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# Unexpected lessons from anthropological fieldwork on "Personalized Genomics"

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**Abstract** As California companies like Navigenics and 23&Me were launching their "personal genomics" products in 2007-2008, I was thrust into a new arena of anthropological fieldwork. In my bioethics position at an academic medical centre, I was asked to review a draft of a proposal requesting that the clinic "test" one of the new products with its population of Executive Health patients. My reflections will explain two parts of the story that ensued.

First, I will explore the dynamics of studying new genomic technologies at what I will call "Prairie Clinic." I will demonstrate how typical approaches to evaluating risk and benefit are inadequate to providing oversight of novel personalized genomics products. In attempting to create a more robust alternative, I spearheaded a clinical trial of one direct-to-consumer product. I acted on the assumption that revealing patients' motivations and care providers' concerns would provide a means of resisting premature adoption of an overly-hyped product while at the same time gathering critical data to guide the design of clinical practice should evidence of efficacy of genomic testing emerge. In true "participant observer" style, I became caught up in a moral dilemma: patients entered the study based on their trust of the Prairie Clinic and its reputation for clinical integrity, they expressed confusion that an unproven product would be offered. By aiding the entrée of personalized genomics into the clinic in order to study it, had I created the very situation I was trying to forestall? As it turned out, patients—although intrigued by the personal genomics discourse—shrugged off the results when they were revealed. In a paradoxical twist, our major publication will be used as evidence that direct-to-consumer tests do not cause harm, and hence should be unregulated.

Second, I will briefly take up a more personal story. While serving as a "beta tester" for one of the personal genomics products, I got the unexpected and surprising news that I carry the gene for sickle cell disease. I have the trait, not the disease itself, but the news nonetheless carries consequences. Of all the "racialized" diseases, sickle cell is most closely linked to African ancestry: it is *the* Black disease. And race remains *the* American dilemma. I am a classic "white" American Midwesterner; all four of my grandparents were born within 100 miles of the Mississippi River. They hail from Norway, Ireland, and Luxembourg, a common mix. I will use the experience to reflect on broader questions of race, genetics and personal identity, revealing the unanticipated consequences of "participant observation" in a genomic age.

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