

## Stephanie Malia Fullerton, DPhil

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### *Offering Aggregate and Individual Research Results to Study Participants: Ethical Considerations*

Tuesday, April 12, Noon – 1pm

PATH, Seattle, Room 226



Participants donate their time, personal health information, and biological specimens for diverse forms of research, generally with no expectation of personal benefit. Nevertheless, studies suggest that many participants value periodic updates of study progress and assume that if the research team identifies information of immediate health relevance that such findings will be offered for return. In the genetics community, consensus recommendations suggest that investigators should offer individual research results that are valid, medically important, and actionable, as a matter of beneficence. Ethical arguments in favor of routine aggregate result return have also been advanced, both to affirm the value of research participation and to build trust in the research enterprise. Dr. Fullerton will draw on her experience with several large research consortia to discuss these evolving norms and their relevance for PATH research.

#### BACKGROUND ON PROFESSOR FULLERTON

Malia Fullerton is Associate Professor of Bioethics and Humanities at the University of Washington School of Medicine and Adjunct Associate Professor in the UW Departments of Epidemiology and Genome Sciences, as well as an affiliate investigator with the Public Health Sciences division of the Fred Hutchinson Cancer Research Center (FHCRC). She is also past Chair of the Social Issues Committee of the American Society of Human Genetics.

Dr. Fullerton's research focuses on the ethical and social implications of genetic and genomic research, biobanking, and clinical genetic testing, including researcher and participant perspectives on data-sharing, secondary use, result return, and clinical implementation. She is affiliated with the UW Center for Genomics and Healthcare Equality (Burke, PI), co-directs the Ethical and Psychosocial Implications Research component of the NEXT Medicine Clinical Sequencing Exploratory Research (CSER) project (Jarvik, PI), and serves as a co-Investigator with the Electronic Medical Records and Genomics (eMERGE) Network project at Group Health Cooperative (Jarvik/Larson, PIs). Dr. Fullerton received a PhD in Human Population Genetics from the University of Oxford in the United Kingdom, and later re-trained in Ethical, Legal, and Social Implications (ELSI) research with a fellowship from the NIH National Human Genome Research Institute.

**PATH is delighted to open our new Research Ethics Lecture Series to the public. Your RSVP is kindly requested. If you will attend, RSVP to Jessica Lee at [REC@path.org](mailto:REC@path.org) by April 11, 2016.**