Ethical, Legal and Social Implications in Epigenetics: Indigenous, National and Global Perspectives

23-25 May 2022

Fondation Brocher, Hermance, Switzerland

Organised by the Ethical, Legal and Social Implications of Emerging Technology (ELSIET) research group, Iverson Health Innovation Research Institute, Swinburne University of Technology, and the Melbourne School of Population and Global Health, University of Melbourne, with funding provided by the Brocher Foundation.

FONDATION BROCHER

THE UNIVERSITY OF MELBOURNE

SWINBURNE UNIVERSITY OF TECHNOLOGY

WELCOME

We are thrilled to be able to welcome you to the beautiful Fondation Brocher for this symposium: Ethical, Legal and Social Implications in Epigenetics: Indigenous, National and Global Perspectives. We hope that many fruitful collaborations arise as a result of this meeting and the discussions that will follow.

CONFERENCE COMMITTEE

Grant recipients
Gareth Baynam
Angeline Ferdinand
Margaret Kelaher
Evie Kendal

Endorsements
Gen(e)quality Network
Deakin Science and Society Network

ACKNOWLEDGEMENTS

The conference committee would like to thank the Brocher Foundation whose symposium grant made this event possible. We would also like to respectfully acknowledge the traditional owners of the lands on which our respective institutions are located, and extend a particular welcome to First Nations participants who are joining us. We also wish to extend our heartfelt condolences to the late Professor Kelaher's family and colleagues and acknowledge her contributions to the workshop proposal and development. We acknowledge as well all members of our original program who are unable to be with us due to personal circumstances, including those associated with the ongoing COVID-19 global pandemic.

Contents

Symposium Outline and Goals

Advances in genetic and epigenetic testing carry with them a plethora of ethical and legal challenges. One of the major clinical applications for this field is in the area of personalised or precision medicine, including targeted cancer treatments. However, both testing and the translation of results into meaningful therapeutic options are currently unequally distributed, with marginalised communities disproportionately experiencing harm from genetic studies, while also experiencing fewer benefits from research due to barriers in accessing personalised medicine and lack of representation in reference databases. There are also broader resource allocation concerns when comparing outcomes for citizens in countries with privately or publicly funded high technology care, versus low resource settings where even basic health needs remain unmet. Where emerging genetic and epigenetic technologies should fit within this paradigm remains an open question. The COVID-19 crisis has highlighted many disparities in healthcare resourcing across the globe and ongoing justice concerns regarding access to vaccines and treatments. However, it has also demonstrated the need to continue genetics research, despite the high costs involved. This symposium considers fundamental issues of health justice as they pertain to genetic and epigenetic research, testing and treatment, with a particular focus on pursuing equitable distribution of the burdens and benefits of this research across diverse populations.

The symposium represents a unique opportunity for Australian, European and American researchers in genetics and gene-ethics, to collaborate with each other and learn from different socio-political perspectives on the issue of genetics and epigenetics research and healthcare

Aims:

- Developing an understanding of the ethical implications of precision medicine approaches for minority populations in clinical settings
- Developing ethical and policy guidance in the areas of data collection, storage and use, particularly in the context of genetic information of First Nations origin
- Developing culturally appropriate approaches to precision medicine in clinical settings, exploring the role of cultural competence and family involvement in individualised care
- Strengthening health system responses to precision medicine for families
- Enhancing public understanding of genetic and epigenetic research, including through improving health communication, informed consent and data privacy

As the original date for this symposium was delayed due to COVID-19, an online version was run May 5, 2021. The presentations are available to be viewed here: https://mspgh.unimelb.edu.au/centres-institutes/centre-for-health-policy/research-group/evaluation-implementation-science/elsi-genomics-symposium

