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Authors
Timmermans, Stefan
Shostak, Sara

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Gene worlds

Stefan Timmermans
UCLA, USA

Sara Shostak
Brandeis University, USA

Abstract
Drawing from a critical sociology of knowledge perspective, we situate the production of genetic information within relevant political, financial, and professional contexts. We consider as well the broad range of social conditions that render genetic knowledge salient in clinical settings and for population health. This sociological analysis of genetic knowledge highlights how genetic knowledge flourishes and shapes social environments and how in turn environments select for particular forms of genetic knowledge. We examine the role of the laboratory, regulatory state, and social movements in the production of genetic knowledge and the clinic, family, and population health as critical sites where genetic knowledge becomes actionable.

Keywords
environment and health, genetics, technology in health care

Introduction

Contemporary US sociological interest in genetics often takes an "ethical, legal, and social implications" (ELSI) perspective, following the mandate—and the funding—of the ELSI program of the National Human Genome Research Institute (NHGRI). Many social scientists were critical of the initial focus of the ELSI program, which assumed a stark division between science and society, as if genetics existed in a temporal and spatial place independent of society (cf. Clarke et al., 2003; Reardon, 2005; Rose, 2007). However, this emphasis was congruent also with the focus of much of the critical work in sociology, which has been powerfully shaped by the critique of the *consequences* of

Corresponding author:
Stefan Timmermans, Department of Sociology, UCLA, 216 Haines Hall, 375 Portola Plaza, Los Angeles, CA 90095-1551, USA.
Email: stefan@SOC.UCLA.EDU

genetic information embedded in the geneticization thesis (Lippman, 1991) and prominent concerns that biological explanations would exist in a zero-sum relationship with sociological explanations (Duster, 2005, but see especially Duster, 2006). The consequences of genetic research for scientific and public understandings of racial categories also has been an ongoing concern in the field, with controversies about whether race is "socially constructed" playing out in the pages of prominent journals (Fujimura et al., 2014; Morning, 2014; Shiao et al., 2012). Further, sociologists see the individualization of disease risks—and, related, the rise of the person genetically at risk (Novas and Rose, 2000)—as a key aspect of contemporary biomedicalization (Clarke et al., 2003). Over time, sociologists of science, knowledge, and technology have demonstrated the importance of examining not only the effects of genetic knowledge, but also the contexts of its production, including laboratories (Fullwiley, 2007), scientific fields (Panofsky, 2014; Shostak 2013), markets (Rajan, 2006), and state projects (Benjamin, 2013).

Social scientists have been more sanguine about the potential of research on gene-environment interaction to elucidate the effects of social and physical environments. For example, Pescosolido (2006) contends that "the success of 'pure' biomedical science has provided new urgency to research that looks up from the microscope to focus on the environment" (p. 191). Similarly, sociologists argue that, "developments in genetics have only served to underscore the importance of social context" (Shanahan et al., 2010). Epigenetics asks "how environments come into the body and modulate the genome" and thereby offers a means of conceptualizing how socioeconomic differences—as manifest in differences in sociomaterial environments—become embodied (Landecker and Panofsky, 2013: 349). However, at the same time, epigenetics may render the social environment as a "fuzzy background" for the bioactive molecules which emerge as the "real" actors shaping human bodies, and their vulnerability (Landecker, 2011: 184). Consequently, social scientists have cautioned that how "the environment" is operationalized in contemporary genetics research is one of the critical challenges facing the life sciences in the post-genomic moment (Shostak and Moinester, 2015).

A group of sociologists has taken on this challenge by working directly with genetic data to examine individual outcomes of long-standing interest in the social sciences (Freese, 2008). They contend that disciplinary knowledge about the multi-level and processual character of institutions, as well as sociological research design, provides sociologists with the conceptual and empirical tools for specifying what the relevant environment is, and when and where it matters for genes (Pescosolido, 2006). Much of the sociological research that directly examines gene-environment interaction highlights the impact of social environments on a wide range of outcomes relevant to human health and well-being (Boardman et al., 2011; Guo and Stearns, 2002; Pescosolido et al., 2008). This "sociogenomic" approach infuses gene-environment research with a more sophisticated understanding of social environment and reminds genetic researchers of the limits of molecular causality.

