What is Precision Medicine?

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INTRODUCTION

Precision medicine came into the national spotlight in 2015, when President Barack Obama announced the launching of the Precision Medicine Initiative in his final State of the Union address. This initiative would include a 1 million-person precision medicine research study, which would be the largest medical research study in history. Though precision medicine received national attention in 2015, it had been an emerging area of science and medicine for over a decade, as it had been linked to the Human Genome Project, with the hope that more knowledge of genetics would lead to more personalized and targeted medicine. But when the initiative was announced, precision medicine was described as more than just using genetics to tailor medical care: it was "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person." So, what is precision medicine? In this primer, we outline a number of key dimensions of precision medicine, including:

- The evolution from personalized to precision medicine
- Precision medicine research's focus on collecting multiple forms of data, and harnessing the power of big data analysis
- The tension between focusing on individual responsibility versus systemic intervention

INTRODUCTION

This primer draws on work conducted through the Fairness in Precision Medicine project, a year-long exploratory study funded by the Robert Wood Johnson Foundation that aimed to identify tensions in the emerging data-driven health research space, the possibility for unintended consequences of the research process, and discrimination that could result from implementing data-driven research insights in health. Our hope is that by bringing awareness to these tensions, we may productively shape conversations and interventions in precision medicine research going forward.

We began by examining how and where the term "precision medicine" is currently being used in the scientific, medical, and health care fields, including in scholarly, popular, and industry contexts. We quickly realized that precision medicine was being used differently in clinical medical practice and biomedical research. To date, the clinical community's definition of, and approach to, precision medicine has focused almost exclusively on genetics, whereas the biomedical research community has taken a more expansive approach to precision medicine. Though there have been important advances and potential for growth in clinical precision medicine, we focus our attention on precision medicine in the biomedical research sphere. Our goal is to understand how precision medicine research projects are developing, as these will shape the future directions of clinical precision medicine.

Researchers in this community are exploring how multiple data streams can be incorporated into their analytic work in order to develop a more sophisticated understanding of environmental, behavioral, and cultural factors that may contribute to or influence health outcomes. Although these researchers incorporate genetic data in their analyses, they also examine how electronic health record data, activity tracker data, and medical imaging data, among other sources, can be used. In addition, researchers are attempting to use sources not traditionally considered health data to develop insights about health, such as environmental data and other public records.

Building on what we learned from the research community, we define precision medicine as the effort to collect, integrate, and analyze multiple sources of genetic and nongenetic data, harnessing methods of big data analysis and machine learning, in order to develop insights about health and disease that are tailored to the individual. Our view of precision medicine and our focus on research in this area is in line with what Rothstein calls "big data health research."[1] We have chosen to focus on the efforts to combine multiple kinds of data because collecting and combining data from different fields poses many opportunities and challenges.

FROM PERSONALIZED TO PRECISION MEDICINE

The terms precision medicine and personalized medicine are often used synonymously, though precision medicine is the newer term. The term "personalized medicine" began to be used around 1997 to emphasize the personalized, individualized form medical care would take when insights from the Human Genome Project would use one's unique genomic information to guide treatment.[2] The Human Genome Project (HGP) was a multi-year private and public effort begun in 1990 to map the entire sequence of human DNA. Project leaders believed that identifying the structure of human DNA would yield insights about its functions, particularly those connected to health and disease.[3] In a brief history of the project, James Watson explained that connecting sequencing efforts to issues of health and disease such as AIDS helped secure its funding, despite human genome sequencing being somewhat "divorced from the main currents of biological research," which at the time was focused on sequencing non-human organisms. Thus, using genome sequencing to understand human health and disease served to establish the value of initiating the HGP and helped to build the narrative that its findings would lead to great improvements in health.[4]

