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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.

spent $2 billion to build the atomic bombs, and not using a weapon that had involved so much cost and labor might anger Congress, which did not yet know that this spending was going on (Malloy, 2008).

These circumstances combined to produce a conviction in elite US policy circles—in the tight group advising the new US. President Harry S. Truman—that the bomb had to be used against Japan as soon as possible. The United States did not want to share Japan with Stalin and wanted the war to be over before Soviet troops reached Manchuria—which was expected by August 10. In this they succeeded, and the horrifying impact of the two weapons ended the war in mid-August. Almost 70 years later, Hiroshima and Nagasaki, of course, are still the only two cities to have been subjected to nuclear attack, and the United States is still the only nation to have used nuclear weapons in war.

What happened in those two cities quickly became the focus of technical attention, from engineers, physicists, physicians, and from both Allied and Japanese scientists of all kinds. They were in a way experimental cities, field sites, and test battlegrounds. For the Japanese, the technical details provided proof of injustice; for US engineers and scientists, the destruction found there was a resource for extrapolation to other circumstances—to guide urban planning in the United States, to assess materials and the impact of the heat generated by the bomb, to help prepare US citizens for nuclear war, and, most importantly for my purposes today, to calculate the human risk of radiation exposure, both immediate and long term (Hacker, 1987; US Strategic Bombing Survey, 1946).

There were no studies planned at the time of the social or psychological consequences of the bombings. It was as though the bombs only destroyed physical things, buildings and bodies (skin, tissue, genes), and not entire societies. But in reading survivor accounts, as a part of my research, I was struck by the ways that the bombs annihilated the social order, the expected patterns of life in socially and psychologically important ways (Sekimori, 1989). Only later, in the early 1960s, when the psychiatrist Robert Jay Lifton began to interview survivors, did the social sciences become involved in studying the social impact of the bomb (Lifton, 1968) and today social scientists routinely play a critical role in the assessment of disasters. It is possible that the biological and physical consequences of the bombings may have seemed more "portable" and generally applicable than the social consequences to US planners who imagined Japan culturally alien, though in reading contemporary planning documents I have not seen this idea explicitly articulated.

The Strategic Bombing Survey recorded and measured the physical damage, and in 1947 the newly created Atomic Bomb Casualty Commission (ABCC), funded by the US Atomic Energy Commission (AEC), and overseen by the US National Academy of Sciences (NAS), began to record medical damage to the survivors and their offspring. It was run by a group of American doctors and scientists but much of the day-to-day work was carried out by Japanese nurses, midwives, staff, and physicians who were employed there (Lindee, 1994; Neel & Schull, 1956). It would be hard to overstate the chaos and the damage in the two cities. The survivors, called hibakusha, suffered profoundly, in their loss of families, homes, businesses, and with both immediate and long-term effects of radiation exposure, blast and fire. They were subject to social discrimination in Japan, furthermore, considered unsuited for arranged marriages, feared as possible carriers of genetic damage, and often horribly scarred with burns and keloids that marked them as weak, sickly, vulnerable (Ishikawa & Swain, 1981).

One director of the ABCC called them "the most important people living." By this he meant that they were people whose suffering could become a resource for managing the New World of atomic risk (Lindee, 1994, 5). What had happened to them, in the eyes of those studying them, could happen to us all. They were pioneers—canaries in a global coal mine of Cold War risk. As atmospheric weapons testing and its associated global fallout geared up in the summer of 1946, with the full-scale media event of the Pacific weapons tests at Bikini Atoll, Operation Crossroads, their experiences seemed relevant to every living person around the world (Weisgall, 1994). Crossroads was meant to be seen and viewed by US citizens but also by leaders in the Soviet Union. Journalists were invited, the detonations were live on the radio, and the tests were filmed and photographed from every angle, and witnessed by honored guests. It was a public, provocative a display of power less than 12 months after Hiroshima and Nagasaki.

