

Race in Biomedicine

22 September 13.15-16.00

Organised by Remeso and Centre for Medical Humanities and Bioethics

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Community Engagement in Biomedical Research: Trust, Equity, and Time

Janet K. Shim, PhD, MPP, is Professor of Sociology in the Department of Social and Behavioral Sciences at the University of California, San Francisco.

In response to concerted attention to the problem of racial and ethnic under-representation in biomedical research in the U.S., a series of efforts and initiatives now seek to include greater proportions of historically marginalized populations in biomedical research. This is the backdrop against which our study is investigating how this call for more inclusion and diversity has been embraced by funders as well as investigators that are working in this space. We are following precision medicine research (PMR) studies, from how they responded to the language and priorities around inclusion and diversity, to how they conceptualized and designed their studies, through the selection and recruitment of populations, through data collection and measurement, and efforts to engage diverse participants and communities. Thinking about communities and engagement has become part of the fabric of doing PMR because of questions that have been raised about the conventional relationships that research, researchers, and participants have with one another. In this talk, I will focus on our emerging findings about community engagement: First, who is thought to represent and stand in for the community? Second, the what and how of engagement, that is, the ways in which researchers define it, and how they go about actualizing it as a set of practices and activities. And third, the why of community engagement — what is engagement for and what is it intended to produce? I will explore the tensions between values of diversity, inclusion, and community engagement, yet persistent encounters with insufficient resources, time, and personnel to meaningfully fulfill these goals, and the conflicting understandings of time, trust, science, and equity that underlie these tensions.

Failures of Biomedical Preparedness amid Enduring Anti-Black Racism, 2001-2020

Anne Pollock is a professor of Global Health and Social Medicine at King's College London.

This talk brings together two themes that have been commonly recognised during the COVID-19 pandemic, but too rarely analyzed together: (1) poor preparedness for health emergencies and (2) racial health disparities. First, it has become clear that despite the past two decades' emphasis on "preparedness" in national and global public health policy many of our social and health care infrastructures have been woefully unprepared for the COVID crisis. Second, in many national contexts, including the U.S. and U.K., the excess morbidity and mortality in this crisis has disproportionately impacted racialized populations. How might these two aspects be generatively analyzed together? In this talk, I draw on my new book *Sickening: Anti-Black Racism and Health Disparities in the United States*, and pay attention to 'paths not taken' since September 11, 2001. I focus especially on one case concerned with the deaths of Black postal workers in the 2001 anthrax attacks, to argue that authentic biomedical preparedness can only be achieved with an anti-racist agenda.