The ELSI Virtual Forum, 30 Years of the Genome: Integrating and Applying ELSI Research

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Abstract: This paper reports our analysis of the ELSI Virtual Forum: 30 Years of the Genome: Integrating and Applying ELSI Research, an online meeting of scholars focused on the ethical, legal, and social implications (ELSI) of genetics and genomics.

Introduction

On March 3, 1989, the National Center for Human Genome Research (NCHGR) at the U.S. National Institutes of Health (NIH) and its partner in the Human Genome Project (HGP), the Office of Health and Environmental Research at the Department of Energy (DOE), requested its first funding applications from researchers in bioethics, philosophy, law, economics, sociology, health policy, and other disciplines to explore the ethical, legal, and social implications (ELSI) of mapping and sequencing the human genome. Today, nearing 20 years after the completion of the Human Genome Project and in the wake of substantial progress toward the implementation of genomic medicine, the ELSI Research Program of the National Human Genome Research Institute (NHGRI) at the NIH continues the work of these original grantmaking programs. More than thirty years of support have grown ELSI research into a robust, global field of study that explores a variety of issues in genetics and genomics research and its clinical translation, as well as broader societal issues raised by emerging technologies in the life sciences

The first forum for U.S. ELSI researchers to present their work, the *ELSI Congress*, was organized by the NIH and held in January of 2001 in Bethesda, Maryland. Three subsequent ELSI Congresses, *Translating ELSI* (2008) hosted by Case Western University; *Exploring the ELSI Universe* (2011) hosted by the Center for Genomics and Society at the University of North Carolina at Chapel Hill, an NHGRI-funded Center of Excellence in ELSI Research (CEER); and *Genomics and Society: Expanding the ELSI Universe* (2017) hosted by the Center for Research on Ethical, Legal, and Social Implications of Psychiatric, Neurologic, & Behavioral Genetics, a CEER at Columbia University, continued the ELSI Congress tradition.

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In 2019, NHGRI awarded the Division of Ethics at Columbia University and the Stanford Center for Biomedical Ethics funding to organize three future ELSI Congresses (2020, 2022, and 2024).

In early 2020, the organizing committee for the 5th ELSI Congress[1] titled the meeting the *5th ELSI Congress: 30 Years of the Genome: Integrating and Applying ELSI Research* in commemoration of the thirtieth anniversary of the ELSI Research Program at NHGRI. They called for proposals, selected topics for the keynote and plenary sessions, invited speakers, scored abstracts, and planned an in-person meeting for 300 attendees with more than 200 panel, paper, flash, and poster presentations at Columbia University in New York City. An innovative feature of their planning process was the drafting and implementation of a Code of Conduct. Prompted by the bullying, sexism, and sexual harassment revealed over past decades in the medical-academic environment and throughout society, and in particular by the #metoo movement, the committee followed the lead of a number of major academic and scientific organizations in developing a Code of Conduct for meetings held under its aegis.

In early March 2020, when the COVID-19 pandemic arrived in the United States, the organizing committee pivoted to a virtual program that retained the scheduled keynote and three plenary sessions and added an abbreviated set of panel presentations. The committee reduced the schedule from three days to two, June 14-15, 2020, and shortened the day length to accommodate a greater range of time zones. Given the time constraints introduced by the reduced program, the committee selected just four of the ten panel proposals with the highest reviewer scores to represent a range of topics, institutions, and speakers.[2] To maximize inclusion, they did away with the registration fee and recorded and posted the entire proceeding online at ELSIhub.org. In its new, online format, the *ELSI Virtual Forum: 30 Years of the Genome: Integrating and Applying ELSI Research* (hereinafter referred to as the *ELSI Virtual Forum*) attracted more than 1,000 registrants and over 400 attendees from 46 countries to its eight-session program.

This paper is based on a post-forum analysis by session notetakers and the *ELSI Virtual Forum* video archive on ELSIhub.org. In the paper that follows, we present the cross-cutting themes we identified during our review of the proceedings with illustrative examples. Our analysis identified concern about the possible appearance of human biases, such as those that influence the selection of socially valued phenotypes, in the translation of genome science as a central focus of the *ELSI Virtual Forum*. As the following examples illustrate, a potential consequence of not attending to these biases is the differential allocation of resources and the ultimate result of disparate health outcomes for subgroups of the human population. In this paper, we use comments from the proceedings and published literature to demonstrate how, as an alternative to accepting this circumstance, justice can be realized in two contexts: 1) by attending to equity in our decisions about how we allocate clinical and research resources, and 2) by attending to the equitable distribution of the benefits and risks of sharing genomic data. In the conclusion, we anticipate the ways in which the conversations of the *ELSI Virtual Forum* might continue at the 5th ELSI Congress, *ELSIcon2022: Innovating for a Just and Equitable Future*, scheduled for May 31 - June 3, 2022.

