viewing	
15:15	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
15:45	Tea & coffee break	
16:00	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
16:45	Prize announcements	Eve Kamau, (Fabulous Minds Founder & Senior Director at Thermo Fishier Scientific)
17:00	Closing address	BBB co-founders
17:15	End of conference [hybrid conference ends]	

Social

17:30 – 19:30 Comedy stand-up Dark Humour, Medicine and Misinformation with Muhsin Yesilada.

PGR Hub Room 2.22 (Bristol Doctoral College), University Of Bristol, Senate House, Tyndall Avenue, Bristol, United Kingdom

We are encouraging a 'come as you are' approach, with plenty of opportunities for conversation, reflection, nourishment and most importantly laughter!

Muhsin Yesilada



Muhsin is a Stand-up Comedian and Psychology PhD. He is making a name for himself on the comedy circuit. He regularly performs in theatres and clubs such as Big Belly Comedy Club, Glee Club, Top Secret Comedy Club, Hot Water Comedy Club, and Backyard. He is also a Chortle Student Comedy Award Finalist, New Act of the Year nominee, and UK PhD Student of the Year Nominee. His comedy sketches and podcast have accumulated over 50 million views across Instagram and TikTok.

"One of the hottest young comedians on the UK live circuit right now is Muhsin Yesilada." - Eastern Eye.

"Yesilada shares these entertaining stories with the poise of an experienced pro in command of the room and his material." - Chortle

Speakers

Keynote address 1, Unforeseen challenges and gatekeepers to progress in bioethics



Keynote Speaker

Sridhar Venkatapuram, Senior Lecturer in Global Health & Philosophy, King's College London

Sridhar Venkatapuram is an inter-disciplinary academic-practitioner in global health ethics and justice. He is a Sr. Lecturer Assoc Professor at King's College London. Since early 1990s he has worked with WHO (HQ & EMRO), NHS, Wellcome Trust, BMA, Human Rights Watch, and others. He lectures worldwide and publishes research on public health and global health ethics; global and health justice philosophy; capabilities approach; social determinants of health; and health equity. His Twitter handle is @sridhartweet.

Session Chair

Agomoni Ganguli-Mitra, Senior Lecturer in Bioethics & Global Health, University of Edinburgh

Dr. Agomoni Ganguli-Mitra is Senior Lecturer in Bioethics and Global Health Ethics, and Deputy-director of the JK Mason Institute for Medicine, Life Sciences and the Law. Dr. Ganguli-Mitra's background is in bioethics, with a special interest in global bioethics, structural and gender justice. She has written on ethical issues related to global health emergencies, public health, global surrogacy, sex-selection, biomedical research, racism in health and the concepts of exploitation vulnerability and power in bioethics.



Fireside chat, Reflections on roles and careers in academia

Fireside Speaker

Tanvi Rai, Senior Researcher, University of Oxford

Tanvi is a Senior Researcher based at the University of Oxford. She has an interdisciplinary and international background that spans across public health and healthcare research and applied social sciences. She leads research about health inequalities, social and structural determinants of health, inclusive research methods and practices, implementation science, reproductive and sexual health, public health communication, as well as studies on sensitive health topics and working with socially marginalised populations.



Fireside Speaker

Anna Dowrick, Senior Researcher, University of Oxford

Anna is a Senior Qualitative Researcher at the University of Oxford. Her research explores how social injustice can be seen and acted on through understanding experiences of health and illness. She is passionate about using qualitative methods to explore how healthcare interventions can address inequality. Anna is an interdisciplinary social scientist, spanning the fields of medical sociology, medical anthropology and science and technology studies.



Fireside Host

Princess Banda, DPhil Anthropology, University of Oxford

Princess Banda (she/ her) is a socio-medical anthropologist who, amongst many things, is primarily a writer, educator, and researcher. Princess is currently a DPhil Anthropology student and is cultivating a research pathway which embraces the intersections and entanglements between socio-medical anthropology, women's health, racial and social justice, and critical qualitative research methods. Her doctoral thesis explores how obstetric racism is not only a significant factor in UK Black women's intergenerational experiences of unequitable maternal health, but how it is also a kind of biopolitics which reflects the UK's wider politics of race and ethics of anti-Blackness.



Keynote address 2, Implementing inclusive bioethics in policy and practice



Keynote Speaker

Rita D'Alton-Harrison, Professor of Law, Royal Holloway, University of London

Professor Rita D'Alton-Harrison is a Professor of Law at Royal Holloway, University of London. Rita is also a qualified solicitor, author and legal education trainer and adviser. Rita has been teaching in higher education for over 21 years and is currently one of the Subject Heads on the LLB course at Royal Holloway. She has taught on both undergraduate and postgraduate professional courses and is a Senior Fellow of the Higher Education Academy. As well as pursuing her interests in pedagogical scholarship, Rita also researches in the field of international surrogacy arrangements and has a particular interest in the different scientific methods enabling family formation and the legal response to such advancements. Rita writes about the intersectionality of race, class and gender in assistive reproduction and its relationship with intimacy and knowledge transfer and its subsequent impact on policy formation. Rita's 2014 publication has been cited by the Supreme Court of Ireland, The Law Commission of England and Wales and the Scottish Law Commission.

Session Chair

Jonathan Ives, Professor of Empirical Bioethics, University of Bristol

Jon is Professor of Empirical Bioethics and Deputy Director of the Centre for Ethics in Medicine, and Head of Section for Health Care Evaluation, in Bristol Medical School. He initially trained in philosophy, and now works as an interdisciplinary bioethicist at the nexus of ethics and social science, with a particular focus on, and expertise in, empirical bioethics methodology, on which he has published widely and delivers training worldwide. His research interests are varied and include surgical innovation; ethics and trust of AI/autonomous systems; best interests decision making; clinical and research ethics; ethics, reproduction and parenthood. Jon is Chair of the BNSSG Risk and Ethics Advisory Forum, is a member of the NICE Highly Specialised Technologies Evaluation Committee, chairs the IME Grants and Awards Committee and is a trustee of the IME.



Panel discussion, *Shaping the Future of Bioethics: taboos, uncertainty and hope*

Panel Speaker

Alya Khan (she/her), Senior Lecturer in Health Ethics, London Metropolitan University.

Alya Khan is a Senior Lecturer in Health Ethics at London Metropolitan University. She did her BA and MPhil at UCL and her PhD at Birkbeck in Philosophy. Her research interests are in social and political philosophy, bioethics, feminist philosophy and critical theory, including critical pedagogy in bioethics education. She also conducts interdisciplinary projects with oral history and philosophy to explore narratives of lived experiences relating to social determinants of health in minoritised communities. She is currently writing a new textbook on bioethics co-authored with Jo Wolff. She sits on the executive committee of the Society for Women in Philosophy, UK.



Panel Speaker

Mavis Machirori (she/her), Senior Researcher, Ada Lovelace Institute

Mavis is a Senior Researcher at the Ada Lovelace Institute. Her research covers data and AI, health data sharing, inequalities and genomic data governance. Mavis was previously a member of the Future Council of Biotechnology at the World Economic forum, and in 2022, co-convened a workshop exploring the concept of the African Genome, held at STIAS in South Africa, funded by Point Sud (Germany). She co-founded a community interest platform (Genetics Engage) and is interested in connections between technologies and social justice and equity, on whole populations for those marginalised by current and historical infrastructures. She holds a PhD in Health Studies and an MSc in Medical Anthropology, and is a midwife by background.



Panel Speaker

José Lingna Nafafé (he/him), Senior Lecturer in Portuguese and Lusophone Studies, University of Bristol

José Lingna Nafafé is Senior Lecturer in Portuguese and Lusophone Studies and co-Director of Teaching for Hispanic, Portuguese and Latin American Studies at University of Bristol. Dr Lingna Nafafé's academic interests embrace a number of inter-related areas, linked by the overarching themes of: the Black Atlantic abolitionist movement in the 17th Century; the Lusophone Atlantic African diaspora; seventeenth and eighteenth century African, Portuguese and Brazilian histories; slavery and wage-labour, 1792-1850; race, religion and ethnicity; Luso-African migrants' culture and integration in the Northern (England) and Southern Europe (Portugal and Spain); 'Europe in Africa' and 'Africa in Europe'; and the relationship between postcolonial theory and the Lusophone Atlantic.



Panel Chair

Rachael Goberman-Hill (she/her), Director of the Elizabeth Blackwell Institute for Health Research, University of Bristol

Rachael is Director of the Elizabeth Blackwell Institute for Health Research and Professor of Health and Anthropology at the University of Bristol. She is a Social Anthropologist by background who applies techniques from anthropology and qualitative approaches in health research. Most of her work has been interdisciplinary in nature and includes work with bioethicists. She also has professional background in, and current active engagement with, matters relating to research integrity.



Abstracts

LIST OF ABSTRACTS (IN ALPHABETICAL ORDER)

Title	Post-Colonial Bioethics in the Face of International Collaboration
Name	Ozan Altan Altinok
Pronouns	he/him
Current position	Post Doctoral Researcher
Institution / Affiliation	Center for Ethics and Law in the Life Sciences, Leibniz University of Hannover
Biographical note	I am a postdoctoral researcher at CELLS, Leibniz University of Hannover working on politics and ethics of science. At the intersection of philosophy of science in practice, hands-on bioethics, and global justice, I aim to understand the structures of local and international inequality to provide a future-looking body of knowledge that is more equitable, responsible, and inclusive towards the publics locally and globally within the concepts of health and disease and the branches of evolutionary medicine, public health, and bioethics.
Keywords	Bioethics as governance, colonialism of the institutions, embedded values, priority setting, methods of pluralism
Abstract	<p>In this research, I will reflect upon the aspects of international cooperation, particularly that of bioethics as governance. I will build the following concerns into full arguments based on the case study that I had, which is an international collaboration program between the Federal Republic of Germany and the Republic of Ethiopia in biotechnology. I will argue for the need to integrate critical perspectives in the making of bioethical discourse and the shaping of institutions within Ethiopia where access to the discourse is weak, but the science governance is quite strict. In the realm of bioethics, the post-colonial perspective represents a critical lens through which ethical considerations are examined in the context of international collaboration. One pressing issue within this discourse is the impact of climate change on various aspects of bioethics, particularly in relation to dryness and drought stress. The changing climate pressures existing bioethical frameworks, necessitating an evolution in ethical considerations and decision-making processes.</p> <p>Sequencing, a fundamental aspect of contemporary bioinformatics, also comes under scrutiny in the post-colonial bioethics discourse. As international collaborations engage in genomic research, questions arise about the equitable distribution of benefits and the potential exploitation of genetic resources from regions that have historically been subjected to colonial exploitation. While in many cases sequencing is seen as a fundamental element of scientific activity in biology, an incomplete and disconnected from other research activities sequencing based science could further injustices in the global south. The existing values within biosciences, such as and draught stress – climate change pressure - are institutionalized within this disconnectedness. One crucial aspect of international collaboration in bioethics is the issue of patents. The tension between the global scientific community's pursuit of knowledge and the local context's affordability and national sovereignty is a complex challenge.</p>