Symposium Agenda

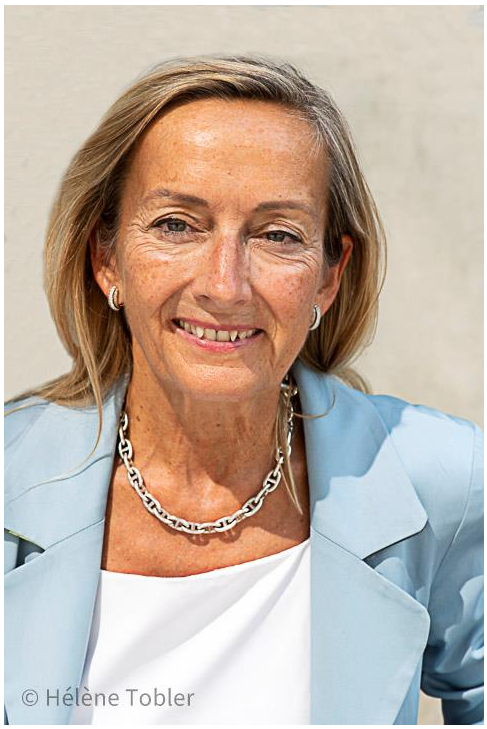
Day 1: 23 May 2022	Day 2: 24 May 2022	Day 3: 25 May 2022
07:30-8:45 Breakfast at Villa Brocher	07:30-8:45 Breakfast at Villa Brocher	07:30-8:45 Breakfast at Villa Brocher
0930-1030 Welcome and opening statements; Introductions Roundtable discussion: Objectives of the Symposium, IJEqH Special Collection (Drs Angeline Ferdinand and Evie Kendal)	0930-1030 Exclusion criteria: intergenerational narratives resist biosocial paradigms of traumatic embodiment in postwar Guatemala (Ms Luisa Rivera)	0930-1000 The Ethics of Pest Control: Balancing Animal Welfare, Conservation, and Indigenous Values (Mr Asher Soryl) 1000-1030 Final address
1030-1100 Morning tea break	1030-1100 Morning tea break	1030-1100 Morning tea break
1100-1200 Equity and personalised medicine in the European data space (Prof Bettina Borisch)	1100-1200 Participation in Genomic Research and Medicine: Perspectives of Indigenous Community Members and Leaders in the United States (Dr Denise Dillard)	1100-1300 Panel discussion IJEqH Special Collection planning session, symposium summary and next steps
1200-1300 Anticipatory ethics for emerging genetic and epigenetic technologies (Dr Evie Kendal)	1200-1300 Epigenetic mechanisms as mediators of long-term and transgenerational community injustice (Prof Angus Clarke)	CLOSE
1300-1400 Lunch at Brocher Centre	1300-1400 Lunch at Brocher Centre	1300-1400 Lunch at Brocher Centre
1400-1445 From proband to provider: is there an obligation to inform genetic relatives of actionable risks discovered through direct-to- consumer genetic testing? (Mr Jordan Parsons)	1400-1445 Epigenetics for Institutional Change? Race, Stigma, and the New Biology of Trauma (Prof Dr Ruth Müller and Assoc Prof Martha Kenney)	
1445-1530 Public knowledge and opinion of epigenetics and epigenetic concepts (Prof Jeff Craig 2245 AEST)	1445-1530 Neuroepigenetics: How childhood trauma can affect descendants via the germline (Prof Dr Isabelle Mansuy)	
1530-1545 Afternoon tea break	1530-1545 Afternoon tea break	
1545-1630 Is self-experimentation ethical in public health emergencies? (Ms Tania Manríquez Roa)	1545-1630 The ethics of reflexive prediction in epigenetic risk profiling (Dr Mayli Mertens)	
1630-1730 Facilitated discussion: Regulation and legislation of genetic technologies	1630-1730 Facilitated discussion: Justice in genomics	
1830-2030 Dinner at Villa Brocher	1830-2030 Dinner at Villa Brocher	

Speakers (alphabetical order)

Bettina Borisch, Institute of Global Health, University of Geneva

"Equity and personalised medicine in the European data space"

ABSTRACT: In circumstances where bioethics are invoked there is frequently a societal issue around the corner. In the present case the pure biomedical way is not practicable: this is quite visible in the case of genetic data in the European data space. As methods of whole-genome sequencing and other genetic tests have become less demanding and less costly so has the wish for clinical application and as a consequence the growth of what is called personalized medicine (PM). The EU parliament has consistently given strong backing of the EU's attempt to take advantage of well-managed data sharing to improve health of Europe's citizens. In 2011 with the cross boarder health legislation and more recently with the European Health Data Space (EHDS). The following aspects will be discussed: 1. plenitude of data 2. Political and legislator environment in the EU and 3. Equity and the determinants of health.

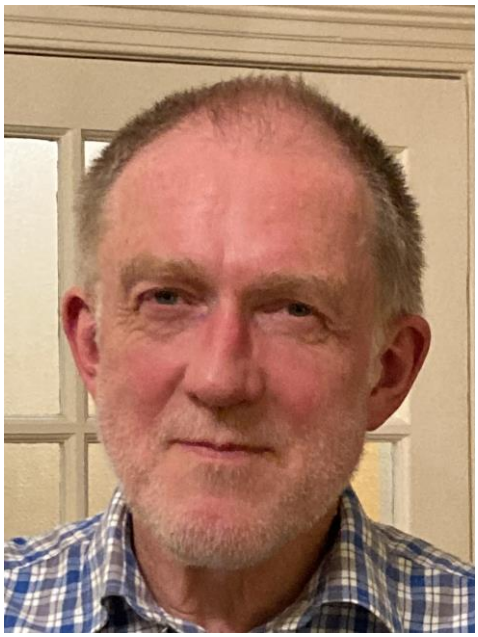


BETTINA BORISCH is a global public health expert. She has a long experience in collaborating with international organizations, both at the UN level as well as at the European level. She also serves in different functions in the NGO sphere, such as President of Europa Donna, CEO of the World Federation of Public Health Associations and board member of several other Public Health organisations. She is a professor of Public Health at the Institute of Global Health, Medical Faculty, University of Geneva. A medical doctor by training she first specialized in clinical pathology and was the director of the Institute of Clinical Pathology, University of Geneva before orienting her work to Public Health. Her research interests include gender health, health systems, universal health coverage and health governance. In her life as a histopathologist, she was involved in cancer research with an emphasis on Non-Hodgkin-Lymphomas and other neoplastic lesions such as breast cancer. This led to up to her public health work in breast cancer screening, early diagnosis and treatment. More recently she focusses on data, AI and Public Health.