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Part I. Attending to Equity in Allocation Decisions about Clinical and Research Resources

A. Constructing Socially Valued Identities

Two *ELSI Virtual Forum* sessions explored the history and legacy of eugenics in the United States [B-1; C-2]. In the plenary session, titled *CRISPR and Human Identity: Governing Germline Gene Editing* and moderated by Josephine Johnston (The Hastings Center), the three speakers considered the ethical permissibility of clinical uses of germline gene editing technology and interrogated the unjust and unequal systems within which this technology will operate. In *Learning from Eugenics*, for example, Rosemarie Garland-Thomson (Emory University and The Hastings Center) noted that the Civil Rights Act of 1964 and the Disability Rights Act of 1990 created enfranchised groups of people based on physiological characteristics and both a federal and moral mandate to protect people with disabilities as well as the "temporarily able-bodied" against unequal treatment and discrimination. As civil and human rights law define justice as the equal distribution of and access to economic, social, and cultural resources, withholding these resources on the bases of disability, sex, or race is both unethical and illegal. Instructive for the present moment, Garland-Thomson described the implementation of eugenics philosophy during the Holocaust as a "massive resource distribution project" that withheld resources from groups that the regime deemed *inferior* and redistributed them to groups that the regime deemed *superior* [C-2].

George Daley (Harvard University) suggested that, if they can be realized safely, there may be some ethically permissible and even beneficial applications of heritable gene editing technologies, especially those that reduce suffering by preventing genetic disease [C-2, Daley]. Furthering the discussion of permissible clinical uses of gene editing technologies, Bartha Knoppers (McGill University) suggested that some of the rationale that could be used as a justification for clinical germline genetic editing for severe and incurable conditions is already present worldwide in the guidelines that allow parents to select embryos in the context of preimplantation genetic diagnosis (PGD) [C-2]. As such, she continued, we may already have international laws, regulations, and guidelines — for example, those that seek to guarantee fundamental global, human rights including the right to the highest attainable state of health, the right to share in the benefits of scientific advances, and the rights of future generations — available for use in our decision-making about the appropriate regulatory structures for germline editing technology. However, a major gap that should be filled, Knoppers concluded, is a public dialogue about whether to proceed with the implementation of germline genetic editing at all [C-2, Knoppers]. Although patients with genetic conditions may express a desire for the clinical implementation of this technology, Garland-Thomson explained, they may have this opinion because, without access to resources like treatments and even social supports, they can experience deficits in their quality of life. If we are going to select against forms of human variation using the argument that we are eradicating human suffering, Garland-Thompson suggested, we need to think about what human suffering is. Is it an absolute state or a state brought on by the lack of resources? As a society, we are charged with determining the most ethical balance between allocating resources to improve the quality of life of individuals with, for example, Huntington's disease (HD) or making investments toward eradicating HD through the application of human germline gene editing [C-2, Garland-Thomson].

The second session on this topic, *Studying America's Eugenic Era through an ELSI Lens: Data, Context, and Relevance*, Natalie Lira (University of Illinois Urbana-Champaign), Nicole Novak (University of Iowa), Elyse Thulin (University of Michigan), and Alexandra Minna Stern (University of Michigan) presented evidence for the asymmetric implementation of forced sterilization in the United States, which disproportionately harmed members of socially devalued age groups, genders, races, ethnicities, disabilities, and nationalities [B-1]. Their analysis relied on a novel dataset built using archival material associated with nearly 35,000 cases of eugenic sterilization in four states (California, Iowa, North Carolina, and Michigan) and employed machine learning text analysis techniques to evaluate mass media portrayals of eugenics throughout the 20th century.

In the early twentieth century, compulsory sterilization became instantiated in state law. It was legitimated and expanded as a practice following the outcome of the U.S. Supreme Court case, *Buck v. Bell*, which affirmed the constitutionality of the sterilization law in Virginia.[3] As one example of the criteria that were used to justify sterilization, a 1909 California law authorized sterilization surgery on patients committed to state hospitals whom hospital superintendents designated as sufferers of a "mental disease which may have been inherited" that was "likely to be transmitted to descendants," without the voluntary consent of the patient. California health officials who implemented the sterilization program argued that it

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was both of therapeutic value *and* beneficial because it relieved the state of the economic burden of care for the progeny of institutionalized women.[4] From 1907–1970, approximately 60,000 individuals in the United States were sterilized based on eugenic criteria about who was fit for reproduction [B-1, Lira].

