

Spring Quarter 2013 Colloquium Series

What Counts as Consent?

Monday, April 29, 12:00 - 1:30 pm

Simpson Center for the Humanities, Communications 202

Lunch will be provided; please RSVP to suzelong@uw.edu by **Thursday, April 25** to be sure you get the sandwich of your choice!

Informed consent is well established as a precondition for medical research and for most research involving human subjects. But what does consent mean when, for example, it is a community rather than an individual whose consent is sought? And what does it require in practice when risks and harms are uncertain, possibly long-term and diffuse, or when research agendas are in formation and it isn't clear what, exactly, consent authorizes? Join our panelists for discussion of these issues as they arise in the context of managing tissue banks, in engineering and energy extraction, and in personalized medicine.



Malia Fullerton (Department of Bioethics and Humanities, UW School of Medicine) *will discuss issues raised by informed consent in the context of tissue donation.*

There is much disagreement about the nature of informed consent required when a scientific investigator asks a study participant to donate a tissue sample for health-related research. Should an investigator make clear which questions will be investigated, how the sample will be stored or destroyed after use, or whether the sample, or data derived from it, will be shared with other scientists? Or is informed consent impossible if the intent is to bank the sample for indefinite future research use? The need for creative approaches to engaging respectfully with research participants will be discussed.



Gwen Ottinger (Interdisciplinary Arts and Sciences, UW Bothell) *will consider standards of informed consent, focusing on environmental hazards, when our knowledge of risks and benefits is uncertain.*

Energy facilities—oil refineries, shale gas extraction, even wind farms—all expose nearby populations to environmental hazards that will persist over decades, a period over which scientific understandings of those hazards are likely to change dramatically. What, then, should be the standards for informed consent when the information on which to base consent is in flux? After detailing the challenges that understanding scientific knowledge as situated and evolving present for the notion of informed consent, I suggest the need for proactive knowledge production and on-going opportunities for consent as aspects of an ethical approach to decisions with long-term consequences.



Chris Wade (Nursing & Health Studies, UW Bothell) *will draw on his experience with the Multiplex Initiative at the NIH to discuss resources that can facilitate consent processes.*

While informed consent is often a key element in the ethical conduct of research, it is unclear what actions on the part of a researcher can best support this requirement. There is a need to explore improved consent procedures since evidence suggests that informed consent documents alone often fail to provide participants with adequate information to support decision-making. Some alternative approaches for communicating key information will be examined for the Multiplex Initiative, a study where participants were offered genetic susceptibility testing for common health conditions. The logic used to design these approaches, as well as some data exploring their success, will be discussed.

Please see following page for panelists' bios and recommended readings.

BFGW Consent Colloquium: About the panelists

Malia Fullerton is Associate Professor of Bioethics and Humanities at the University of Washington in Seattle. She received a D.Phil. in Human Population Genetics from the University of Oxford and later re-trained in Ethical, Legal, and Social Implications of genetic research with a fellowship from the NIH National Human Genome Research Institute. Her work explores researcher and participant perspectives on data-sharing, secondary use, and result return in the context of contemporary genomic research. She holds adjunct positions in the UW Departments of Genome Sciences and Epidemiology, and is a core faculty member with the UW Institute of Public Health Genetics as well as an affiliate investigator with the Public Health Sciences division of the Fred Hutchinson Cancer Research Center.

Gwen Ottinger is Assistant Professor in Interdisciplinary Arts and Sciences and coordinator of the undergraduate major in Science, Technology, and Society at the University of Washington-Bothell. Ottinger's research examines the micro-politics of science in environmental justice controversies, especially how scientific studies produced by ordinary citizens can unsettle—or not—credentialed scientists' claims to technical authority. She is co-editor of *Technoscience and Environmental Justice: Expert Cultures in a Grassroots Movement* (MIT Press 2011) and author of *Refining Expertise: How Responsible Engineers Subvert Environmental Justice Challenges* (NYU Press 2013). She holds a Ph.D. from the University of California, Berkeley and bachelor's degrees in Science, Technology, & Culture and Aerospace Engineering from Georgia Tech.

Christopher Wade is an Assistant Professor at the University of Washington Bothell in the Nursing and Health Studies Program. He received his B.A. and Ph.D. from Wesleyan University, and later a MPH from Johns Hopkins University. Dr. Wade's research has applied strategies to create interdisciplinary teams that address issues related to public health genomics. Using his knowledge of genomics, health behavior, and social science research methods, his work explores the social and ethical implications of applied genomic technologies. In particular, he seeks to identify approaches for providing people with personal genomic information that maximize social and health benefits.

Background readings: available online at <https://catalyst.uw.edu/gopost/board/aw26/32579/>

- S. B. Trinidad, S. M. Fullerton, E. J. Ludman, G. P. Jarvik, E. B. Larson, W. Burke. "Research Practice and Participant Preferences: The Growing Gulf." *Science* 331 (2011: 287-288).
- G. Ottinger. "Changing Knowledge, Local Knowledge, and Knowledge Gaps: STS Insights into Procedural Justice." *Science, Technology and Human Values* 38.2 (2013: 250-270).
- K.A. Kaphingst, C.M. McBride, C.H. Wade, S.H. Alford, L.C. Brody, A.D. Baxevanis. "Consumers' Use of Web-Based Information and Their Decisions About Multiplex Genetic Susceptibility Testing." *JMIR* 12:31 (2010: e1-10).