Angus Clarke, School of Medicine, Cardiff University, Wales UK

"Epigenetic mechanisms as mediators of long-term and transgenerational community injustice"

ABSTRACT: There are multiple ways in which the implementation of genomics in healthcare could impact social justice. Here, we consider how epigenetic modifications to the genome can act to reinforce inequity in health. We relate this to the health consequences of malnutrition, poverty and stress over the course of a life, or even across generations, and to inequity in access to healthcare. Epidemiological studies suggest that maternal malnutrition and disease can alter the fetus, impacting the development of the common, complex degenerative diseases in the adult human many years later. The great disparity in incidence of such disorders between populations raises questions about the extent to which these differences result from simple genetic difference or whether environmental factors may be involved, perhaps in a complex, delayed-response pattern over the life course of individuals. Molecular studies support the principle of epigenetic mechanisms mediating some of these biological effects, although studies in humans are inevitably difficult to conduct. In the absence of clear proof, medicine and society need to decide how to respond to the evidence as it is now and how to grow in understanding in the future. How can we best employ the science of epigenetics to generate an explanatory account of chronic disease, recognizing the burden of long-term physical and mental ill health as the biological consequence of social disadvantage and powerlessness? Can we use this in making decisions about public health and political life? Or even to discover how to reverse some of the ill-effects of early life deprivation?

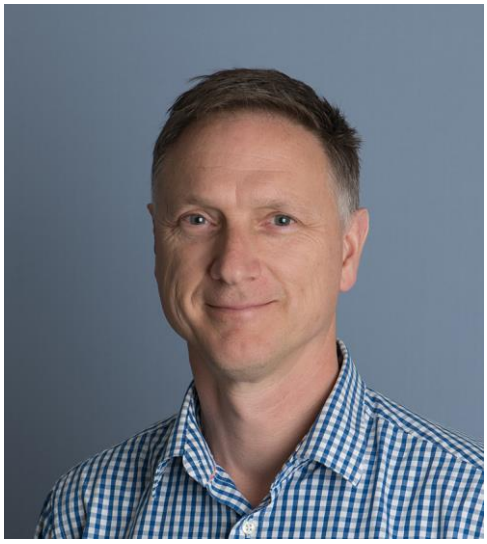


ANGUS CLARKE Coming from a background in paediatrics, Angus has worked in Clinical Genetics at Cardiff since 1989, with particular interests in ectodermal dysplasia, Rett syndrome, newborn screening, the genetic counselling process and the social and ethical issues around human genetics. He has authored or edited ten books, often with colleagues, and numerous research papers and book chapters. He directed the Cardiff University MSc course in Genetic Counselling from when it was launched in 2000 until 2018. He contributes to policy discussions - he was a member of the Human Genetics Commission - and the drafting of policies and reports for the British Society for Genetic Medicine and the European Society of Human Genetics. He is now researching how patients make decisions and working on justice in the implementation of genomics. Angus has actively supported patient organisations for many years, including the Ectodermal Dysplasia Society UK; he is the Chair of their Medical Advisory Board and involved with clinical trials for X-linked hypohidrotic ectodermal dysplasia. He has also supported Rett UK for many years, including work on the British Isles Rett Syndrome Survey and the Cardiff Rett Syndrome clinic.

Jeffrey Craig, Deakin University

"Public knowledge and opinion of epigenetics and epigenetic concepts"

ABSTRACT: Limited research exists on public opinion and understanding of epigenetics. Using an online questionnaire, we investigated the Australian public's understanding of epigenetics and related concepts, including the concepts of the developmental origins of health and disease (DOHaD). Over 600 questionnaires were completed, with 391 included in the analysis. Data were analysed using predominately descriptive statistics, with free-text responses scored based on concordance with predetermined definitions. While participants' recognition of epigenetic terms and phrases was high, their understanding was limited. The DOHaD hypothesis was more accurately understood than epigenetics itself. Female participants without children were more likely to recognise the term epigenetics, while age also had an impact. This research provides a solid foundation for further detailed investigation of these themes, all of which will be important data to help inform future public health messages regarding epigenetic concepts.

