



The Center on American Indian and Alaska Native Genomic Research

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What Am I Doing Here?

- I am a cultural anthropologist by training, spent 13 years in Psychiatry at the University of Colorado
- My doctoral research was on alcoholism in an urban American Indian community, while at CU I developed two parallel lines of research in genetics and child development
- I have been at OU since 2008, recruited there because of my work on the Ethical, Legal, and Social Implications of genomics (ELSI)
- I met Lori (and Klaas) when we collaborated on a proposal to bring clinical sequencing to two tribal health systems in OK

Background on Genomics in Indian Country

- Processes by which genomic knowledge has been generated have been controversial
- Most significantly with the Human Genome Diversity Project
- But recent events have also contributed, e.g., the Havasupai case
- At the same time, there is awareness that genomics might matter to native people, e.g., PMI, the Cancer Moonshot
- interest in finding ways to generate that knowledge
- and models of success. As our colleague, Brian Kemp, has noted, only the failures get media attention.



The Goals of Our Center

- In research,
 - to articulate protocols for genomic research,
 - to investigate the dynamics of translation
- In education and training, to prepare investigators for this work
 - both technically, through separate mechanisms
 - and through the CEER and associated funding for future clinicians and ELSI researchers
- In service,
 - to provide tribes with tools to engage in this work,
 - to support them in making use of genomic knowledge



Science and Its Publics

- Engagement is fundamental to our work
- The importance of engagement is seldom questioned now
- But the processes of engagement require on-going attention
- Our work is premised on the idea that science must respond not just to its payers, but also to its participants
- And that includes an honest appraisal of its value



Genomics and Public Health

- One concern about our proposal was that we planned to begin with health disparities rather than genetics
- Reflecting, I think, one of my core concerns: is genomics really that relevant to health disparities?
- To paraphrase Gloria Steinem: Do native people need genomics like a fish needs a bicycle?
- The effort to identify meaningful connections to public health is key to our work



Our Work on the Human Microbiome Project

- Based on a collaboration between OU/OMRF and the Cheyenne and Arapaho Tribe in OK (about an hour away from us).
- Initial conversations focused our attention on dietary change and disease
- which we were able to explore through a microbiome protocol
- Working with the tribe and participants as new questions emerged
- We continue to work with the tribe,
 - both on pending microbiome research to better understand disease associations
 - and emerging research on food to better understand opportunities for intervention



Our Research Priorities

- Our experience with C&A gave us hope for wider discussions
- on tougher questions
- Throughout, we remain committed to beginning with the health concerns of communities
- and then identifying connections for genomic research
- The PMI and Cancer Moonshot have catalyzed much discussion in Indian country, which we plan to build on



Our Research Consortium

- Our work will occur in parallel in three different sites: The Chickasaw Nation in Oklahoma; Missouri Breaks Industries Research, Inc, in SD; and Southcentral Foundation in AK
 - Chickasaw Nation runs its own health care system and its research review; Southcentral runs its own health care and uses an IHS IRB; Missouri Breaks is a non-tribal entity that serves mostly direct service (IHS) tribes and uses an IHS IRB.
 - All have experience in biomedical research, Southcentral intensively in a previous center at UW, the Center for Genomics and Health Care Equality
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Our Research

- We seek to advance the science of community engagement
- This work is required now in multiple settings, but could benefit from additional systematic attention
- especially in comparative cross-cultural work
- We begin with a commitment to deliberative democracy
- But also with an awareness of what its limits might be
- In subsequent phases of the research, sites will explore more locally meaningful fora (or is that forums)



Our Center Faculty

- On the Norman Campus, a partnership between biological and cultural anthropology (Cecil Lewis and myself) and Native American Studies (Amanda Cobb-Greetham)
 - Linkages to other social and biological scientists (Justin Reedy in Communication; Pat Gaffney and Dave Jones at OMRF), also to law (Taiawagi Helton)
 - The center seeks to cultivate a dialogue between the humanities and the social and biological sciences
 - Already we have also interested History of Science and Philosophy
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Our Education and Training

- The University of Oklahoma has more AI/AN students than any other Carnegie One in the country
 - But few of these students are engaged in STEM, even fewer in ELSI
 - Our connections to NAS are intended to grow this community
 - At both the undergraduate and graduate levels
 - Supported by a postdoctoral program
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An Eye Toward Sustainability

- We are already mindful of the end of our funding
- The Center links three independent research/service units on our campus:
 - The Center for Applied Social Research (which I co-direct);
 - The Native Nations Center (which Amanda directs); and
 - The Laboratories of Molecular Anthropology and Microbiome Research (which Cecil co-directs).
- We begin in the context of
 - A significant hiring initiative in the life sciences, with a focus on the connections between humans and microbes
 - And strategic planning in Anthropology with regard to an emphasis on ecology and health
- A major goal of the center is the identification of projects that can be funded separately, i.e., that involve biological samples



Possible Connection to Your Work

- Within your region, we are already working in the Dakotas and Oklahoma
 - A major focus of our work is on identifying clinical utility and the dynamics of translation
 - We have funds for pilot research that engages tribal communities on these questions
 - And we would love to foster work in maternal and child health
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