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Ethics and Epidemiology Workshop Report: Towards Ethics-Informed Epidemiology and Epidemiology-Informed Ethics

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ETHICS AND EPIDEMIOLOGY WORKSHOP REPORT

Towards ethics-informed
epidemiology and epidemiology-
informed ethics



MEETING OVERVIEW

Two key groups of researchers have worked in parallel to advance health equity—one on the descriptive component (those in public health sciences, e.g., epidemiologists) and one on the normative component (those in the humanities and social sciences, e.g., philosophers and ethicists). Yet a significant gulf exists between their respective research. Consequently, advances in thinking regarding the philosophical underpinnings and normative requirements of health equity have been largely divorced from the design of public health interventions that seek to reduce health inequities. As a consequence, public health interventions aiming to advance health equity may fail to target the most appropriate populations or the most ethically important health disparities and therefore likely fail to achieve the most ‘equitable’ health outcomes. At the same time, without empirically testing different philosophical criteria of health equity, philosophers will end up producing guidance for the design and implementation of public health interventions that may ultimately have undesirable (or less desirable) outcomes in practice.

To discuss the contours of this challenge and possible avenues to address it, a meeting was held on December 5, 2022 at the University Club of Toronto with support from the Canadian Institutes of Health Research (CIHR), Public Health Ontario, Western University, and the University of Toronto. In this meeting report, we summarize the workshop proceedings, report key findings based on the expert contributions of meeting participants, and identify next steps.

Meeting Objectives

The central objective of this meeting was to support a first-of-its-kind, international, transdisciplinary meeting to examine the ways in which advances in philosophical scholarship in the areas of health equity and social justice can be meaningfully incorporated into epidemiology and quantitative population health intervention research. Moreover, the meeting aimed to catalyze a programme of research that will seek to empirically model different philosophical conceptions of health equity to explore their respective impacts on population health outcomes. Learnings from this meeting are intended to guide the development of future grant applications.

Format and Methods

Following initial ‘igniter’ talks that provided a starting point for discussions, a ‘fishbowl’ methodology for facilitating structured discussions occurred, where each participant was given equal opportunity to contribute and listen to ideas, perspectives, and discussion. The fishbowl methodology asks participants who share a particular perspective or role in relation to the topic (e.g., philosophers studying health equity) to form an “inner group” and discuss their perspectives. Other participants comprising an “outer group” are asked only to listen and reflect on the perspectives raised by the members of the “inner group” before interacting with the inner group. Follow-up discussions where all participants can contribute were then conducted to facilitate the cross-pollination of ideas and ultimately lead to the establishment of a research agenda that is responsive to a multitude of interests, values, needs, and perspectives.

This meeting report was prepared with special thanks to Zoe Ritchie, with input from Brendan Smith and Maxwell Smith. Funding support was provided by a CIHR planning grant. For more information please contact Dr. Maxwell Smith at maxwell.smith@uwo.ca or Dr. Brendan Smith at brendan.smith@oahpp.ca.

Participants

The workshop was attended by 12 participants representing philosophers, epidemiologists, data scientists, legal scholars, ethicists, and population health specialists, among others. We extend our gratitude for their contributions, insights, and ongoing enthusiasm for fostering a community of practice at the intersections of ethics and epidemiology.

Adrian Viens (Director and Associate Professor of Global Health Policy, York University)

Anthony Skelton (Associate Professor of Philosophy, Western University) (regrets)

Arjumand Siddiqi (Professor of Epidemiology and Public Health, University of Toronto)

Brendan Smith (Scientist (Epidemiologist), Public Health Ontario; Assistant Professor, Dalla Lana School of Public Health, University of Toronto)

Ceinwen Pope (Resident (Public Health and Preventive Medicine), University of Toronto)

Christine Warren (Epidemiologist, Public Health Ontario)

Douglas MacKay (Associate Professor of Public Policy, University of North Carolina at Chapel Hill)

Julian Gitelman (Resident (Public Health and Preventive Medicine), University of Toronto)

Katherine Saylor (Fellow in Ethical, Legal, and Social Implications of Genetics and Genomics, University of Pennsylvania)