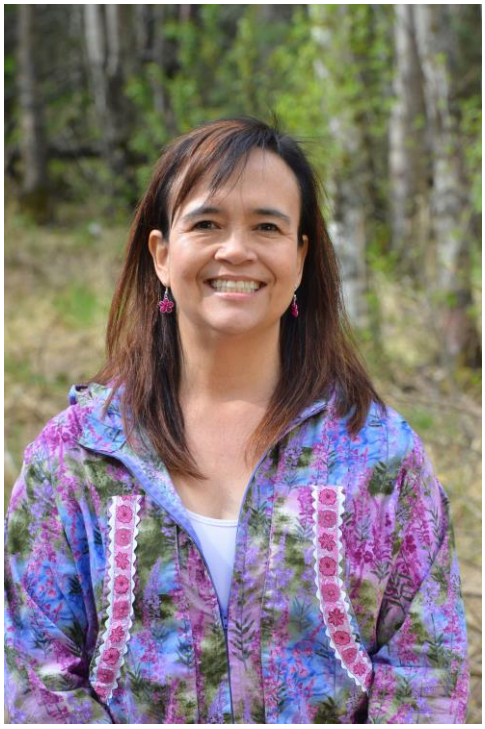


JEFFREY CRAIG is Professor of Epigenetics and Cell Biology at the School of Medicine, Deakin University, Australia. His goal is to use epigenetic and cytological techniques to develop biomarkers of health and disease. This includes a focus on the role of epigenetics in mediating the effects of early life environment on the risk for chronic conditions. Jeff has established many longitudinal cohorts in collaboration with clinicians and epidemiologists. Most have involved twins because of their ability to measure how genes and environments interact. His longest-running cohort is the Peri/postnatal Epigenetic Twin Study (PETS) for which he is currently funded by the NHMRC to study cognition and brain structure and function in 11-year-olds. Prof Craig is a Chief Investigator on the NHMRC-funded Twins Centre of Research Excellence, Deputy Director of Twins Research Australia, and President of the International Society for Twin Studies. He is also an advocate for twins and their families. In 2018, Jeff established the multidisciplinary Gen(e)quality network. His broad aim is to develop ideas on the technical, ethical, legal and social implications of epigenetics research and testing. He is also an active science communicator and over one million people have read his articles in The Conversation.

Denise Dillard, South Central Foundation

"Participation in Genomic Research and Medicine: Perspectives of Indigenous Community Members and Leaders in the United States"

ABSTRACT: American Indian and Alaska Native peoples (AI/ANs) in the United States are underrepresented in genomics research and some argue that advances in genomic medicine and precision medicine may exacerbate rather than ameliorate health disparities. Underrepresentation in genomics research is compounded by mistrust due to past abuses and harms, concerns about privacy as well as data ownership and governance, and cultural considerations about this type of research. Results of empirical ethical, legal, and social implications (ELSI) research in Alaska will be presented with a focus on genomics and pharmacogenetic research and practice. Perspectives of AI/AN community members as well as leaders will be described and implications for future research and clinical practice presented.

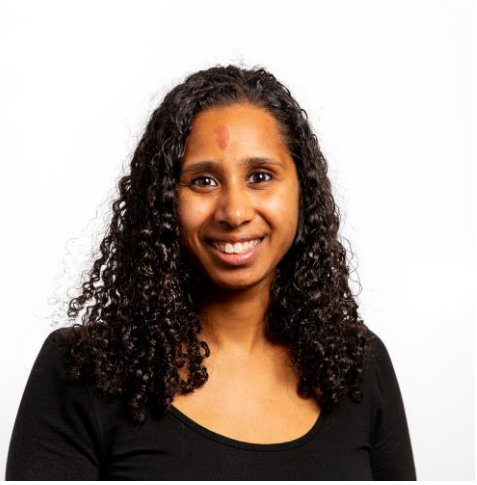


DENISE DILLARD is Inupiaq Eskimo and was born in Fairbanks, Alaska and raised in Anchorage, Alaska. She is a licensed psychologist and has conducted quantitative and qualitative research with American Indian and Alaska Native peoples since 1998 . She is currently the Director of Research for Southcentral Foundation (SCF), a tribal health organization in Anchorage, Alaska. She oversees the direction of a diverse portfolio of research studies addressing the wide-ranging needs of American Indian and Alaska Native community served by the organization including research about the ethical, legal, and social implications of genetic research. She works directly with tribal leadership at SCF as they consider approval of research proposals, abstracts, and manuscripts and is a member of the Alaska Area Institutional Review Board. At a national level, she serves as the Alaska Delegate of the National Institutes of Health Tribal Advisory Committee and is a member of other committees including the Tribal Collaboration Working Group of the All of Us Research Program.

Angeline Ferdinand, The University of Melbourne
Conference organiser and grant recipient

ABSTRACT: This symposium considers fundamental issues of health justice as they pertain to genetic and epigenetic research, testing and treatment, with a particular focus on pursuing equitable distribution of the burdens and benefits of this research across diverse populations.

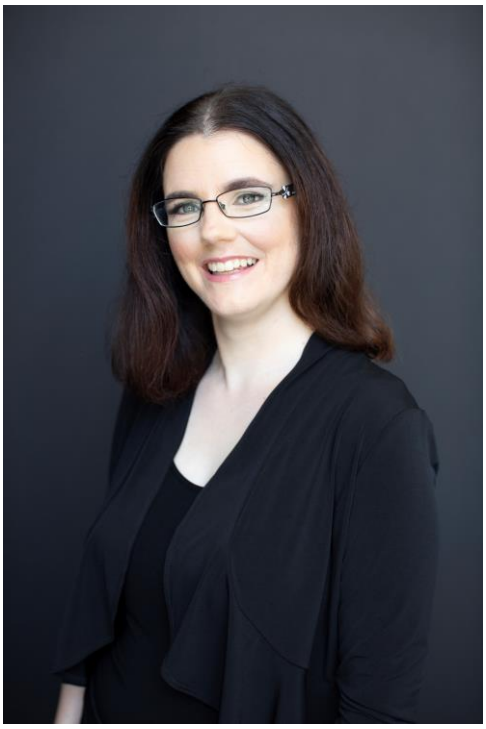
ANGELINE FERDINAND has had a wide-ranging academic career that has focused on applied research that addresses complex problems of health equity, social determinants of health and the implications of new technologies in public health practice. She has conducted large-scale evaluations of health policies and initiatives, and her work has had substantial policy impact. Angeline is currently leading a multi-jurisdictional project in collaboration with genetic health care providers to improve equity in access to genetic health services for Aboriginal and Torres Strait Islander patients and their families. She is also undertaking a world-first body of work evaluating the application of microbial genomics in public health surveillance and outbreak control. This includes assessment of platforms designed to facilitate cross-jurisdictional sharing of SARS-CoV-2 genomic data and development of recommendations for future pandemic preparedness.