ELSI Virtual Forum panelist Nicole Novak employed data visualization tools to demonstrate that the impacts of sterilization were more extreme for specific groups of people in certain time periods.[5] These trends provide evidence for the operation of ideologically constructed, mutable notions of fitness for reproduction, normality, and disability in the implementation of state-mandated deprivation of reproductive capacity [Novak, B-1]. In their 2017 paper that draws on the same dataset, the panelists called for reparations in the form of monetary compensation to the estimated 831 survivors of California's sterilization program.[6] Similarly, in his keynote remarks, Eric Juengst (University of North Carolina) noted the appearance of "wellness genomics" in the commercial sector, part of a broader interest in the discovery of beneficial gene variants, or those associated with traits at the high end of the normal functional variation curve. Selecting socially valued traits, identifying exceptional individuals for study, and using the knowledge derived from studies of beneficial variants to develop interventions that might enhance the human genome, also raise many issues worthy of ELSI study [A-1].

B. Human Bias and Artificial Intelligence in Precision Medicine

Precision medicine promises a solution to the problems of the "one-size fits all approach to healthcare" among which, said panelist David Magnus (Stanford University), is the potential for bias in clinical decision making, limitations on the number of variables that physicians can consider in their interactions with patients, and the fact that most clinical decision making is based on "data" derived from individual snapshots of patients in particular moments in time, as opposed to a continuous data stream. A recognized feature of precision medicine is its utilization of so called "big data" (e.g., genomic data, electronic health record data, data from wearable mobile health technologies, etc.) to classify groups of people for treatment, diagnosis, or prognosis and predict their health outcomes — the goals of which are to improve quality of care and reduce healthcare costs. Given the vast predictive analytics requirements, achieving this vision will rely on artificial intelligence (AI). AI, Magnus explained, could also one day be integral to the feedback loop in the "Learning Healthcare System" in which every patient is a research subject who contributes their data to the study of improvements to the healthcare system [B-2, Magnus].

In the session titled *New Models for Ethical AI in Precision Medicine: Empirical and Normative ELSI Inquiry*, moderated by Mildred Cho (Stanford University), Magnus and the other panelists examined the practices, work processes, and contexts in which design decisions are made by those developing AI for clinical applications and caution that the implementation of these technologies could amplify human bias. This possibility arises because of three distinctive features of AI in precision medicine: 1) the development process is technically and organizationally complex, requiring multiple types of expertise, including software engineers and computer scientists who may not be familiar with the regulatory and ethical frameworks that guide medicine; 2) sources of systematic bias in AI models have been identified, but responsibility for preventing discriminatory decision-making and action on the basis of biased AI is not established; and 3) third-party developers and users of AI for precision medicine may have divergent interests and needs. For example, clinical decision support powered by AI for the purpose of reducing healthcare costs may conflict with patient interests, if those interests are better served by more costly alternatives [B-2, Magnus; B-2, Sankar; B-2, Nichol]. AI developers may also be tempted to program machine learning algorithms to prompt clinical users to select actions that would improve health care quality *indicators* but not necessarily improve care and/or generate profits for various stakeholders by recommending drugs, tests, or devices.[7]

Ariadne Nichol (Stanford University) presented the results of research on the characteristics of companies involved in the production of predictive machine learning products developed to reduce healthcare costs, while improving quality of care, that have been implemented in health care systems across the United States. This information, Nichol argued, is essential to the assessment of the ability of these organizations to self-regulate considering the movement of the FDA toward a pre-certification program for companies that develop these products [B-2]. Based on searches of two literature databases, Nichol and colleagues identified 106 machine learning-based products that used electronic health record data and were implemented by a health system or provider with the goal of improving healthcare efficiency. These products were developed by 96 organizations, most of which were computer software companies. Among computer software companies, those specializing in healthcare were

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more likely to have a clinician at an executive level of management or on their board, than the general computer software companies. The latter were often large companies (over 1,000 employees) with very limited clinical expertise at any level of leadership. In their interviews with developers at these 96 organizations, Nichol and colleagues identified a lack of clinical expertise, lack of familiarity with handling procedures for medical data and medical regulation, and conflicts between business interests of providers of machine learning products and patient interests (for example, when start-ups are pressured to serve the needs of healthcare insurance companies in order to access the patient charts necessary to the development of their products) as potential barriers to the development of safe, effective, and ethical machine learning healthcare products [B-2, Nichol].