3. Scientific studies in Japan

Of particular interest to both scientists and public commentators in 1945 and 1946 were the possible genetic effects of radioactive fallout and other forms of human exposure. The discoveries by fly geneticist H.J. Muller of the mutagenic effects of X-rays in Drosophila, and by agricultural geneticist Lewis Stadler of similar effects in barley and maize in 1928 established the genetic damage-inducing effects of radiation (Carlson, 1981, 135–164). Muller won the Nobel Prize in 1946, just as Crossroads gave these effects a new urgency, and the possibility that the bomb survivors might have children who expressed mutated genes was being widely recognized. The NAS-National Research Council (the official research arm of the US National Academy of Sciences) committee appointed to review the scientific options at Hiroshima and Nagasaki, however, was cautious in its formal expectations:

> "Although there is every reason to infer that genetic effects can be produced and have been produced in man by atomic radiation, nevertheless the conference wishes to make it clear that it cannot guarantee significant results from this or any other study on the Japanese material. In contrast to laboratory data, this material is too much influenced by extraneous variables and too little adapted to disclosing genetic effects. In spite of these facts, the conference feels that this unique possibility for demonstrating genetic effects caused by atomic radiation should not be lost …" (National Research Council Committee on Atomic Casualties, 1947, 33).

The person charged with taking on this thankless task of finding genetic effects that were not expected to be found, but that were probably there, was James V. Neel (1915–2000), a University of Michigan geneticist and physician sent to Japan in 1947. Neel's role in the development of human genetics in the United States and around the world is widely recognized today. He is perhaps most cited now for his work on what he called the "thrifty genotype," a genotype that confers the advantage of rapid fat storage under conditions of limited food availability, now, as he put it, "rendered detrimental" by prosperity (Neel, 1962). This work of course relates to the obesity epidemic around the world, and while his ideas have been elaborated on and modified since their initial publication in 1962, Neel remains a critical figure in this literature today. But in his own lifetime he was perhaps better known for his work with the atomic bomb survivors, and with other "special" populations, including consanguineous families in Japan, the Yanomami (an isolated indigenous group living on the Orinoco River in Venezuela and Brazil, made famous by the University of Michigan anthropologist Napoleon Chagnon in his film "The Fierce People"), and male twins who had served in the US armed forces in World War II. Neel was a population geneticist with strong interests in human evolution and a trained physician with an interest in genetic disease (See Lindee, 2005; Neel, 1994).

Neel directed the project to study genetic effects in the survivors, which was funded almost entirely by the US Atomic Energy Commission. He figured out how to navigate the social world of occupied Japan, how to work with the survivors, midwives and doctors he needed to enroll in his project, how to collect data, make sense of confusing findings, and keep the ABCC project alive (the project was more or less in constant crisis). Neel and his co-author William J. Schull focused throughout the 1950s and 1960s on describing the first generation born to the atomic bomb survivors. They were watching infants for signs of malformation (Lindee, 1994; Neel & Schull, 1991).

Shaping their work was public outrage after the accidental exposure of 23 Japanese crew members on the fishing boat Lucky Dragon (the *Fukuryu Maru*) during a 1954 Pacific test at Bikini Atoll in the Marshall Islands. The exposure of the crew, all of whom were sickened by radiation and one of whom later died, heightened political concerns about radiation risk and touched off a firestorm of protest in Japan: Japanese citizens had again been exposed to US atomic weapons (Lapp, 1958). The ABCC, as a US-run agency studying victims of a US attack, had long been resented by some Japanese scientists and physicians who felt that they were not given access to data and whose own scientific publications were subject to stringent censorship during the Occupation. Many survivors cooperated with the ABCC but wanted the ABCC to provide medical treatment rather than diagnosis only. And sometimes ABCC policies and practices offended Japanese participants—most notoriously a brief practice in the Growth and Development study that involved taking nude photographs of adolescent subjects. The Occupation of Japan by Allied Forces ended in 1952, which provoked more public criticism of the ABCC, and calls for greater Japanese control of the scientific studies. Both US and Japanese scientists believed that national loyalties could shape the interpretation of the data: US scientists feared that their Japanese counterparts would exaggerate the risks, and Japanese scientists said US reports downplayed them (see Lindee, 1994; Schull, 1990).

4. Fighting about Atoms for Peace

Meanwhile in December 1953, President Dwight Eisenhower announced at a meeting at the United Nations that the United States was launching an Atoms for Peace program, an international effort to promote the "peaceful" uses of atomic energy (Creager, 2013). If atomic energy did become an important energy source, more people would be at risk of radiation exposure—workers, nearby residents, perhaps larger populations in the event of accidents, an expectation that has most unfortunately proven accurate, at Sellafield, Three Mile Island, Chernobyl, and Fukushima, and many other places around the world (Lindee, 2015).