Evie Kendal, Swinburne University of Technology

"Anticipatory ethics for emerging genetic and epigenetic technologies"

ABSTRACT: Advances in genetic and epigenetic technologies pose unique ethico-legal challenges, partly due to the family nature of genetic information and partly due to uncertainties regarding what will be possible using these technologies in the future. The need to "future-proof" informed consent, particularly in the context of providing biosamples for genetic testing and research, is similar to many other areas of emerging technology ethics, but the special nature of genetic information implies such consent might need to extend beyond the individual. In this presentation I consider various possible methods for securing "societal consent" for the collection, use and reporting of genetic and epigenetic data, paying particular attention to the potential social harms accruing to families, minorities, and special interest groups, e.g. genetic disease communities.



EVIE KENDAL is a bioethicist and public health researcher at the Department of Health Sciences and Biostatistics, Swinburne University of Technology. Evie's research interests include ethical dilemmas in emerging biotechnologies, space ethics, and public health ethics.

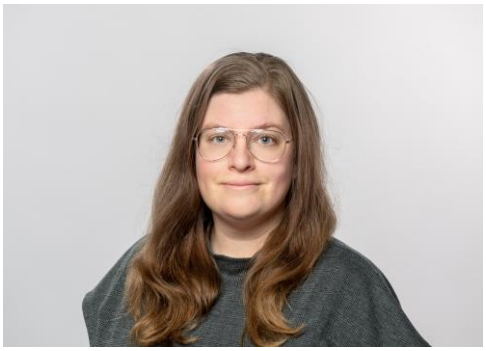
Evie is also one of the conference organisers and grant recipients for this symposium.

Martha Kenney, San Francisco State University

"Epigenetics for Institutional Change? Race, Stigma, and the New Biology of Trauma"

ABSTRACT: While epigenetic research can lead to biomedical interventions such as precision medicine, it is also increasingly mobilized to affect institutional change in healthcare, education, and criminal justice (Müller and Kenney 2020). Based on the premise that adverse childhood experiences (ACEs) can change the way bodies respond to stress, actors in these fields are drawing on resources such as trauma-informed care and restorative justice to address the epigenetic, neurological, and endocrinological effects of trauma and toxic stress. Although these new biosocial narratives have been transformative in some contexts, not all institutions have readily embraced the biology of early life adversity. In this talk we draw on fieldwork from a large urban school district in California that has encountered these biosocial narratives but have not adopted them as a central part of their behavioral health and restorative justice programs. Specifically, actors in these fields were concerned that the biology of early life adversity could stigmatize students and their communities, many of whom were already racialized and pathologized in many other ways. Starting from these objections, we consider whether biosocial research could be designed to support the school district and secure funding for necessary staff and programming. We pay particular attention to how scientific research could detract from or contribute to the district's efforts to achieve racial equity and interrupt the U.S. school-to-prison pipeline. Overall, we argue that researchers in epigenetics, neuroscience, and other fields that study the biological effects of early life adversity can learn from school districts who aim to address trauma and inequity in their schools.

MARTHA KENNEY is Associate Professor of Women & Gender Studies at San Francisco State University. Located in the tradition of feminist science studies, her research examines how narratives from new fields of biomedical research—such as environmental epigenetics and precision medicine—support, contest, and reconfigure collective visions of social justice, environmental justice, and health equity. She is the co-founder of the Science, Technology, and Society Hub at San Francisco State University—a multi-disciplinary incubator for research at the intersection of science and social justice.



Martha is presenting on behalf of herself and Ruth Müller (bio included below).

RUTH MÜLLER is a researcher in the field of Science & Technology Studies (STS). Her work explores the nexus of science, technology, society, and policy, focusing particularly on how institutional norms and values shape and interact with scientific knowledge production practices, on emergent knowledge cultures in the life sciences and in biomedicine, and on the circulation and interpretation of life science knowledge and biotechnologies in society and policy. Across all her lines of work, she emphasizes the need to considers social equity and justice as key categories for analyzing relations between science, technology, society and policy.

Tania Manríquez Roa, University of Zürich

"Is self-experimentation ethical in public health emergencies?"

ABSTRACT: Scientists around the world have been conducting experiments on themselves to develop a vaccine against Covid-19. Self-experimentation is currently in a grey zone – it is not addressed directly in key research ethics regulations, including the Declaration of Helsinki, and its legal status is often unclear. Some self-experimenters claim they might develop an open source vaccine against Covid-19 that could benefit populations that still largely lack access to vaccines. We are conducting an exploratory Delphi study that aims to contribute to the debate on ethical research during health emergencies. Ethical issues will be discussed among a group of experts to identify convergence and divergence on whether self-experimentation is ethical in emergency contexts and if so, under what conditions. We will address the issues of accessibility, public trust, responsibility, solidarity, safety, efficacy, and the role of ethical committees and regulatory agencies. We will select purposively a panel of 10-20 experts in self-experimentation, including self-experimenters, policymakers, scholars, and members of research ethics committees and regulatory agencies of medical products. The study comprises three rounds. In the first round we will request experts to state their level of agreement or disagreement with statements provided by the facilitators of the study, and to comment on each statement. We will analyse and summarise the results and provide feedback. In the subsequent rounds, experts will comment on anonymised and summarised opinions of others, and reconsider their views. The outcomes and conclusions will be available in summer 2022 and may be used for future regulations on self-experimentation.