As algorithm developers select outcomes for optimization and apply weight to different input variables, value decisions become embedded in the design of machine learning algorithms and may result in unequal and inappropriate allocation of healthcare resources [B-2, Magnus]. For example, when health care cost was used as a proxy for health care needs in the design of an algorithm employed to allocate resources to outpatients with serious health conditions, it resulted in systematic racial bias against African Americans because the proxy failed to account for differences in health care utilization that are patterned by race.[8] The potential for bias against minority groups is similarly amplified, Magnus explained, by the "unbearable whiteness of most research repositories" [B-2, Magnus]. Although the situation is beginning to improve, currently available genomic repositories are composed almost entirely of data from individuals of European descent.[9] As a result, the predictions of any machine learning algorithms trained with data from these repositories as a reference set, are not accurate when used to predict outcomes for non-Europeans. To reduce health disparities, researchers will need to collect data from other populations. However, data alone will not ensure equitable outcomes for all users of precision medicine [B-2, Magnus].

Panelist Pamela Sankar (University of Pennsylvania) agreed and cautioned forum attendees not to look for simple, technology- or data-based solutions to intractable social problems. In her presentation, Sankar noted that when machine learning in precision medicine is discussed in the ethics literature, authors often portray machine learning as an independent actor that is itself the cause of bias. In this way, machine learning becomes the problem, as opposed to flawed applications or uses. Sankar suggested that locating problems within the technology can lead to the proposal of solutions that involve changing the technology in lieu of solutions situated in the broader context in which the technology is used or those that involve an interrogation of who is making decisions about its use and how we are using it. In the case of solutions to the possibility that machine learning will exacerbate health disparities, the solution that the authors in Sankar's analysis proposed tended to be increasing enrollment numbers of minority participants in research in the hopes that this will result in access to unbiased treatment. This numerical goal, Sankar argued, obscures the obdurate social practices and histories of discrimination that are the true, upstream causes of health disparities and masks the difficulties posed by finding durable solutions to these issues [B-2].

Data that can be interpreted by AI as evidence of differences in health outcomes between population groups may be the result of biased treatment decisions upstream [B-2, Magnus]. For example, 43% of pediatric programs "always" or "usually" take neurodevelopmental delay into consideration when making transplant listing decisions.[10] When the patients with neurodevelopmental delays die in some programs because they are not considered for transplants, this produces outcome data indicating that the condition is fatal. When the biased treatment decisions that resulted in death are codified into the dataset used to train machine learning algorithms and then deployed as clinical decision support tools, the biased treatment decisions are recreated. In the same way, these algorithms could code variables related to socioeconomic determinants of health as predictive of poor outcomes and reproduce bias against populations most impacted by these determinants [B-2, Magnus]. The panelists urged developers and manufacturers to seek an understanding of unintended consequences of machine learning algorithms ahead of their deployment in the healthcare setting by conducting rigorous modeling and pilot testing [B-2, Magnus; B-2, Sankar; B-2, Nichol].

C. In Pursuit of Data Justice

In the healthcare setting, genomic researchers and ELSI scholars alike are recognizing the need to collect data from diverse populations to make the equitable distribution of the benefits promised by advances in genomic medicine possible. However, especially in the case of non-clinical applications of genetic data, the achievement of this aim must be tempered by the potential for data collection to disproportionately harm members of marginalized groups. Unlike the datasets utilized in precision medicine, DNA profiles

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in forensic databases, such as CODIS, the national forensic DNA database, contain a disproportionate number of DNA profiles collected from African American people. CODIS data is collected from individuals convicted of crimes as well as, in some states, individuals who have been *accused of* a crime. Panelists in this session expressed concern that the representation of DNA profiles in the CODIS database reproduces the racial disparities of the United States criminal justice system [B-4, McGuire; B-4, Hazel]. African Americans comprise 13.26% of the U.S. population and 34.47% of the profiles in federal and state forensic databases.[11] James Hazel (Access to Medicine Foundation) noted the recent expansion of DNA collection by law enforcement at the federal and state level to include individuals that have neither been accused or convicted of a crime. These collections are purported to be voluntary; however, in light of the power dynamic between members of the public and law enforcement, it is possible that consent may be coerced [B-4, Hazel]. The popularity of direct-to-consumer genetic testing and expanded collection of genomic information in research and healthcare settings, has impacted the pool of data that is potentially available to law enforcement. This is especially concerning because privacy protections, such as HIPAA in the case of medical data, have largely been untested in the courts [B-4]. As a thought experiment to resolve the issues presented by data disparities by race, Hazel proposed a universal genetic forensic database with improved privacy protections, accessible only in response to a warrant.[12]

Other panelists explored the ethical permissibility of investigative genetic genealogy (IGG) technology, a technique used by law enforcement to generate leads when they are unable to generate them using traditional investigative methods. In common practice, if a DNA sample is found at a crime scene, law enforcement will attempt to make a match between a suspect and a profile in CODIS. However, in cases in which law enforcement has not been able to identify a suspect, it might use IGG to match the DNA sample from the crime scene to related individuals in genetic genealogy databases *beyond* those controlled and managed by law enforcement or federal and state governments. These databases can include those owned by private companies, provided that their terms of service and privacy policies are favorable to this use. Using these data, law enforcement will construct a family tree, investigate individuals on the tree to identify a potential suspect, collect a new DNA sample from that person, and then test it to determine if it matches the sample from the crime scene. Importantly, law enforcement is expanding its reach into additional genetic data repositories [B-4, McGuire].