In the mid-1950s, new international bodies, and national groups in the United States and Britain, began trying to compile data that could guide public policies relating to acceptable levels of exposure. Questions about the mutagenic effects of radiation were therefore questions about the US management of Cold War, about public health risk, worker safety, and about public policy and international cooperation. As Hamblin showed in his 2007 paper, the National Academy of Science's 1956 study on the Biological Effects of Atomic Radiation (BEAR) was constructed to assess conflicting statements about radiation risk, and its members collaborated with scientists trying to produce a report in Britain by the Medical Research Council in an effort to manage public concern. "The NAS [which had created the BEAR committee] and the MRC made personal contacts, traded drafts, and coordinated release dates to ensure conformity and to maximize the effect of their reports. In addition, the Academy acted to ensure the proper coverage of the reports in the media, particularly through the *New York Times,* owned by a Rockefeller Foundation trustee, and the *Scientific American*, which asked the Academy to write its own headline." (Hamblin, 2007, 149). In this context of a multiplicity of industrial, political and public interests in genetic effects, the stakes for geneticists themselves, as experts engaged in a public debate, came to seem very high.

In 1956, Neel engaged in a bitter, and revealing, dispute with Muller. In this small fight, we can see how radiation risk was a resource for geneticists, a problem that could justify significant public support, and a highly charged technical problem. The evolutionary biologist Ernst Mayr, observing a different dispute between H.J. Muller and Theodosius Dobzhansky, once asked "what makes the geneticists such a bunch of emotional prima donnas?"[4] Indeed, Muller was the first president of the American Society for Human Genetics, a eugenicist to the end, and on the faculty at Indiana University. In the 1930s Muller's leftist politics made him a focus of FBI suspicion in the United States and in 1934 he accepted an invitation to move to a genetics research institute in the USSR where he stayed three years. He returned to the United States to hold positions at Amherst College in Massachusetts and finally at Indiana University in Bloomington. His general tendency to defend his ideas with considerable energy led to a series of public and scientific disputes, with T.H. Morgan, Theodosius Dobzhansky, Neel and many others. He was no stranger to controversy (Carlson, 1981; Lindee, 2013a).

Muller also published alarming reports for public consumption that called into question AEC standards for exposure and predicted a disturbing biological future. His ideas about a "load of mutations" that would eventually cripple the species attracted journalistic interest and he was at one point proclaimed to be "the world's greatest scientist" in a magazine profile about radiation risk (Pollack, 1962). Muller had that kind of visibility and public edge. He was generally seen as a thorny adversary of the AEC, though he also received significant AEC support (like almost every prominent geneticist in this period), having been awarded $279,312 by the AEC from 1951 to 1962—about $31,000 per year, at a time when the US average annual salary was less than $3000 (Lindee, 2013a). This funding seemed to be uninflected by his sometimes florid public pronouncements about irresponsible medical uses of radiation or about the high risks of fallout and the disastrous future they threatened to produce.

In their 1956 dispute, Muller and Neel disagreed about what results with flies meant for human risk. Neel took the position that results with flies meant very little or even *nothing* and that more research with humans was crucial; Muller argued that the fly results meant a great deal for human exposure and more research with flies was crucial. Their anger was disciplinary, technical, and strategic. Each wanted to emphasize the crucial role their research could play in setting standards for radiation risk. The question of how to reach conclusions about human radiation risk based on experiments with mice or flies was the critical issue (Lindee, 2013a).

While some scientists viewed critics of atomic energy and atmospheric weapons testing as "hysterical," many others thought that it was logical to expect that fallout and worker exposure would have medical and genetic consequences. And yet what Neel and his colleagues found in Hiroshima and Nagasaki was ambiguous, uncertain. The medical effects on the survivors themselves were unequivocal and included radiation cataract, leukemia, many other forms of cancer, and other long-term effects. But documenting genetic effects on the next generation was much more difficult. Did the offspring of atomic bomb survivors experience higher mutation rates than would be expected in a normal population? Even in 1991,

[4] Mayr to Lerner, June 27, 1960, Lerner Papers. Quoted in Beatty (1987), note 12.

after almost 50 years, Neel and Schull wondered if they "could be just manipulating the noise in the system" as they tried to calculate a doubling dose for genetic effects. (Neel & Schull, 1991, 6).

5. Normality, indigeneity, risk, and the ticking clock

In the early years, in the 1950s, the AEC began a program of significant support for studies of isolated and "primitive" populations as a part of its efforts to understand the genetic effects of radiation. Geneticists began to travel around the world, often with anthropologists in tow, to study groups that they expected would soon be gone. These isolated populations selected for study were often construed by those who studied them as living outside of time, and outside of history, and presumably also outside of the reach of atomic fallout. They were "primitive" and their conditions of life could be expected to reveal the conditions under which human beings had evolved hundreds of thousands of years ago. For many of those who came to study them, isolated groups were the equivalent of living fossils (Bangham, 2014a, 2014b; Bangham and de Chadarevian, eds., 2014; Lindee and Santos, 2012; Radin, 2013; Santos, Lindee and Vanderlei, 2014).