Title	Eugenics Revisited: A Critical Examination of its Historical Roots and Contemporary Implications in the Era of CRISPR
Name	Rigobel (Rigo) Azanwi
Pronouns	he/him
Current position	PhD candidate
Institution / Affiliation	King's College London
Biographical note	<p>Rigobel (Rigo) Azanwi is a Ph.D. student at King's College London; his research centres on "Tackling Inequities in Healthcare Access by Reconfiguring Priority-Setting Decisions." The awareness of health disparities stems from his upbringing in a developing country, motivating his commitment to understanding and alleviating these inequities through academic inquiry and practical efforts. During his undergraduate studies in Cameroon, he had the transformative opportunity to study abroad at Dickinson College Carlisle, PA, where he was introduced to the field of bioethics. This initial exposure ignited his interest, leading him to pursue further exploration during his Master of Divinity program at the Catholic University of America. Immersed in coursework that embraced diverse perspectives on bioethics, he encountered the transformative potential of Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) technology. Driven by the conviction to contribute ethically, he chose to delve deeper into bioethics, explicitly focusing on the ethical implications of investing in innovative therapies like CRISPR for treating sickle cell disease (SCD). This interest holds personal significance, as he has witnessed the impact of SCD on persons close to him. Given the disproportionate prevalence of SCD among Black populations, he believes he has an ethical imperative to contribute to finding solutions. In addition to his academic pursuits, Rigo is a Capuchin Franciscan Priest with almost a decade of participating and holding leadership roles in faith communities. As a recent graduate from the Harvard Medical School--Centre for Bioethics, and a recent Public Health Ethics fellow at Tuskegee University, his overall research interest focuses on health justice and equity. He considers himself a dare grasp the least opportunity he gets for an adventurous activity. He is even referred to as 'Air Friar' as he enjoys skydiving, helicopters etc.</p>
Keywords	Eugenics, Holocaust, CRISPR, Gene-editing, Inclusivity, Diversity, Ethics
Abstract	<p>Eugenics, a once-prominent pseudo-science in the late 19th and early 20th century United States, advocated for selective human breeding to enhance the population's genetic makeup. This paper explores the potential modern-day manifestations of eugenic principles surrounding the use of gene editing technologies, focusing on CRISPR. The recent approval of the first CRISPR drug for treating sickle cell disease underscores the reality of gene editing technology. Despite the dark legacy of eugenics, contemporary ideals, particularly in the realm of gene editing technologies, raise concerns. Although CRISPR has the potential of realizing tremendous good in medical science this paper emphasizes the need for ethical considerations and the prevention of unintended consequences using gene editing tools. Drawing parallels between eugenics and historical atrocities, such as the Holocaust, the paper aims to raise awareness about the connections between these horrific chapters in human history and the potential of its repetition. I argue that a vigilant understanding of the past is crucial for preventing the recurrence of ethically questionable practices. Therefore, this paper will advocate for the integration of eugenics framework into bioethical deliberations surrounding gene editing technologies. By harnessing knowledge of the past, gene editing technologies can possibly progress without perpetuating the harmful ideologies of eugenics.</p>

Title	Addressing Anti-Black Racism in Research: An Ethical Imperative to Center Black Scholars in the United States
Name	Alicia Best
Pronouns	she/her
Current position	Associate Professor
Institution / Affiliation	Morehouse School of Medicine



Biographical note	<p>Dr. Alicia Best is an Associate Professor in the Department of Public Health Education at the Morehouse School of Medicine in Atlanta, GA. Her interdisciplinary and community-engaged research examines social, cultural and systematic factors that contribute to cancer and other health inequities among Black and African American populations. She was principal investigator of a National Cancer Institute-funded study to develop and test a multilevel communication intervention to increase cancer screening in federally qualified health centers (FQHCs) in Florida (2018-2023). She also engages in a variety of teaching and service activities focused on anti-Black racism and social justice.</p>
Keywords	<p>Anti-Black racism; power; social justice; health equity</p>
Abstract	<p>National efforts are currently being implemented to foster racial equity and inclusion, and to tackle structural racism within the research field. Considering that anti-Black racism, bias, and other forms of oppression are evident throughout the entire research process, it is crucial for these national initiatives to actively prioritize the inclusion of Black scholars in positions of authority. Centering Black scholars not only promotes justice, but it contributes to dismantling harmful policies and practices, ultimately leading to the attainment of health equity.</p> <p>As anti-Black racism can be perpetuated throughout the research process, I will discuss the ethical importance of prioritizing Black scholars in the funding, execution, and application of health equity research. I will also highlight the value of interdisciplinary collaboration between bioethics, public health ethics, and health equity to facilitate meaningful discussions, provide valuable suggestions, and tackle the unequal distribution of power caused by anti-Black racism. In this presentation, I will also draw on personal encounters and firsthand knowledge as a Black health equity researcher who actively engages with marginalized populations to offer context-specific insight. Ultimately, these efforts align with and contribute to the ethical imperative by elevating Black scholars and balancing power dynamics within scientific research.</p>

Title	Weighing the Harms: How BMI as a screening tool minimizes societal utility
Name	Isabella Braga
Pronouns	she/her
Current position	Graduate Student in Bioethics and Philosophy
Institution / Affiliation	McGill University
Biographical note	<p>Isabella Braga is a master's student in Bioethics and Philosophy at McGill University, where she conducts research on the ethics of neurodegenerative disorders. In 2020, Isabella earned her Bachelor of Arts in philosophy at Rollins College, publishing a thesis supporting advance euthanasia directives on the basis of posthumous harm, before completing a Fulbright grant in South Korea and subsequently pursuing her degree in bioethics. Of Puerto Rican and Filipina descent, Isabella strives to promote inclusivity, diversity, and cultural sensitivity through the critical examination of medical institutions and practices built on imbalances in power and privilege. Isabella's research interests are broad: she has explored topics ranging from animal to reproductive to neuro ethics, and is currently developing a graduate thesis arguing for a medical reconceptualization of death based in a loss of identity. Her most recent publication is entitled "Is the Right to a Healthy Environment Enough? Reckoning with a History of Failures in Chemical Valley" (The American Journal of Bioethics, 2024). In this commentary piece, she and her co-researchers examine the Canadian government's involvement in a notoriously polluted indigenous community, arguing that the added right to a healthy environment alone is insufficient to achieving tangible environmental progress for underserved communities.</p>
Keywords	body mass index, body fat percentage, waist-to-height ratio, obesity, screening tool, inclusivity, diversity, utilitarianism
Abstract	<p>At the advent of the 20th century, weight gathered traction as a population-based medical issue. Life insurance companies collected data on individuals' body weight adjusted by height, labeling this figure a determinant of life expectancy, and in 1959, the Metropolitan Life Insurance Company "published tables of average body weight for heights (Wt/Ht) by gender and at different ages" (Nuttall 2015, 118). Despite this method's inability to differentiate lean and body fat mass (Nuttall 2015, 120), it remains in practice in its evolved form: body mass index, or BMI. Critically, BMI as a screening tool specifically disadvantages women of color insofar as it fails to consider fat distributions and body types nonconformant to the white, male body types upon which initial BMI averages were based.</p> <p>In my research, I apply a hedonistic utilitarian framework to the use of BMI as a screening tool to argue that this practice minimizes utility in our society and should be revised. In doing so, I utilize case studies, statistical analyses, and philosophical argumentation to demonstrate the inefficacy of BMI as a screening tool, as well as the ethically problematic nature of the overmedicalization of weight which grounds the ubiquity of BMI analyses. Ultimately, I defend the adoption of a screening procedure which 1) treats obesity as a risk factor only insofar as it confers suffering, and 2) combines waist-to-height ratio and body fat percentage analysis as an alternative approach to BMI. I argue that this alternative approach subsumes the benefits of BMI (affordability, convenience, simplicity, and lack of invasiveness) while proving more efficacious and accurate across demographics. Furthermore, I argue that the widespread adoption of this procedure will increase utility for both society and medically underrepresented populations, such as women of color. This presentation investigates: How can we dismantle the underlying biases within our most basic health screening tool? How can we evaluate weight in an inclusive, effective, and ethically praiseworthy way?</p> <p>Nuttall, Frank Q. "Body mass index: obesity, BMI, and health: a critical review." <i>Nutrition today</i> 50, no. 3 (2015): 117.</p>

Title	Abolition in Medicine or Abolition of Medicine?: Exploring Carcerality in Biomedical Contexts
Name	Whitney Cabey
Pronouns	she/her
Current position	Assistant Professor, Center for Urban Bioethics
Institution / Affiliation	Lewis Katz School of Medicine at Temple University
Biographical note	Whitney V. Cabey, MD, MSHP, MA is an assistant professor in the Center for Urban Bioethics, the co-director of Doctoring: The Art and Science of Medicine, and a practicing emergency physician in the Department of Emergency Medicine at Temple University's Lewis Katz School of Medicine in Philadelphia, Pennsylvania. She earned her MD at the University of Michigan, her MSHP at the University of Pennsylvania, and her MA in Urban Bioethics at Temple University. Her areas of interest include abolitionism, emancipatory approaches to medical education, trauma-informed care, physician socialization, and imagining radical societal change.
Co-author(s)	Nicolle Strand, JD, MBE, MPH
Keywords	Health equity, health justice, abolition, political economy, structural determinants of health
Abstract	<p>A growing number of scholars have articulated that bioethics, like many other fields and sectors, shares a responsibility to divest from police and prisons in order to advance the goals of wellness, health justice and liberation. Addressing the concept of abolition in medicine has heretofore been a conversation about the health of the incarcerated, the complicity of the medical establishment with the goals of the prison industrial complex (PIC), and deputization of the healthcare system as a tool of the state to advance carceral aims.</p> <p>A focus on complicity may not fully or adequately implicate biomedicine to the extent that is deserved or needed for radical change. This presentation explores the theory that restriction and incarceration are unstated goals of medicine, not just tools inappropriately adopted and adapted by medicine. If biomedicine has carceral aims, it may itself require abolition. The author will explore three trends undergirding this theory: (1) the abysmal health outcomes of millions of black and brown people across the globe should be recognized as a form of restriction and infringement of liberty, (2) most evident in the United States, the political economies of the PIC and the Healthcare System have parallels such as the inverted relationship between cost and outcomes (3) the bodies most at risk for the various forms of physical, structural or bureaucratic incarceration found in healthcare are identical to those ensnared in the PIC: poor, black, brown, gender diverse, and those with behavioral and mental health needs.</p> <p>Exploration of the above trends situates the concept of medical abolition in relation to more established explorations of policing and state surveillance in other sectors (eg. the PIC, the child welfare system). This contextual comparison also permits us to evaluate the strengths, weaknesses and applicability of existing abolitionist frameworks for achieving emancipatory aims in health.</p>

Title	Gone with the Pandemic? Reflections from the RIFF Project on Racism in Bioethics
Name	Chioma Dibia
Pronouns	she/her
Current position	PhD student
Institution / Affiliation	University of Edinburgh
Biographical note	<p>Chioma is a PhD student at the University of Edinburgh. Her research provides a socio-legal analysis of how racism shapes the way the Mental Health Act 1983 operates in relation to Black people with mental disorders. Although her current research focuses on mental health law, she is broadly interested in understanding how social, political and economic factors shape and are shaped by the law.</p> <p>Prior to undertaking her PhD, Chioma worked actively in legal and policy development in the medical law area in Nigeria. She has also worked as a research assistant on a project on anti-racism and anti-colonialism in bioethics at the University of Edinburgh. She currently tutors on the Medical Ethics unit of the Social and Ethical Aspects of Medicine (SEAM) course for first-year medical students.</p>
Co-author(s)	Agomoni Ganguli-Mitra, University of Edinburgh
Keywords	Racism, Racial Justice, Social Justice
Abstract	<p>Prior to the COVID-19 pandemic, the concept of racism had received limited attention in the field of bioethics. Although scholars had highlighted the need for bioethics to engage meaningfully with racism and exhorted other bioethicists to do the same, the topic received sporadic attention from the discipline. However, the disproportionate impact of the COVID-19 pandemic on racially minoritised people as well as the killing of George Floyd by police officers and subsequent protests around the world for racial justice triggered a renewed attention to racism within the discipline.</p> <p>In this presentation, we suggest that the recent focus on racism in the bioethics literature might have lost momentum. Using the findings from our recent project which gathered existing scholarship on racism in bioethics, we document the ways in which attention to racism in health peaked during the COVID-19 pandemic and then seemed to have declined. We shall also explore some potential reasons for these changes and consider how the commitment to racial and social justice can be sustained in bioethics education and practice going forward.</p>

Title	Lack of Diversity and Biased AI mediated Healthcare System
Name	Amina Farooq
Pronouns	she/her
Current position	Main Author
Institution / Affiliation	Hamad Bin Khalifa University, Qatar
Biographical note	Graduating Masters Student/Research Assistant
Keywords	Biased AI Algorithm, Artificial Intelligence, Bioethics, AI mediated Healthcare system, Diversity and Inclusion
Abstract	<p>The rapidly increasing advancement in the field of artificial intelligence-based healthcare systems and the interest of stakeholders in incorporating AI technology in the healthcare sector have led to many benefits, risks, and ethical challenges. The lack of diversity and the biased nature of AI algorithms is one of the major bioethical challenges which has arisen in the healthcare sector through advancing technology. In the modern age, overall low representation and engagement of diverse populations in healthcare is now extended to the level of lack of diversity in the data used for training computer algorithms. The bias of AI and healthcare algorithms is increasing the health disparities for people of certain religions, ethnicities, genders and backgrounds. This will especially impact minority groups and people from underrepresented ethnicities and women of colour. The recent surveys and statistics have shown that the biased AI-based healthcare data is less accurate for black women as compared to white women. All this will lead to further health disparity and fairness in the healthcare system. The reason for this bias is not just the developers but the whole system, which has failed to engage diversity and create a healthcare system which is fair for all populations. This brings attention towards the root cause and the major source of biased AI algorithms, which is the lack of diverse representation. The question is, how can we engage diversity in the biased AI-mediated healthcare system? What practice should be implemented to combat this ethical challenge and achieve health equality and fairness in the system? Overall, in the modern age, to achieve a fair AI-mediated healthcare system, diversity and inclusion in the algorithm system are the keys to creating an unbiased AI-mediated healthcare system.</p>