Jennifer Wagner (Penn State University) provided examples of how successive acts of Congress including the DNA Identification Act (1994), the DNA Analysis Backlog Elimination Act (2000), the USA Patriot Act (2001), the Justice for All Act (2004), the DNA Fingerprint (2005), and the Rapid DNA Act (2017) have expanded the scope and reach of DNA databases controlled by law enforcement (e.g., CODIS), by enabling expanded collections across time [B-4]. Wagner cautioned that IGG and facial recognition technologies are not immune to their potential to be used by law enforcement to contribute to and perpetuate structural violence. The data disparities we have, Wagner emphasized, result in the hyper-surveillance of the data rich and hypo-surveillance of the data poor in both law enforcement and biomedical contexts. Data justice, she asserted, must equitably distribute the benefits and burdens of genetic/omic technologies, including "datafication" [B-4, Wagner]. "Datafication," a transformation in how society processes information made possible by improvements in computer memory and processing power among other advances, refers to the rendering of previously unquantified aspects of the world, including previously private information, into data for use in prediction applications[13] (see Clarke, 1988[14] for the origin of the concept).

Other presenters were similarly concerned about another use of "big data" for the purposes of prediction. The development and aggregation of huge datasets of genomic information, often including hundreds of thousands of participants, has enabled large-scale genome-wide association studies (GWAS) of a variety of phenotypes. Although much of this work has focused on medical conditions, panelists in the plenary session, *Polygenic Risk Scores & Behavioral Traits: Interrogating the Science & Ethics,* moderated by Paul Appelbaum (Columbia University), noted an increased scholarly interest in the analyses of behavioral phenotypes, e.g., same-sex sexual behavior and social outcomes like educational attainment and income. This session began with an overview by Dalton Conley (Princeton University) of how polygenic scores (PGS) or polygenic indexes (PGI) are constructed and applied to social traits [C-1, Conley] (see Box 1 of Becker et al., 2021[15] for a discussion about terminology). The approach used in candidate gene studies, which use one single nucleotide polymorphism (SNP) to predict an outcome, has largely proven to be unsuccessful for the prediction of social and behavioral traits, because they are polygenic; in other words, their genetic components are the result

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of the small effects of many individual SNPs spread across the entire genome. The polygenic score has become a popular tool for aggregating the effects of variations at multiple loci. Conley argued that PGS can be used productively to advance our understanding of long-standing social science research questions, if for example, they can be used to "control for" personal and peer genetic influences on social and behavioral traits or, as another example, examine the directionality of parent-child influences to garner a greater understanding of the mechanisms of familial socialization [C-1].

In cases in which PGS are nearing clinical utility as components of an individual risk profile, such as in calculations of risk of myocardial infarction, Steve Hyman (Harvard University) suggested that it may be appropriate to use them, especially when the information they provide is actionable. However, he expressed concern about the potential for misguided policy applications of premature technologies or poorly understood datasets, particularly in the cases of polygenic scores for educational attainment, cognitive ability for educational tracking purposes, or selection among IVF embryos for implantation. It is important to remember that even highly heritable traits exhibit change at the population level in conjunction with changes in the environment over time (e.g., mature height increases as nutrition improves) and can also be modifiable at the individual level (for example in the prevention of phenylketonuria with a phenylalanine-free diet). Hyman noted that polygenic scores exhibit lower predictive value when scores are developed in one population group and applied to other groups that were not represented in the reference set. This is an important limitation because, as mentioned previously, genomic data in available repositories is mostly from individuals of European ancestry [C-1, Hyman].

Part II. Attending to the Equitable Distribution of the Benefits and Risks of Sharing Genomic Data

A. Participants as Partners

Several presenters considered ways to include diverse stakeholders in both the genomics research process and the discussion of ethically permissible uses of advances in genomics. For example, presenters Alecia Fair (Vanderbilt University) and Karriem Watson (University of Illinois) are members of the Engagement Core of the *All of Us* Research Program, a longitudinal study that aims to collect genomic, lifestyle, and environmental data from more than one million individuals over 10 years, especially individuals who have been underrepresented in biomedical research. They opened the session titled *Engaging Participants as Partners: ELSI Considerations in Large Scale Precision Medicine Research* with a description of how the *All of Us* "participants as partners" model differs from the traditional, unidirectional relationship between research participants and academic researchers. The *All of Us* model involves a national set of participant partners, selected by the researchers to be diverse in terms of race, ethnicity, geographic location, health status, sexual orientation, and gender identification, who are active in all aspects of the research, including priority setting, study oversight, and the design of protocol elements [B-3, Fair; B-3, Watson].