We use the opportunity of the 20-year anniversary issue of *Health* to advance a different sociological analysis of genetics, engaging the topic from a critical sociology of knowledge perspective that asks both: (1) how clinical genetic knowledge is made possible and (2) what are its consequences for the worlds in and through which it travels? Following Becker's (1982) *Art Worlds*, we can think of equivalent *gene worlds*,

networks of people whose cooperative activity, organized via their conventional ways of doing things and subjected to regulations and resource constraints, produces current genetic knowledge. Echoing the example of McKinley, John B. (1979), we then seek to look at both the upstream factors that make clinical gene worlds possible, and the downstream dynamics that shape their uses and meanings.

Regardless of whether we take geographical areas, diseases, or populations as starting point, genetic information about health and disease is unequally distributed. Genetic knowledge becomes only possible in conducive social environments, and when acted upon, creates new understandings of disease, biographies, families, and social groupings. Our goal is to highlight the social worlds in which genes flourish, which include the political, financial, and professional contexts that enable genetic knowledge. Similarly, we are interested in the effects of genes in these contexts, especially the myriad social consequences for medical care, families, and population health. This is an important correction to early sociological work on genetics, which assumed that genetic information would always and already have tremendous power—for better or worse—across social milieus. It is also warranted by the extensive empirical literature on the social consequences of genetic information, which provides evidence of the multiple and contradictory effects of genetics across diverse social settings (Freese and Shostak 2009).

We start with the observation that even as genetic information is becoming increasingly available in clinical settings, whether this information is meaningful and actionable depends on a host of irreducibly social factors. These factors, in turn, may dialectically affect the production of genetic information, with consequences for both its availability and content. This observation directs analysis to the deeply social and material process of generating genetic data using information technologies, samples, databases, pedigrees, computing algorithms, assays, divisions of labor, and so on, characteristic of any laboratory practice. At each point in the genetic testing and sequencing process, assumptions about what qualifies as a genetic cause and how phenotype and genotype are related will affect the specifics of genetic knowledge production. The production of genetic knowledge then reflects a biomedical environment attuned to genetic causality, supported by research-funding agencies and corporations, authorized by public and private insurance agencies, and promoted by genetic professionals and their allies. These agencies not only set the conditions for genetic knowledge, but will also affect what genetic knowledge is available in clinical settings and who may take action as a consequence. These effects include the emergence of formal associations of families affected by specific genetic conditions which partner with scientific researchers to both set research agendas and provide the biological materials and first-hand reports that make them possible (Navon, 2011; Rabinow, 1996).

Our analytic lens also problematizes the social environments that allow clinical genetic findings to flourish. The notion of geneticization (Lippman, 1991) pointed to the opportunity costs of locating genetic causes of disease at the expense of fundamental causes of health and illness (Link and Phelan, 1995). A critical sociology of knowledge approach takes issue with the idea that knowing one's genome or disease-causing genetic variants automatically leads to preventative or curative action. The ability to act will be circumscribed not only by the specificity and clinical utility of the genetic information (penetrance, evolutionary conservation, predicted pathology, inheritability, etc.), but it

will also depend on the resources people have to act on the information and other, more pressing considerations. Importantly, as predicted by the theory of fundamental causality (Phelan et al., 2010), insofar as effective, individual-level interventions emerge based on genetic information, it may thereby exacerbate health inequalities at the population level.

In this short article, we have only space to highlight some of the many ways through which gene worlds operate. Our account of the social origins and consequences of genetic information is meant to be suggestive rather than exhaustive.

Genetic knowledge production

In practice, laboratories, state agencies, and the clinic are deeply intertwined. Indeed, the production and circulation of genetic knowledge is itself part of the apparatus that links the goals and concerns of science, governance, and clinical practice. Nonetheless, here we consider each as a separate locale where gene-environment interactions take place.

The Laboratory

Clinical genetic research and testing begins with the availability of genetic variations of the reference human genome. Yet, chromosomes, genes, and alleles are quintessentially invisible and to render them visible requires expensive and resource-intensive laboratory work. Laboratories can be viewed as archeological sites offering layered clues of diverse social worlds with every tool, assay, protocol, and animal as the outcome of collective social action. Due to the exponential increase in genetic knowledge, locating a genetic cause with exome sequencing, for example, depends heavily on curated databases such as Human Gene Mutation Database (HGMD) or Online Mendelian Inheritance in Man (OMIM), which aim to provide up-to-date compilations of the entire clinical genetic literature, showing the current association of genetic variants with various phenotypes based on gene functions. Such databases, however, are only as good as the quality of the published literature and mistakes and omissions are inevitable. Such mistakes will void causal correlations, leading to false positive and false negative test results (Timmermans, 2015).