Title	Cultural Humility in the Care of Female Muslim Patients
Name	Asma Fazal
Pronouns	she/her
Current position	Senior Clinical Ethicist
Institution / Affiliation	Advocate Health, Chicago, Illinois, USA
Biographical note	Dr. Asma Fazal is an Irish-trained pediatrician. Due to her growing interest in ethical issues in patient care, Dr. Fazal joined the University of Toronto and completed MHS in Bioethics in 2019. Her bioethics education and training opened a new career pathway for her, and she completed a fellowship in adult and pediatric bioethics from Children's Minnesota in June 2022. Dr. Fazal joined AAH family in June 2022 as Clinical Ethicist. Besides providing ethics consultations, Dr. Fazal is passionate about ethics education, policy-making, and academic research. Her current areas of research are Islamic bioethics, consent and capacity, patient confidentiality, moral distress among healthcare professionals, ethical issues involving refugees and migrants, and organ transplantation.
Keywords	Cultural Humility, diversity, Muslim, Female, privacy, religious values
Abstract	The world's population is becoming increasingly diverse. With the world becoming a global village, several challenges have arisen for healthcare providers. Religious beliefs and cultural customs have become a barrier to the provision of high-quality care when doctors deal with a growing diversity of patient groups and socioeconomic situations. Muslims make up sizable segments of the population in many non-Muslim countries. In these non-Muslim countries, physicians often face the challenge of Muslim women delaying seeking care for their health needs. Delayed care-seeking is linked to negative health consequences. Muslim women may delay obtaining care for religious reasons, including a predilection for female doctors and worries about maintaining modesty, privacy, and touch limits. Recognizing and honoring the cultural diversity of patients and their families is part of the cultural humility approach to healthcare. Being culturally competent means having the attitude of modifying one's practice approach to fit the needs and values of patients, in addition to having a solid understanding of the cultural practices of various patient populations. Experts frequently recommend growing cultural competence to decrease healthcare inequities caused by cultural and value differences between patients and caregivers. I recommend that a cooperative and adaptable care model is necessary to enhance patient care, respecting and considering patients' needs, offering opportunities for provider and patient education, and implementing the required systemic changes. By doing this, healthcare practitioners will be able to offer this patient population competent and effective culturally sensitive care when they are able to identify and comprehend the distinctive cultural features and religious beliefs that Muslim women follow.

Title	Responsibility Gap(s) Due to the Introduction of AI in Healthcare: An Ubuntu-Inspired Approach
Name	Brandon Ferlito
Pronouns	he/him
Current position	PhD Researcher
Institution / Affiliation	Department of Philosophy and Moral Sciences, Bioethics Institute Ghent, Ghent University
Biographical note	Brandon Ferlito is a bioethicist and researcher with a passion for applied ethics. His research covers a wide range of areas, including applied ethics in both private and public spheres, professions, health, technology, and law, as well as applied animal ethics, public health, and health policy. In 2022, Brandon joined Ghent University as a doctoral researcher. His current focus involves conducting a critical analysis of the evolving moral responsibilities in healthcare caused by disruptive innovations. His doctoral research revolves around the examination of changing dynamics in responsibilities, specifically the shift from healthcare providers to data collectors.
Keywords	Responsibility gap · Artificial intelligence · Ubuntu · Healthcare · Collective forward-looking responsibility
Abstract	Due to its enormous potential, artificial intelligence (AI) can transform healthcare on a seemingly infinite scale. However, as we continue to explore the immense potential of AI, it is vital to consider the ethical concerns associated with its development and deployment. One specific concern that has been flagged in the literature is the responsibility gap (RG) due to the introduction of AI in healthcare. When the use of an AI algorithm or system results in a negative outcome for a patient(s), to whom can or should responsibility for that outcome be assigned? Although the concept of the RG was introduced in Anglo-American and European philosophy, this paper aims to broaden the debate by providing an Ubuntu-inspired perspective on the RG. Ubuntu, deeply rooted in African philosophy, calls for collective responsibility, and offers a uniquely forward-looking approach to address the alleged RG caused by AI in healthcare. An Ubuntu-inspired perspective can serve as a valuable guide and tool when addressing the alleged RG. Incorporating Ubuntu into the AI ethics discourse can contribute to a more ethical and responsible integration of AI in healthcare.

Title Addressing Anti-Black Racism in Research:
An Ethical Imperative to Center Black Scholars
in the United States

Name Faith E. **Fletcher**

Pronouns she/her

Current position Associate Professor

Institution / Affiliation Center for Medical Ethics and Health Policy,
Baylor College of Medicine



Biographical note

Dr. Faith Fletcher is an Assistant Professor in the Center for Medical Ethics and Health Policy at Baylor College of Medicine, a senior advisor to The Hastings Center, and a Hastings Center Bioethics Fellow. Her research program examines barriers to scientific research and healthcare engagement facing medically underserved populations and is grounded in approaches from the fields of public health, bioethics, and behavioral science. Dr. Fletcher was recently named to the Greenwall Faculty Scholars Program in Bioethics Class of 2026. Her work examines the role of bioethicists in advancing maternal health equity among Black women in the US. In collaboration with an antiracism task force, Dr. Fletcher is the lead editor of The Hastings Center Special Report (2022), entitled “A Critical Moment in Bioethics: Reckoning with Anti-Black Racism Through Intergenerational Dialogue.” In 2017, she was named one of the National Minority Quality Forum’s 40 under 40 Leaders in Health for her commitment to advancing health equity. This prestigious award acknowledges the next generation of leaders primed to reduce health disparities. She recently received the 2022 Baylor College of Medicine Women of Excellence Award for her outstanding contributions and accomplishments in advancing health and healthcare equity as a field leader.

Co-author(s)

Sophie Schott, Center for Medical Ethics and Health Policy, Baylor College of Medicine and Alicia Best, Associate Professor, Morehouse School of Medicine)

Keywords

reproductive ethics canon, African American women, reproductive justice, health equity

Bioethicists play a crucial role in shaping the discourse on social justice to address the existing inequities in health and healthcare. However, despite its roots in justice, the field of bioethics has not given due attention to healthcare inequities, especially those driven by structural racism. Moreover, it has failed to prioritize the work of scholars who focus on these issues, particularly concerning reproductive justice and its impact on African American women and their families. Reproductive Justice frameworks emphasize that reproductive choices and outcomes are shaped by one's social, structural, political, and physical environment. These frameworks also highlight the importance of the human right to give birth and parent in safe and sustainable environments. Therefore, it is crucial to apply these insights to address the structural injustices that hinder human flourishing.

Abstract

This presentation utilizes personal narratives and justice-oriented scholarship to draw attention to the significance of bioethicists taking the lead in discussing and actively engaging with the reproductive healthcare needs and preferences of African American women. These reflections and perspectives are fundamental in developing comprehensive reproductive bioethics frameworks that responsibly address ethical and equity issues in the healthcare of African American women. Furthermore, achieving equitable and respectful reproductive healthcare has significant implications for equipping future healthcare professionals with the necessary knowledge, skills, and structural competency to challenge long-standing oppressive practices in medicine. This important work aligns with the United States' bioethics initiatives to promote diversity, equity, and inclusion, as well as to prioritize and integrate equity into bioethics scholarship and practice.

Title	A qualitative study of the needs of Black, Indigenous, and People of Colour students in higher education	
Name	Deborah Francis	
Pronouns	she/her	
Current position	Doctor of Science in Rehabilitation and Health Leadership Graduate	
Institution / Affiliation	Queen's University, Kingston, Ontario, Canada	
Biographical note	<p>Debi Francis graduated from the Doctor of Science in Rehabilitation and Health Leadership program at Queen's University, Kingston, Ontario, Canada where her research focused on the experiences of racialized students in higher education. Debi won the National Coalition of Occupational Therapist Advocates for Diversity Outstanding Faculty Award. She was nominated by occupational therapy students at D'Youville University in Buffalo, New York, USA based on her leadership and embodiment of social justice. Her passion for equity and belonging is displayed by her dedication and devotion to facilitating inclusive and accessible academia to empower future healthcare professionals. As an occupational therapist for over 25 years, Debi works with clients, families, and service providers to facilitate inclusive and accessible health care. Currently, Debi is a research coordinator for evaluating the Indigenous Community Research Partnerships training resource. The purpose of the training resource is the provision of guidance on how to conduct research that reflects and meets expectations for ethical, collaborative, and culturally supportive engagement with Inuit, Métis, and First Nations individuals and communities.</p>	
Co-author(s)	<p>Dr. Janet Jull, Queen's University, Canada; Dr. Yolanda Suarez-Balcazar, University of Illinois Chicago, United States; Dr. Megan Whelan, D'Youville University, United States; Emmanuel Fagbola, Queen's University, Canada; Trinda Penniston, Queen's University, Canada; Cortney Clark, Queen's University, Canada</p>	
Keywords	<p>Students of colour, racism in higher education, educational needs assessment</p>	
Abstract	<p>A small body of literature on racism in higher education exists in Canada. The limited knowledge, education, and training on Black, Indigenous, and People of Colour (BIPOC) student issues enable university cultures to reinforce racist programs, policies, and practices. Our study aimed to explore the lived experience of BIPOC students at a mid-sized publicly funded research Canadian university to inform university practices.</p> <p>The study followed a narrative inquiry qualitative study design with a critical race theory lens grounded in principles of community-based participatory research. Based on 13 counter-narrative interviews, the researchers explored the results of the needs assessment to impact academic policy change. The research team consisted of a steering committee of five BIPOC university students and the thesis advisory committee. Based on the results of the needs assessment, we established recommendations for academic leadership that highlight the challenges BIPOC students experience, as well as strategies to address the challenges. Additionally, we co-created a learning resource for the university faculty and staff on what BIPOC students need to support their participation in student life. Although many universities have created anti-racism initiatives, the findings of the study indicated that BIPOC students are neither consulted nor included in the development of resources that are aimed to benefit them. Working with BIPOC students is a powerful method to dismantle structural racism in programs, policies, and practices in higher education.</p>	
X (formerly Twitter)	<p>@ProfessorOT</p>	

Title	'My Illegal Abortion Regrets': An Ethical Analysis of a woman's abortion experiences in Ghana
Name	Fred Yao Gbagbo
Pronouns	he/him
Current position	Lecturer
Institution / Affiliation	University of Education, Winneba
Biographical note	<p>Dr. Fred Yao Gbagbo is a Public Health Consultant with a specialization in Population and Health, Sexual Reproductive Health and Rights, Bioethics, Health Policy Analysis, and Policy Reviews. Trained in the University of Ghana, University of Cape Coast, University of Education, Winneba, Marie Stopes International, and New York University, School of Global Public Health. Currently, a Senior Lecturer at the University of Education, Winneba. Previously, Director of Medical Services and Master trainer at Marie Stopes International, Head of the Reproductive Health Unit at the National Population Council, Ghana, and Senior Clinical Officer at Lucida Clinic, Tema. I have 25 years of work experience in Maternal Health, Child Health, Sexual & Reproductive Health and Rights, Family Planning and Comprehensive Abortion Care; Health Research, Clinical Quality Assurance, Curricula Development, Clinical Training, Project management, Grant and research proposal development, Project/donor report writing, Health policy formulation and analysis within public, private and NGO Health sectors in Ghana and internationally. I have served on several boards/committees in various capacities, collaborated with various institutions on sexual reproductive health projects, and have over 35 research publications in reputable peer-reviewed journals.</p>
Keywords	illegal abortion, Experiences, Ghana, Narrative-Analysis, Regrets, Women
Abstract	<p>Regrets following induced abortions have been generally explored and discussed from the individual and various collective dimensions over the years. This study used a Narrative Analysis design to explore a woman's lived-induced abortion experiences in Ghana. The issues identified were critically examined and discussed within the context of reproductive health ethics. It was deduced from the analysis that, although there could be some initial and temporal relief following an induced abortion at a particular time, the consequences after the abortion may be very devastating and life-threatening leading to long-term regrets with the associated psychological and emotional trauma. It was recommended that such narratives and related others may therefore constitute the basis for an ethical inquiry into the implementation of legal and policy frameworks for safe abortion care in Ghana and Africa as a whole.</p>

Title "Privacy is a Privilege" – A Thematic Analysis of Crowdfunding Campaigner's Concerns and Advice

Name Ashmita **Grewal**

Pronouns she/her

Current position MSc Candidate/Research Assistant

Institution / Affiliation Simon Fraser University



Biographical note Ashmita is completing her MSc in Health Sciences at Simon Fraser University's Faculty of Health Sciences, in British Columbia, Canada. Her MSc thesis is embedded in a research project funded by the Social Sciences and Humanities Research Council of Canada, which aims to explore the privacy implications of charitable crowdfunding for health and housing reasons, led by Dr. Jeremy Snyder and Dr. Valorie Crooks. She is passionate about uncovering and addressing the inequities in society, that impede the ability of select individuals to live free and prosperous lives.