The presentation by Elizabeth Cohn suggested that *All of Us* investigators and program staff valued community member participation in the study, particularly in specific roles [B-3]. Director of the *All of Us* Engagement Core, Consuelo Wilkins (Vanderbilt University), spoke to some of the challenges inherent in adding an engagement component to an academic research study [B-3, Wilkins]. Wilkins also shared the results of a survey of more than 100 community members who were involved in research with academic institutions. Only a quarter of respondents reported that researchers were well prepared to work with communities (Skinner et al., 2018). Wilkins suggested that strategies are needed to prepare researchers for engagement and manage power imbalances that arise in the context of engaged work. These might include modeling humility, having self-awareness, allowing space for the voices of community members, and valuing the lived experience (both in the community and in the study) that community members bring [B-3, Wilkins].

In a related plenary, comprised of Indigenous researchers and community leaders, *Ethical Frameworks for Research Collaboration with Indigenous Communities,* moderated by Vanessa Hiratsuka (University of Alaska Anchorage), Chief Lynn Malerba (Mohegan Tribe) stressed the importance of the respecting tribal sovereignty which requires that the United States Government and all its agencies engage with tribes as sovereign nations, in other words, they must understand that tribes are governments and are self-governing. Chief Malerba suggested that federal programs that propose genetic studies need to engage in tribal consultation as a first step and co-develop agreements that are periodically revisited and assessed to prevent unintended consequences that may arise after the start of the research. Importantly for research involving smaller tribes, there is increased potential for incidental identification, particularly when a research participant identifies their tribe of enrollment. For

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these reasons, Malerba explained, the consent of the entire tribe is required for research involving tribally affiliated individuals. Researchers should also consider using dynamic consent to enable participants to withdraw a consent that was previously given. Other issues Chief Malerba urged genomics researchers to consider included risks to participants that might arise because of the publication of stigmatizing research results, community benefits in exchange for participating in the research, data sovereignty (discussed further below), the intellectual property rights of Indigenous People over their traditional knowledge, and the need for tribal researchers at every level of the research process, including in access boards [C-3, Malerba].

Among reasons for the low participation by Indigenous People in genomic research is distrust, which is itself the result of the exploitation and lack of benefit they have experienced in the research context.[16] In *Regulating Genomic Research through an Indigenous Lens*, Nanibaa' Garrison (University of California, Los Angeles) presented empirical results of research focused on learning the perspectives of American Indian, Alaska Native, and Native Hawaiian People — stakeholders underrepresented in genomics research — on data sharing. Among other findings, Garrison found no consensus among the tribal leaders that she interviewed on whether tribes should share research data or have oversight over their research data.[17] She also presented the results of a policy review she conducted in conjunction with a group focused on indigenous data sovereignty. The review compared the Indigenous Research Protection Act with similar policies in the U.S., Canada, New Zealand, and Australia.[18] Compared to other countries, the United States had fewer clear statements or stances on policies that protect Indigenous Peoples in biomedical and genetic research [C-3, Garrison]. Indigenous data sovereignty describes the right of Indigenous Peoples and nations to govern the collection, ownership, and application of their own data.[19] Garrison discussed the need for policies to govern genetic research with Indigenous peoples that put them in control of data that are about them as individuals or nations and about their resources (land, water, geology, sacred sites, plants, etc.) [C-3, Garrison].

Katrina Claw (University of Colorado) presented *Enhancing Ethical Genomic Research with Diverse Communities* which focused on a framework for ethical research with Indigenous communities that she co-developed with members of the summer internship for INdigenous peoples in Genomics (SING) Consortium.[20] The framework outlines the ways that researchers can foster stronger collaborations with Indigenous communities including: 1) understanding existing regulations, including those that pertain to tribal sovereignty and research regulation; 2) fostering collaboration through community engagement, 3) building cultural competence in research studies, 4) improving transparency, 5) supporting capacity building in Indigenous communities, and 6) disseminating research findings in ways that are appropriate for tribal communities [C-3, Claw]. Claw demonstrated the application of the framework to her work with the Northwest-Alaska Pharmacogenomics Research Network (NWA-PGRN), a group consisting of multiple research institutions and tribal organizations formed to conduct pharmacogenetic research in partnership with Native American communities.[21] Beyond traditional research practices, engaged research by NWA-PGRN involved completing the research oversight approval process at each tribal location [C-3, Claw]. Tribal research oversight bodies may oversee review and approval of new studies, research results, and study publications.[22] According to Claw, engaged research with tribal communities also requires building long term relationships by creating engagement plans or forming community advisory groups, obtaining both individual and group consent, striving for enhanced transparency in consent forms, and building capacity by engaging community members in collaborative analysis and including them as coauthors, and disseminating study results in formats other than peer-reviewed journals, including pamphlets and newsletters[23] [C-3, Claw].