Any causal genotype-phenotype correlation distilled in a database from a research article rests on co-segregation and linkage studies, genome-wide association studies (GWAS), and on functional and mechanistic experimental cell line or animal research determining the role of the gene in the disease pathway. In order to statistically power studies so that they are able to genotype rare disease-causing variants, linkage panels require patient cohorts in research consortia and biobanks, while presumed monogenic disease causality requires the study of multiple large families with similar clinical phenotypes. Never mind the computing and statistical challenges to detect the small effect sizes of gene-environment interactions in such endeavors, setting up such population cohort studies or biobanks is a complex social act requiring collaboration among scientists deliberating authorship rights, consent procedures, and exchange flows of information. Commercial genetic companies, for example, are often reluctant to deposit mutation data in repositories, rendering population estimates and penetrance assessments inaccurate.

A large sociological and bioethical literature has examined the setup of biobanks as a unique form of health policy that crosses regulatory, academic, and commercial concerns (see (Hoeyer, 2007; Waldby and Mitchell, 2006)). Support for biobanks remains large among the public (Lipworth et al., 2011) and researchers have explained this by examining broad public trust and local trust relationships between donor and clinician, which mediate the perception of risk and the perception for personal control. Every biobank input, or request for a donation, and every output, or research collaboration, is then steeped in structural power relationships involving a balance between trust and coercion as well as a culture of altruistic utilitarianism, in which individual body tissues serve the collective good.

The Regulatory State

Genetic research both relies upon and reproduces biopolitical paradigms, that is, "framework[s] of ideas, standards, formal procedures, and unarticulated understandings that specify how concerns about health, medicine, and the body are made the simultaneous focus of biomedicine and state policy" (Epstein, 2007: 17). As such, the apparatus through which the state "sees" and governs populations (i.e. vital statistics) represents an important context for genetic knowledge production.

The social construction of racial categories in biomedical genetic research provides a vivid example of how genetics both draws upon and recapitulates social categories that are central to contemporary governance. Faced with government mandates to include underrepresented groups and show population differences in biomedical research (Epstein, 2007), researchers have been puzzled with how to best classify people in racial and ethnic categories. Fullwiley (2007) documented how geneticists developed a technology called ancestry informative markers (AIM) to correspond human DNA with three to four major racial phenotypes. These markers, however, reflected historical environmental exposure as well as shared ancestry. They embed assumptions about the unique and direct ancestry tied to geography and historical time conforming to how North Americans imagine race. Similarly, Whitmarsh (2008) and Montaya (2011) observed that even researchers with a socially expansive view of race ended up resorting to pragmatic and expedient genetic markers of racial admixture. Shim et al. (2014) also find that genomic researchers consider self-identified racial categories convenient but blunt tools while embracing AIM as necessary, if imperfect, techniques suitable to capture an increasingly racially heterogeneous world. This body of research then captures how existing forms of social differentiation receive a new lease of life with genetic markers, even as, in the process, race and ethnicity are stripped from their associations with broader social determinants of health.

The state also plays a central role in shaping access to genetic testing, both in setting financing mechanisms for health care and in promulgating public health policy. The ever-shrinking cost of genome sequencing only captures part of the true cost of a clinical genetic test. In every country, there is a genetic financial gatekeeper, either a government regulatory agency or a private insurance company. In the market-driven US health care system, for example, every state determines what conditions to include for newborn screening, creating a patchwork of tests based on patient group advocacy and past

practices. Consequently, in 2006, the American College of Medical Genetics and Genomics issued recommendations to standardize the screening for 57 conditions based, in large part, on the capacity of new screening technologies rather than direct patient benefit (Watson et al., 2006). Patient advocacy organizations such as the March of Dimes picked up these recommendations and lobbied various statehouses to make the recommendation a national norm by 2008 (Timmermans and Buchbinder, 2013). This professional intervention kept newborn screening as a quasi-mandatory public health program rather than an optional private service. In the United Kingdom, in contrast, the National Screening Committee recommended that the National Health Service expanded the number of screened conditions from five to nine rare genetic conditions after a pilot study in January 2015 (Editorial, 2015). Here, we can see one possible feedback loop of how genetic information leads to further genetic testing: the experience and attributed successes of the United States are held up as an impetus for program expansion in other countries.