They were also groups that were highly threatened by modernity. Isolated groups in Latin America, Africa and Asia, were seen as unlikely to remain isolated, primitive, natural, or pure. Global economic and environmental change seemed to threaten their survival, and anthropologists and geneticists who came to work with them often saw themselves as engaged in a salvage project. Isolated groups would, they expected, soon be wiped out by the forces of modernity. Their bodily traces, including blood and tissue, should therefore be collected and frozen for future scientific uses "as yet unknown," the information contained in their bodies indefinitely accessible to scientific analysis. In her analysis of this new kind of field work in the 1950s and 1960s, Joanna Radin has tracked the so-called cold chain, from the fields to the laboratory freezer, which made this salvage project possible. Frozen materials from isolated groups were expected to preserve the scientific data that their bodies contained, even as the groups themselves were expected to disappear (Radin, 2013).

The 1950s was also the highpoint of research on the geographical distributions of blood-group frequencies, a related endeavor that privileged mass collection of bloods and the analysis of human populations in racialized terms. One of the most prolific scientists in this area was British geneticist Arthur Mourant, whose work Jenny Bangham has helped us to understand and contextualize. Mourant's 1954 book, *The Distribution of the Human Blood Groups*, was the largest compilation of blood-group data ever produced, reflecting data from half a million people, on 9 maps, and 40 tables of frequency data. Mourant was in charge of the Blood Group Reference Laboratory (BGRL) at the Lister Institute in London, which was responsible for standardizing and distributing antisera to blood grouping laboratories around the world. He sought samples from both "pure" populations believed to be still in isolation, and from industrialized populations in Britain. We often speak today of "big data" (García-Sancho, 2016) but we can already see that as early as in the 1950s there were large-scale collecting, cataloging and standardizing projects. Human genetic disease and biological variation were emerging as the significant focus of a globally oriented blood collection program (Bangham, 2014a; Strasser, 2012).

6. Into the clinic: newborns, chromosomes and blood

In the same historical moment, 1955–1965, as blood from isolated groups was being collected and stored in massive databases, blood was also the focus of a range of neonatal testing programs in both Britain and the United States. The original purpose of such programs was to identify at birth infants with phenylketonuria, PKU, who could be treated with dietary intervention. The disease had first been identified by Asbjorn Folling in 1934 as a disease of phenylalanine metabolism. Lionel Penrose almost immediately suggested that a low-phenylalanine diet might be an effective treatment and a few years later the American biochemists George Jervis and Richard Block proposed the same idea. But the low-phenylalanine diet was not tried until 1951, when two British biochemists tested the diet on three small children, all of whom showed some improvement (Lindee, 2005; Paul & Brosco, 2013).

By 1955, two other groups of researchers had tried low-phenylalanine diets in affected children with some reports of success. British physician Horst Bickel and his colleagues reported that a three-year-old girl they were treating stopped having convulsions. Bickel proposed that if the diet had begun earlier, mental retardation might have been avoided (Paul & Brosco, 2013). The possibility of therapy and cure that this dietary intervention promised led almost immediately, in 1956, to a British screening program to test infants' urine for the presence of phenylpyruvic acid. This testing was facilitated by the British practice of home health visits to young infants. A similar program in the United States had to await the development by University of Buffalo microbiologist Robert Guthrie and his laboratory assistant Ada Susi of a test that could detect the presence of excess phenylalanine in a newborn infant's blood. The Guthrie test provided the technological frame for a massive blood collection program, and this led eventually to much broader testing—in some places newborns are tested for more than 30 possible conditions. PKU testing created an infrastructure for other kinds of newborn testing, and panels around the world continue to add new diseases, even when effective clinical interventions are not available (Lindee, 2005, 90–119; Paul & Brosco, 2013).

Meanwhile the human chromosomes had been accurately counted only in 1956, and they were only conclusively distinguished from each other, by banding techniques, in the 1970s. In the 1960s they were the known cause of "four well-established and reasonably common syndromes and a great number of rarer variants, less well-studied" (Lennox, 1961, 1049). They were therefore both medically important, and easy to misidentify. They were the focus of intense debate (Santesmases, 2014; de Chadarevian, 2014).