Laura Rosella (Associate Professor, Dalla Lana School of Public Health, University of Toronto)

Maxwell Smith (Assistant Professor, School of Health Studies, Western University)

Nicholas King (Associate Professor, Biomedical Ethics Unit, McGill University) (regrets)

Sam Harper (Associate Professor, Department of Epidemiology, Biostatistics and Occupational Health, McGill University)

Yukiko Asada (Faculty Member and Investigator, Department of Bioethics, National Institutes of Health)

Zoe Ritchie (PhD Candidate, Health and Rehabilitation Sciences, Western University)



WORKSHOP PROCEEDINGS



Igniter Talks

Igniter Talk #1: “Philosophical Debates Regarding Health Equity” **Douglas MacKay**

Douglas MacKay is an Associate Professor of Public Policy at the University of North Carolina at Chapel Hill whose research and teaching interests concern questions at the intersection of justice and public policy. In the workshop’s first morning talk, Professor MacKay discussed current philosophical debates on how health equity is defined and operationalized. For example, Professor MacKay discussed the differences between Free-Standing (Direct) and Derivative (Indirect) approaches to health equity. Recognizing the philosophical differences between the motivations and outcomes of health policy, Professor MacKay differentiated between theories of health equity. Those discussed included equity as priority to the worse off, equity as equality of health outcomes, equity as relational equality, equity as sufficiency, and equity as social justice. Following this introduction into theories central to current discussions on health equity, Professor MacKay concluded his talk with pertinent questions for the intersection of ethics and public health, including: have philosophers been too quick to dismiss Whitehead’s (1992) definition of health inequities? Is health consequentialism a worry? Is it a mistake to think of health as a currency of justice? May we dispense with some philosophical debates when doing policy-relevant work?

Igniter Talk #2: “How Numbers and Ethics Meet in Addressing Health Inequity”

Yukiko Asada

Yukiko Asada is a faculty member and investigator in the Department of Bioethics at the National Institutes of Health. Dr. Asada’s talk invited participants to consider the opportunities and challenges inherent in operationalizing equity considerations in research with quantitative data and information. Reflecting on her work in public health research, Dr. Asada highlighted two ways to operationalize equity considerations in quantitative information: (1) providing equity-relevant information (what information to offer); and (2) making explicit ethical assumptions underlying methods used to obtain equity-relevant information (how the information is shared). To demonstrate, Dr. Asada considered how one might measure health inequity (equal opportunity for health and policy amenability) using the analytical steps and categories of legitimate vs. illegitimate factors proposed by Fleurbaey and Schokkaert (2009).

The talk concluded with Dr. Asada’s reflections that undergoing the process of making implicit ethical assumptions which underlie methodological choices explicit can reveal overlooked ethical questions in individual projects and in the wider domain of public health research. Dr. Asada also reiterated this work requires interdisciplinary integration between philosophers, ethicists, and epidemiologists who might otherwise find themselves easily “siloeed” in their respective fields.

Igniter Talk #3: “Fairness-Informed Cost Utility Analysis”

Katherine Saylor

Katherine Saylor is a postdoctoral fellow in ethical, legal, and social implications of genetics and genomics at the University of Pennsylvania. Dr. Saylor’s talk invited attendees to consider how the adoption of theories of allocation (even if done implicitly) might influence methodological considerations when applied to cost-utility analysis (CUA) measurements. Dr. Saylor furthered this line of thinking with an application to a case study of genetic screening for hereditary breast and ovarian cancer. Dr. Saylor concluded the talk with three considerations: (1) CUA has the potential to inform distributional considerations; (2) identifying specific equity questions/goals is essential to choosing the right approach to answering them; and (3) even relatively simple CUA modeling approaches (like distributive CUA) can answer questions about efficiency, equality, and equity.