Regulatory, legal, and financial conditions that allow genetic testing to take place are the work of genetic enablers, entrepreneurs, and rationalizers: health economists conduct cost-benefit analyses showing that population testing for a rare genetic condition such as Gaucher's disease is cheaper than caring for an affected infant (Katz and Schweitzer, 2010), even though such analyses do not include the financial and social cost of false positives. Bioethicists call for liberal eugenics (Agar, 2004), a moral imperative to use genetic knowledge to avoid disability in the reproductive process. Anthropologists and social scientists suggest that parents and relatives will welcome even uncertain genetic information (Bailey et al., 2005). And then, of course, the field of genetic scientists (Panofsky, 2014), geneticists, and genetic counselors themselves promote not only the technologies but also a genetic mindset.

Citizenship and social movements

Genetic variants may also become a leverage point for groups to advocate for human rights to the state. The notion of genetic citizenship refers to the obligations, rights, duties, and forms of care that circulate between citizens and the state (Epstein, 2007; Petryna, 2002). Genetic citizenship may matter not just in health care but also in immigration procedures, criminal law, and employment (Kerr, 2003). It may both reinforce existing divisions between have and have-nots and offer new grounds for exclusion. Genetic information used in such claims-making may lack biomedical legitimacy, as in the case of nuclear test veteran's claim that illnesses are genetically transmitted due to epigenetic exposures (Trundle and Scott, 2013).

Genetic information is also a highly contested means of making and adjudicating claims to "indigeneity" and tribal citizenship. However, as Tallbear (2013) notes, "indigenous articulations of indigeneity emphasize political status and biological and cultural kinship constituted in dynamic, long-standing relations with each other and with living landscapes," in contrast to laboratory based measures of "genetic ancestry" (p. 509).

Lastly, observed inequities in exposure to health risks, such as environmental contaminants and chronic stress, and persistent health disparities among populations (Williams et al., 2010) may motivate individuals to participate in genetic claims-making

about the genetic effects of environmental exposures. Specifically, genetic knowledge is becoming a means by which disadvantaged populations—and population health researchers—seek to demonstrate the harms caused by such exposures. At the community level, we note efforts to use genetic biomarkers as evidence that environmental pollutants are causing DNA damage, and thereby harming human health (Shostak, 2013). Population health scientists are also increasingly interested in using genetic measures, including telomere length (Geronimus et al., 2015) and gene expression (Landecker, 2011), as a means of understanding the mechanisms by which social inequalities become embodied. This kind of gene-environment interaction inverts the more typical individual-level understanding of genetic risks, and may provide leverage for activism and policy initiatives to address the social determinants of health inequalities.

Reception of genetic information

No individual has done more to align genetic science with clinical medicine than Francis Collins, the former head of the Human Genome Project and current director of the National Institutes of Health. He starts his book, *The Language of Life* (Collins, 2010), with a story about a genetic condition running in his own family. His father-in-law tested positive for a variant in a gene associated with the neurological Charcot-Marie-Tooth disease. As this is an autosomal dominant disorder, his children have a 50 percent chance of inheriting the pathological variant. To Collins' surprise, his wife and her sister, who had struggled with neurological issues, refused genetic testing and thus the opportunity for a genetic diagnosis and information that may affect their children. Besides expressing puzzlement about their decision, Collins does not pause about the refusal to undergo genetic testing but builds the case for a genetic foundation for personalized medicine.

Clinical Encounters

Viewed sociologically, the refusal to take a genetic road is where the story lies because it questions the rationalist assumption that people welcome genetic information and will act on this information in ways that align with professional medical values and prerogatives. In fact, even individuals' stated preferences regarding hypothetical genetic testing do not equate with actual uptake, when tests are made available. For example, in early studies of Huntington disease, most individuals at risk expressed interest in presymptomatic genetic testing, but uptake rates have been less than 10 percent (Krukenberg et al., 2013); a similar pattern has been observed in regard to genetic testing for hereditary breast and ovarian cancer, although uptake has increased in recent years (Ropka et al., 2006).

