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Human genetics after the bomb: Archives, clinics, proving grounds and board rooms

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ABSTRACT

In this paper I track the history of post-1945 human genetics and genomics emphasizing the importance of ideas about risk to the scientific study and medical management of human heredity. Drawing on my own scholarship as it is refracted through important new work by other scholars both junior and senior, I explore how radiation risk and then later disease risk mattered to the development of genetics and genomics, particularly in the United States. In this context I excavate one of the central ironies of post-war human genetics: while studies of DNA as the origin and cause of diseases have been lavishly supported by public institutions and private investment around the world, the day-to-day labor of intensive clinical innovation has played a far more important role in the actual human experience of genetic disease and genetic risk for affected families. This has implications for the archival record, where clinical interactions are less readily accessible to historians. This paper then suggests that modern genomics grew out of radiation risk; that it was and remains a risk assessment science; that it is temporally embedded as a form of both prediction and historical reconstruction; and that it has become a big business focused more on risk and prediction (which can be readily marketed) than on effective clinical intervention.

1. Introduction

The history of human genetics in the twentieth century runs through Hiroshima and Nagasaki, where the atomic bombs created large populations exposed to puzzling genetic risks. While Mendel seems to be the usual starting point for modern genetics, I here highlight the role that radiation risk has played in the development of human genetics and genomics after the Second World War. This is necessarily a view from 30,000 feet—roughly the height from which the bombs were dropped in early August, 1945.[1]

Like other scholars in the history of science, technology and medicine, I have become increasingly interested in the "big pictures" that emerge from the archives only gradually, as the density of detailed case studies and available archives grows. John Pickstone's analysis of "ways of knowing" captured the growing consensus, and for many sciences after 1945 such approaches are only now becoming possible (Pickstone, 2001). The extant archival records of post-1945 science are quite frankly too rich, voluminous, dispersed, and complicated to be easily tamed. It is easy to lose your way (de Chadarevian, 2016). But the historical story of post-1945 science around the world in general is finally achieving some measure of the necessary range of focused case studies to facilitate broader pictures. Newly opened and available archival collections have attracted a generation of scholars who bring to these collections novel questions, as this volume demonstrates. That such collections are also limited, incomplete, and structurally biased has consequences for the kinds of historical stories we tell. In my case, critical issues unfold at the intimate level of scientists and research

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[1] One of the key interlocutors at this nexus was the late geneticist James V. Neel, whose autobiography *Physician to the Gene Pool* (1994) remains a fascinating portrait of a way of seeing the relationships between the bomb and the genome. But see also Cook-Deegan (1996), Kevles (1985), Kevles and Hood (1993), Lindee (1994) and Kay (1993, 2000).

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subjects, and in the embodied encounters of healers, patients and family members as they navigate scientific knowledge and new biotechnologies. I would suggest that this point of contact—this charged interaction of expert and subject, or physician and patient—is so fundamental to the power structure of modern biomedicine that we have barely begun to grasp its significance or understand its operations.

In this paper, I reflect on that charged point of contact, drawing on perspectives from my own scholarly concerns of the last 25 years, and on the work of other scholars in the field, both established and rising. Because I am convinced that this history must include attention to the experiences of those who live with genetic diseases, and must come to terms with the day-to-day social and medical management of genetic difference and risk, I include observations about politics, popular culture and clinical care.[2] While I recognize that there are many other paths through this complex story, I suggest that seeing the emergence of "the genome" by the late twentieth century as the focus of a capitalized, industrialized risk assessment science, shaped by radiation and the Cold War, but newly engaged with corporate interests, helps us understand contemporary genomics and the promised future of improved human health. Genetic and genomic information are often applied today to assess future risks, of disease in the fetus or newborn, in the adult, in aging populations or in populations exposed to environmental risks, radiation, toxic waste and other agents. This predictive quality of the science of genetics has shaped its social and political meanings and its medical uses (Hogan, 2012, 2013; Löwy, 2013; Parthasarathy, 2007; Paul, 1999). Modern genomics also establishes historical connections between different human populations, which can suggest patterns of global migrations in the past and can illuminate questions of human origins and evolution, not to mention, most controversially, ideas about racial difference (Braun, 2014; Fulwilley, 2011; Koenig, Lee and Richardson, 2008; Montoya, 2011; Wailoo, Nelson and Lee, 2012).