Igniter Talk #4: “Modelling Ethical Standards of Health Equity: An Application to Diabetes Prevention”

Brendan Smith

Brendan Smith is a Scientist (Epidemiology) at Public Health Ontario. Dr. Smith’s talk, explored through a case study, described the extent to which adopting distinct ethical standards of health equity differentially impacts population-level diabetes outcomes. He described the study's aims, including operationalizing ethical standards in population health data, examining intervention benefit and scope, and estimating the impact of social inequities in diabetes. *(Continued)*

Dr. Smith then examined four counterfactual scenarios, including health sufficiency, health equality, social sufficiency, and social equality. Dr. Smith found the choice of ethical criteria of health equity was demonstrated to have a significant impact on the target population, intervention benefit and scope, and remaining differences (inequalities) in diabetes across education groups. Dr. Smith also found sufficiency scenarios were estimated to be less effective in preventing diabetes, but required less intervention resources, and that educational inequities in diabetes were reduced to a greater extent in the social status scenarios. He concluded the presentation with probing questions on what accounts of justice can offer us for considering the motivations of public health research, including: which populations should we target to reduce health inequities? Which differences in health should we prioritize? How should we address health inequities in an ethical manner? How should we define the standards of evaluation for population health interventions?

CROSS CUTTING THEMES

01

Philosophical Dimensions/Debates Concerning Health Equity

Diverging definitions of health equity and its associated aims and outcomes emerged early in our discussion as a barrier to the application of applied philosophical thinking in epidemiology. Which philosophical dimensions/debates concerning health equity should be further explored? (e.g., differences in currencies of justice, free-standing vs. derivative approaches, inequalities vs. inequities, equal opportunity, personal responsibility and luck, among others).

02

Meaningful Philosophical Distinctions on Population Health Outcomes

Numerous presenters and participants highlighted the complexity of understanding the relevance of philosophical debates in health equity to the conduct of research and practice in epidemiology. Which philosophical dimensions/debates reflect potentially meaningful philosophical distinctions but do not have much, if any, bearing on population health outcomes in reality? Do some philosophical dimensions/debates relevant to health equity belong exclusively in a philosophical realm? Our group also discussed whether philosophers/ethicists should attune their scholarly agenda pragmatically to dimensions/debates that have a bearing on population health outcomes in practice.

03

Considering Resource Allocation Ethics in Public Health Philosophy

Resource constraints inherent in public health might challenge the utility of certain empirical activities that explore philosophical conceptions/dimensions of health equity. In empirically exploring how different philosophical conceptions/dimensions of health equity 'cash out' in reality, to what extent should we incorporate the resource constraints faced by public health authorities? How should we incorporate such resource constraints? We identified these as critical questions to consider if we intend for collaboration between epidemiologists/quantitative population health researchers and philosophers/ethicists to influence public health policies.

04

Collaboration between Quantitative Population Health Researchers and Ethicists/Philosophers

The potential, and inherent challenges in, collaborations between quantitative population health researchers and ethicists/philosophers was a recurring theme throughout the majority of our conversations. What key bits of knowledge/information/methods do quantitative population health researchers need to be aware of/want to be more informed about that ethicists/philosophers possess, and vice versa? What common language do we need to productively speak to one another? We discerned both disciplines lack an awareness of how the other discipline reasons through and completes their work (e.g., what questions are important to them, what questions challenge them, what shifts in their disciplines are changing the way they work?).

05

Public Health Ethics Consultation

Numerous presenters and participants highlighted that, unlike some fields such as medicine where clinical ethics consults are commonplace, an ethics consult in public health is a relatively new idea. Is there a role for 'ethics consultation' for quantitative population health researchers/policymakers to help navigate the philosophical/ethical contours/dimensions of health equity? What would a digestible product or tool be that would help epidemiologists better understand/incorporate the ethical standards into their work? The idea of a digestible product or tool was viewed as potentially useful for our epidemiologists/quantitative population health researcher participants.

06

Incorporating Intersectionality

If we explicitly affirm that we have a responsibility to operationalize principles of health equity in public health practice and research, a challenge our group discussed was whether we have the data and indicators available to measure the ethical standards of health equity we are aiming to change. We also discussed the relationship between measurement and accountability. What dimensions of health equity should be measured? Race may be relatively straightforward to measure; however, the impact of systemic racism is harder. Does measuring owe a duty to act if a serious inequity is found? Other challenges we discussed included how to account for intersectionality and how to account for personal responsibility in conceptualizing and modelling health equity.