high-resolution diversity

Our understanding of differences between human beings is evolving. Over the next decade, advances in technology will help us perceive our differences and similarities at the level of cells, molecules, genes, and brain patterns. This high-resolution diversity will reveal meaningful variations of risks and capacities. Some variations will point to health patterns too subtle for us to fully grasp. Others will have less of an impact on our health but will influence the identity with which we navigate our self-care, social networks, and environment. The evolving lines of difference will provide fresh ammunition for old battles for equality, introduce new norms arising from new ways of measuring ourselves, and create new capacities for personalizing health interventions.

Over the next decade, the greatest advances in understanding diversity will come not from creating new categories, but from seeing the ways that human diversity is fluid and evolving. We'll see the plasticity of human diversity and identity play out in new areas of intervention—on the scale of bodies, networks, and environments.

bodies: personal variation

Emerging brain-imaging technologies are uncovering differences in human thought patterns, cognitive functions, and mental aptitudes. We're just beginning to learn how plastic and diverse human minds can be. Genes, once seen as independent code that program our bodies, are now understood in the larger context of our personal experience and our interactions with the environment. We're also discovering that our capacities change dramatically over the course of a lifespan, and even just a day.

networks: populations of choice

Our social networks—families, friends, coworkers, and others—have always defined and reinforced our identities. Over the next ten years we will be able to visualize these relationships in high resolution, revealing waves of subtle influences that we have on each other's health decisions. Seen in high resolution, "populations" take on new meaning. We'll see the contagious effect of not only behavior like obesity and smoking, but also of health practices such as alternative treatments and unique interpretations of medical compliance. This interconnectivity will define us as much as, if not more than, traditional categories such as race, ethnicity, and gender.

environments: a sense of place

Diversity has always been produced and defined by place, from geographic latitudes to neighborhood histories. Now technology is refining our ability to see the differences environment inscribes on our bodies. Advances in sensors and analytics enable us to see the effects of degrading air, water, and soil quality at finer resolution, from the residents of countries, counties, and zip codes to the inhabitants of individual buildings and passers-by on a street. We're learning how our environments can affect our brains and genomes during childhood and throughout our lives.

—Jake Dunagan and Miriam Lueck Avery

an interview with **katherine haynes sanstad**

Katherine Haynes Sanstad is currently the Executive Director of Diversity for Northern California Kaiser Permanente, where she is working to enhance actionable performance metrics to drive improvement in care and service for KP's diverse membership. She has over 25 years of experience in marketing, communication, public health and health care, philanthropy, and futures research.

by **miriam lueck avery** and **jake dunagan**

Research Manager, Health Horizons Program
Miriam's background in ethnography allows her to explore how the choices in people's everyday lives shape the future and their health.

Research Director, Technology Horizons Program
Jake's research examines the role of emerging technologies in culture, governance, and health.

Miriam: What are the key challenges and opportunities posed by high-resolution diversity for health care organizations?

Katherine: The biggest challenge is really the doubt and fear that come from historic experiences of discrimination. I think a finer-grain understanding of identity won't directly reinforce old patterns of discrimination; it will build on our human tendency to discriminate, but it will allow us to do it in new ways.

If you look at the health and health care challenges, it's the challenge of making information actionable. Often our technology outstrips our wisdom. The ethical and moral frameworks to govern the use of knowledge lag behind the attainment of that knowledge, and policy lags even further behind that.

Miriam: What does that lag look like, when an organization is trying to deal with those ethical and moral implications?

Katherine: My first thought was about the early struggles with HIV antibody home testing. With home testing, people were afraid of getting a positive test. So they set up a whole system for giving the test results, with rigid security mechanisms, before it was licensed. Of course, the whole subject of HIV was highly politicized. It was a rare example of the concerns for privacy, the mechanisms of policy, and even product licensing taking into account the risks of using information to discriminate against people.

Kaiser Northern California's Division of Research grapples with this issue all the time. We build extreme firewalls between the parts of Kaiser. All the data collected in any study are protected by stringent requirements of our Internal Review Board (IRB), and owned by the Division of Research. The medical group and the health plan can't access data for individual participants; rather we aggregate the results and integrate that knowledge into practice.