Personalized medicine is an aspirational and anticipatory term that was coined and discussed before any widespread shifts in medical practice had occurred. One well-known conceptualization of personalized medicine is the four P's model. The P's stand for predictive, preventative, personalized, and participatory and describe what post-HGP medicine would ideally look like. Instead of waiting for disease onset, medicine could predict disease development using genomic risk variants, then these diseases could be prevented through altered treatment programs based on one's disease risk

profile. Medicine would thus shift from a "reactive to a proactive discipline."[5] Medical care would be personalized to the individual because the treatment program adjustments would be made based on personal risk levels, rather than population disease risk averages. And it would be participatory, meaning that patients and their providers would work together on an individual basis as well as through "the creation of new types of strategic partnerships between patients, large clinical centers, consortia of clinical centers, and patient-advocate groups."[6] There have been calls to add a fifth P – "population" – that would incorporate public health or population views into personalized medicine.[7] In 2013, a group of researchers conducted a systematic review of the definitions of personalized medicine in the scientific literature and proposed that it should be understood primarily in terms of "molecular disease pathways" using genomics and the study of proteins.[8]

In addition to personalized medicine, a related term, pharmacogenomics, is sometimes used as a synonym. Pharmacogenomics examines how genomic and pharmacologic information can be used together to guide medication prescription and dosing decisions. For example, researchers have identified how variations in a particular gene affect the way people metabolize painkillers.[9] This is an example of how genomic information can be used to guide dosing in medical care, and since it is based on an individual's genotype, it is personalized. Because pharmacogenomics uses genomic information in an individualized way, the two terms are semantically linked. However, personalized medicine was meant to be a more expansive term within the medical literature, including the use of genomic information to guide drug dosing, but also the ability to locate and use genomic information about disease risk to guide health care.

Though the completion of the Human Genome Project showed that there is still much more to learn about genes, their functions, and their connections to disease, the hope for genetics-based personalized medicine remains. Around 2010, the term precision medicine began to emerge. References to precision medicine in major scientific publications doubled in that year, and then in 2011, the National Academies released a report that distinguished the two terms—stating that although both communicate a notion of individualized medicine, precision medicine is the preferred term because it conveys that medicine will be more accurate for individuals, not that each individual will get unique treatments.[10, 11]

This report was important not just because it disambiguated the two terms, but also because it mentioned how other sources of data, not just genomics, would be a part of precision medicine. Specifically, the report mentions the opportunity to use digital data from electronic health records. The digitization of medical records

had become widespread, following the passage of Health Information Technology for Economic and Clinical Health (HITECH) Act two years before, which led to significant investments in health information technology.[12] This report marks a moment when precision medicine shifted from genomics-only medicine to multi-data medicine. Later, when the White House launched the Precision Medicine Initiative, precision medicine was defined by the National Institutes of Health (NIH) as "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person" and as the process of "delivering the right treatments at the right time, every time to the right person."[13] It is important to note that this definition includes genetic variation alongside environment and lifestyle variation. Indeed, the PMI-linked proposal by the NIH to create a 1-million person precision medicine research study (later renamed the All of Us Research Program) included a commitment to collect multiple forms of data, including genetic information and electronic health record data. These moves show how the term precision medicine expanded to include multiple forms of data, not just genetic information.

HOW WE ARRIVED AT OUR DEFINITION OF PRECISION MEDICINE

At the beginning of this report, we highlighted major tensions in how precision medicine is defined and how our research helped us narrow the scope of our analysis with an eye to forward-facing implications of precision medicine. In this section, we want to return to that research to illustrate various definitional differences, drilling down into how different stakeholders approach this term. While there may be value to stabilizing one definition of precision medicine, we believe that the multitude of definitions sheds light on where the field of precision medicine research may be going.

In addition to attending a number of conferences where precision medicine research was discussed as well as reviewing relevant academic and popular literature, press releases, and other documents from precision medicine research projects, we interviewed 21 stakeholders in precision medicine, including researchers working on large precision medicine studies, experts in health data analysis, and patient advocates. These interviews yielded rich insights about the specificities of analyzing different kinds of data, as well as the particularities of institutional and scientific culture and other dynamics that can impact precision medicine research. Here, we focus on the ways that our participants defined precision medicine. Though these data are not representative of the views of all precision medicine researchers, health data analysts, or patient advocates working in precision medicine, they do raise issues that are important broadly across the emerging field of precision medicine research.

