

Medical Anthropology Quarterly

International Journal for the Analysis of Health | Society for Medical Anthropology

Title: Commentary: Thinking through Public Health Genomics

Author: Rayna Rapp

Medical Anthropology Quarterly 27(4): 573–576; 2013.

This is the author's post-print. Please cite the final version of the article, available at
<http://dx.doi.org/10.1111/maq.12062>.

Medical Anthropology Quarterly is collaborating with the University of Florida Libraries to digitize, preserve, and extend access to the journal's content. The Digital Library Center (DLC) at the University of Florida is a nonprofit center responsible for the collection and preservation of digital resources for education. For more information about DLC, please contact DLC@uflib.ufl.edu.



Rayna Rapp
Department of Anthropology
New York University

Commentary: Thinking through Public Health Genomics

As these diverse essays on public health genomics point out, scientific knowledge always emerges from the social contexts of its production. This larger sociological truth is deeply historical, despite powerful claims that scientific truths are universal precisely because they have escaped their conditions of creation. In this special issue of MAQ, perspectives moored in medical anthropology and science studies continually highlight the work that such universalism does, and what it muffles, as well. As editors Sahra Gibbon and Karen Sue Taussig assert in their introduction: “The social is never after the fact of technological innovation.” This claim is substantiated by these MAQ authors in at least three registers.

First, national context counts mightily in fashioning scientific data, public health goals, and the resources on which both old and new strategies of intervention into the health of a given population are designed. Sandra Lee shows this truth in the market-driven work of U.S. “recreational” genetics companies. These for-profit innovations systematically muddy the popular and compelling search for ancestry, now in a genomic register, with a re-created personal risk profile for diseases, disorders, and drug metabolism based on assumed racial/ethnic background.

As any bioinformatics savvy researcher will quickly point out, such genomic test kits are only as good as their database to which individual samples are compared: If the database is overrepresentative of one or more groups, and underrepresented for others, it will surely reproduce existing truths of the categories in which it is collected. Yet both commercial and most academic research databases are premised on highly biased and skewed samples, heavily dependent on “white” American DNA specimens that assimilate the diversity of much of the world’s populations into meager samples from Africa or Asia despite the African-derived origins of all other continent-of-origin populations.

Lee interviewed 50 consumers of 23&Me testing services, illustrating how this skew was nontrivial in the disease profiles of people whose genome markers for disease risk were underrepresented in their commercial database. The corporation is responding to their scientifically disproportionate Euro-American-derived database by conducting a public-private effort entitled “roots for the future” to recruit a more diverse ancestry sample that focuses on African Americans. In the process, the company is reinstating older notions of “race” in their efforts to construct a product that will appeal to a wider, more diverse consumer market whose profits they have barely begun to tap.

23&Me.com is as American-as-apple-pie in the assumptions behind the admixture technologies they use to probe DNA samples for “continent of origin”; the lopsided samples that currently make up their database and that they are attempting to expand and realign for more successful market share; and the unreflexive categories of race that undergird the collection of data that is belied by a very ethnic-sensitive explication of “choice” in self-labeling explained on their website. In other words, the very scientific problem, its potential solution, and its larger goals are all market based, reinforcing categories and strategies of what a “public-health” genomics might look like for many Americans.

It is easy to contrast this commercialized project with the efforts described by Sahra Gibbon. Her fieldwork followed Cuban health care workers in their efforts to make genetic knowledge valuable to families and communities, not necessarily to individuals. Cuba is far from the promissory ideology, prevalent in many Western countries, of “personalized medicine.” Cuban commitment to “community genetics” is rooted in its longstanding and highly successful programs of maternal/child health; there is neither an ideological valorization of nor a technological drive to explore personal medicine using genomics as its portal.

In any case, the resources required to mount a genomic approach to individual testing and intervention are lacking in Cuba. Yet Cuban records focus attention on family pedigrees with dense cases of late-onset diseases like Alzheimers, heart disease, diabetes, and common cancers: Cuban health care workers learn about such tests, their genetic linkage, and their value as part of demystifying the widespread stigma of diseases that are understood to run in families. At present, such pedigrees are used to enhance community education but not to design personal genome-based interventions, for which there is no support. Health care workers in community genetics are overwhelmingly women; they link their own personal narratives, and those of the families they serve, to ongoing revolutionary commitments to “the peoples’ health,” as they understand it. Although this does not affect individual testing beyond prenatal and neonatal screening, it enables a social–biological imaginary to be linked to the future of new, potentially heroic state-based medicine. This is surely a project specific to Cuban history, aimed to build community loyalty and mobilization through state-provided health care, even when resources are scarce. Thus, national context shapes public health genomics.

Second, ethnographic and allied methods provide powerful keys to unlock the “black box” of scientific research, illuminating the complex assumptions, aspirations, and practices around which new knowledge is rigorously manufactured. This is surely the case in Susanne Bauer’s analysis of public health genomics, through what she describes “the epidemiological apparatus as a generative machine that is socially performative.” Contemporary genomic epidemiology is, in large measure, based on the limits of prior notions of genetics.

