



## “Let’s Pull These Technologies Out of the Ivory Tower’: The Ethics, Values, and Politics of Participant-Driven Genomic Research.”



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**Lunch/Workshop, January 21, 2016 from 12:30 - 2pm, Cone Center 210**

**\*\*\*Due to limited seating, please RSVP at the Center’s Website at (<http://ethics.uncc.edu/>) by January 15, 2016. Reservations will be accepted on a first-come, first served basis.\*\*\***

**Abstract:** In the last few years, the landscape of translational genomic research has been changing and is no longer confined to strictly academic research or institutionalized health care. New voices from advocacy organizations, direct-to-consumer companies, hybrid forms of university/advocacy/corporate research groups, and most recently ‘citizen scientists’ are shaping significant outgrowths in both research and transmission of biomedical knowledge. Drawing on data from interviews with leading figures in participant-driven genomic research (PDGR), this presentation will explore how these groups challenge and complicate traditional approaches to and the ethics of genomic research as the boundaries are challenged between experts and amateurs, funders and researchers, institutions and scientists. Results reveal that these groups, despite their diversity, share commitments to promoting alternative modes of housing, conducting, and funding genomic research, and, ultimately, sharing knowledge. The practices of PDGR therefore challenge existing approaches to research ethics as well, especially the regulation and oversight of human genetic information. As traditional genomic research evolves to embrace the ethos espoused by PDGR, these once anti-establishment sentiments are now poised to become compatible with the larger goals of the conventional genomic science community.

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