Scenario

Solving tomorrow's problems

This is a world where smart and deliberate innovation is broadly distributed. Advances in big data and artificial intelligence help create effective, inexpensive genetic diagnostic tools that are applied globally. Diseases become more predictable and, informed by new insights about why illness occurs, the focus of health care evolves to emphasize prevention. New treatments also emerge. Technological advances not only lead to remarkable new therapies but contribute to curbing increases in health care costs.

In the early 2020s, governance and regulatory mechanisms are at first overwhelmed by technological advances and have difficulty adapting quickly enough. Over time, government entities at the international, national and local levels catch up and put in place policies and regulatory approaches to ensure the benefits of medical advances are broadly distributed and risks minimized. Indeed, big data and AI help inform development of evidence-based policy frameworks that are at the heart of these new governance mechanisms.

This doesn't happen overnight. In the mid-2020s, a series of experiments around the world leads to new governance structures emerging, first in small countries and then at the provincial/state level in large nations. California assumes a leadership role, and its practices come to be widely adopted by other states in America and some medium-sized countries. Some innovations also come from middle-income countries that have invested heavily in information technology and thus possess the infrastructure needed to implement broad-based digital health strategies on a national scale. Once success is demonstrated in smaller settings, new governance measures get adopted broadly around the world.

People's genetic data and health histories come to be collected and curated as a public good. The tagline "23 and Me for Free" comes to be widely used, since the price of genetic testing drops enough that governments can offer testing for all citizens and more than defray the modest costs

by selling data to stakeholders in the health care system. The All of Us project, launched by the National Institutes of Health in 2015, spreads globally, first in the European Union and later throughout East Asia, and becomes the global repository for health data. Subsidiary organizations in each region establish rules about how data is collected, translated, shared and then accessed. These efforts not only involve setting protocols that allow data sets to be interoperable across regions but also encourage harmonization on privacy regulations and security approaches, so citizens can be assured that their data will be used for their benefit and only by authorized researchers.

Individuals have ultimate control over their own information and can choose to share it on a true opt-in basis, with appropriate protections. A variety of mechanisms emerge for patients to receive some of the benefits generated by the use of their data. In some cases, corporations that access the global repository and develop innovations based on it share a percentage of the revenues from their discoveries with the people who provided their data. In other cases, funds generated by the use of data help to pay for the national data banks that feed into the global repository.

The widespread availability of vast stores of data allows for rapid advances in personalized medicine and new approaches to prevention, diagnosis and treatment based on genetic information. Artificial intelligence also plays a big role in helping health care professionals make decisions about what to do for a particular patient.

These developments quickly raise a series of vexing ethical issues. Should genetic knowledge be used only to alert people that they are susceptible to serious rare diseases or also to let them know they have a predisposition to common chronic diseases? How much genetic alteration is proper? Should modifications to improve mental or physical performance be allowed? Are designer babies okay? Similar questions arise around the use of AI, specifically regarding what AI algorithms should optimize for: health of the individual patient, health of the population as a whole or cost? An additional question that arises relates to how reliable the treatment recommendations made by AI algorithms are.

The cooperative governance mechanisms put in place to establish standards for the handling of genetic data allow the global health care system to address these ethical challenges. Society decides not to implement certain medical advances even though they are technically feasible, since they are judged to be socially undesirable. Similarly, rules governing what AI can—and cannot—do in connection with patient care are established. These deliberations also generate a consensus that providing broad access to care is a worthy societal goal.

The emphasis overall is on advances that can help large numbers of people rather than ones that will enhance the lives of a select few. This is accomplished through a combination of formal legal constraints, standards and widely held agreement among medical professionals about what is and isn't okay. These rules and universally held norms prevent ethically questionable pathways from being pursued even in the lab.

These same collaborative mechanisms lead to innovations in the approval process for new therapies. Computer simulations come to be substituted for human trials in some parts of the approval process. Individual patients have a "digital twin"—which replicates, in silico, the workings of an individual's body based on his or her particular genetic endowment—that can be used to test their likely reaction to a regimen under consideration. Once the safety of a new therapy has been established, widespread testing is permitted, with real-world evidence then used to evaluate efficacy and validate or improve simulation models. Greater genetic knowledge also allows more elaborate protocols for prevention, so approval processes related to prevention emerge.