Co-author(s) Jeremy Snyder, Professor, Simon Fraser University, Canada.

TITLE: "Privacy is a Privilege" – A Thematic Analysis of Crowdfunding Campaigner's Concerns and Advice

Background: Crowdfunding campaigners often struggle with protecting their personal information, while providing a compelling case for why their campaign is worthy of support from friends and strangers alike. Privacy, understood as control over personal aspects of oneself, can be compromised during the practice of crowdfunding. Little research has examined charitable crowdfunding campaigners' experience in protecting their sensitive information while trying to maximize donations. Our research synthesizes the concerns of individuals utilizing donation-based crowdfunding for themselves and their advice to others considering utilizing crowdfunding.

Methods: We interviewed 24 participants from across Canada. All participants were above the age of 19 and crowdfunding for their own health and/or housing-related needs. After reviewing the interview transcripts, we decided to focus on the privacy concerns of individuals crowdfunding for themselves and their advice on how to navigate these concerns. Using NVivo software, a thematic analysis was conducted to create various broad themes that encapsulate the concerns of our participants and the advice they have for other's.

Results: Our interview data was placed into four themes of concerns: 1. Campaign Accessible by All; 2. Potential Risk to Oneself or Others; 3. Intrusive Probing; and 4. Information Collection and Sharing by Platforms. We synthesized participants' advice into three broad themes: 1. To be both cautious and specific; 2. To be Informed; and 3. To Consider the Uncertainties Related to the Practice of Crowdfunding.

Conclusions: Crowdfunding campaigners' concerns are complex and intertwined. There is considerable variability in our participants' concerns depending on contextual factors (e.g., the type of need being addressed) and other demographic variables (e.g., ethnicity or gender). Nevertheless, all campaigners need protection from the negative-privacy related consequences of this practice, but it is essential to recognize that these harms are not experienced in the same way or to the same degree by all campaigners.

Abstract

Title	Seeking Inclusivity: Bioethical Hurdles in Justifying End-of-Life Care in Bangladesh
Name	Asmat Islam
Pronouns	she/her
Current position	Lecturer & Visiting Assistant Professor
Institution / Affiliation	Jagannath University & North South University
Biographical note	Asmat Islam is a Lecturer of Philosophy at Jagannath University. In addition, she teaches Ethics as a Visiting Assistant Professor at North South University, Dhaka. Recently, Asmat Islam received her Ph.D. in Healthcare Ethics (Center for Global Health Ethics) from Duquesne University, Pittsburgh. Prior to that, she earned an MA in Philosophy from the University of Nottingham, Nottingham. Her research expertise concerns bioethics, ethics of death and dying, ethics of emerging technologies in healthcare, and research ethics. Some of Asmat Islam's recent research has appeared in the Journal of Religion and Health and Developing World Bioethics.
Keywords	end-of-life care, Bangladesh, patient autonomy, pluralism, inclusive bioethics, global health
Abstract	The diverse interactions of law, religion, and culture in Bangladesh complicate justifying a standard for end-of-life care. Often, the moral justification of global end-of-life care is exclusively grounded on the principle of patient autonomy. Critics worry about the applicability of the principle to societies with diverse cultures. Euthanasia, within strict limitations, has recently become legal in India. Nevertheless, even with the efforts of lawyers and physicians, the issue is substantially more complex in the context of Bangladesh. I argue that the more we understand about the bioethical hurdles to applying the principle of autonomy in multicultural societies, the better we can compare the principle's relevance in realising and implementing the principle of autonomy, especially in the context of global health. To support this argument, I explore pertinent pluralistic values interacting with autonomy in end-of-life care. First, I identify the moral dynamic between religious fatalism, dukkha, poverty, and negative attitudes towards death that shape South Asian understandings of dignity in dying. Next, I examine the relationship between the lack of understanding surrounding the values of the medical humanities and the need to include ethicists in the shared decision-making surrounding end-of-life care, especially through multidisciplinary institutional ethics. Finally, having identified the problem that end-of-life care is understood in a non-inclusive sense in Bangladesh, I conclude that the main worry about the principle of respect for autonomy needs more scrutiny so that the principle captures the shared decision-making in end-of-life care in Bangladesh. My argument is crucial not only for developing and furthering bioethics in Bangladesh and South Asia but also for understanding elderly care planning in multicultural societies so to enhance inclusivity in bioethics.

Title	Should vaccination status be a consideration during secondary triage?	
Name	Isaac Jarratt-Barnham	
Pronouns	he/him	
Current position	Academic Foundation Doctor; Ethox Teaching Fellow, University of Oxford; Retained Lecturer, Pembroke College Oxford	
Institution / Affiliation	1) Stoke Mandeville Hospital, Buckinghamshire; 2) Ethox Centre, University of Oxford; 3) Pembroke College, University of Oxford	
Biographical note	<p>Isaac is an Academic Foundation Doctor working in Thames Valley. After completing a degree in Philosophy and Psychology at the University of Cambridge, and then holding Research Assistantships in a number of UK Psychiatry departments, he returned to study Graduate Entry Medicine at Oxford University.</p> <p>During the latter stages of his study, Isaac took up a Teaching Fellowship at Oxford. His teaching commitments focus on providing seminar and small group teaching for the University's Graduate Entry Medicine course.</p> <p>He intends to pursue a career as an academic surgeon, and has particular clinical and research interests in both Hand, and Head and Neck surgery. His current research commitments include an ongoing Research association with the Fernandez-Egea Lab within the Cambridge University Psychiatry Department, and work under Professors Furniss and Rodriguez at Oxford University.</p>	
Keywords	<p>Vaccine refusal, Discrimination, Resource allocation, Pandemics</p> <p>The rapid development of widely available and effective vaccines has been integral to the international response to the COVID-19 pandemic. However, a significant minority of those offered vaccination have refused, often due to anti-vax beliefs.</p> <p>During the pandemic, calls were made for those voluntarily refusing vaccination to be deprioritised when allocating scarce healthcare resources. Whilst these were rejected, the likelihood of the same calls being made during future pandemics necessitates thorough examination of the ethical implications of such a policy.</p> <p>I consider perhaps the most intuitive argument for vaccination status' use when allocating healthcare resources – that refusers in some sense 'let the side down'. This argument asserts that, by avoiding vaccination, vaccine refusers fail to fulfil a social obligation to protect those around them from harm by facilitating herd immunity, and are thus less deserving of healthcare resources than the vaccinated.</p>	
Abstract	<p>I explore two objections to this argument. The first, asserting that no individual can be held responsible for a failure to develop herd immunity, fails. However, an argument highlighting the harms deprioritising vaccine refusers would cause to disadvantaged minorities, succeeds. There is greater prevalence of vaccine refusal amongst marginalised communities, often due to thoroughly justified historical mistrust of medical institutions. However, these justifications for vaccine hesitancy are not reflected in media narratives surrounding vaccine refusal, which prefer to focus on sensationalising 'bizarre' justifications for refusal.</p> <p>That vaccine refusal is assumed to result from such beliefs, rather than from historically grounded mistrust, reflects the siloed nature of the vaccination debate. Discrimination by vaccination status risks further reinforcing such echo chambers and justifying the alienation such groups feel from the medical establishment, impacting healthcare participation more broadly and causing substantial patient harm.</p> <p>Vaccination status should not, therefore, be considered during healthcare resource allocation, as such discrimination would disproportionately harm marginalised communities.</p>	

Title Restorative Justice Bioethics: Addressing Racial Disparities in Clinical Trials

Name Georgios **Kalaitzidis**

Pronouns he/him

Current position PhD candidate

Institution / Affiliation Charles University in Prague



Biographical note I am a 3rd year PhD candidate at Charles University in Prague, at the faculty of Humanities. My PhD is in Applied Ethics/Bioethics. My research investigates several ethical dilemmas of the healthcare sector including confidentiality and privacy of patient health information and allocation of scarce drugs while drug shortages. My research interests include distributive justice, moral responsibility in healthcare and equitable allocation of scarce resources. This conference presents an invaluable opportunity for me to contribute to and learn from discussions on enhancing inclusivity in bioethics. I am passionate about fostering equitable healthcare practices and policies that truly represent and serve diverse populations, making my participation in this conference not only relevant but essential for my continued professional growth and contribution to the field.

Keywords Restorative Justice Bioethics; Clinical Trial Diversity; Racial Disparities in Healthcare; Ethical Research Reform; Community Engagement in Medicine

This paper explores the Restorative Justice Bioethics (RJB) framework to address racial disparities in clinical trial participation, focusing on the underrepresentation of Black and Hispanic communities. To my knowledge, this endeavor represents an innovative effort, as it has not been undertaken previously. In 2020, the participation of Black and Hispanic communities in clinical trials was only 41% and 58% respectively, compared to the expected levels based on U.S. Census data. Additionally, these communities represent less than 5% of participants in trials for chronic diseases and cancers, despite higher disease mortality rates. RJB, grounded in restorative justice principles, offers a holistic approach to this ethical issue. It emphasizes the need for repairing harm caused by historical injustices, shifting the ethical focus in medical research from individual autonomy to historical accountability and systemic equity.

Abstract The framework calls for acknowledging the historical context of racial disparities, recognizing systemic barriers that have led to such disparities. It advocates for the direct engagement and empowerment of affected communities in shaping research, aligning with participatory justice principles of collaboration, dialogue, and mutual respect.

Furthermore, the paper argues for reparative actions that are grounded in the principle of distributive justice. This involves ensuring that the benefits and burdens of research are distributed more equitably, addressing the imbalance in clinical trial participation. Policy reforms, therefore, must not only incentivize diversity but also tackle the broader social determinants of health that underlie these disparities..

In conclusion, by grounding clinical trial diversity efforts in the philosophical principles of the RJB framework, this approach offers a more comprehensive, ethically sound, and just path forward. It emphasizes the need for a paradigm shift in how we approach and rectify racial disparities in clinical research, ensuring that the trials are as diverse as the populations they aim to serve.

Title Effects of understaffing on health care delivery among health workers at Kilifi County Referral Hospital

Name Christopher **Kalu**

Pronouns he/him

Current position ICU Nursing Officer

Institution / Affiliation Kilifi County Referral Hospital



Biographical note A nursing officer, BscN from Pwani University ang part time. Lecturer at portreitz KMTC.Has 5 year practicing experience in ICU including guiding diploma students in research and follow up of clients. He is currently the CEO of Kaluje Enterprises. A church member at St. Patrics Catholic Church, Kilifi.

Abstract Health is key elements for success and development of a country. The standard patient doctor ratio is 2-4 in ICU and 8-20 in general ward. However, it is 1-2 in ICU and 1-4 patients for nurses (WHO 2021).In contrary, Kilifi county hospital, this proportion is not met leading to delays in service delivery thus contributing grossly to loss of lives. The objective of the study was to identify effects of understaffing that were related to the providers, clients and resources utilization. A non-probability convenient sampling technique was used to select the sample. Health care workers from medical, surgical, pediatric newborn unit, intensive care unit, maternity, theatres and emergency departments participated in data collection and closed ended questionnaire was used. A sample size of 67 health providers was reached by utilizing the fisher’s formula. Data was collected and analyzed through utilization of SPSS version 20 and the findings were 47(70.1%) of health providers suffers from stress and willing to quit given another opportunities. A total of 43(64.2%) of clients return home unattended and seek care from private facilities. However, 65(95%) stay longer time in wards and 35(61%) of provider have expiring items every year in their units. In addition, 7(10.4%) death occur every month in each unit.

CONCLUSION: Health service delivery is greatly are affected by understaffing that led to unmet medical needs of people living Kilifi County.