Miriam: What are the advantages and disadvantages of firewalling in making information actionable?

Katherine: At Kaiser we are trying to understand health disparities that correlate with race and ethnicity. The Division of Research knows the race and ethnicity of over 90% of our membership. As a health plan and hospital, we're required to collect this data and report it to the Office of Statewide Health Planning and Development. We directly collect from 43% of the population that have been seen in these settings, and we're going to collect more. We need explicit consent from our members to include the information in clinical records. Only then can we look at patterns of access, patterns of care, patterns of illness and begin to understand the disparities that arise from a myriad of societal, genetic, and environmental reasons—where they emerge in the population and where to focus our expertise on mitigating the effects. We can only and should only use data for the reasons it was collected. Data collected as part of care delivery can be used to improve that care. Data collected as part of research can only be used to increased the knowledge base. That is as it should be. But we cannot and should not use research across those firewalls.

Miriam: What are the most important strategic considerations for health care organizations trying to navigate the future of high-resolution diversity?

Katherine: Privacy and security. Whenever you collect potentially important information, it may also be dangerous information. That's something people need to think about. And there's a moral and ethical question: how do you accrue benefit for the people who give you the information? The truth is that the knowledge we gain often helps future generations, not necessarily the generation that gave it to us. Our challenge is to make the best use of the knowledge we gain for current and future generations.

I also think that we need to link the information we pursue to the burden of disease. Chronic disease is a problem for everyone, not just for the individual who suffers from the condition. It's a problem for the medical system when it comes to rendering high-quality, affordable care and it's a problem for insurers and purchasers because chronic disease is very costly, in terms of managing it and in terms of lost labor. I want to fiercely pursue information about individuals that we can convert into tools for preventing and managing the conditions that plague us most.

Jake: In a blue-sky scenario, if you had a magic box that could tell you whatever you want to know about someone, what would it show you?

Katherine: We've spoken a little bit about neuro-diversity in terms of making information useful; how can we best personalize support for care management?

Here's an example. A woman with diabetes has an epiphany; she learns that she can take insulin at any time, not just before meals. This is after years of grappling with the condition unsuccessfully.

Is there a way we can somehow look into people's brains and identify the best modality for communicating actionable, fulfilling information to them? In this woman's case, the barrier wasn't just emotional. It was cognitive. There was a breakdown in her understanding of what was possible. If we could have given her a short-cut to her epiphany, who knows how many months or years of blood sugar control she might have gained?

Diabetes and obesity are especially complex, from both physiological and behavioral standpoints. It's about health in the social environment and that requires collaboration and integration. These kinds of conditions would benefit greatly from insight into the correct modality for intervening with the individual at the micro level.

Jake: But there's also a danger of measurement bias: we go where the flashlight is shining instead of where we need to be. The health information on the Web might lead us to some insight, but it's a relatively narrow view for people who can access those tools.

Katherine: Right. I think it will be interesting is to see how some of this plays out in lower-resource environments. At the Mobile Health Conference a few years ago, an Indian doctor, Dr. Krishnan Ganapathy, spoke about innovation in rural India. There are lessons we can learn about getting higher-resolution information in low-resource settings. We usually think of technology transfer going in opposite direction, from the developed to the developing world. Because of leapfrog technology and the need to innovate without making huge investments in brick and mortar, low-resource settings outside the U.S can show us a future where we can use information to help a broader cross-section of the U.S. population.

PHOTO OF KATHERINE HAYNES SANSTAD BY ELIOT KHUNER, 2006

SCENARIO 1: **BODIES**

from trial-and-error to seeing results

Set in 2020, these three scenarios illustrate the ways that emerging technologies and sciences are creating new kinds of human diversity. The scenarios suggest possible approaches to using these understandings to create new capacities to improve well-being.

Quantitative EEG (QEEG) is a high-resolution process that matches particular neurological patterns and responses to pharmacological treatment options.[1] This high-resolution view of diverse and clinically significant neural correlates of mood disorders is a powerful tool for effective care.