The new focus on prevention helps to contain costs. Preventive measures and treatments become more effective thanks to the proliferation of personal sensors, which are paired with apps that provide positive reinforcement to help people adhere to healthier lifestyles and follow therapeutic regimes after they've been diagnosed—or even before. These apps are augmented by AI algorithms and rely on new insights into the workings of human behavior developed by researchers armed with rich genetic data. As overall costs fall, funds become available for further investment in innovation, which in turn further reduces costs, thereby setting a virtuous cycle in motion. Lower costs also help to achieve the goal of providing broad access to health care. By 2040, life expectancy exceeds 100 years in most countries.

However, the explosion of new knowledge creates complexity for individuals facing decisions about what treatments to undertake and even which preventive measures to try. In response, requirements for a growing profession—health care advocate—emerge to help patients weigh the benefits and risks of the array of choices they face in this brave new world. Primary care providers, with some of their duties now assumed by AI algorithms, also provide counsel of this sort.

Widespread genetic profiling also has impacts outside of health care. Uploading a DNA sequence becomes a routine part of signing up for dating apps, and startup companies help people find others who have compatible genetic profiles. At first, this genetic matching is controversial and the companies entering this domain get accused of trying to "engineer love." Other critics note that DNA matching echoes the eugenics movement that swept across the United States and Western Europe in the early 20th century, with disastrous consequences in Germany. Much as online dating was met with resistance initially and then came to be widely adopted, over time the practice of DNA matching as one aspect of the quest to find a suitable mate comes to be seen as routine.

This world is one of widespread cooperation: to create globally accepted standards for the handling of health data (including strict privacy and cybersecurity measures), to establish the boundaries of where genetic interventions may (and may not) occur and to set rules governing the use of AI. The presence of these standards serves to create broad trust in the health care system. Indeed, deep trust between key stakeholders—providers and patients, government officials and executives at the corporations that serve the health care sector—is a cornerstone of this future.

Implications

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Regulators and standards setters are central in establishing the rules and protocols that enable this future. Benefits are widely shared, so there is broad public support for the organizations—primarily governments and NGOs—that take the lead in establishing the rules of the game that govern health care. The health care system as a whole is seen favorably, since it delivers broad benefits for most.

In this world, innovation initially focuses on developing data protocols and security mechanisms that allow patient data to be widely shared while still ensuring privacy. This certainly requires technical development but also innovative governance mechanisms that ensure data is used ethically for the benefits of patients. Once a global data repository is in place, a flowering of new developments in genetic diagnostics, treatment and prevention takes place. A round of innovations in the use of AI, especially in diagnostics, occurs in parallel. Needed innovation also occurs in the development of ethical frameworks to determine which genetic treatments and which applications of AI are allowed.

Regulators play a big role in this future by establishing the rules of the game for data, genetically based medicine and use of AI. Getting these rules in place is a big task and requires cooperation of government entities with stakeholders in the health care sector at many levels, from local to national and international. New approaches get developed first at local levels, and those that work see broad adoption. Over time, a set of harmonized, global rules comes to be in place for data, genetic medicine and AI.

Data standards are crucial and are the cornerstone on which this future is built. While regulators need to establish certain legal mandates (for example privacy protections), standards-setting bodies working with industry also play an important role. Data standards allow protocols that encourage globally dispersed systems to collect and exchange the relevant data. Standards are also needed to ensure that complex genetic therapies are delivered safely and effectively. Standards-setting bodies also play a key role in another important realm: establishing protocols for synthesizing the vast array of patient data—genetic profile, health history and lab tests—as it gets interpreted and translated into a recommended treatment plan by AI algorithms.

This is a future of high trust, made possible by successful mobilization to establish globally accepted standards around the handling of genetic data, which genetic modifications/alterations are acceptable and how AI ought to be deployed to assist human judgment in health care. Because access to care is broadly shared and the system focuses on doing the best for the most, everyone trusts in the system because all believe it is working to benefit them.