RECOMMEDATION: Employment of more healthcare workers should be done to meet the WHO standard

Title	Engaging Diversity in Multireligious and Multicultural Malaysia: Jehovah's Witnesses and Blood Transfusion
Name	Munita Kaur Harban Singh
Pronouns	she/her
Current position	Lead, Research Team
Institution / Affiliation	Clinical Ethics Malaysia
Biographical note	Munita Kaur is currently leading the Research Team at Clinical Ethics Malaysia. Munita was until recently an Advocate and Solicitor in Malaysia practicing civil law. She holds an LL.M from University Malaya and an MA in Healthcare Ethics and Law from the University of Manchester. Prior to legal practice Munita was part of a team of leading academics at Malaysia's Premier Private Law Schools. She was a visiting law lecturer at both Lingnan University and Polytechnic Hong Kong and at Intect Tertiary College, Singapore. She has taught Healthcare Ethics and Law at both University Malaya and the International Medical University Malaysia, and Research Ethics at University Malaya's Masters of Research Ethics Program in collaboration with John Hopkins University. Munita is an active member of Malaysia's Bioethics Community and also serves as a consultant with Clinical Ethics Malaysia.
Co-author(s)	Dr Aaron Lai Kuo Huo, Emergency Physician, Serawak General Hospital, Malaysia
Keywords	Jehovah's Witnesses, Case Study, Moral Distress, Scientifically Confusing Advance Care Directive, Ethics
Abstract	<p>There are approximately 8.5 million Jehovah's Witnesses worldwide and less than 0.02% of the Malaysian population identify themselves as Jehovah's Witnesses. Their relatively small presence means that the complexities of treating Jehovah's Witnesses is often underappreciated in Malaysia's mainstream healthcare. Using a case study, this paper highlights a Malaysian doctor's dilemma in managing treatment of an incapacitated Jehovah's Witness requiring blood transfusion for life saving neurosurgery. Faced with a Standard Form Advance Care Directive (common to Jehovah's Witnesses) which prohibited blood transfusions, there was much confusion and moral distress caused by a handwritten paragraph in the same Advance Care Directive which read, 'Accept blood fractions only (fractions of red cell, white cell, platelets and plasma)'. The patient's next-of-kin insisted that there be no blood or blood products used in treating the patient. The doctor was not convinced that the patient had indeed signed-off on a prohibition of all blood or blood products.</p> <p>Advance Care Directives have no legal standing in Malaysia, and healthcare providers seldom override the wishes of a next-of-kin when a patient is unable to communicate his. Against this setting, the following questions are examined: How do we balance a doctor's duty to respect a patient's autonomy and his obligation to do no harm? Is it ethical to proceed in the patient's best interest when there is an apparent conflict in an Advance Care Directive?</p> <p>The above case study highlights glaring gaps in the ethical treatment and management of Jehovah's Witnesses. Lack of understanding, individual perspective or conscientious considerations among healthcare providers, scientifically confusing Advance Care Directives, and pressure from a next-of-kin, are all factors which do no justice to either patient or provider. Equity for Jehovah's Witnesses demand the need for guidance and awareness, Dialogue with and inclusion of Jehovah's Witnesses in mainstream healthcare will help alleviate ethical dilemmas and promote better care.</p>

Title	Myths and Documentation during the Consent Process among the Learned community
Name	Saidah Menya
Pronouns	she/her
Current position	Research Officer
Institution / Affiliation	Adara Development Uganda
Biographical note	Saidah Menya was born on 29th June 1984 to Mr. Menya Sowali and Ms. Namugga Aisha Kibirige in Mukono District. She went to Menk Junior School from 1990-1997 for Pimary Leaving Examinations, Mbogo High School for Ordinary and Advanced Level from 1998-2003. In 2004-2007, I joined Masaka School of Comprehensive Nursing, where she obtained a Diploma in Registered Comprehensive Nursing. In 2010-2014, I successfully obtained a Degree in Public Health (Bachelor of Science in Public Health) from International Health Sciences University. In 2016, I joined Bugema University School of Graduate Studies for a Master’s Degree in Public Health that I successfully completed in 2018. I attained many professional short courses covering different areas including, Good Clinical Practice, Program for Infant and Young Child Feeding, Research and Ethics, Knowledge Exchange Enterprise and Commercialization among others, with a diversity of experience. I have 15 years of working experience in Clinical Nursing and TB Clinical Trial Management and Research. Currently I work as a Research officer in maternal, new-born and child health care at Adara Development Uganda.
Keywords	Consent, Myth

Background

Consent is a process of getting permission before something happens or an agreement to do something. When two or more people agree upon the same thing and in the same sense. Consent is the first process if any research is to be conducted. Before permission is granted it is vital that all the information about the research is provided to the participant. Understanding of the research and acceptance of participation through signing and appending signatures is vital. Consent was obtained from the research participants through projection of the consent. Each participant had an individual consent so that they could also follow through and sign individually on the consent form.

Methodology

It was a retrospective review of consenting records of all participants who consented to participant in a co design workshop.

Main results and findings

Results from the study showed that out of the 20 participants who were consented and appended signatures to accepting participation 7(35%) had documentation problems by signing in wrong places as well as writing ineligibly. This was also accompanied by re writing and over writing on the consent form. When it came to the way they perceived the information, different perceptions came across. A total of 8(40%) participants had different feelings towards their signatures that included, whether the signed copies were not to be used for something else and felt that, if possible, they would participate without signing a consent form.

Conclusions

In conclusion, during the consent process, whether to the learned or not perception is the same. Participants will have some unclear feelings and writing challenges when it comes to the consent process. Therefore, giving clear explanations and enough time to process the study information is critical in the research process of obtaining consent.

Abstract

Title	Social research ethics codes and institutional ethics processes: Perspectives of researchers working with ethnic minority communities in the UK	
Name	Nishita Nair	
Pronouns	she/her	
Current position	Research Officer	
Institution / Affiliation	IOE UCL's Faculty of Education and Society	
Biographical note	<p>Nishita Nair works as a Research Ethics Officer at the IOE, UCL's Faculty of Education and Society. She coordinates the ethics review and approval process and works collaboratively with the IOE Research Ethics Committee to develop and implement strategic initiatives in relation to ethics matters within the institution. She also manages the training of ethics reviewers and advises applicants on the ethical considerations within their research. Nishita has recently completed a Masters in Bioethics at King's College London and is driven by the passion to understand what makes one ethical and how to cultivate ethical thinking.</p> <p>Nishita previously managed a research funding programme at the National Institute of Health Research (NIHR) and led on the Patient and Public Involvement activities within the team. She also served as the Chair of the NIHR EDI Committee.</p>	
Keywords	Social Research Ethics, Ethics review, Ethnic minorities, Diversity	
	<p>Do social research ethics codes and institutional ethics processes aid researchers in their work with ethnic minority communities in the UK?</p> <ol style="list-style-type: none"> 1. What aspects were beneficial and where are the barriers or gaps? 2. Do these codes and processes guide ethical thinking? <p>I conducted semi-structured qualitative interviews with 8 social science researchers (across 2 UK HEIs)</p> <p>Social research ethics codes were found to be influenced by positivist orientations from the biomedical space. They propose a universality to ethical norms and adopt a Western philosophical approach which causes difficulties when conducting social research with ethnic minority communities.</p>	
Abstract	<p>Institutional ethics applications benefitted researchers during the planning stages of their project. However, researchers critiqued the rigid nature of the application form and expressed concerns on the quality of reviewer feedback. Biomedical influences focused unduly on the risk of harm and promoted positivist stances among reviewers. Western concepts within the informed consent process and during coproduction posed further impediments. Both the ethics codes and institutional ethics processes lacked considerations to positionality and reflexivity which were considered vital for research in such culturally diverse settings. They were also largely silent on ethical guidance brought about by one's personal values and practical experiences on the field.</p> <p>I recommend that social research ethics codes must invite further contributions from social scientists. They must also undergo continuous cycles of revision such that innovative and novel research methodologies are considered.</p> <p>Within institutions, separate committees for reviewing social and medical sciences must be retained. Furthermore, increasing REC member diversity and relationship building initiatives between REC members and researchers/applicants must be encouraged. Both the codes and processes must be supplemented with formal spaces where REC members and the research community can discuss ethical issues and share best practice. This will present opportunities for effective ethical dialogue and promote 'true' capacity building.</p>	

Title	Practices and attitudes of herbalists regarding informed consent in Uganda: A qualitative study
Name	Sumayiya Nalubega
Pronouns	she/her
Current position	Bioethicist and TASO Research ethics committee administrator
Institution / Affiliation	The AIDS Support Organisation
Biographical note	<p>Sumayiya Nalubega is a dedicated Bioethicist with expertise in research ethics, community engagement, clinical trial monitoring and clinical ethics. Holding a Master's degree of Health Sciences in Bioethics from Makerere University, Sumayiya combines a strong educational foundation in Biochemistry and Chemistry with extensive practical experience. As the Administrator of The AIDS Support Organization Research Ethics Committee since 2020, she ensures compliance with ethical regulations, provides guidance on ethical principles in the conduct of research including clinical trials, and prepares committee meetings.</p> <p>Sumayiya served as the Principal Investigator for the study "Attitudes and Practices of Herbalists towards the Informed Consent Process" at Makerere University from 2018 to 2021, demonstrating her skills in proposal development, data analysis, and report dissemination. As a Research Assistants' Supervisor at Mildmay Uganda, she contributed to crucial surveys, assessing community awareness on various health and Bioethical issues.</p> <p>Sumayiya's competencies include certified training in research ethics and community engagement, effective presentation skills, and proficiency in scientific and grant writing. Committed to influencing policy development, she envisions a healthcare research landscape prioritizing integrity and community well-being. Sumayiya's career is marked by dedication to ethical practices and a vision for a future where healthcare research aligns with comprehensive ethical guidelines.</p>
Co-author(s)	Paul Kutyabami ;Makerere Univeristy; Adeline Twimukye; Infectious Diseases Institute; David. K. Mafigiri ;Makerere University ; Nelson. K. Sewankambo; Makerere University Uganda
Keywords	Herbal medicine, informed consent, communal consent, ethical principles
Abstract	<p>Background: Informed consent (IC) is a fundamental principle in medical ethics that upholds respect for patient autonomy. Although widely applied in healthcare, its feasibility and implementation in herbal medicine have been underexplored. This study therefore aimed to explore the practices and attitudes of herbalists regarding informed consent.</p> <p>Methods: To achieve these objectives, a qualitative cross-sectional study was conducted from June to December 2020. Twenty-one in-depth interviews with herbalists and four key informant interviews with leaders of the different traditional medicine organizations were also conducted. The data were analyzed thematically using NVivo version 12 software.</p> <p>Results: Sixteen of the twenty-one participants acquired oral herbal medicine knowledge from their relatives. Although a positive inclination toward obtaining IC was evident, the focus was on disclosing basic information. Discussions of alternative treatments and herbal specifics less frequent. Disease management decisions often involve shared responsibility within families or societies. Documented IC procedures are rare among herbalists, who deem consent forms unnecessary, although they recognize the potential benefits of IC in fostering trust and professionalism. Challenges hindering IC implementation included regulatory gaps, inadequate skills, and the absence of mechanisms to protect the intellectual property rights of herbal medicine.</p> <p>Conclusion: This study illuminates how educational, cultural, familial, and regulatory factors influence herbalists' practices and attitudes toward informed consent.</p>