In 1961 the University of Glasgow pathologist Bernard Lennox noted that the British medical journal *The Lancet* was recently "freely littered" with images "said to look like masses of squashed spiders" (Lennox, 1961, 1046). The spiders were highly processed human chromosomes, shaped roughly like Xs. Either photographed or drawn for journal publication, they appeared in papers detailing the medical impact of chromosomal abnormality, and new methods of preparation produced images that were a triumph of human cytogenetics. In 1963 Lionel Penrose drew a distinction between gene-level mutations, "mistakes of an imaginary printer," which are too small to be seen, and chromosomal aberrations, "mistakes of a binder," that could be observed microscopically. Over the next decade, conferences at Denver, Chicago and London produced a standardized nomenclature for the human chromosomes (Lindee, 2005, 106–9).

In 1956 the human chromosomes were barely differentiated from each other. By 1970 they were distinct, stable objects of sustained technical and medical attention, and the locus of a wide range of diseased states. Chromosomes became visual markers of pathology and critical images in a new, broader conception of genetic disease. For a brief period, human cytogenetics "developed into the most popular branch of human genetics." Visual images appealed strongly to physicians and to many biologists. The "surging popularity" of clinical cytogenetics was "all the more

remarkable since during the first decade almost no practical significance of these results for medical therapy or prevention, apart from diagnosis and genetic counseling, seemed to be in sight." This "changed dramatically" when prenatal diagnosis became possible (Vogel & Motulsky, 1986, 24).

7. Dreaming of the genome

In his address to the 1966 Chicago Conference, Penrose, then president of the Third International Congress of Human Genetics, proposed that "much underlying variability is still hidden from view until some new technical devise discloses the finer structure of chromosomes."[5]

This "finer structure" would eventually come to be seen as a complete map of the human genome. While a version of the word "genome"—Genom—had been coined in 1920, by German botanist Hans Winkler, it was not a term that was widely used by human geneticists until the 1980s. Thanks to a journal paper describing it, we actually have a very specific origin story for the expanded word *genomics*: it was coined in 1986 by Jackson Lab geneticist Thomas H. Roderick, over beer, in a meeting at an oyster bar in Baltimore, where Frank Ruddle, Victor McKusick and others were meeting to plan a new journal (Kuska, 1992; see also Lederberg & McCray, 2001; Powell, O'Malley, Müller-Wille, Calvert, & Dupré, 2007). Later "ome" became useful in other ways—for proteomics in 1995, and it has now been applied to many other fields. Its Latin origins of course are in soma, the body, and it mimics chromosomes—colored bodies.

In any case, mapping human genes posed certain technical problems. Genes in other organisms had been mapped as early as the 1910s, by geneticists who carried out controlled crosses with the intention of locating genes along the chromosomes. But the map of the human genome being proposed in the early 1980s would be one made possible only by new technological capabilities which permitted direct study of the genetic material itself. Human DNA could in theory be sequenced until all of the estimated three billion bases were known.

The need to understand the *normal* rate of human mutation, in populations not exposed to radiation, led eventually to Department of Energy support for a possible Human Genome Project. In his detailed chapter about the origins of the Department of Energy's interest in mapping the complete human genome, "Genes and the Bomb," Robert Cook-Deegan provides an excellent explanation of how the genome seemed to be a resource for documenting genetic effects of radiation, by demonstrating at a molecular level both normal and abnormal variations in DNA. One key player at the DoE was the new head of the Office of Health and Environmental Research, Charles DeLisi, and in March 1984 DeLisi participated in a special genetics conference in Hiroshima, at the Radiation Effects Research Foundation (RERF), successor agency to the ABCC. This group concluded that the "direct examination of DNA" might finally provide a way to see and understand the genetic effects of radiation. The DoE sponsored another scientific meeting at Alta, Utah, in December 1984, to discuss the possibility of mapping the entire genome, with the intention of developing a more robust picture of the genetic effects of radiation. After that meeting, DeLisi reached the conclusion that the DoE should sponsor a major project devoted to DNA sequencing *writ large,* not just relating to the survivors. By this time, and under DeLisi's vision, the agenda was growing to encompass all possible medical benefits and DeLisi was making grand comparisons to the space program with DoE the "natural organization" to play the lead, because of its long role in funding genetics research as a result of its responsibilities in terms of radiation risk (Cook-Deegan, 1996, 94–99). Eventually, in 1988, the project shifted to the dominant control of the NIH (after an internal and political wrangle well captured in Cook-Deegan's book) though the DoE continued to play a role (Cook-Deegan, 1996, 148–160). The new HGP seemed to promise a biotech windfall, supported by public largesse, and the biotech industry was supportive, to say the least.