FORECASTS
QUANTIFYING THE SUBJECTIVE
BIOLOGICAL PREVIEWS

TECHNOLOGIES
NEUROIMAGING
PHARMACOLOGY

Imagine in 2020:

Diagnosed with depression, Jim has spent the last few years alternating among Paxil, Wellbutrin, and Effexor with mixed results. One would seem to be working, but the depression would come back. A dosage increase produced side-effects. When Jim began to spiral into debilitating depression, he started examining other treatment options. A colleague recommended that he see a doctor who was using EEG data as a guide for selecting medicine. The EEG scans were relatively easy, and they allowed Jim and his doctor to literally see how the drugs were affecting his brain. It took several visits to get the right medication, but Jim was soon feeling better than he had in years.

Jim
Source: IFTF

Scenario explanation

The pharmacological treatment of depression and other mood disorders has traditionally been a low-resolution clinical practice. Individuals react to the same drugs and dosages in very different ways, and clinicians have relatively little understanding of the actual neurological and biochemical mechanisms that cause these radically disparate outcomes. Treatment algorithms, patient profiling, and trial-and-error are the current methods, so it's no wonder that it often takes months or even years to find the right combination of medication and dosage for a given individual. Even then, 30% to 40% of patients suffering from a major depressive disorder still fail to respond to medication.[2] With fast, high-resolution experimentation, new patterns may emerge to turn this process from a painful, idiosyncratic one to the application of meaningful clinical types.

QEEG scans of neurological patterns
Source: www.brainmaster.com

ENDNOTES

1. Melville, Nancy A. Quantitative EEG can guide treatment of depression. http://www.rhistl.com/index.php?/qeegdepression.html
2. http://clinicaltrials.gov/ct2/show/NCT00157547

SCENARIO 2: **NETWORKS**

from risky genes to potential advantages

Science has linked variability in genetic expression to an individual's experience and environment: epigenetics. Most research into this linkage has focused on how certain environments can amplify negative behaviors and conditions associated with specific genetic variations, but a newer approach is also showing how people with these "vulnerability" genes can benefit greatly when exposed to nurturing environments. A high-resolution view of genetic diversity and environmental conditions will help us design more personalized and appropriate levels of care for our children.

FORECASTS
PROBABILISTIC MEDICINE
EPIGENETIC IMPRINTS

TECHNOLOGIES
GENETIC DIAGNOSTICS

Imagine in 2020:

Margaret had read all the books and tried all the methods, but her 3-year-old son Zack was still a "handful." He always had a temper, but lately it was getting much worse. Biting, throwing tantrums, and hitting, Zack was generally combative and irritable. With no relief in sight, Margaret decided to take Zack to a specialist in child behavior.

As Margaret expected, the specialist observed Zack remotely, and interviewed both her and Zack. She also sent Zack to a lab for a genetic screening test. At the next visit, the specialist told Margaret that Zack possessed a particular genetic allele that made him very sensitive to certain kinds of environmental conditions.

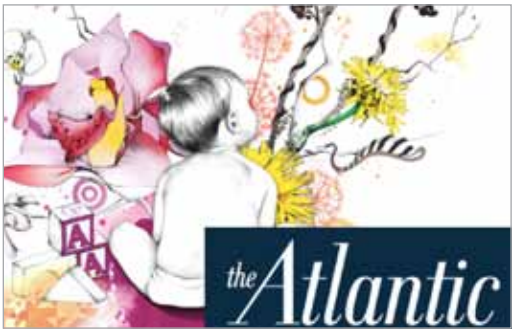
The doctor directed Margaret to a class and support group that would teach her how to best care for Zack. The resources provided Margaret with some much-needed relief and gave her a prescribed course for Zack that would create a nurturing environment and give him an opportunity to grow into a creative and happy person.

Margaret and Zack
Source: Flickr user seandreilinger

Scenario explanation

Finding and linking genes to health indicators and behaviors has been a scientific cottage industry for decades. Out of this research, a new understanding of the interdependency between genetic variation and environmental conditions has emerged. David Dobbs, in a recent article in *The Atlantic*, "The Science of Success" calls for rethinking many of our assumptions about genetic vulnerability and risk, and becoming aware of so-called Dandelion and Orchid children. Dandelions are kids who thrive under almost any condition, whereas Orchid children require high-levels of attention and nurturing in order to thrive.