MULTIPLE FORMS OF DATA

We asked our participants to provide us with their understanding of precision medicine, and as expected, they defined "precision medicine" in multiple ways. Most perceived precision medicine as including more than just genetic information to tailor medical care, but there were differences in how much our respondents emphasized precision medicine as using different types of data, or precision medicine as processes of analyzing data, or delivering tailored treatments. Regardless, it was clear that

our respondents thought of precision medicine as a data project. What emerged from our interviews is that a key aspect of precision medicine is the focus on collecting multiple forms of data, and collecting as much data as possible. For example, as one of our respondents remarked:

> "I think of precision medicine as bringing into account all of the data we can about a patient in order to make decisions for this patient's health care. It could be treatment decisions or it could be recommendations about lifestyle in order to avoid future kinds of health problems. I think some people consider precision medicine just to be about genomic data but I consider it to be about clinical history, genomics, environmental data, anything that we can collect and use."
>
> **David Page**—Biostatistician

For this respondent, precision medicine is about collecting all available kinds of data that could be informative of an individual's health. He also emphasizes in his definition that the multiple forms of data that will be collected are individual-level data such as genomics and clinical records, but others are beyond the scale of the individual, such as environmental data. For this respondent, collecting multiple kinds of data means that the analysis of these data can lead to different kinds of applications. He notes that the applications could be biological like "treatment decisions" or "recommendations about lifestyle."

BIOLOGICAL AND SOCIAL FACTORS

Multiple forms of data did not just mean multiple forms of biological or medical data. Instead, many of our respondents argued that precision will include data about social conditions. The comments below from multiple respondents illustrate this viewpoint:

> "A lot of my definition about precision medicine stems from the whole definition of personalized medicine. I define precision medicine as research and treatment that is tailored to address the unique biological as well as social influences. . . . Because that's when I think about epigenetics. I think about the fact that you can be born not having gene mutations that put you at elevated risk

> for a certain kind of cancer, but the very environment you live in, based on the stressors, nearby toxins, exposures, all those things, the epigenetic exposures still can add to your cancer outcome."

> **Karriem Watson**—Biomedical Researcher

Another respondent explained:

> "This sort of precision is not going to come from genetics, as it's going to come by studying the context in which people live, work, and play. That's what matters the most. To me understanding if you are in an abusive relationship, you have stable housing, you have stable income, that information and that data is going to be far more insightful in your well-being and your health than any genetic information that I collect from you."

> **James Faghmous**—Technologist

These respondents' comments show that their definition of precision medicine is closely linked to their understanding of personalized medicine. To them, "precision" means using multiple forms of data in order to build a better and fuller picture of the factors that influence health. "Precision" is also associated with a view of health that includes biological and social factors, and further, that the lines between biological and social factors are becoming blurred. Multiple respondents mentioned the field of epigenetics, or the study of how factors influence gene function but do not change the sequence, to illustrate how thinking in genetics has shifted. Research in epigenetics shows that factors such as nutrition or environmental stressors can impact gene expression, physiological processes, and health risks and outcomes. According to our respondents, precision medicine, as a data project, attempts to gather a picture of health not in the moment, but as a set of inputs about medical, social, and environmental experiences.

INDIVIDUALS AND POPULATIONS

A number our respondents explained that another key element of precision medicine is using data to stratify individuals into groups. As one participant explained:

> "The way I define precision medicine is, using all available data to
> sub-stratify patients into as specific a core as possible. Get down
> to an N of one ideally, but usually it's going to be some variant
> of restrictive cohort. Precision medicine applies to the use, not only
> of genomics data but also other omics, sensors such as those in
> home-based devices, environmental data, etc. All of these serve to
> create as homogeneous a subgroup/cohort as possible."

Robert Greenes—Bioinformaticist

Here, Greenes' definition includes multidimensional data, including sensor data. He emphasizes that "precision" means getting down to a "small core" of individuals. Other respondents in our study described this as getting down to the "unique individual." For our respondents, precision, targeting, and individualizing care could be achieved through creating smaller and more refined groups.