In 1988 a group of geneticists founded the Human Genome Organization, an international professional group that coordinated work across laboratories and countries. They reached an agreement about how to divide up the mapping of the 24 human chromosomes to avoid duplication—individual chromosomes were literally assigned to different national groups—and they sponsored a series of international workshops and meetings. The same year, the NIH created an Office of Genome Research and hired James Watson to run it. The genome began to be sold to Congress and the public as a 15-year project that would have tremendous medical benefits and that deserved significant public funding (Cook-Deegan, 1996, 148–160).

8. Clinical practices, missing links

I want to close by turning to a single story drawn from the clinic, that intimate site where disease, risk, genetics and scientific knowledge coalesce around a key social actor, the patient. I call up an evocative clinical transformation that could call attention to paths not taken. Genomics and prenatal testing offer a form of prevention of genetic disease so cost-effective that other forms of intervention may seem unreasonable and expensive. But in terms of the actual human experience of genetic risk, clinical interventions have had powerful and effective consequences that should matter to us all. Genomics is not the only way to address the genetic disease burden. Genetic diseases have been transformed through clinical care—not high tech science but piecemeal, everyday medical labor.

My example is cystic fibrosis (CF), a disease that emerged only in the 1930s. For more than two decades CF was viewed as fatal in early childhood, a death sentence by age 5 or so. But in the late 1950s, in a clinic in Cleveland, Ohio, CF became a disease consistent with survival into adulthood. Today there are CF patients in their 60s who have pursued careers and raised families, including Paul M. Quinton, a leading CF scientist at the University of California San Francisco.[6] The architect of the transformation of this disease was the physician LeRoy Matthews. Mathews turned his attention to CF in 1955, after a stint as a radiation safety officer for Pacific bomb tests (1952–54) and as director of the Isotope and Endocrine Laboratory at the US Naval Hospital in San Diego. Though the disease has systemic effects in all epithelial cells, lung failure is the most important cause of death and Matthews attributed some of his key insights to his understanding of how inhaled radioactive materials moved through smaller airways in the lungs (Doershuk, 2001a, 2001b, 68).

In only three years, between 1957 and 1960, Matthew's Cleveland Comprehensive Treatment Program for Cystic Fibrosis reduced annual mortality from 10% to 2% in CF patients being treated there. Other clinicians had been using every technology and practice that Matthews adopted: mist tents, antibiotics, nutritional supplements,

[5] Penrose, 3 September 1966. "Introductory Address" Typescript, "Chicago Cytogenetics Conference" Papers of Curt Stern, MS Coll. 5, American Philosophical Society, Philadelphia, PA.

[6] Quinton talks about his experiences as both patient and scientist on the youtube video, "Kicking Butt with CF at 67", https://www.youtube.com/watch?v=oMKdeksK8UY, accessed May 6, 2014.

enzyme therapy and daily postural drainage. Yet in these other clinics these methods were used intermittently and only in the clinic, rather than at home, and often began only after lung function in patients had begun to falter. Techniques like postural drainage were considered too difficult for parents to undertake every day. Many patients were taking antibiotics almost constantly but without consistent testing for particular pathogens, even though antibiotic resistance was already a well-recognized problem. Matthews' innovation was to combine all of these technologies, and to imagine them as a daily part of protecting the lungs of every CF child from the moment of diagnosis. He and his team pulled them all together in a daily regimen of chest percussion, postural drainage, antibiotics and dietary supplements to manage pancreatic symptoms. He also delegated much of the daily care to parents, despite the objections of physical therapists that parents could not manage it. Matthews taught parents how to loosen mucus and drain the lungs, beginning each patient's care with a 2–3 week family boot camp that taught them how to keep lungs clear.

Patients and parents required "considerable encouragement and support" and needed to be shown charts, photographs, lab studies, chest films and the results of pulmonary function tests in order to recognize and appreciate the value of the demanding regimen. Compliance was not strictly a matter of medical authority. Rather, it required bringing the patients and their parents to the technical data, letting them see the visual representations of risk and health that the CF clinic produced, and see for themselves that the hours of hard labor were making a difference for the patient. From day to day, the difference might not be obvious, but from year to year, it would be (Matthews et al., 1964).