Title	A Critical Retelling of Dental Ethics Told Through "George Washington's Complete Denture"
Name	Patricia Neville
Pronouns	she/her
Current position	Senior Lecturer
Institution / Affiliation	Bristol Dental School
Biographical note	<p>Dr Patricia Neville is a qualitative sociologist who works in the field of dental education and oral health. A first generation sociology graduate of the University College Cork and University of Limerick, Republic of Ireland, she joined Bristol Dental School in 2014 and is currently Senior Lecturer in Social Sciences and Theme Lead for Ethics, Law, Professionalism and Social Accountability. Previously she lectured at University of Limerick, Griffith College Cork and University College Cork. She is also the Chair for the Faculty of Health Sciences Student Research Ethics Committee, University of Bristol.</p> <p>She is a research active sociologist who advocates for a social science perspective to dental and oral health research. Her current research interests are in equality and inclusion issues in dentistry, digital technology and social media in dentistry, dental/healthcare professionalism and a sociology of oral health. These research projects build on her previous/ongoing work in the sociology of gender, health, and education. Her work has been published in such journals as British Dental Journal, European Journal of Dental Education, New Media & Society, Health Sociology Review, Journal of Mental Health, Journal of Mens Studies, and the Journal of Gender Studies.</p>
Co-author(s)	Eleanor Fleming, University of Maryland School of Dentistry, USA
Keywords	Dentistry, ethics, teeth, racism, power, reflectivity
Abstract	<p>Dental ethics and diversity are thought to be at odds within the practice of dentistry. Dentistry centers on ethical clinical practices which assume dental ethics are both value neutral and singular with no need for diverse perspectives. Dental ethics are thought to be static, and yet, they are dynamic and problematic in terms of values in dentistry: cosmetic dentistry and its aim for a white smile and the dentist as a clinician, businessperson when there are glaring oral health disparities in communities.</p> <p>In this presentation, we will use the artifact of George Washington's complete dentures to tell a story of how ethics and diversity are relevant to dentistry. Through narrative storytelling, we will center key ethical dilemmas often missed in dental ethics: settler colonialism, biopolitics, whiteness, power, and racial capitalism. Every country has its own myth making, and part of U.S. oral health lore is this complete denture from the country's first president. The denture is problematic because it composed of teeth from enslaved African people. Unnamed African people are removed from history, and yet their teeth are national lore. As an object, the denture is not a mere artifact of history, but is celebrated to show a nation's founding father's connection to a profession. To celebrate the denture without appreciating these ethical dilemmas is to miss the importance of critically engaging history and context in both oral health practice and dental education. As two dental educators and social scientists, we bring an interdisciplinary praxis to problematize dental ethics and reframe through diversity lens. Instead of having a monolithic discourse of dental ethics, we invite critical reflectivity to decenter white, Eurocentric bioethics.</p>

Title	Research Ethics: Influence of participant dynamics on data validity
Name	Dr. Loice Njeri
Institution / Affiliation	Kaimosi Friends University
Biographical note	<ul style="list-style-type: none"> • Faculty member: Kaimosi Friends University (KAFU), Kenya • Key research area: Traditional medicine and non-communicable diseases particularly diabetes. • Research work: Carried out comprehensive surveys on the prevalence of diabetes among the Kikuyu and Maasai communities in Kenya. • Responsibilities: Has been a member of the University Research Board and Institutional Research Ethics Board at KAFU • Publications: <ul style="list-style-type: none"> i. Knowledge and demand for medicinal plants used in the treatment and management of diabetes in Nyeri County Journal of Ethnopharmacology; 2016 Volume 189:218-29. ii. Ethnobotanical survey and threats to medicinal plants traditionally used for the management of human diseases in Nyeri County, Kenya. Tang Humanitas Medicine; 2016 / Volume 6 / Issue 3 / e21 iii. Medicinal Plants used in the management of diabetes by traditional healers of Narok County, Kenya. Tang Humanitas Medicine. 2017 / Volume 7 / Issue 2 / e10 • Awards: PhD fellow by Carnegie Corporation of New York – (CR-AFNNET) • Education and qualifications: <ul style="list-style-type: none"> i. Bachelor of Education in Science (Zoology and Botany) – Kenyatta University (KU) ii. MSc in Cellular Biology and Applied Physiology – University of Nairobi (UoN) iii. PhD in Comparative Animal Physiology – University of Nairobi (UoN)
Keywords	Data validity, Participant dynamics
Abstract	<p>Data validity and reliability are key drivers of informed decision making by government officials, policy makers and funding agencies. Although data validity is dependent on correct methodologies and tools, there are other influencing factors such as the integrity of the researcher as well as the respondents; which may obscure correct research findings.</p> <p>Invalid data becomes unreliable and misleading, this can lead to misplaced and inappropriate decision making and intervention measures, with far reaching socio-economic implications. Its therefore imperative that researchers evaluate and understand the participant dynamics that may lead to incorrect data or skewed conclusions in their research findings.</p> <p>In this review, google scholar, Pubmed, Medline, Web of Science, Science direct, Scopus, among others have been used to review existing data on participant dynamics in research. This paper also seeks to underscore key psycho-social and economic factors as drivers of incorrect responses and information from participants; and the role of the researcher in controlling data validity at different levels of collection and processing.</p>

Title Decolonising Research Ethics in Empirical Legal Research

Name Oluseyi **Olayanju**

Current position Doctoral candidate

Institution / Affiliation Durham University Law School

Biographical note Oluseyi is a doctoral candidate at the Durham Law School. Her research interests include the right to health and medical ethics

Keywords socio-legal research, empirical legal research, decolonisation, ethics guidelines, Nigeria

Abstract

Over the years, the calls to decolonise research have covered several disciplines, including the ethics of conducting research itself. Concerning this issue, the source of definition of research ethics, the extent to which the codes of ethics have incorporated local peculiarities and the power imbalance between the ‘northern’ researcher and the ‘southern’ review boards are some of the issues that have received attention. In this paper, the spotlight is turned on the application of medical and bio medical ethics guidelines to health-related empirical legal research and social science and humanities research – medicalisation or over-medicalisation. In this presentation, the firsthand account of the author’s experience in a sub-Saharan country, Nigeria, and discussions from relevant research articles are employed to illustrate this challenge. This presentation argues that the barriers are double fold in the global southern countries because this situation follows the trend already established in developed northern countries suggesting that, it is part of the transplantation package. Thus, the blanket application of the standards is not only disproportionate, but also difficult to implement for the ethics review authorities and onerous for the non-medical Nigerian researcher. The author, a legal researcher, reports that in Nigeria, there is a dearth of empirical legal research undertaken by legal scholars. Additionally, many of the empirical health-related social science or sociolegal research, presently mostly conducted by non-lawyers, do not obtain ethics approval which, considering the essence of research ethics, is alarming. The aim of this presentation is a simple one – to argue that the lens of the decolonisation discussions concerning research ethics in Global South jurisdictions be extended to this drawback of the imported research ethics regulations.

Title	De-mystifying the organ donation decision
Name	Grace Wankiiri Orsatti
Pronouns	she/her
Current position	Assistant Professor of Clinical Legal Education
Institution / Affiliation	Thomas R. Kline School of Law of Duquesne University
Biographical note	Grace Orsatti, Clinical Assistant Professor of Law, directs the Duquesne Kline School of Law Wills & Healthcare Decisions Clinic & Pro Bono Programs. Her work centers on promoting justice through law clinic collaborative work and pro bono initiatives. Her research operates at the intersection of aging and the law and bioethics. Her scholarship examines legal and ethical aspects of estate and incapacity planning, with a particular focus on older adults, alternatives to guardianship, health and financial decision-making, and age-related health disparities, and has been published in leading journals. Grace is currently pursuing her Master of Science in Bioethics at Harvard Medical School.
Keywords	organ-donation, health-disparities, end-of-life, advance-healthcare-directives, determination-of-death, brain-death

For minority groups in the United States and the United Kingdom, organ donation rates are far below the rates of donation for White patients.[1][2] In the U.S. this is attributed in part to historical distrust of the healthcare system among Black Americans, along with a lack of culturally-sensitive approaches to organ donation, while in the U.K., religious or cultural beliefs that disfavor donation contribute to low donation rates. [3][4] Low donation rates among minority communities have resulting health effects given that genetic factors can impact organ transplant viability. [5] Although a global organ shortage exists across demographic groups, in both the U.S. and U.K. minority patients in need of organs often experience longer wait times and poorer outcomes. [6][7] In both U.S. and U.K legal systems, next-of-kin must be informed before organ donation occurs, particularly where the organ donation decision is unknown. Under certain circumstances, the family may refuse consent to donate the decedent's organs. However, families who know the decedent's wishes and are prepared for the organ donation decision generally react more positively to the donation request, and are more likely to consent.[8] Conversely, unprepared families are less likely to donate, further depressing organ donation rates, and for such families, the donation request can feel like an intrusion, adding distress during a difficult time of grieving and loss.[9] This presentation will explore difficulties that can arise where families are unprepared for the organ donation request, and how organ donation mistrust, and lack of education can affect outcomes. The presentation will additionally examine bioethical issues surrounding organ donation, including determination of death and brain death controversies. Finally I will consider how collaborative efforts across disciplines can prepare individuals to make and record meaningful and informed organ donation choices that honor their wishes and relieve the burden on families unprepared for donation requests at end-of-life.

Abstract

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Title Precision breast cancer screening and breast cancer disparities in South Asian people in Canada

Name Manisha **Pahwa**

Pronouns she/her

Current position Postdoctoral Fellow

Institution / Affiliation McGill University, Canada



Biographical note I'm a bioethics and health policy researcher interested in advancing health equity and well-being for culturally diverse communities in Canada. Using normative and empirical approaches, my research is an inquiry into the values, needs, and lived experiences of culturally diverse groups related to their health and well-being, as well as the social and political determinants of health in these communities. I translate my research to the health policy arena by suggesting how health policies should be implemented to promote health equity and well-being for culturally diverse groups. I also translate my research to theory, helping to enrich theories of justice and autonomy that can be used to guide action on health equity in Canada. One avenue through which I pursue these objectives is by researching ethical issues in personalized cancer screening, where I have a special interest in how risk-based approaches can be fair and effective for culturally diverse communities. I earned my PhD in Health Policy at McMaster University in Hamilton, Canada in 2023. Previously, I contributed to research on the epidemiology and prevention of occupational cancer in Canada and Latin America and the Caribbean.

Co-author(s) Ananya Banerjee, McGill University, Canada; Ryoa Chung, University of Montreal, Canada; Elizabeth Anne Kinsella, McGill University, Canada; Tajinder Kaura, University of Toronto, Canada; Simerpreet Sandhanwalia, Hamilton Health Sciences, Canada; Matthew Hunt, McGill University, Canada

Keywords Breast Neoplasms; Mass Screening; Genes; Ethics; Health Equity; Asian

Abstract Breast cancer is the leading type of cancer diagnosed in women in Canada. Breast cancer disparities adversely impact the health of South Asian people, who comprise large, diverse, and rapidly growing communities in Canada. One such disparity is that South Asian women are more likely to be diagnosed with advanced stage breast cancers compared to non-South Asian women in Canada. Previous research has postulated that if South Asian women participated more in breast cancer screening, then they would have lower risk of late-stage diagnosis. This hypothesis is relevant as breast cancer screening evolves to precision approaches, which tailor screening to an individual's breast cancer risk and may incorporate breast cancer genetic information.

This presentation argues that precision breast cancer screening (PBCS) may widen existing breast cancer disparities by reifying the historical exclusion of South Asian people in breast cancer screening research and policies in Canada. Limited knowledge about breast cancer risk in South Asian communities in Canada might lead to incorrect risk assessment and challenges accessing genetic counselling, impacting the health of South Asian families in Canada and abroad. PBCS may also perpetuate harmful ideas about ethical citizenship embedded in breast cancer screening policies in Canada.

An alternative hypothesis is that if breast cancer screening research and policy were more inclusive of South Asian people, then this may help ameliorate breast cancer disparities and improve the health of South Asian communities in Canada. Empirical bioethics research may contribute by co-constructing intersectional, strengths-based knowledge about PBCS values with the engagement of South Asian communities in Canada. Though much more needs to be done with a global perspective on South Asian breast cancer risk factors, disparities, and values, this research can help inform the fair and effective implementation of PBCS for South Asian communities in Canada and suggest further equity-promoting research avenues.

Title AI for COVID-19 Surveillance and Policing: ethical implications for vulnerable populations

Name Vittoria **Porta**

Pronouns she/her

Current position DPhil Candidate in Population Health

Institution / Affiliation University of Oxford



Biographical note Vittoria Porta is a DPhil Candidate at the Ethox Center, Nuffield Department of Population Health, University of Oxford. She is also a Research Fellow at the European Institute of Oncology IRCCS (IEO). Vittoria before commencing her DPhil has been awarded a one-year pre-doc scholarship funded by the IEO in 2022.

Keywords Ethics, Vulnerable Populations, AI, Infectious Disease, Policing, New Technologies

Surveillance of new infectious diseases is a matter of global relevance that requires global health interventions. Recent developments have included the use of AI tools and new technologies to trace and combat the spread of viruses, such as COVID-19.

In particular, technologies such as mobile phone tracking (digital contact tracing apps) to identify possible infection routes and facial recognition technologies (e.g., dome-shaped surveillance cameras, thermal scanners with facial recognition cameras, and drones) have expanded in recent years and have played a key role in public health surveillance and reducing contagions. While these innovations hold promises for public health, the potential misuse and abuse of health data collected by AI technologies in the context of policing and social control, particularly for vulnerable populations, is still underexplored.

Abstract

The work presents the results of a literature review within two interlinked domains. Its primary objective is to analyse the ethical concerns associated with AI tools developed during the COVID-19 pandemic and assess their potential (and effective) repurposing in policing. Simultaneously, the study explores the intricate intersection of policing, health data, and technology. By doing so, it aims to clarify the boundaries regarding the re-use of technologies designed for COVID-19 surveillance in policing in terms of ethical legitimacy and social desirability, paying special attention to the impact on vulnerable populations.