TANIA MANRÍQUEZ ROA is an ethicist and qualitative researcher working in the field of global health. She holds a BA in Social Anthropology (University of Chile), an MA in Global Ethics (King's College London) and is conducting her PhD in Bioethics (University of Zurich). She is part of the Excellence Program at the Digital Society Initiative (University of Zurich). Her current research addresses ethical issues that arise with the development and use of digital mental health tools, and she is also developing a project on self-experimentation in public health emergencies. Before starting her PhD, Tania worked as a policy consultant in projects for the World Health Organization, UNICEF, the European Commission, the World Wildlife Fund, the Center for Development and Cooperation (ETH Zurich), the Human Rights Center (University of Chile) and the Department of Social Studies (Catholic University of Chile). She has conducted fieldwork in Chile, Mexico, Mozambique, and Switzerland.

Isabelle Mansuy, University of Zürich

"Neuroepigenetics: How childhood trauma can affect descendants via the germline"

ABSTRACT: Behavior and physiology in mammals are strongly influenced by the environment and life experiences, particularly in childhood. While positive factors can favor proper development and good mental and physical health later in life, childhood adversity and traumatic events increase the risk for cancer and psychiatric, metabolic and autoimmune diseases. Such disorders can affect exposed individuals directly and in some cases, impact the offspring across generations. The biological mechanisms underlying transmission are thought to involve epigenetic factors. We developed a transgenerational mouse model of postnatal stress that recapitulates trauma symptoms including increased risk-taking, depressive behaviors, cognitive and social deficits, and metabolic and cardiovascular dysregulation in adulthood. The symptoms persist throughout life and are transmitted to the offspring, in some cases, up to the 5th generation. Comparable symptoms affect traumatized children, indicating conserved effects in mouse and human. Symptoms are associated with molecular changes involving RNA in germ cells, that in mice, are causally linked to symptoms transmission. MiRNAs are also affected in extracellular vesicles in the reproductive tract. Circulating factors were identified as mediators of alterations in germ cells. Chronic injection of serum from trauma-exposed mouse males into controls recapitulates metabolic phenotypes in the offspring, suggesting information transfer from serum to germ cells. Circulating factors involving peroxisome proliferator-activated receptor (PPAR) pathways are causally involved, and pharmacological PPAR activation in vivo affects sperm transcriptome and metabolic functions in the offspring and grand-offspring. These results suggest an ensemble of mechanisms from the periphery to germ cells for the inheritance of acquired traits.

ISABELLE MANSUY is Professor in neuroepigenetics at the Medical Faculty of the University of Zurich and the Department of Health Science and Technology of the Swiss Federal Institute of Technology (ETH) Zurich. She is known for her work on the mechanisms of epigenetic inheritance in relation to early life adversity in mice and humans, and on the implication of RNA as vector of inheritance. Mansuy studied molecular biology and biotechnology at University Louis Pasteur and the École Supérieure de Biotechnologie de Strasbourg in France and got a PhD in development neurobiology at the Friedrich Miescher Institute in Basel, Switzerland. She conducted a postdoc in neurobiology in the Kandel lab at Columbia University in New York where she worked on the molecular mechanisms of memory. She established her lab at ETH Zürich in Dec 1998 and studied the role of protein phosphatases in forgetting for many years before switching to epigenetic inheritance. Her current research is dedicated to the mechanisms involving chromatin remodeling in the brain and germline that underlie the expression and the transmission of acquired traits across generations in mice.

Mayli Mertens, Københavns Universitet - University of Copenhagen

"The ethics of reflexive prediction in epigenetic risk profiling"

ABSTRACT: With the field of epigenetics growing and the study of gene-environment interaction providing more insight, we are increasingly learning how changes in gene expression take place. Environmental influence can come from outside, "including the external world in which the organism is located or develops" as well as from inside the organism itself, including "factors as its hormones and metabolism" (Lobo, 2008). One environmental factor that is often overlooked is our own knowledge production and beliefs. Scholars have raised concerns that beliefs about genetic information impacts the expression of genes to match that information, a so-called self-fulfilling prophecy (Vineis 2004). A more recent study showed that "learning one's genetic risk changes physiology independent of actual genetic risk" (Turnwald et al 2018). We also know that when therapeutic interventions are offered to diminish that risk, the risk can be alleviated or eradicated. Ongoing studies on epigenetic risk profiling are aimed at fulfilling precisely that purpose. If we decide to make assertions and predictions about gene expression, we better have some understanding about the impact of those assertions and predictions. My aim then is to theorize the different ways in which reflexive prediction in epigenetics work and, while laying out a descriptive account of the different models, offer an analysis of the epistemic and ethical implications of their reflexivity.