Our greater understanding of the contextual influence on genetic expression is answering the key question of how genes survive that encourage individually and socially destructive behaviors. Dobbs points to research showing not only how genetic vulnerabilities to environmental conditions are linked, but also, in certain cases, how those seeming vulnerabilities can be turned into distinct advantages for individuals and for groups.



The Science of Success, David Dobbs
Source: *The Atlantic*, vault49

SCENARIO 3: **ENVIRONMENTS**

from at-risk categories to real-time sensing

Sensor-enabled treatment gives doctors, patients, and researchers more accurate views of the causes of chronic illnesses often associated with persistent health disparities. Crowdsourced high-resolution perspectives on our health practices reveal us to be people who do things, rather than categorical statistics who suffer illness. High-resolution perspectives will also enable more personalized care that emphasizes an understanding of causes and triggers.

FORECASTS
CROWDSOURCED RESEARCH
ECOLOGICAL HEALTH

TECHNOLOGIES
SENSORS AND SENSOR NETWORKS

Imagine in 2020:

Maria hadn't experienced asthma attacks this severe for over a decade. The attacks were especially mysterious because she was taking better care of herself than ever before, including getting more exercise by biking to work across town; in fact, the attacks began soon after she started biking. She went to a nurse practitioner, who prescribed an inhaler with a GPS-enabled cap that would track her daily use and share it with him and the local public health department via the Web.

Dozens of other members of the community suffering from asthma were also tracking their daily use. It soon became apparent that most had their worst attacks on the same 200-foot stretch of the city bike trail. A certain type of gum tree planted along the trail turned out to be the culprit. Armed with a report from her nurse practitioner Maria and the others got the city to replace the gum trees with a more benign variety. Soon after, the frequency of her attacks dwindled to almost none.

City bike path
Source: Flickr user fernando

Scenario explanation

Over the last two decades we've correlated the disparate prevalence and severity of asthma with the usual low-resolution categories: age, ethnicity, income, and neighborhood. The old tools, although improving, are still blunt instruments with their own unique blind spots.

The common research practice of tracking hospitalizations is not only a blunt instrument but is the most extreme and costly point of intervention. Analyzing inhaler prescription renewals yields patterns by zip code, but is very low-resolution in terms of time. Self-reported surveys can probe for multiple factors, but are error-prone.

Over the next decade, solutions based on sensor networks, GPS, and life-blog camera diaries will ultimately change many of the categorical assumptions that define us. Although physician monitoring helps people comply with medical instruction, so does contributing to research, toward a greater good. Asthmapolis, a research project in the Midwest employs GPS attachments to inhalers, Web diaries, and patient-doctor-researcher partnerships to understand asthma, is helping to remove blunt instrumentation from the equation.

Asthmapolis Spiroscout Inhaler Tracker
Source: Asthmapolis.com

enabling technologies

Communication technology extends our reach and medical technology extends our lives, and these effects of discovery and extension are at work when it comes to advances in diversity. Our ability to see the world differently, from the workings of the brain to the complexities of genes, is making us re-examine our traditional categories of difference, including race, gender, and intelligence. We're beginning to define ourselves by particular genetic alleles or patterns of neural connections. Technology is also making demands on how we think and behave, from cognitive-enhancing drugs to algorithms that help us predict disease outbreaks.

The three scenarios depict how these emerging technologies will change the ways we think about diversity in our bodies, networks, and environments.

Neuroimaging

We can now measure electro-chemical, heat, and blood-flow signatures of the brain with strong magnets and electrical signal capture, and through the behavior of light shone through the brain. With this data, we can accurately map the structure and function of the brain, revealing previously unseen neurological variations between individuals and within populations.

Quantitative and computational neuroscience

Quantitative and computational neuroscience sees the brain in terms of information. It relies on mathematical and statistical modeling of neurological functioning to understand and simulate processes such as memory formation and brain region connectivity. These models offer a computational view of how brains work, and can reveal patterns of difference in the numbers.