Title	The attitude and behaviors of the different spheres of the community of the United Arab Emirates toward the clinical utility and bioethics of secondary genetic findings: a cross-sectional study	
Name	Azhar Rahma	
Pronouns	she/her	
Current position	Instructor	
Institution / Affiliation	Institute of Public Health, College of Medicine and Health Sciences, United Arab Emirates University, Al Ain 15551, UAE	

Biographical note Azhar Talal, obtained her bachelor's degree in pharmacy and health sciences, from the Faculty of Pharmacy, AUST -UAE, in 2001 and then had her MPH from the United Arab Emirates University – UAE in 2015, afterward she obtained her PhD honor merit from the Institute of Public Health, Zayed Bin Sultan Center for Health Sciences, United Arab Emirates University, Al Ain, UAE in 2021. Topic of thesis “Establishing the Road map for Genomic Medicine and Pharmacogenomics in the UAE”. Azhar is a graduate of the first cohort of PhD Teaching Academy of United Arab Emirates university. Azhar is a Certified Professional of Patient Safety from The National Patient Safety Foundation. Besides she holds an American board in medical quality (ABMQ). Azhar is a mentor in public health associated with Global Health Mentorships (GHMe).

Keywords Healthcare providers, Academia, Diabetes, Blindness, Gender

Introduction: Genome sequencing has utility, however, it may reveal secondary findings. While Western bioethicists have been occupied with managing secondary findings, specialists' attention in the Arabic countries has not yet been captured. We aim to explore the attitude of the United Arab Emirates (UAE) population toward secondary findings.

Method: We conducted a cross-sectional study between July and December 2022. The validated questionnaire was administered in English. The questionnaire consists of six sections addressing topics such as demographics, reactions to hypothetical genetic test results, disclosure of mutations to family members, willingness to seek genetic testing, and attitudes toward consanguinity. Chi-squared and Fisher's exact tests were used to investigate associations between categorical variables.

Results: We had 343 participants of which the majority were female (67%). About four-fifths (82%) were willing to know the secondary findings, whether the condition has treatment or not. The most likely action to take among the participants was to know the secondary findings, so they can make life choices (61%).

Conclusion: These results can construct the framework of the bioethics of disclosing secondary findings in the Arab regions

Title	Addressing Health Inequalities Within Healthcare Through the Lens of Intersectionality
Name	Melissa Rajalingam
Pronouns	she/her
Current position	Medical student
Institution / Affiliation	Brighton and Sussex medical school
Biographical note	<p>I have long been intrigued by the application of scientific knowledge and technical understanding to diagnose and treat disease. The evolving nature of medicine and the contribution of academic research on clinical practice allows for equality in the delivery of healthcare services as well as competency concerning ethical and social challenges. I hope to pursue research projects to further my understanding of the ethical dilemmas and injustices within the healthcare system and postulate possible resolutions to address these inequalities.</p> <p>The practice of preventative and contemporary medicine encompasses intellect, scientific knowledge, compassionate abilities, and decision-making skills to benefit the lives of others by addressing academic and ethical challenges. As a Medical student I have learned the importance of empathy, communication skills and treating people with a holistic approach. I am familiar with the skills required to deal with difficult situations and how to raise safeguarding concerns. I am open to have conversations about contentious or sensitive topics which I believe is important to removing barriers and understanding awareness of inclusivity. Working with various medical teams in a hospital has enhanced my analytical skills and communication skills when liaising with patients and multidisciplinary teams. I understand the protocol and regulation governing healthcare and the importance of personalized care. This has inspired me to work towards improving awareness and understanding of the social inequalities within healthcare to ensure patients receive the best possible care. I believe treating patients holistically improves their wellbeing and achieve the best outcome.</p>
Co-author(s)	Dr Peter West-Oram, Brighton and Sussex Medical School
Abstract	<p>Mirroring historic trends, the COVID-19 pandemic has had a disproportionate adverse impact on the health of ethnic minorities. The inequalities highlighted by the COVID-19 pandemic demonstrate the health impacts of wider social injustices on marginalised ethnic groups, placing them at a greater risk of poorer health outcomes, regardless of social or economic status warranting urgent reform to protect communities. This paper aims to examine the impacts of impacts of discriminatory and racist practices in healthcare and offer an intersectional framework to combat these injustices. Firstly, public policy during the COVID-19 pandemic was critiqued to examine the disproportionate impact on ethnic minorities. Marginalised groups are disadvantaged through the intersection of socioeconomic and geopolitical factors which persists in healthcare and public policy, this resulted in inadequate protection during the COVID-19 pandemic and continued inequalities. Second, to dismantle structural racism within healthcare, an analysis of the mechanisms through which implicit bias and discriminatory practices emerged and persist was conducted to appreciate established discourses and rhetoric which perpetuate structural racism in healthcare. The snowball effect of implicit bias and discrimination results in a lack of inclusivity and representation of positions of authority, thus robbing ethnic minorities of autonomy. The intersection of disenfranchisement and the repeated impact of discrimination manifests as heightened risks for marginalised ethnic groups who experience a disproportionality higher risk of morbidities including diabetes, hypertension, and mental health. Education of this intersectionality is warranted to reduce stereotypes of practitioner attitudes and prompt the development of personalised treatment. Third, contemporary critical theorists' explanations of structural racism were analysed with application to modern healthcare inequalities, ethnic minorities experience a culmination of unique challenges and inequalities owing to systemic racism, and reform is warranted to challenge drivers of inequality including education to address implicit bias and discriminatory practice. An intersectional framework enables practitioners and policymakers to appreciate the multiple layers and interconnecting impacts of social, economic, and structural inequalities within healthcare to enable reform to improve patient outcomes for ethnic minorities.</p>

Title International Governance of Biosafety and Biosecurity in the Global South

Name Vorathep **Sachdev**

Pronouns he/him, they/them

Current position PhD Candidate

Institution / Affiliation University of Edinburgh



Biographical note

Dev is a PhD candidate at the University of Edinburgh, focusing on improving biosafety and biosecurity governance in Southeast Asia. They are from Thailand and aim to use Thailand as a case study for their work. They primarily focus their analysis on how governance and funding mechanisms can be characterised as neocolonial. In their free time, they like to play sports, watch tv series and talk about 'taboo' topics.

Keywords Biosecurity, Biosafety, Global South, International Governance, Epistemic Injustice

Abstract

This paper focuses on international governance in the context of biosafety and biosecurity in the Global South (GS), such as 'gain-of-function' research that genetically enhances the virulence of potential pandemic pathogens. The author examines the role of international law, specifically soft law instruments, in governing biosafety precautions and biosecurity risks in the GS. This paper specifically focuses on the WHO's recent publications, the WHO 'Laboratory Biosafety Manual (4th edition)' (LBM 4) and the 'Global guidance framework for the responsible use of the life sciences: mitigating biorisks and governing dual-use research' (WHO dual-use framework) and associated examples of biosafety and biosecurity. It does so by first articulating the influence of the World Health Organization (WHO) and its published guidance documents on biosafety and biosecurity in the world, particularly in the GS. It then navigates how international law interacts with biosafety and biosecurity before focusing on the WHO and documents published by and related to the WHO. In doing so, this paper reveals a deficit of GS voices and expertise and discusses how this is a form of (neo) coloniality and epistemic injustice. Finally, the paper concludes by emphasizing that better representation of GS voices in the development of soft law instruments and more research into solutions to avoid similar practices of (neo) coloniality is essential.

X (formerly Twitter)

@vorathep112

Title	Perception and practice of post-Trials Access among Institutional Review Board members, Researchers, and Funders in Sub-Saharan African Countries: (A qualitative study)
Name	Yemisrach Seralegne
Pronouns	she/her
Current position	Main Author
Institution / Affiliation	Armauer Hansen Research Institute, University of Oslo
Biographical note	Mrs. Yemisrach Zewdie is an associate researcher working at the Armauer Hansen Research Institute under the Clinical Trial Directorate for more than 8 years with different roles and responsibilities in different research projects. She is a member of the AHRI/ALERT IRB and served for more than five years as a member and one year as an IRB Secretary. She has an MA in Sociology with a clinical nursing background. Currently, she is a PhD fellow at the University of Oslo in the Medical Ethics department. She has a big interest in the field of Research Ethics and Bioethics.
Keywords	Post-trial access (PTA), Clinical trial, study participants, researchers
Abstract	<p>Post-trial access (PTA) is the sponsor's provision of investigational products for clinical trial participants after their trial participation ends. Post-trial access may include open-label trial extensions, rollover studies, separate protocols, or protocol amendments. Even though it is one of the human beings' ethical rights of human beings, it is not planned and implemented by most trials conducted in Sub-Saharan Africa.</p> <p>Post-trial access (PTA) is well known in different countries, but its implementation relies on the rules and guidelines of each country. Brazil and Argentina are currently the only countries where there are binding regulations to provide PTA, whereas in a few Low and Middle-Income Countries (LMICS), such as Uganda, India, and South Africa non-binding national guidelines support the provision of PTA. However, these are not mandatory.</p> <p>In the in-depth interview process of data collection, there is a knowledge gap in understanding of the word PTA; lack of written legally binding agreement between the researcher, funder, and legally binding guideline in the country; weak ethical review system and regulatory bodies and follow-up on PTA implementation process are the main findings and identified gaps from study participants that represent IRB members, researchers and funders in sub-Saharan countries.</p> <p>Training of Institutional Review Board members (IRB), researchers and funders; availability of written legally binding agreement between the researcher and funder; following strict research ethical review system and a written directive on follow up of PTA implementations by the regulatory bodies like Food and Drug Authority (FDA) will contribute a lot to maximize PTA implementation in Sub-Saharan countries.</p>

Title Ad sustentationem autonomiae: A Call for Greater Engagement of Diverse Bioethics Scholars in Law & Bioethics Discourse

Name Sibil **Shibu**

Pronouns she/her

Current position Clinical Ethics Consultant

Institution / Affiliation University of Alabama Birmingham
Academic Medical Center



Biographical note

Ms. Shibu is currently working as a Clinical Ethics Consultant at the University of Alabama Birmingham, and is pursuing her Doctorate in Bioethics (DBE) through the Neiswanger Institute for Bioethics at Loyola University Chicago. Prior to starting her position as a Clinical Ethics Consultant, she graduated with a Master of Bioethics and a Certificate in Leadership for Public Health and Healthcare from Johns Hopkins University Bloomberg School of Public Health & a Bachelor of Arts in Bioethics and Health Studies, and a minor in Theology from Saint Louis University. Various health care ethics internships, research opportunities, conferences, and fellowships she partook in have equipped her with various skills to become an innovative leader in this field. Her multifaceted research interests include ethics and mission integration, bioethics education, clinical ethics, the intersection of religion/spirituality and medicine, ethical and policy issues regarding genomic and technological developments in maternal-fetal medicine, reproductive ethics, holistic health care & accessibility for immigrants, legal determinants of health, and systems ethics. She hopes to utilize her background in bioethics to compliment her fervent drive to serve a community of diverse individuals, as an advocate of health equity and social justice.

Keywords Law, Bioethics, Medical Malpractice, Diversity, Engagement, Autonomy

Abstract

Throughout history, it has been evident that the legal system has influenced the field of Bioethics, and Bioethics has been utilized to determine what morally permissible legal standards ought to be. Various famous legal cases that have been addressed in Bioethics discourse around the globe revolve around notions of medical malpractice where the principles of autonomy, beneficence, non-maleficence, and/or justice were violated. Although the intersectionality between Law and Bioethics is pivotal in discussions, there is a failure to engage diversity in these conversations. In this project, I present how in current medical malpractice cases, determining case value poses various ethical concerns. Specifically, when determining case value, economic damages and non-economic damages are assessed. Economic damages include medical expenses, lost wages, technological necessities, medications, etc. Non-economic damages include pain, anguish, distress, suffering, etc. An assessment of economic damages and non-economic damages are utilized to inherently calculate a price on a life based on “potentiality”. Such practices pose various injustices, especially for patients from minority groups. In this project, I attempt to present alternative forms of calculating case value without violating the autonomy of patients, especially those who may be most vulnerable. These alternative approaches require a call for greater engagement of Bioethics scholars from minority groups in determining what ethically appropriate legal standards ought to be.