Initially, many epidemiologists hoped that complex diseases would be understood through new genomic technologies, yielding an interactive picture of multiple genes in consort with one another. However, the limits of such thinking were quickly and empirically reached over the last decade in international, collaborative research; contemporary epidemiological genomics is now based on epigenomic phenomena, exploring how cascades of interactive genomic stretches are activated or silenced by environmental triggers that have long-lasting effects. This is, of course, a much more complex model, one that proliferating databases and genomic tools enable many scientists to explore.

Susanne Bauer parses this process in its still-evolving methods. Interpreting emergent theories of environmental complexity as they are embedded in measurable genomic patterns and then sorted into risk categories, Bauer shows how the powerful statistical tools of epidemiology are built to travel across individual and population “exposures,” producing norms of health behavior. These change over our collective and abstracted life cycles. Indeed, in the new PH genomics, we have all become individual data points that move through shifting risk patterns as we age, are exposed, do or don’t have children, exercise, follow changing nutritional instructions, and so on. For such open-ended, associational, algorithmic patterns to become credible, their elegance is constructed in large measure through the exclusion of unknown, complex contingencies. Instead, Bauer describes and analyzes a “traveling apparatus” that can

produce health recommendations at the population level that individuals are then urged to adopt/adapt as new heuristics of health.

Epidemiological methods, expertise, and large-scale data are all recruited in the service of new descriptions of public health problems as if they indexed new interventions. Whether they actually make a difference at the individual, or even population level, remains a very open question. All of this would be science-as-usual in the service of larger public health goals. Yet the very complexity of tools, tasks, and productive algorithms is so far removed from public conversation that authority and mystification are almost inevitably structural doppelgangers of one another.

From a very different perspective, Ian Whitmash also analyzes emergent science and its multiple black-boxes: in his framework, evolving notions of the environment work as classic Levi-Straussian operators that confer “mana” and reenergize the largely unsuccessful field of genomic medicine. They link new understandings of genomic complexity to the promise of intervention into Barbados’ astoundingly high rate of asthma. Barbadian health care providers, planners, regulators, and families caring for members with the disease all cooperate in longstanding international research endeavors. Their diverse and unruly understandings of the environment focus on various notions of pollution in the island’s recent development; locals speak disapprovingly about the noticeable increase in dust as roadwork and housing become more high-tech. International research teams, however, are more likely to focus on indoor toxin load, measurable through their samples. For local health care providers and families with asthmatic members, there is also widespread concern about dramatic increases in consumption of commercialized, imported food that has replaced locally grown “ground produce” in recent memory.

How can all these concerns be domesticated into quantifiable measures of genomic interaction? Databases from these endeavors reduce and regularize more polysemic notions of dust and overprocessed food that characterize local descriptions of the rapid social-environmental changes experienced as asthma-genic. The scientific focus on atopy/allergic responses can usefully be linked to measurable household pollutants on the one hand, and genomic variation on the other. Missing is the common-sense critique of modernity that stands behind the development of susceptibility as environmentally triggered. Yet none of the data—here, an Afro-Caribbean stand-in for “African” genomics in well-funded international comparative research for which Barbadian data collection stands as an alluring model—would have been made possible (i.e., manufactured) without those dusty notions and experiences.

Collectively, these articles point toward a third instance of the co-production of the bio-social as a necessarily heterogeneous, entangled entity: Biopolitics in the post-genomic era is emergent, complex, and increasingly focused on gene/environment interactions. It is not accidental that sites as diverse as 23&Me and the Barbadian Ministry of Health are both collecting genomic samples that are conducive to data mining. Whether in the Euro-American data assemblages described by Suzanne Bauer or the proliferation of DNA databases enumerated across many parts of the globe in our editors’ introduction, multiple publics have become part of exquisitely stratified research populations and now serve as both potential global resources and market beneficiaries. This stratified heterogeneity, as subject/object of database research, is found in biotech efforts in South Africa, China, Estonia, and many other parts of the world beyond those necessarily few national contexts tracked in these articles.

Depending on how environment and biopolitics are understood and enacted, public health governance of individual/citizen risk and intervention is rapidly shifting toward new models in

which capital investments and technology races for market share often hold a key place. These are, almost by definition, mixed public/private endeavors (with the exception of Cuba, well described here and throughout the work of Sahra Gibbon, Sean Brotherton, Elyse Andaya, and others): Cuba as neoliberal exception? Or as part of how neoliberal markets stratify? We see such re-stratification through large-scale genomic research and testing in consort with various market forms rapidly emergent in many parts of the globe: These essays point us toward the many issues a history of the biopolitical present raises.

The ethnographers whose accounts you have just read enable us to ask: Qui bono? Where might the field of medical anthropology best do the long-term work of ferreting out and highlighting the shifting means and meanings to which public health genomics is now subject? MAQ gives us inspiration to address this special issue in a doubled sense, as we read and revise our collective work to include heightened attention to public health genomics.