B. Public Dialogue

Several *ELSI Virtual Forum* speakers explored the science communication challenges associated with genomic science. Plenary speaker Bartha Knoppers stressed the necessity of including members of the public in discussion about the ethical permissibility of applications of human germline gene editing [C-2, Knoppers]. An important component of this will be learning the experiences of parents and children who live with conditions targeted for elimination to inform decision making about the ethical allocation of our clinical and research resources [C-2, Knoppers; C-2, Garland-Thompson]. Yet, as Christi Guerrini (Baylor College) explained, public opinion can be based on confusion or incomplete information and can change in response to changes in the technology, usage practices, personal experiences, publicized incidents, and social movements [B-4]. Guerrini shared the results of a survey of U.S.-based, adult, Amazon Mturk workers that explored public support for the use of IGG technology by law enforcement. The survey was deployed following the use of the technique to identify the "Golden State Killer," a serial rapist and murderer. A

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strong majority of respondents (91%) approved of the law enforcement use of IGG to identify violent offenders but were less likely to support its use to identify non-violent offenders. Respondents who identified as female were more likely to approve of law enforcement use of IGG than those who identified as male.[24] However, as Guerrini noted, public opinion today might be different than when the survey was fielded. In a 2021 paper, Guerrini and colleagues dispel four misconceptions they observed in media accounts, online forums, and other venues to sharpen public debate about how IGG is used in criminal investigations and how it departs from traditional investigative techniques.[25]

Studying Genes and Social/Behavioral Phenotypes Under Broad Consent, a plenary presentation by Michelle Meyer (Geisinger), presented preliminary results of a study of participants' understanding of the category "health related research" as it appears in broad consent documents commonly used for biobank enrollment, specifically, whether the category included research aimed at the development of polygenic scores for behavioral and social outcomes [C-1]. Meyer and colleagues also examined participants' moral, religious, or cultural concerns about the use of their data to study behavioral phenotypes, and sociodemographic or individual-level variables that predicted their attitudes. The dominant reason that enrollees in the MyCode biobank at Geisinger and the Estonian Biobank at the Estonian Genome Center, University of Tartu, reported social and behavioral outcomes such as drug addiction, personal income, sexual orientation, etc. as inappropriate to study under the category "health-related research" was because they perceived those traits to be unrelated to genetics. Like the results of both surveys deployed in the study, the results of the ten focus groups conducted by Meyer and colleagues suggested that participant thinking about phenotypes was often binary — either genetic or environmental. In the case of genetic traits, focus group participants perceived genetic traits to be immutable. These findings led Meyer to conclude that educating the public about the influence of genes on a wide range of human traits in ways that prevent misconceptions is another formidable science communication challenge [C-1].

Conclusion

The proceedings of the June 2020 convening of ELSI researchers, the *ELSI Virtual Forum,* make visible the ways that human bias in the implementation of precision medicine has the potential to exacerbate the disparities in health between population groups in the United States. The examples in this paper illustrate the importance of realizing justice in precision medicine by attending to the equitable distribution of clinical and research resources and of the benefits, burdens, and risks of sharing one's genomic data in research, medical, and consumer contexts. Some presenters argued that justice can also be advanced by attending to the inclusion of additional stakeholders in genome science, especially those who have been underrepresented in biomedical and genomics research. However, as the examples in this paper demonstrate, inclusion will require investment in communities and major reworking of the traditionally separate and unequal relationship between researchers and research participants. Engaging the broad genomic science stakeholder group will also require reckoning with the actual and potential roles of genetic research in perpetrating harms against marginalized people.

Reflecting on thirty years of ELSI research, speakers in the *ELSI Virtual Forum* keynote session invited changes to both the ELSI and genomics workforces so that these more closely reflect the composition of society [A-1, Ossorio; A-1, Green; A-1, Juengst]. Other action items the keynote speakers raised for ELSI researchers included the interrogation of the unscien-

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tific use of race in genomics research [A-1, Juengst], support for the recruitment of diverse stakeholders to ensure that genomic data include and can benefit all of humankind [A-1, Green], and instituting modifications to the NIH data sharing requirements to protect Indigenous communities [A-1, Ossorio].