Title The development of culturally-congruent mental health evaluation guidelines for an African context centering gender, socioeconomic, and health equity

Name Mercury **Shitindo**

Pronouns she/her

Current position Chairperson

Institution / Affiliation Africa Bioethics Network



Biographical note

A seasoned researcher and Bioethicist based at St Paul’s University, with over 19 years of progressive management experience. Currently serving as the Chairperson of the Africa Bioethics Network, Mercury collaborates with individuals and organizations across Africa to advance bioethical practices on the continent. In addition to her leadership role, she holds positions on various advisory boards, including the BCA-WA-ETHICS II Project Advisory Board and the Tropical Health and Education Trust (THET) Program Quality Committee. Mercury's impact extends globally as a member of eLife’s Global South Advisory Committee for Open Science and the Training Advisory Committee for the Scaling Up Capacity to Support Conduct of Clinical Trials in the East African Community (SCALE-IT) project. A co-editor in chief of the African Journal of Bioethics, she is also the lead PI for a Kings College-funded research project exploring the environmental sustainability of AI health research perspectives in Kenya. Furthermore, she is a co-founder of the Centre for the Sustainability of Digitally Enabled Health (SHADE).

As an Ethics Course/Curriculum Developer and Trainer, Mercury contributes to Global Impact, emphasizing human rights, human dignity, and ethical research conduct. Her volunteer roles at Africans Rising and as an Ambassador for Crossref underscore her commitment to regional resource mobilization and scholarly collaboration. Mercury's research interests focus on fostering equitable access to basic needs, education, and health through ethical research, community development, and adherence to human rights and bioethics.

Co-Author(s) Farah Nabil, University of Zaragoza, Spain

Keywords Bioethics, Mental health, Research ethics, Ethics review, Gender, Health equity, Access, Cultural sensitivity, Ethical guidelines.

Abstract

Background: Mental illness in Africa constitutes a silent epidemic, exacerbated by structural challenges, including deficient healthcare infrastructure, a shortage of mental health specialists, pervasive stigma, discrimination, and limited access to comprehensive care. The persistent burden of mental illness necessitates innovative treatments and ongoing research in mental health therapy. Research ethics committees acknowledge the significance of advancing in this field, yet the journey is fraught with ethical dilemmas, legal intricacies, and social implications. Urgently needed are guidelines providing direction for research ethics in mental health participant involvement.

Methods: We developed guidelines for ethically reviewing mental health research protocols, aiming to enhance health equity and access in Africa and other low-income countries. Systematic analysis of 13 program, research, and policy evaluation tools was conducted, considering mental health and cultural attributes.

Results: The outcome is a comprehensive 54-item assessment tool facilitating ethical evaluation of mental health research protocols, mindful of ethical, gender, and sociocultural factors in the African context.

Conclusions: The identified themes—research governance, background and justification, methodology, and ethical impact—are interlinked with bioethical principles of respect for autonomy, beneficence, non-maleficence, and justice. Their application in study evaluation not only underscores their significance but also enhances practical implementation, promoting equitable health access in Africa and other resource-constrained settings, irrespective of diverse contexts.

X (formerly Twitter) [@m_shitindo](#)

Title	Exploring Knowledge, Beliefs, and Attitudes of Individuals in Data-Driven Health Research in Kenya	
Name	Mercury Shitindo	
Pronouns	she/her	
Current position	Chairperson	
Institution / Affiliation	Africa Bioethics Network	
Biographical note	<p>A seasoned researcher and Bioethicist based at St Paul’s University, with over 19 years of progressive management experience. Currently serving as the Chairperson of the Africa Bioethics Network, Mercury collaborates with individuals and organizations across Africa to advance bioethical practices on the continent. In addition to her leadership role, she holds positions on various advisory boards, including the BCA-WA-ETHICS II Project Advisory Board and the Tropical Health and Education Trust (THET) Program Quality Committee.</p> <p>Mercury's impact extends globally as a member of eLife’s Global South Advisory Committee for Open Science and the Training Advisory Committee for the Scaling Up Capacity to Support Conduct of Clinical Trials in the East African Community (SCALE-IT) project. A co-editor in chief of the African Journal of Bioethics, she is also the lead PI for a Kings College-funded research project exploring the environmental sustainability of AI health research perspectives in Kenya. Furthermore, she is a co-founder of the Centre for the Sustainability of Digitally Enabled Health (SHADE).</p> <p>As an Ethics Course/Curriculum Developer and Trainer, Mercury contributes to Global Impact, emphasizing human rights, human dignity, and ethical research conduct. Her volunteer roles at Africans Rising and as an Ambassador for Crossref underscore her commitment to regional resource mobilization and scholarly collaboration. Mercury's research interests focus on fostering equitable access to basic needs, education, and health through ethical research, community development, and adherence to human rights and bioethics.</p>	
Co-Author(s)	Gabrielle Samuel, Kings College London; Brenda Odero, Strathmore University, London	
Keywords	Data-driven health research, Environmental sustainability, Ethical considerations, Artificial intelligence, Big data, Sustainable practices, Kenya, Research ethics	
Abstract	<p>Data-driven health research, driven by artificial intelligence and big data, holds the potential to revolutionize global healthcare access and delivery. This study aims to investigate how professionals involved in data-driven health research in Kenya perceive and address the environmental and ethical challenges associated with these technologies. The objective is to gain insights into the ethical, social, and regulatory issues that emerge when considering the adverse environmental and health impacts of data-driven health research within the African research ethics context.</p> <p>Methods: This ongoing pilot research employs a qualitative case-study approach, conducting in-depth interviews with professionals engaged in data-driven health research in Kenya. These interviews aim to uncover their perspectives, awareness, and strategies to mitigate the adverse environmental and health consequences. The study delves into the unique contexts, challenges, and potential solutions from the standpoint of African research ethics.</p> <p>Results: Preliminary findings from this pilot study will provide insights into how Kenyan professionals in data-driven health research navigate the intricate landscape of environmental and ethical concerns. By highlighting their perspectives, practices, and potential barriers to addressing these issues, this research seeks to identify the ethical, social, and regulatory challenges associated with considering environmental and health impacts within the African research ethics context. The full results of this pilot study are expected to be available by the time of the conference in May 2024.</p> <p>Discussion: Understanding how Kenyan professionals approach the environmental and ethical aspects of data-driven health research is essential. This research aims to stimulate dialogue that acknowledges the challenges and seeks sustainable, ethical, and environmentally responsible practices in the development and application of data-driven health technologies in Kenya. The potential impact of this study lies in the creation of context-specific solutions that promote responsible and sustainable data-driven health research in Kenya. We anticipate sharing the full results of this research upon completion.</p>	
X (formerly Twitter)	@m_shitindo	

Title	A Queer Feminist Posthuman Framework for Justice: The Case on Antimicrobial Resistance
Name	Tiia Sudenkaarne
Pronouns	she/her
Current position	Postdoctoral researcher
Institution / Affiliation	University of Helsinki
Biographical note	<p>I'm a queer feminist philosopher working in bioethics. A postdoctoral scholar at University of Helsinki, I've spent the last five years at Center for the Social Study of Microbes, a cutting-edge interdisciplinary hub for social scientists and artists thinking with microbes. I've realized there is a lacuna on bioethical theory keeping gender and sexual variance, more-than-human such as ecojustice and classic social justice issues such as racist oppression and health disparities in the same ethical framework. Moreover, there is lacuna in moral theories that could facilitate such frameworks, particularly due to nonexistence of departures from the neoliberal concept of justice. I would very much like to attend the conference to discuss my queer feminist posthuman framework for justice as a bioethical principle and learn how to best make it work for abolitionist, antiracist and decolonial aims.</p> <p>Antimicrobial resistance (AMR) has been declared by the WHO as one of the top ten global public health threats facing humanity. Moreover, it seriously endangers the health, wellbeing and survival of ecosystems and more-than-human-animals.</p> <p>From a moral philosophical viewpoint, it can be argued that humans are exceptionally accountable for AMR. Yet moral components like accountability, rights, duties and principles in their dominant frameworks seem to offer dissatisfying solutions to issues such as AMR as they seem to entail irreconcilable injustices. Indeed, AMR presses urgent dilemmas that consistently raise the most difficult ethical question: how to manage conflicting interests of environments, more-than-human animals and humans with intersecting vulnerabilities around gender, race and class, in an ethically sustainable way?</p>
Abstract	<p>I approach this dilemma with justice as a bioethical principle. Crucially, however, ethically sustainable resolutions require new frameworks to define and apply the principle of justice. I begin by discussing bioethical principlism: its relation to AMR and its queer feminist critiques. I then analyze the issues with current ethical frameworks of AMR, focusing on the critique of anthropocentrism. In dialogue with the concepts of and discussions around multispecies justice and ecojustice, I offer my queer feminist posthumanist framework to contribute to bioethics. Ultimately, I strive for bioethics in which the “bio” is not limited to human life, without losing intersectional insight into the existing social justice issues between groups of people. Acknowledging the grave moral harms nifty slogans like “Make kin, not babies” can cause to BIPOC communities in an ethical climate supporting white pronatalism and unable to compute racist anomalies of bioethical justice, I am keen to discuss how to improve the framework for abolitionist, antiracist and decolonial aims.</p>

Title Using deliberative process to resolve race-based requests in medicine

Name Peter **Young**

Pronouns he/him

Current position Researcher

Institution / Affiliation Ethox Centre

Biographical note Peter D. Young is a researcher at the Ethox Centre, University of Oxford. He is also the director of the Philosophy of Medicine course at the Worshipful Society of Apothecaries in London. He has held research positions at the University of Pennsylvania, Johns Hopkins University, and the World Medical Association's secretariat office in Ferney-Voltaire. He has interests in medical ethics education, the ethics of prenatal and genetic testing, physician–patient relationships, and providing equitable healthcare access to marginalised groups.

Keywords Race-based concordance, Deliberative process

Abstract Leading scholars in the social sciences have argued that when a healthcare professional's and patient's race align, the professional can provide better advice with regards to certain beliefs, religious practices, and cultural norms of their patients. There might also be subtler, yet equally important benefits of having your provider look like you, including patient-compliance as well as the potential for less polarizing power dynamics in the professional–patient relationship. But not all reasons for race-based requests should be accepted. This session will begin by providing background to some race-based requests that might arise in clinical practice. From here, several cases will be presented that test our intuitions about what are acceptable and problematic race-based requests. This will raise a more fundamental question about how we deliberate troubling ethics cases in clinical practice. I will suggest that professional guidance and definitive ethical stances put forth by commentators in the ethics literature cannot account for all the complexities that might occur in clinical practice. Instead, through a deliberative process, power is shifted from the authority vested in policy documents, algorithms, and professional guidance back to the healthcare professionals who make judgements about the facts and values that arise in each case. The result of this shift places less concern on universally right and wrong answers and more concern with the process through which difficult cases are adjudicated.

Website and social media

Website

The main conference event page is on the BBB website at <https://blackbrownbioethics.blogs.bristol.ac.uk/event/bbb-conference-2024/> . Presentations from this conference will be posted on the site shortly after the event. We will also post videos to our YouTube channel <https://www.youtube.com/@BlackandBrowninBioethics>

e-Poster Gallery

Delegates of the BBB conference 2024 are invited to browse through all online Posters at our e-Poster exhibition during the conference and on-demand until the end of July 2024. You can find Poster Abstract Presentations at <https://event.fourwaves.com/bbb2024/abstracts>

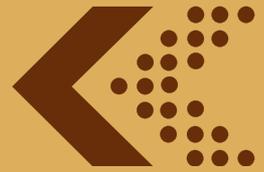
Social Media

We encourage the use of social media to engage in conversation and to spread the discussions to those unable to attend the conference itself. If you use Twitter, please use the hashtag #BBB24 to tag your tweets about the conference.

Social media etiquette

Please follow these guidelines to ensure that social media is used in a positive way that benefits the conference and its participants:

1. **Be polite and constructive.** If you are going to tweet during a presentation or discussion, make sure you do so on a positive note. Share what you learned from the session or pose an interesting key question that would warrant further discussion. If the presenter has a social media profile, tag them in your post, and use the conference hashtag #BBB24.
2. **Respect presenters' requests for no social media.** Some topics discussed may be sensitive or present early findings from research that has not yet been published. The chair should indicate at the beginning of a session if the presenter would prefer their talk not to be tweeted.
3. **Engage with others.** The meeting is an opportunity to learn from others, to hear about their experiences and perspectives. Social media is a useful tool for these interactions but do take the opportunity to talk to people as well!



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EMAIL: BBB-NETWORK@BRISTOL.AC.UK