Though many of our respondents discussed stratification as key to precision medicine, there were differences in how they discussed how processes of stratification would lead to interventions. For example, for some respondents, getting to smaller groups of individuals with specific characteristics and susceptibilities for disease meant that there would be more emphasis on providing tailored interventions. These could be recommendations about medication, different clinical treatment options, or even behavioral interventions. As one of our respondents described:

> "[Precision medicine is] different types of data from different data
> streams and you can look at that and learn from what we know
> about individual things within each of those data streams. Combine
> that knowledge and develop a treatment tool or a paradigm or a
> method or, in some cases, treatments or drugs for that individual's
> own health needs."

Anna McCollister-Slipp—Patient Advocate

Her comments show that the goal of gathering and analyzing multiple forms of data in precision medicine research will be to develop individualized treatments. Others described this as precision medicine being able to better "match" people with treatments, echoing the National Academies' definition and Barack Obama's description of precision medicine as the right treatment for the right patient at the right time. However, not everyone in our sample felt that precision medicine could, or should,

lead to interventions at the level of the individual. For example, another participant pointed out the limitations of focusing on the individual:

> "In popular imagination and popular accounts and political accounts of precision medicine, which is the right intervention or the right medicine for the right patient at the right time, that localizes the inquiry in the intervention and the identification of the risk and the opportunity within individual patients. I think there can be a more accurate and holistic view of precision medicine, or at least of the use of all the tools that feed into precision medicine, to really intervene on environmental factors, social problems, health risks, that will benefit populations more broadly. I think those are more preventive approaches. . . . The intervention doesn't really make sense to point out people at particular risk of say obesity, or heart disease, or asthma. Would it be better to intervene more broadly?"

Lisa Parker—Bioethicist

For Parker, the value of precision medicine would be understanding how factors outside the individual body impact health and designing interventions to address those external factors. This difference in how our participants talked about the ultimate focus of precision medicine – as on the individual or the population – is an important one to bring into relief because this difference may impact how the field develops. This also speaks to what some see as a tension between precision medicine and public health. In a 2015 commentary in the New England Journal of Medicine, Bayer and Galea argued that the increased focus on precision medicine is "willfully blind" to the evidence that "health differences between groups and within groups are not driven by clinical care but by social-structural factors that shape our lives."[14] This refers to the significant subfield of study in public health that examines how structural factors such as income, education, and neighborhood characteristics impact health outcomes, so that one's zip code can be a more important influence than one's genetic code.[15]

In 2016, University of California, San Francisco, hosted a "Precision Public Health Summit" where participants argued that a focus on the individual as well as the population are not "opposing approaches" but could both be part of the domain of precision medicine. Parker's "holistic" precision medicine, as described, would be an example of what Kirsten Bibbins-Domingo described as the ability to "telescop[e] down with increasing clarity to define the biology of the individual person" as well as "telescop[e] back out. . . . back out to the family and the community."[16]

DATA COLLECTION TO SUPPORT PRECISION MEDICINE RESEARCH EFFORTS

As part of our work on the Fairness in Precision Medicine research project, we identified several US-based efforts to bootstrap the data collection phase in an effort to support the research needed to achieve precision medicine. Major multistate projects included: 1) the aforementioned All of Us Research Program, sponsored by the NIH; 2) the Million Veterans Program which collects survey, genetic, and electronic health record data from veterans and is sponsored by the US Department of Veterans Affairs; 3) the American Heart Association's My Research Legacy; and 4) Verily's Project Baseline. These research cohort studies aim to enroll large numbers of participants, follow them longitudinally, and collect multiple forms of data from them, including genetic data, electronic health record data, environmental data, and behavioral data.

There are a number of other regional or single-state studies that are collecting and analyzing genetic, medical record, and other data to learn about health such as Kaiser Permanente's Research Bank in California. The Kavli Foundation and New York University have also partnered to sponsor the Human Project, which focuses on New York and plans to collect multiple forms of health data from ten thousand participants. These prospective observational studies do not have specific research questions, but aim to build a data resource that researchers can then use for multiple studies. Furthermore, although our definition of precision medicine is at the nexus of big data and health, we do not focus on projects like Google Flu Trends because these efforts do not involve collecting and analyzing multidimensional data on a cohort of participants.