Within a few years he was claiming at meetings to have an annual mortality rate that was less than two per cent. Mortality in CF was generally about 20% a year, and patients were generally dead by the age of 3. He told one conference "How long [our patients] will live remains to be seen, but I expect most of them to come to my funeral" (Gawanda, 2004). In 1964, Matthews group had not had a single death among patients younger than six in at least five years. This was an incredible result to others treating CF at the time. Early reports of its effects were so incredible that they were considered implausible by others treating CF. After an investigation sponsored by the US CF Foundation in 1961 the protocol was introduced in the then 31 Cystic Fibrosis Foundation Centers nationwide and annual mortality began to fall nationally. In modified form, the program developed in Cleveland in the late 1950s is still used in CF Centers in the United States today and in other CF clinics around the world. Matthews and his team made Cystic Fibrosis *an adult disease* (Doershuk, 2001a, 77, 2001b).

Like other genetic diseases in the late twentieth century, CF was clinically remade, its biological properties reconfigured as a result of a suite of cyborg-like interventions: mist tents, propylene glycol, enzymes, antibiotics, nebulizers, compression vests, airway clearance practices, and strict parent and patients training. Dreams of simple, effective gene therapy for CF were dashed in the 1990s (though some forms of CF are responding to new kinds of gene therapy in 2015).[7] The most important advances for most CF patients have depended on careful clinical management like that fostered by Matthews' team. (Lindee & Mueller, 2011). When we tell the history of human genetics, these clinical approaches should be as celebrated as any kind of DNA test or genome map. Privacy restrictions on medical records, and the tendency for archives in general to "follow the money" or follow the bureaucratic structures of science and medicine (de Chadarevian, 2016; Shaw, 2016) make staying close to the human interactions I highlight more challenging. But historians should be attentive to sources that can provide insights, including first-person accounts, bioethical protocols, legal records, and advice literature to physicians and patients.

9. Conclusions

In 1945, human genetics in Europe and the United States looked a lot like Nazi racial hygiene or like the American eugenics movement. There were a few known familial diseases, some twin studies, hypotheses about mental illness, and some odd ideas about the political control of reproduction that were supported even by leading and respectable scientists. The situation of human genetics as a scientific discipline in 1945 was indisputably vexed. Physicians were taught almost nothing about heredity—the first serious textbooks appeared in the 1950s—and both diagnostic capabilities and interventions were limited. Forty years later human genetics was a thriving discipline with significant public support and intense medical and industrial interest. It was possible for its proponents to proclaim that all disease was genetic disease and to promise both bewitching cures for devastating genetic diseases and bewitching profits.

It is common today for historians to take as their question something like: is modern genomics resuscitated eugenics? That is what animates two recent books, one by Ruth Cowan, who says no, and one by Nathaniel Comfort, who says yes (Comfort, 2012; Cowan, 2008). It also played a role in the influential synthesis of Daniel Kevles (Kevles, 1985). My own view is that the relationships between contemporary genomic medicine and early twentieth century eugenics (and there are some) do not explain what is most important to understand about our current circumstances. The key relationship for understanding contemporary genomics is the relationship between academic scientists and private industry, and between public and private investments in the human genome. That is what explains the genome project (biotech interests around the world supported the project), the new race sciences, ancestry testing, race-based therapeutic marketing, the selling of DNA for leisure consumption (genotainment), the roles of patenting in genetic sciences, the rise of pharmacogenomics, the ethics industry and issues of conflict of interest in the scientific community. The commercialized genome of 2014 would I suspect astonish those pioneers in human genetics who first promoted medical interest in human heredity in the 1940s, and even the genomics promoters of the 1980s are presumably surprised to find that their work led not to miraculous cures, but to an ancestry testing industry that tells consumers how closely they are related to Phoenicians (Lindee, 2013b). While eugenics in various forms expressed a social ideal linked to race and class, genomics sells an ideal of individualized consumption, racial identity and responsible parenthood. These new ideals are no less linked to class, race, and nationality, but they have a different vocabulary—a vocabulary of rational risk assessment.

Beginning in the 1940s with radiation risk, and funded by the Atomic Energy Commission, research in human genetics and genomics has been understood to be a public good, medically useful. There has been a consistent engagement with risk, at first radiation risk and then medical risk, and a sense that human genes connect with both the past and the future. They are widely understood to reveal individual and group history and to be a critical future resource, shaping species success in a rapidly changing environment. Public investments intended to stimulate the growth of private investments in genomics and biotechnology have yielded profits not through cures or effective gene therapy, but through

[7] A useful summary of the current state of this work is at http://blogs.plos.org/dnascience/2014/05/22/checklist-gene-therapy-uk-cystic-fibrosis-trial/ (accessed May 6, 2015).

what some have called genotainment, particularly the ancestry testing industry. Such an outcome would presumably not have provided a compelling justification for significant public expenditure thirty years ago.