The 2022 ELSI Congress Organizing Committee[26] is currently identifying topics to be explored at *ELSIcon2022: Innovating for a Just and Equitable Future.* These include further consideration of clinical applications of polygenic scores, methods for improving complex trait mapping and PGS scores for members of minority groups in the United States, the ethics of implementing interventions for rare genetic disorders, legal issues in genetics, racism, and ableism. As the examples in this paper illustrate, members of the ELSI and genomics communities must be not only vigilant, but thoughtful and focused to ensure that Western-centric, ableist, sexist, and/or racist biases are not implemented along with genomic medicine. This will require, at the least, reflexivity, self-awareness, perspective taking, and humility.

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2. To provide a timely forum for accepted ELSI Congress 2020 proposals that could not be included in the ELSI Virtual Forum program, the organizing committee created a new virtual seminar series, ELSIconversations hosted by the Center for ELSI Resources and Analysis (CERA). CERA is funded by NHGRI (1U24HG010733-01) and is co-led by the Stanford Center for Biomedical Ethics and the Division of Ethics at Columbia University in partnership with The Hastings Center and the Personal Genetics Education Project (pgEd) at Harvard University. Recordings of work presented in the ELSIconversations series are hosted on ELSIhub.org, the CERA web platform.
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Appendix

A-1 **Opening Keynote**: Integrating ELSI and Genomics: Past, Present, and Future
Speakers: Eric Juengst, PhD **[A-1, Juengst]**; Pilar Ossorio, JD, PhD **[A-1, Ossorio]**; Eric Green, MD, PhD **[A-1, Green]**
Moderator: Amy McGuire, JD, PhD

B-1 **Panel 1**: Studying America's Eugenics Era through an ELSI Lens: Data, Context, and Relevance
Speakers: Natalie Lira, PhD **[B-1, Lira]**; Nicole Novak, PhD, MSc **[B-1, Novak]**; Elyse Thulin, MS **[B-1, Thulin]**; Alexandra Minna Stern, PhD **[B-1, Stern]**
Moderator: Alexandra Minna Stern, PhD

B-2 **Panel 2**: New Models for Ethical AI in Precision Medicine: Empirical and Normative ELSI Inquiry
Speakers: David Magnus, PhD **[B-2, Magnus]**; Pamela Sankar, PhD **[B-2, Sankar]**; Ariadne Nichol, BA **[B-2, Nichol]**
Moderator: Mildred Cho, PhD

B-3 **Panel 3**: Engaging Participants as Partners: ELSI Considerations in Large-Scale Precision Medicine Research
Speakers: Alecia M. Fair, DrPH **[B-3, Fair]**; Karriem Watson, DHSc, MS, MPH **[B-3, Watson]**; Elizabeth Cohn, RN, PhD **[B-3, Cohn]**; Consuelo Wilkins, MD, MSCI **[B-3, Wilkins]**
Moderator: Consuelo Wilkins, MD, MSCI

B-4 **Panel 4**: To Catch a Killer: Law Enforcement Uses of DNA Databases
Speakers: James Hazel, JD, PhD **[B-4, Hazel]**; Jennifer Wagner, JD, PhD **[B-4, Wagner]**; Christi Guerrini, JD, MPH **[B-4, Guerrini]**; Amy McGuire, JD, PhD **[B-4, McGuire]**
Moderator: Amy McGuire, JD, PhD

C-1 **Plenary 1**: Polygenic Risk Scores & Behavioral Traits: Interrogating the Science & Ethics
Speakers: Dalton Conley, PhD **[C-1, Conley]**; Steve Hyman, MD **[C-1, Hyman]**; Michelle Meyer, JD, PhD **[C-1, Meyer]**
Moderator: Paul Appelbaum, MD

C-2 **Plenary 2**: CRISPR and Human Identity: Governing Germline Gene Editing
Speakers: Rosemarie Garland-Thomson, PhD **[C-2, Garland-Thomson]**; George Daley, MD, PhD **[C-2, Daley]**; Bartha Knopper **[C-2, Knopper]**
Moderator: Josephine Johnston, LLB, MBHL

C-3 **Plenary 3**: Ethical Frameworks for Research Collaboration with Indigenous Communities
'Speakers: Chief Lynn Malerba, DNP, MPA **[C-3, Malerba]**; Nanibaa' Garrison, PhD **[C-3, Garrison]**; Katrina Claw, PhD **[C-3, Claw]**
Moderator: Vanessa Hiratsuka, PhD

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