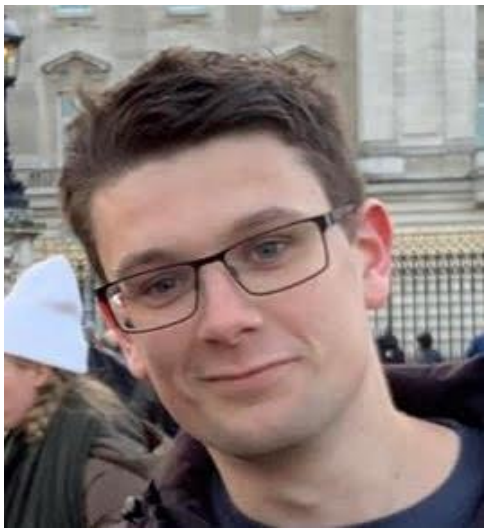
MAYLI MERTENS specializes in analyzing cognitive, cultural, and contextual biases in medicine and is currently working on reflexive prediction in clinical innovation, specifically in neuroprognostication and epigenetic risk profiling. Mayli's work focuses on the ethical and epistemic impacts of innovative practices and technologies. She obtained her PhD with her work on 'Responsible Prediction under Critical Uncertainty', an epistemic analysis of neuroprognostic innovation practices after cardiac arrest. Mayli was awarded with 'Best Formal Paper by a Graduate Student' by the Association for Practical and Professional Ethics (APPE) for her work 'Objectivity behind the red line: A case for binocularity in war reporting' at Linköping University in Sweden and received the honorary award 'Excellence in Teaching' from the Yale University Interdisciplinary Center for Bioethics, where she's been teaching 'Bias in Bioethics' and 'Environmental Justice'.

Jordan Parsons, University of Bristol Medical School

"From proband to provider: is there an obligation to inform genetic relatives of actionable risks discovered through direct-to- consumer genetic testing?"

ABSTRACT: Direct-to-consumer genetic testing is a growing phenomenon, fuelled by the notion that knowledge equals control. One ethical question that arises concerns the proband's duty to share information indicating genetic risks in their relatives. However, such duties are unenforceable and may result in the realisation of anticipated harm to relatives. We argue for a shift in responsibility from proband to provider, placing a duty on test providers in the event of identified actionable risks to relatives. Starting from Parker and Lucassen's (2004) 'joint account model', we adapt Kilbride's (2018) application of the rule of rescue and balance it against the relative's right not to know, placing responsibility on the providers of direct-to-consumer genetic testing. Where the risk of disease to a relative is actionable, we argue providers ought to share results even in the face of the proband's objections. Confidentiality issues are navigated by a pre-emptive consent model, whereby consumers agree to the sharing of certain information with their relatives ahead of testing and as a condition of testing. When a relative is informed, the proband's privacy is protected by maximal deidentification, and the rights of the relative are met by a stepwise approach to informing that allows them to decide how much information they receive.

JORDAN PARSONS is a Research Associate and PhD Candidate at the University of Bristol Medical School in the UK. His doctoral research is funded by the Wellcome Trust and explores "best interests" decision making in the context of kidney failure. Jordan's wider research interests include organ donation and transplantation law and policy, ethical issues in nephrology, access to sexual and reproductive health, and genetic privacy. He has also written on empirical bioethics methodology.

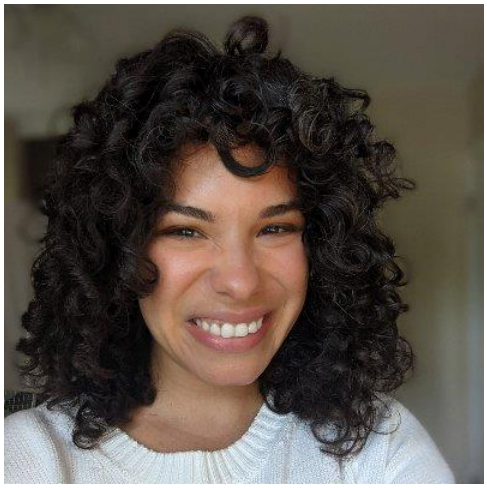


Luisa Maria Rivera, Emory University

"Exclusion criteria: intergenerational narratives resist biosocial paradigms of traumatic embodiment in postwar Guatemala"

ABSTRACT: In this paper, I analyze intergenerational trauma in the narratives of grandmothers who lived through the Guatemalan genocide and their adult daughters living in a community founded by repatatriated war refugees in in the borderlands of Guatemala and Chiapas. I explore how these narratives reveal limitations of epidemiologic paradigms examining the embodiment of intergenerational trauma and the mechanisms of its transmission. Psychiatric and epidemiological models of war trauma center on its impact on men and on the accumulation of discrete traumatic exposures as risk factors. By contrast, intergenerational transmission narratives emphasize the biological and behavioral primacy of mothers. I contrast three triads who 'transmitted' intergenerational trauma (through either traumatic re-exposure and high levels of depressive symptoms) and three who "resisted" transmission, revealing the limits of traumatic accumulation and psychological vulnerability as key drivers of intergenerational trajectories of intergenerational transmission. Rather, I argue for an intersectional view that takes up differing axes of historically and colonially produced structural vulnerability (indigeneity, gender, trans-nationality, land-tenure) to understand how trauma, resilience, and recovery are understood and negotiated across time, family, and the body incarnate.