THEMES AND ISSUES IN PRECISION MEDICINE

Though there is much excitement about precision medicine, there is also skepticism about the promise of a data-driven future of medicine. For example, historian of medicine Nathaniel Comfort wrote an assessment of the hype surrounding precision medicine as part of a longer history of "inflated medical promises."[17] There are also divergent interests among stakeholders in precision medicine—patients might want different things than clinicians or pharmaceutical or other industry players, and the field will need to face the challenge of bringing together these "misaligned" interests.[18] For example, researcher Gina Neff has argued that although bringing big data solutions to health may be exciting for some, "Doctors often see data as costs, risks, and liabilities. And for many in health care, data are not seen as a source of value, but of additional work."[19]

Precision medicine efforts also raise concerns about data privacy and security, data sharing, diversity and inclusion, and equitable access. Although there are privacy policies that protect health data in both the clinical space and in research, scholars have argued that de-identified medical data can be re-identified, and that the current health data privacy and nondiscrimination regime may not be adequate protection as precision medicine develops.[20, 21] In addition to the challenge of keeping data private and secure, sharing data in precision medicine introduces questions regarding how to share information with patients and between research projects. Scholars have argued that participants should receive their genetic data when participating in research as a matter of respect for autonomy.[22] On the other hand, the return of genetic results has introduced challenges related to interpretability and the responsible communication of risk.[23] There has been an increased emphasis on involving participants and patients as active participants in medical research, and organizations such as the Patient Centered Outcomes Research Initiative (PCORI) have supported patient data sharing for precision medicine research.[24]

Regarding the use of data for multiple research projects, The Common Rule, which governs human subject participation in research, has recently been changed to allow for researchers to ask participants to agree to broad consent for use of their biospecimens. For researchers, this lowers some of the barriers to accessing biospecimens that can produce health data, and would thus provide greater access to information, such as genomic data. Others have warned that though health data may be more available to researchers through broad consent or voluntary donation, there is a risk of privatization of health data that is held by technology companies such as the direct-to-consumer genetics company 23andMe or Apple. If not openly shared, health data that is inaccessible could prevent researchers from conducting rigorous scientific research.[25]

Diversity and the inclusion of women and minorities has been a long-standing issue in biomedical research in the United States. Though proposed precision medicine research projects are often intended to address health disparities, questions remain about whether these studies will be able to tackle this problem. It is not clear whether a representative sample based on traditional methods (e.g., Census categories) or oversampling of traditionally underrepresented populations will be the best strategy to achieve diversity in precision medicine research cohorts. Furthermore, the complexity of demarcating between race and genetics introduces a challenge for precision medicine recruitment. Cohn and colleagues have argued that recruiting for precision medicine studies using racial categories may not yield genetic diversity in study cohorts.[26] Still, others have argued that even if precision medicine is able to move past "crude" markers like race in medicine, these treatments may not be equally accessible once they are developed.[27, 28]

CONCLUSION

Precision medicine research is poised to make important contributions to our understanding of disease and show how the increasing availability of data and advances in computing can lead to breakthroughs in research and medical care. The field has expanded to include not only genetics, but multiple forms and sources of data with the hope that new methods of analysis can provide information about the complex determinants – both biological and social – of health outcomes. Major precision medicine research efforts that are just launching are collecting data on unprecedented scales, while attempting to meet long-standing challenges in medical research, like enrolling diverse participants, protecting privacy, and allowing for data sharing and participant engagement. Although there are multiple definitions of precision medicine, there is an understanding of it as a data project that focuses on analysis, intervention, and collecting data from various sources. The question as to whether precision medicine should focus on individual interventions or broader structural strategies is one that is dividing the community and may impact the kinds of work that can be done with precision medicine cohort studies. These studies are significant investments of resources, so it is important to identify points of conceptual agreement and divergence so that the promises of precision medicine can be fulfilled.