When Dorothy Nelkin and I first started thinking twenty-five years ago about what we later came to call the DNA mystique, we expected the image of the all-powerful gene in popular culture to be a brief, odd, popular wave that would soon be gone (Nelkin and Lindee, 1995, 2004). Instead, the DNA mystique is now tuned to a high pitch by teams of marketing professionals, public relations firms, and highly creative writers and image experts. DNA is the hook for products like living room art (your own ancestry map in full color, with frame) and for moving experiences of historical connection (often with famous historical individuals like Genghis Khan or well-known, historically interesting populations like the Phoenicians) recounted in emotional first-person narratives on web sites. DNA is now marketed to consumers as a way to understand themselves, their families, and their history. The DNA experience is the central product of an industry that promises consumers various kinds of truth, generally for $79 to $399. The DNA mystique is what they are selling, along with "stunning" personalized ancestry maps (Lindee, 2013b).

Consumers buy a lot of experiences and there is nothing wrong with selling an experience. But the marketing of the DNA experience is interesting and complicated, and it is not trivial for the scientific community or for our understanding of the implications of genomic medicine. It could play a role in the long-term consequences of increasing access to genetic information by individuals, employers, health insurers, and research institutions and the medical efficacy with which that information is applied. The 2009 American College of Clinical Pharmacology consensus was that "the response of consumers to such advertising can have both immediate and long-term effects on public health and the future adoption of pharmacogenetic/genomic testing"[8] The intense marketing of the powers and importance of DNA began with a group of scientists in the 1980s, who were promoting the importance of their laboratory work to Congress and the public. Some of their more ridiculous claims have migrated into mass advertising, in a PR narrative that may threaten all the potential benefits of genomic medicine which geneticists have struggled to establish since 1950. The scientific community (perhaps regretting earlier claims?) is right to worry about these promotions which could undermine public trust and ascribe more to DNA than it can possibly provide.

For most of his life, until his death in 2000, James Neel searched for genetic effects in the offspring of the survivors. But despite all the methods of contemporary molecular genetics, the genetic effects remained undetectable at a statistically significant level. A 2006 summary of results noted that no genetic effects could be identified despite almost 60 years of analysis of birth defects (untoward pregnancy outcome; namely, malformation, stillbirth, and perinatal death), chromosome aberrations, alterations of plasma and erythrocyte proteins as well as epidemiologic study on mortality (any cause) and cancer incidence (the latter study is still ongoing) (Nakamura, 2006).[9] Even molecular biological techniques and human genome sequence databases have not been able to document these effects—though genetic effects of radiation are readily tracked in experimental organisms like mice and flies (see Harper, 2008; Kay, 1993, 2000). The original purposes of mapping the human genome—to establish the impact of radiation exposure on the atomic bomb survivors—have therefore never been fulfilled. The NRC's cautious 1947 assessment still holds and is worth quoting again—genetic damage is probably there, but it cannot be detected:

> "Although there is every reason to infer that genetic effects can be produced and have been produced in man by atomic radiation, nevertheless the conference wishes to make it clear that it cannot guarantee significant results from this or any other study on the Japanese material. In contrast to laboratory data, this material is too much influenced by extraneous variables and too little adapted to disclosing genetic effects. In spite of these facts, the conference feels that this unique possibility for demonstrating genetic effects caused by atomic radiation should not be lost …" (National Research Council Committee on Atomic Casualties, 1947, 33).

The impact of the atomic bomb on genetics has been scientifically and technologically extremely productive. The frustrating search for genetic effects of the atomic bomb opened many new paths of research, and justified significant public spending and tremendous public interest. The risk of mutation haunted the Cold War and directly provoked the Human Genome Project, which was arguably born (or fledged) at the March 1984 meeting at the Radiation Effects Research Foundation high on Hijiyama Hill overlooking Hiroshima. But the story has not unfolded as expected and there have been many unintended consequences. The history of path breaking science, I would suggest, is never just a story about technical details, inside the laboratory, never even just a story about personalities and disciplines. It is also about politics, risk, desire, prediction and war. Why do we know what we know about the human genome? It is as much a historical question as a technical one.

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[8] See Ameer and Krivoy (2009).

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