LUISA MARIA RIVERA, MPH is a biocultural anthropologist studying biosocial mechanisms of intergenerational trauma transmission. She has co-authored 13 articles on the psychological and biological consequences of intergenerational and early life trauma, with a focus on the interplay between development, neuroendocrinology, and the immune system. Her dissertation research critically appraises the limitations of psychobiological paradigms for capturing the situated nature of traumatic embodiment in racialized communities in the U.S. and Latin America.

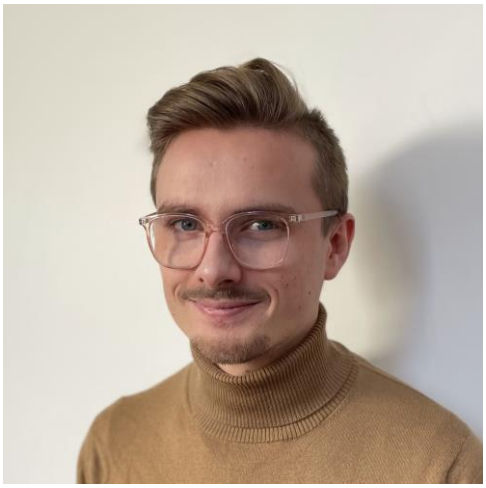


Asher Soryl, University of Otago

"The Ethics of Pest Control: Balancing Animal Welfare, Conservation, and Indigenous Values"

ABSTRACT: The presence of invasive species (pests) within ecosystems represents a serious threat to the continued existence of native populations and can cause significant environmental and economic damage if left unchecked. Within New Zealand, pest control operations are considered to be a necessary step for the complete eradication of invasive species, but evidence suggests that current methods (e.g., baiting, trapping) are insufficient to achieve this goal. Newer and more effective techniques for managing pest populations are being considered as a potential solution to this problem, including genetic technologies such as gene drives. However, the ethical implications of using these technologies has not yet been fully explored in a New Zealand context, taking into consideration the wide range of different values that are involved. This presentation explores ethical issues related to pest control, focussing on the welfare of animals who might be affected in addition to conservation objectives and the attitudes of indigenous populations. I argue that by working to achieve a more holistic balance of these values, future practices can be made more effective and ethically robust than current practices that take place.

ASHER SORYL is a PhD candidate from the University of Otago Bioethics Centre in New Zealand, currently visiting the Uehiro Centre for Practical Ethics at Oxford University as a recognised student. His doctoral research explores philosophical and practical issues concerning the welfare of wild animals, and his educational background is in analytic philosophy. Outside of this topic, Asher is very interested in applied ethics, the neuroscience of perception, personal identity, and consciousness research. He has previously studied at the University of Amsterdam, the University of British Columbia, and the University of Canterbury, and has been actively involved in Effective Altruism for the past several years.



Discussions

Facilitators: Dr Angeline Ferdinand and Dr Evie Kendal
"Objectives of the symposium"

MONDAY 23 MAY 0930-1030

Facilitator: Professor Bettina Borisch
"Regulation and legislation of genetic technologies"

MONDAY 23 MAY 1630-1730

Facilitator: Associate Professor Martha Kenney
"Justice in genomics"

TUESDAY 24 MAY 1630-1730

Special Issue details

Advances in genetic and epigenetic testing carry with them a plethora of ethical and legal challenges. One of the major clinical applications for this field is in the area of personalised or precision medicine, including targeted cancer treatments. However, both testing and the translation of results into meaningful therapeutic options are currently unequally distributed, with marginalised communities disproportionately experiencing harm from genetic studies, while also experiencing fewer benefits from research due to barriers in accessing personalised medicine and lack of representation in reference databases. There are also broader resource allocation concerns when comparing outcomes for citizens in countries with privately or publicly funded high technology care, versus low resource settings where even basic health needs remain unmet. Where emerging genetic and epigenetic technologies should fit within this paradigm remains an open question.

The COVID-19 crisis has highlighted many disparities in healthcare resourcing across the globe and ongoing justice concerns regarding access to vaccines and treatments. However, it has also demonstrated the need to continue genetics research, despite the high costs involved. This symposium considers fundamental issues of health justice as they pertain to genetic and epigenetic research, testing and treatment, with a particular focus on pursuing equitable distribution of the burdens and benefits of this research across diverse populations.

This call for papers is for a topical collection in International Journal for Equity in Health, edited by Angeline Ferdinand (University of Melbourne) and Evie Kendal (Swinburne University of Technology). Full paper submissions are due **21st October, 2022** and authors are encouraged to contact the editors with proposals in advance of this date at a.ferdinand@unimelb.edu.au and ekendal@swin.edu.au.

Submissions are invited for both short comment pieces and longer research papers. Topics of interest include, but are not limited to:

- Issues in informed consent, data privacy and clinical research ethics for emerging genetic and epigenetic technologies
- Reproductive bioethics and the ethics of emerging genetic technologies
- The impact of technology on community and belonging
- Biobanking, repatriation of biospecimens, cryopolitics and data ownership
- Cultural awareness in epigenetics research, clinical genetics and policy, especially on marginalised communities
- Public engagement and education on epigenetics and direct-to-consumer genetic testing

Submissions should be made in .DOC, .DOCX or RTF format, double-spaced and styled according to IJEqH's guidelines, available here: https://equityhealthj.biomedcentral.com/submission-guidelines/preparing-your-manuscript