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APPENDIX 1: INTERVIEWEES

Louise Bier, MS, CGC: Louise Bier is the Director, Genetic Counseling and Clinical Engagement at Columbia University's Institute for Genomic Medicine. Bier was formerly affiliated with the Icahn School of Medicine at Mount Sinai Hospital in New York City.

Shawneequa Callier, MA, JD: Shawneequa Callier is an Associate Professor of Clinical Research and Leadership at George Washington University. Prior to joining GWU faculty, Professor Shawneequa Callier completed a postdoctoral fellowship at the Center for Genetic Research Ethics and Law, an interdisciplinary center for excellence funded by the National Human Genome Research Institute and located in the Bioethics Department of Case Western Reserve University's School of Medicine. From 2006 to 2009, Ms. Callier practiced health care law in Washington, D.C. Earlier in her career, she also interned at the World Health Organization and the Nuffield Council on Bioethics where she examined international health care ethics policies and human genetics laws and guidelines.

Arthur Caplan, PhD: Arthur Caplan is the Drs. William F. and Virginia Connolly Mitty Professor and founding head of the Division of Bioethics at New York University School of Medicine in New York City. He is also co-founder and Dean of Research of the NYU Sports and Society Program. Dr. Caplan currently serves as the ethics advisor to DOD/DARPA on synthetic biology, a member of the University of Pennsylvania's External Advisory Committee for its Orphan Disease Center, and a member of the Ethics and Ebola Working Group of the World Health Organization. Dr. Caplan also serves as the Chairperson of the Compassionate Use Advisory Committee (CompAC), an independent group of internationally recognized medical experts, bioethicists, and patient representatives which advises Janssen/J&J about requests for compassionate use of some of its investigational medicines. Dr. Caplan is also a regular commentator on bioethics and health care issues for WebMD/Medscape, for WGBH radio in Boston, and WMNF public radio in Tampa.

Christy Collins: Christy Collins is a mother and macrocephaly-capillary malformation (M-CM) patient advocate. Christy Collins founded and is the president of a rare disease advocacy organization called M-CM Network after her daughter was diagnosed with the condition. The founding objective was to create a longitudinal registry of advocacy-owned data and sample repositories so that these research assets can't be siloed in any one institution.

James H. Faghmous, PhD: James H. Faghmous is a visiting assistant professor of medicine at Stanford University. He develops novel machine learning and artificial intelligence methods to measure how social, environmental, and economic factors interact to create health disparities. In 2016, James was selected as an NIH health disparities fellow for his work on the topic. James received a PhD in computer science from the University of Minnesota where his dissertation on applying machine learning to global climate change problems was selected for the "Outstanding Dissertation Award in Physical Sciences and Engineering". James graduated magna cum laude from the City College of New York where he was a Rhodes and Gates scholar nominee. At the time he was interviewed, James was the founding CTO of Arnhold Global Health Institute at the Icahn School of Medicine at Mount Sinai in New York City where he launched the precision global health platform, ATLAS, with generous support from USAID and Gates Foundation.

Paul Glimcher, PhD: Paul Glimcher is Director at NYU's Institute for the Interdisciplinary Study of Decision Making, and professor of Neural Science, Economics and Psychology, at New York University. His postdoctoral training was in oculomotor physiology, researching the brainstem and mesencephalic nuclei that control eye rotations. Paul's laboratory has focused on the identification and characterization of signals that intervene between the neural processes that engage in sensory encoding and the neural processes that engage in movement generation. These are the signals which must, in principle, underlie decisionmaking.

Robert Greenes, MD, PhD: Dr. Greenes is a faculty member at Arizona State University. He joined ASU in September 2007 to lead the new Department of Biomedical Informatics (BMI). This unit, originally in the School of Computing and Informatics, in the Fulton School of Engineering, and for three years reporting directly to the Provost's Office, became part of the new College of Health Solutions in July 2012. After six years leading the Department, Dr. Greenes took a sabbatical for the 2013–14 year, to work on creating a collaboration initiative for interoperable health care apps, and returned in mid-2014 to ASU as Professor in BMI and to continue to pursue this initiative. He is also Professor of BMI at Mayo Clinic.