The temporal elements in the science of genomics—its relevance to both past and future—make it more like geology or even meteorology than say, mathematics. It is a historical science and a predictive science. Sometimes it can predict with relative precision; at other times its predictions are probabilistic and uncertain. The same is true of its status as a historical resource. Sometimes genomic information can provide powerful and compelling perspectives on human history, and sometimes its claims are vexed and uncertain. This is a problem well-recognized by the scientific community, which confronts the quandary of possessing a high volume of information, yet not knowing exactly what that information means, particularly in terms of the arc of an individual life (Pyeritz, 1998; Reiff et al., 2013). Genomics combines extreme technical specificity with extreme uncertainty.

Also important to our understanding of post-war genetics and genomics is the network of evolving relationships between academic scientists, the national security state, and, later, private industry (García-Sancho, 2010, 2012). After 1945 geneticists of all kinds received public funding that reflected the policy concerns raised by radiation risk, atmospheric weapons testing, and the rise of the nuclear power industry (Mozersky, 2013; Sommer, 2008, 2010). Over the last three decades or so, with shifts in patent law and new interventions and technologies, geneticists became entrepreneurs, their research supported by both significant public funding (and expectation of public benefit) and significant private investment (and expectation of private profit). In the twenty-first century, capital, investment and profit are simply part of the reality of contemporary genomics—in the genome project, Direct-to-Consumer testing, the new race sciences, patent disputes, the use and promotion of forensic DNA, pharmacogenomics, ethics, and conflict of interest issues in the lab and clinic. Most of the literature in science studies includes some critique of the commercial stakes animating much contemporary genomics. But it is possible to engage too completely in a kind of genomic exceptionalism here. Modern biomedicine in general is a system for the production of profit. That is why diseases that plague the global south are often accorded less attention, because they cannot be expected to generate profit. This is a sad commentary on the state of modern biomedical research and its supposed flagship interest in alleviating human suffering, but it is not unique to genomics (Parry, 2004; Rajan, 2006).

These are therefore my overarching themes: modern genomics grew out of radiation risk, it was and remains a risk assessment science, it is a form of both prediction and historical reconstruction, and it has become a big business (that's the surprise ending—at least it would have surprised that generation of pioneers in the 1940s who struggled to inspire medical interest in human genetics).[3] What I try to do here is to suggest some of what these origins might mean moving forward—as we enter an era of low-cost full-genome sequencing, and mass marketing of ancestry and disease DNA testing. If there is a twenty-first century eugenics, I would propose, is a eugenics animated by private profit.

Mid-century geneticists like James Neel and H.J. Muller saw their work as a critical contribution to the public debate about atomic weapons and their possible future use in the coming nuclear war. While Neel and Muller did not always agree about the exact risks involved, they did share a commitment to quantifying that risk in as much detail as possible. Risk is both an elaborate technical invention, codified in quantitative terms, requiring consensus standards for agreed-upon levels that trigger institutional action, and a viscerally embodied experience, engaged with the moral and social problem of anticipatory trauma. By no means is the world of risk calculation void of moral order: it is about the modern moral order of who can suffer, when, and why. Studying the systems that produce the rules about risk is a way of seeing or excavating the 21st century distribution of both vulnerability and safety. By emphasizing the emergence of genomics as a risk assessment science, I call attention to this systematic property of genetic information: that it is an available resource for action by some kinds of people, and a way of predicting and preventing certain kinds of suffering.

2. Hiroshima, Nagasaki, and genetic legacies

While there is no scientific consensus that the two atomic bombs used against Japan in August of 1945 had statistically significant genetic effects on the next generation, they did have measurable effects on public support for research in genetics.

United States leaders chose to bomb Hiroshima and Nagasaki with the newly developed weapon in an effort to produce a rapid Japanese surrender. Tokyo had been firebombed for months, with devastating human and material consequences, and Japan's inner circle was close to surrender in any case. Soviet troops were also on their way to join in the Pacific war—on the promised date three months after the end of the war in Europe, as Stalin had agreed at Yalta in February 1945. The Cold War was not yet officially underway, but it was brewing, and Allied authorities were enraged by Soviet management of the East German sector that they had only controlled for a few months. The Army Corps of Engineers had also

[2] Relevant publications of mine are listed in the bibliography.

[3] See special section on "Follow the money" in Isis, 103(2), 2012.