And, indeed, why would genetic knowledge differ from any other kind of medical knowledge that is filtered based on disease characteristics, life priorities, and resources available to act on information? Genetic information, even with its heritability implications, still remains a result communicated by a medical expert entering a patient's biography at a particular time and place with consequences for a future (Bury, 1982). As such, all the issues that affect what clinicians call the "intractable problem" of compliance or adherence and what health services researchers point to in terms of access of care will impact the demand for and reception of genetic test results.

Such observations raise questions about how genetic information becomes a meaningful sign in an already over-determined clinical situation. Often, it fails to signify. Many potential patients and their relatives refuse genetic testing. Browner et al. found that Mexican-origin women refused prenatal genetic testing in part due to the non-directive nature of genetic counseling and problems of trust (Browner et al., 2003) while other women employed their own risk assessments to forego prenatal testing (Markens et al., 1999). Rayna Rapp (2000) noted the clash of worldviews between genetic counselors and women about the need to test for reproductive disorders with amniocentesis and draw the "appropriate" conclusion from test results.

The central message of social science studies in genetic clinics in locations as diverse as France, the United Kingdom, Canada, the Netherlands, New Zealand, Israel, and the United States is that molecular information is rarely conclusive in biomedicine but requires interpretation along with other signs and symptoms (Atkinson et al., 2001; Bourret and Rabeharisoa, 2008; Callon and Rabeharisoa, 2004; Conrad and Gabe, 1999; Latimer et al., 2006; Rabeharisoa and Bourret, 2009; Raz and Vizner, 2008; Wood et al., 2003). The informative value of genetic analyses is filtered through relevant disease, patient, clinician, and genetic characteristics. More important than the genetic nature is the actual content and the context in which the information was sought, given, and received. Thus, if the genetic information confirms a diagnosis after a patient has had debilitating unexplained symptoms, the results are often accepted with a sense of quiet resignation. Patients with neurological symptoms expressed relief after finally obtaining a conclusive diagnosis of a progressive, degenerative neurological disease, which would also likely be the patient's cause of death (Browner and Preloran, 2010). This sense of relief is unsurprising considering the literature on contested illnesses, where the presence of unexplained symptoms might raise the suspicion of mental instability and where not knowing is often experienced as worse than having a disease (Barker, 2005; Dumit, 2006).

If the genetic information confirms a condition associated with mental retardation—such as fragile X syndrome—but the symptoms at the time of diagnosis are not clear, patients and their caregivers may find value in the prognostic uncertainty of the results (McLaughlin, 2008; Whitmarsh et al., 2007). The diagnosis may well be definitive but the actual manifestation of the syndrome in the specific patient remains indeterminate.

These disease-based contextualizations are not only an issue for patients and their relatives but also for professional geneticists. One team of social scientists observed that geneticists routinely qualified molecular test results in light of symptoms and morphological signs (Latimer et al., 2006). Various social scientists in different countries have demonstrated that genetic testing leads to the expansion of disease categories and requires reconciling molecular with other bases of disease (Hedgecoe, 2003; Keating and Cambrosio, 2000; Timmermans and Buchbinder, 2012; Vailly, 2008). Close analysis of doctor-patient interactions has shown that that geneticists draw upon various communication strategies to contextualize the probability that a genetic disorder may manifest in a patient (Sarangi et al., 2003). Thus, one team noted with respect to cancer and psychiatric genetics "mutations, far from reifying and simplifying pathological situations, expand and recompose them in different ways" (Rabeharisoa and Bourret, 2009: 699).

Families

Genetic information almost always raises questions about similarity, difference, and intergenerational transmission, which interpellate the family as critical "downstream" gene world. The family is an especially salient site in the case of disease risks that are transmitted intergenerationally. Moreover, with the rise of epigenetics, the maternal body itself is positioned as an environment with long-term consequences for the disease risks of offspring (e.g. adult onset diseases) (Richardson, 2015). With the availability of pre-implantation genetic diagnosis (PGD), the prospect of designer babies sparks the cultural imagination, even in the absence of such medical practice (Franklin and Roberts, 2006).