Genetic diagnostics

Genetic diagnostics is a screening process that examines points of difference in specific genes associated with predicted outcomes in our bodies and our health profiles. We can use this information to determine possible drug reactions, disease probabilities, and health vulnerabilities based on actual genetic information instead of proxy categories such as race or ethnicity.

Predictive search and data mining

We can use algorithms that process Internet navigation patterns and search-term frequencies to predict user behavior and forecast events. Search-term algorithms have already identified outbreaks of diseases, and changing environmental conditions with long-term impacts on different populations, before they were revealed by traditional public health strategies.

Psychopharmaceuticals

Psychopharmaceuticals act on cognitive and emotional neurological processes and are used for a wide range of applications, including treating degenerative disorders, modulating mood, and enhancing cognition. Pharmaceutical companies are developing and testing many of these drugs against specific genetic profiles of possible recipients, leading to the rapid growth of the field of pharmacogenomics.

Neuromodulation

Neuromodulation alters the brain and nervous system for the treatment of medical conditions, to change behaviors or enhance cognition. Technologically aided neuromodulation can be accomplished with psychotropic drugs, invasive or deep-brain stimulation, and less invasive electrical, magnetic, or optical stimulation. Soon, we'll have the tools to "program" our brains with far more granular control—leveling and creating new human differences.

The future of high-resolution diversity is riddled with traps as well as opportunities. We can see the promise in understanding how specific individual and group variations create vulnerabilities and affect health outcomes. And we're uncovering personal and collective capacities and learning where to best apply them. How can we turn diversity into an asset in our quest to transform our bodies and lifestyles and pursue well-being. The following are response strategies to the forecasts in this perspective. They can be mapped onto the "Well-being Response Landscape" described in the Overview: they are immediate, intermediate or long-term, and are aimed at either treating or managing illness or building new health capacities.

Personalize care and target offerings

If we can agree on the meaningful points of diversity—for example, learning styles for chronic disease management, place and activity space, and salient indicators of health—we can gain unprecedented abilities to personalize care. We can also target offerings for those who need it the most, in ways that are comprehensible and meaningful. And we can find new shortcuts, tests and proxies to vet care for effectiveness. (Long-term illness response)

Set priorities to identify relevant diversity

The most important long-term strategic consideration for any organization lies in setting priorities: identifying what kind of high-resolution diversity is relevant and useful, and putting it in the right context. What we do along these lines depends on what we're seeking—what the differences are that matter. This involves considering not only which kinds of insights about human difference are technically feasible, but also which will have a meaningful impact. (Long-term illness response)

Translate insights across silos

Once we know what we're looking for, how do we find it and make sense of it? Research, marketing, HR, and clinical functions of organizations all have different channels for learning about people. The future of high-resolution diversity is deeply interdisciplinary, multi-role, and cross-functional. They key to harnessing this future as a resource to build well-being will be to translate insights across hardened organizational and disciplinary silos. (Immediate capacity building response)

Value diversity

Higher-resolution diversity may be our gateway to new kinds of tolerance. Understanding the full cognitive and behavioral effects of different age cohorts adapting to constantly evolving technologies may show us ways to work better together in diversifying workforces. We may also see our values shifting; traits once considered jarring may prove to be associated with new adaptive behaviors. Personal health management strategies in workplaces, and diversity within research samples, may be key to creating and maintaining resilient organizations, societies, and individuals. (Long-term capacity building response)

Secure information vs. tangible benefit

Start-ups, community groups, academics, health care companies, and clinicians are all subject to laws and moral obligations to protect people's privacy. They also have different assumptions about what it means to give people direct benefits from research and to protect them from discrimination. This will constrain the ways that people can form effective communities around these practices.

Effectiveness vs. cost

A tension exists between investing in understanding the differences that matter, and reaping the long-term rewards of effectiveness, customer loyalty, and eventual decreased costs. For example, QEEG screenings for psycho-pharmaceuticals, although costly, will lower costs in the long run by reducing the stress caused by trial-and-error methods.

For more information about IFTF's Health Horizons Program contact **Dawn Alva** at (650) 233-9585 or **dalva@iftf.org**.