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 ongoing 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
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
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
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