Bradford Hesse, PhD: Bradford (Brad) Hesse, PhD, was appointed Chief of the National Cancer Institute's (NCI) Health Communication and Informatics Research Branch (HCIRB) in November 2006. He served as the Acting Chief of HCIRB from 2004–06. Dr. Hesse's work focuses on bringing the power of health information technologies to bear on the problem of eliminating death and suffering from cancer. While at NCI,

he has championed several initiatives that evaluate and progress the science of cancer communication and informatics, including the Health Information National Trends Survey (HINTS) and the Centers of Excellence in Cancer Communication (CECCR). As director of NCI's biennial Health Information National Trends Survey (HINTS), Dr. Hesse leads a team of scientists in the development and execution of this nationally representative, general population survey of American adults.

Jake Marcus, MPH: Jake Marcus is a software engineer who works on the Google Brain team (a part of Google AI) applying machine learning to health care. He works on using EHR data to predict clinical outcomes. He builds models as well as the infrastructure to learn from the data.

Sara Meeder, MA: Sara Meeder was the Research Compliance Specialist for ISDM's flagship study, The Human Project, where she is responsible for all things regulatory. Her mission is to ensure that the participants in the project are protected and that the project itself is run within the context of research regulations and ethical standards. Sara has been involved in various areas of research in her career, with an emphasis on human subjects research, infrastructure, and ethics.

Anna McCollister-Slipp, MA: Anna McCollister-Slipp is Chief Advocate for Participatory Research for the Scripps Translational Science Institute (STSI). In addition, she is the founder of VitalCrowd, a Web-based collaborative platform aimed at crowdsourcing the design of health research and is the co-founder of Galileo Analytics, a visual data exploration and data analytics company focused on democratizing access to and understanding of complex health data. Anna seeks to build platforms for better understanding of and engagement with the needs of patients. She speaks frequently about the need for innovation in medical device data and technology, promoting data standards, device interoperability, and user platforms aimed at empowering patients to better manage their health.

Camille Nebeker, MS, EdD: Camille Nebeker is a faculty member at UC San Diego in the Department of Family Medicine and Public Health. Her work there is primarily to do research on research ethics. For the past 15 years, her research has focused on designing instruction to educate the public about science and the scientific method with a particular focus on community health workers who were assisting academic researchers to conduct studies in the Latino community. She, along with her bilingual/bicultural team, has developed and tested a course called "Building Research Integrity and Capacity" (BRIC) that is accessible to people who have little or no for-

mal scientific research training or academic research training. Nebeker also leads the Connected and Open Research Ethics (CORE) program to develop and crowdsource resources to help investigators design technology-enabled research studies that are ethical and responsible.

David Page, MD: Dr. David Page is a professor at the Department of Biostatistics and Medical Informatics and Department of Computer Sciences of the School of Medicine and Public Health at University of Wisconsin-Madison. Dr. Page works on algorithms for data mining and machine learning and their applications to biomedical data, especially de-identified electronic health records and high-throughput genetic and other molecular data.

Lisa Parker, PhD: Lisa Parker, a philosopher, is Professor of Human Genetics in the Graduate School of Public Health and Director of the University of Pittsburgh's Center for Bioethics & Health Law. Dr. Parker has published extensively on ethical concerns related to the design and conduct of research, particularly genetic research and mental health research, as well as on aesthetic surgery, confidentiality, and informed consent.

Chelsea Ratcliff, MA: Chelsea Ratcliff is a doctoral student at the University of Utah focusing on health, science, and risk communication. Her scholarly interests and current projects pertain to: (1) the use of heuristics in health decision making; (2) precision/personalized medicine communication; (3) psychological reactance and other forms of message resistance; (4) news coverage of health research, public use of, and trust in health journalism; and (5) public understanding of science. She recently published a review in Journal of Health Communication on the potential for patient resistance in precision medicine.