Across diverse conditions, including Alzheimer's disease, epilepsy, cancer, and mental illness, researchers have observed that when genetic information offers a likelihood of risk for a familial disease such as cancer, its informative value will be evaluated against the observed experience of other relatives with the disease and their experiences (Scott et al., 2005). Family members use their personal observations as a means of calibrating their response to genetic information. For example, if their relatives have a disease that is not considered debilitating on a daily basis, as in thrombophilia (Saukko et al., 2006), prospective patients may ignore the information. Research with parents and siblings of a child with disabilities on prenatal testing shows that the possibility of prenatal testing becomes a referendum on the disabled child and depends on that person's quality of life and position within the family (Boardman, 2014; Rapp, 2000; Raspberry and Skinner, 2011). More important than genetic information, *sui generis* is what social scientists called the "subjective badness" of the information or the extent to which an unwanted outcome matters to a patient (Bogardus et al., 1999).

Genetic information has the potential to create new biological ties between relatives, shifting even potential kin relationships (Atkinson et al., 2013). In contrast to formal scientific understandings of genetics and heredity, many individuals hold "personal theories of inheritance" (Shostak et al., 2011) which emphasize their perceptions of commonalities among family members, what Lock et al., (2007) call theories of "blended inheritance." Genetic information can also affect the formation of family ties. People living with sickle cell disease, for example, may demand that their partners get tested for the trait, and then break-off relationships if carrier status is revealed, because they do not want any children to live the pain they are living (Ross, 2015). Conforming Rabinow's prophetic vision about biosociality, genetic information may also form a new foundation for social group formation, where a single genetic variant becomes the element bringing people together (Navon, 2011).

Populations

Alongside its potential to create new individual and collective identities, genetics also interacts in important ways with existing populations. Collective identities that pre-date genetics can shape not only what genetic information means, but also how it is created, distributed, and acted upon. Additionally, population-level differences in the resources that allow individuals to both access and leverage biomedical knowledge (Link and

Phelan, 1995) can be expected to shape perceptions of genetic information, as well as whether and how it is used.

The association between specific conditions and identifiable racial and ethnic groups is often overstated in genetics research, due in no small part to inadequate conceptualization of what race and ethnicity are and how they matter to health and illness (Sankar et al., 2007). Given the history of eugenics and the use of purported genetic knowledge to justify the oppression and abuse of racial and ethnic groups, there is well-founded concern about how genetics may reify socially constructed categories of race and ethnicity (Bliss, 2012; Wailoo and Pemberton, 2006).

However, genes also interact with subjectively meaningful ethnic identities. For example, the *Dor Yeshorim* (DY) program was started in the 1980s, by an orthodox Rabbi, after four of his children died from Tay-Sachs disease. DY tests young Ashkenazi Jews for recessive genetic diseases relatively prevalent among this population. Rather than simply informing individuals about their carrier status, the leaders of DY developed a sophisticated social arrangement aimed at preventing disease while avoiding the stigmatization of individual carriers. The individuals being tested are not informed of the results. Instead, two young people contemplating a relationship can enter a code to check if they are carriers of the same genetic disease. If that is the case, the prospective partners are told that marriage is not advisable. DY locates genetic risk at the "jointness" of the couple, rather than making it an individual-level trait (Prainsack and Siegal, 2006). This program has been lauded for reducing the births of affected children, and now makes its services available worldwide. Importantly, DY also exemplifies how individuals can shape the contexts in which genetic information becomes available and actionable (Raz and Vizner, 2008).

Insofar as genetic information allows individuals to take steps to reduce their risk of disease and/or improves treatment options, then populations with different resources will interact with genetic knowledge, irrespective of whether these resources serve as a basis of subjective social identity. Of particular concern is the possibility that this kind of interaction may exacerbate health disparities. For example, there is some evidence that lower maternal education is associated with higher child blood phenylalanine among children with phenylketonuria (PKU), apparently as a result of poorer adherence to a low phenylalanine diet (Macdonald et al., 2008). Consequently, while there is obvious value to the genetic knowledge that allows for prevention of PKU, this form of genetic testing may have created an education-related health disparity where none existed before. A similar dynamic might be predicted in regard to genetic testing for susceptibility to various cancers, given that research suggests that racial/ethnic disparities in cancer mortality are associated with the degree to which the kind of cancer is amenable to medical interventions (Tehranifar et al., 2009). As science increases the leverage that humans have over genetic risks to their health, population level sociodemographic differences in Socio-Economic Status (SES), education, and their correlates may become relevant for understanding variation in the utilization of knowledge, technology, and ultimately outcomes of genetic knowledge.

Conclusion

Genetic knowledge is produced and consumed in *gene worlds*, networks of people who work toward the common goal of clinically actionable genetic information in a context

of government regulations, profit motives, and limited resources. Gene worlds thrive upon the hope that genetic diagnoses will open up opportunities for disease management and treatment. There are many such gene worlds, and they vary by disease categories, by patient population, and by geographical areas. Some niches are genetically well-populated: for certain cancers, metabolic and psychiatric disorders in the United States, genetic testing is increasingly becoming the standard of care, especially for patients with generous insurance policies or the ability to pay out-of-pocket. For other diseases and patient populations, genetic testing is available only under research protocols or as yet inconceivable. In other worlds, genetic testing remains uncertain and contested. In gene worlds, configurations of genetic knowledge emerge out of available resources and genotype-phenotype correlations and, in turn, laboratory, state, and other gene promoters—and resisters—are built around genetic findings.

We have argued that it is exactly these gene worlds that require sociological scrutiny as a means of challenging the self-fulfilling prophecy of genetic research across social contexts. The self-fulfilling character does not only relate to the rebooting of diseases as genetic due to the relentless search for phenotype-genotype correlations, but also to the ability to change a genetic make-up when, for example, reproductive matches are no longer advisable. A critical sociology of knowledge approach highlights that genes are embodied in people with biographies, life goals, communities, differential access to resources, and varying ways to act on genetic information. Our ability for introspection and to take genetic information, even if still uncertain and tentative, reflexively into consideration renders this information actionable. Myriad power relations structure these dynamic processes, with multiple feedback loops from genes to environments, shaping both the somatic and population body.

We have listed some of the drivers behind the contemporary focus on building gene worlds on gene-environment interaction but it is unclear what the desired endpoint is of this massive investment of resources, especially for clinical management. The literature shows preciously few instances where the hype or fear about genetic determinism is confirmed. Instead, we find skepticism, resistance, snubs, workarounds, appropriations, and modest clinical payoff of genetic test results. Only occasionally is there a culture of reaction that has shifted individual patient trajectories and population health (breast cancer (BRCA) screening is the clearest example). Rather than a clinical revolution, we now witness the institutionalization gene worlds with start-ups, academic spinoffs, and established laboratory multinationals vying to corner the genetics "market." Geneticists describe how their national conferences have shifted from low-key gatherings to heavily sponsored events replete with trinkets from competing laboratories, sponsored talks, and paid lunches.

Genes, environments, and their interactions matter as epistemic projects, though, because they indicate the opportunity costs of the inequitable proliferation of genetic knowledge. While we have to be careful not to presume that the mere presence of genetic information implies a loss of focus on social and environmental factors, the possibilities for social action are different when, for example, race and ethnicity become established through genetic biomarkers rather than through self-identification. We also predict instances of increasing health disparities because populations have disparate access to genetic information and the ability to act on genetic information is stratified by access to social and medical resources.

Our purpose has been to contextualize the social worlds that make genetic information possible and actionable. As such, this project fits in with a long tradition of sociology of knowledge to demonstrate the socially manufactured nature of quickly reified knowledge (Berger and Luckmann, 1966). However, it bears repeating that this is not the only possible sociological engagement with genetics, or with gene-environment interaction: others have conducted innovative research that expands the role of the environment from cellular to more conventional social factors and that show the disproportionate genetic embodiment of environmental insults among marginalized groups. Both sociological research approaches carve out a space for complicating our engagement with proliferating and expanding gene worlds.

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Author biographies

Stefan Timmermans is Professor of Sociology at UCLA. His research interests include sociology of health and illness, death and dying, and qualitative research methods. He is the author, most recently, of *Abductive Analysis: Theorizing Qualitative Research* (Chicago, 2014, with Iddo Tavory).

Sara Shostak is Associate Professor of Sociology at Brandeis University. Her research interests include the sociology of health and illness, science and technology studies, and environmental sociology. She is the author of *Exposed Science: Genes, The Environment, and the Politics of Population Health* (University of California Press, 2013).