Prabhjot Singh, MD, PhD: Prabhjot Singh, MD, PhD, is Director of the Arnhold Institute for Global Health and Chair of the Department of Health System Design and Global Health at the Icahn School of Medicine at Mount Sinai, as well as Special Advisor for Strategy and Design at the Peterson Center for Health Care. Previously, Prabhjot was a professor of International and Public Affairs at Columbia University and Director of Systems Design at the Earth Institute. He completed a BA and BS at University of Rochester, an MD at Cornell and PhD in Neural & Genetic Systems at Rockefeller University, with a postdoctoral Fellowship in Sustainable Development at Columbia University. He completed residency in Internal Medicine at Mount Sinai Hospital. He is a Robert Wood Johnson Foundation Young Leader, a Truman National Security Fellow, and term member of the Council on Foreign Relations.

Sabrina Suckiel, MS, CGC: Sabrina Suckiel is a genetic counselor at Icahn School of Medicine at Mount Sinai Hospital in New York City. Her research projects have had the underlying rationale that there will be more of a demand for, and use of, genomic sequencing in health care as the cost of sequencing goes down. The first project aimed at the general public, the second at early adopters, and the third at health professionals. Her research projects include developing an educational pamphlet on whole genome sequencing, conducting a study of healthy individuals who undergo whole genome sequencing, and developing a tool to measure health professionals' knowledge of genomics.

James Tabery, PhD: Dr. James Tabery is an Associate Professor of Philosophy at the University of Utah. His research focuses largely on the philosophy of science and applied ethics, as well as the intersection between those domains. On the philosophy of science side, he investigates questions of causation and explanation in biology; while on the applied ethics side, he explores how the answers to those questions have ethical, legal, and social implications.

Karriem Watson, DHSc, MS, MPH: Karriem Watson is a Senior Research Scientist with the University of Illinois Cancer Center and the Director of Community Engaged Research for the UI Cancer Center at UIC and the Mile Square Health Center, a group of Federally Qualified Health Clinics (FQHCs) affiliated with the University of Illinois Hospital and Health Sciences System. Dr. Watson has a Doctorate in Health Science in Global Health, a Master of Science in Basic Medical Research, and a Master's in Public Health in Community Health Sciences. Dr. Watson's work has resulted in the creation of community-based cancer screening, prevention, and navigation programs for breast, lung, colorectal, cervical, and prostate cancer. His work to support community-based breast cancer screening and navigation afforded him recognition by the Metropolitan Chicago Breast Cancer Task Force as a "Community Champion." He is a faculty member at the UIC School of Public Health in the Division of Community Health Sciences and is an Adjunct Faculty at DePaul and Northwestern University. Dr. Watson is also the Core Co-Lead of the Community Engagement Core for a five-year NCI-funded multi-institutional grant with the Robert H. Lurie Comprehensive Cancer Center at Northwestern University, the University of Illinois Cancer Center, and Northeastern Illinois University to address cancer disparities in Chicago. He also serves as Co-Investigator for a four-year NCI-funded grant to develop a partnership with the UI Cancer Center and Governors State University to increase the number of faculty and students from underserved communities who engage in cancer disparities research.

Dr. Watson is also a Co-Investigator of the Illinois Precision Medicine Consortium that was funded by the NIH Precision Medicine Initiative, now called the All of Us Initiative and a newly awarded NIMHD Center of Excellence in Health Disparities at UIC.

John Wilbanks, BA: John Wilbanks is the Chief Commons Officer at Sage Bionetworks and a Senior Fellow at FasterCures. Wilbanks leads the Sage Governance team and serves as Co-Principal Investigator on Sage's award for the All of US Research Program. In conjunction with Academy Health and the Electronic Data Methods Forum, he co-developed novel visual consent processes for mobile clinical health studies that were integrated into Apple's ResearchKit open-source framework.

Stefan Zajic, PhD: Stefan Zajic, PhD, is a research scientist at Coriell focused on the Coriell Personalized Medicine Collaborative (CPMC), a research study examining the clinical utility of genetic information. Prior to joining Coriell, Stefan was a principal scientist in research and development with Merck & Co., contributing to quantitative pharmacology and pharmacometrics analyses and using mathematical modeling and simulation. Dr. Zajic's team has published extensively on the effects of genetic counseling in the CPMC, and continues to be interested in the psychological effects of receiving genetic risk information.