

Stanford Medicine 2018 Health Trends Report

The Democratization of Health Care

December 2018

Foreword from Dean Minor

Data and the democratization of health care.

In last year's inaugural **Health Trends Report**, we discussed the explosion of data in medicine and what it meant for patients, researchers, and physicians. This year, we drill down into operation and implementation, exploring how this wealth of information is changing traditional health care roles, the experience of patient care, and access to services in the digital age. What we've found has vast implications for medicine writ large, and especially for patients: all early signs point toward the democratization of health care.

For our second annual report, we again interviewed industry experts and conducted a comprehensive review of publicly available data from a variety of media, analyst, and academic sources. We also spoke to our own faculty to gain insight into the trends influencing their work and the issues they see driving the future of health care.

In short, more individuals and organizations now hold more data than ever before, and the pace at which data is moving between them is accelerating. At the same time, new tools are now available that can rapidly and accurately interpret medical data—from radiology imaging to genomics—and push insights directly to the point of care, which is less and less defined by physical location.

Together, these trends have the potential to bring about a future where

sophisticated medical knowledge is no longer confined to the clinic. One day, perhaps soon, this expertise will live in our smart devices—readily accessible, whenever and wherever it's needed. This kind of access could have an enormously positive impact on global health, especially for patients who lack high quality care close to home.

Today, we're starting to see walls come down in the health care industry, allowing data to flow more freely to where it can do the most good. Realms of historically siloed expertise are opening up to more and more people. Patients can now get access to their personal health information. And digital tools are giving rise to new health platforms that are increasingly useful to physicians and patients alike.

With all of this said, we haven't yet reached the promised land of digitally enabled health care and open access to data. Health care lags other industries when it comes to data sharing and interoperability. Case in point: We can manage our money from mobile devices anywhere in the world, but we still can't manage our health records in this way. It's clear that we have work to do when fewer than one in three hospitals can electronically find, send, receive, and integrate patient information from another provider.

We must also address the very real issues around privacy and ethics with regard to patient data. The opportunities we stand to realize are huge, but the risks are similarly significant. Maximizing the



potential of patient data while ensuring its privacy and security at every step will be one of the defining challenges of this new era.

But we are undoubtedly on our way to a future of care that is more predictive, preventive, and personalized. This is our vision for Precision Health at Stanford Medicine, one in which we build a health system that goes beyond curing disease and moves toward preventing it before it strikes. It's a future that is good for patients, physicians, and the long-term viability of the American health care system, and it's one that we are earnestly working to achieve.

This report is not intended to offer firm conclusions, but rather to begin a conversation about how we can best realize the promise information gleaned from data offers our patients and those who care for them. I hope you find the report valuable, and I look forward to hearing your thoughts in the coming year.

flord B. Minor

Lloyd B. Minor, MD Dean Stanford University School of Medicine

Table of Contents

Introduction	1
1. Data is Growing and Flowing	1
2. New Technologies and Industry Players	1
Three Pillars of Health Care Democratization	3
Intelligent Computing	3
Sharing	8
Security, Privacy, and Safety	12
The Road Ahead	16
References	17



Introduction

In last year's Health Trends Report, we took a global look at the emergence of big data in the clinical and experimental fields of medicine. The explosion of data sources, data types, and analysis tools foreshadowed a sea change coming for health care: in the laboratory, in the clinic, in the living room.

This year we continue to track the exponential growth in the volume and utility of that data but begin to take a deeper look at how data sharing and its use will transform research, medical practice, and the role patients play in their own health care. We have seen this year a rapid increase in the flow of data and information across an increasingly wide range of stakeholders. More people hold more data than ever before. As a result, for the first time in history, there is an opportunity to truly democratize health care.

This health care democratization is characterized by two major factors: the distribution of data and the ability to generate and apply insights at scale. It promises a world in which patients—armed with data, technology, and access to expertise—can take charge of their own well-being and manage their own health.

Democratization will mean that providers focus less attention on routine tasks and more on the areas where they provide the most value and find the most satisfaction. And individuals managing their health care concerns will put less strain on the health care system, lower costs, and improve public health overall.

1. Data is growing and flowing—across our health care system faster than ever before.

Historically, health care has operated as a closed ecosystem of siloed institutions, with the research hospital as the hub. And within this environment, physicians have served as the primary gatekeepers of medical information. The flow of information has gone in one direction: from expert to patient.

Largely due to the digitization of patient health records—rare a decade ago but now nearly ubiquitous-data is flowing more freely. Patients are now engaged with the wider health care system in more complex forms of information sharing. More people are using digital devices, from smart watches to internet-connected insulin pumps, to monitor and manage their health. DNA testing is increasingly popular and convenient—one in 25 American adults has access to their personal genetic data.¹ Patients no longer get all of their health care information from the physician. This one-to-one relationship between expert and patient is giving way to a

multiplicity of information-sharing relationships—one-to-many, many-to-one, and many-to-any.

This transformation puts the patient at the center, encouraging the spread of medical knowledge in unprecedented ways. It is also challenging the health care sector to adapt. The net result is that the public now has access to medical data, both personal and general, in ways it never has before: 93% of hospitals and health systems enable patients to access their health data, interact with health data, and obtain health services.²

2. New technologies and industry players are taking medical knowledge from a human scale to a digital scale.

The growth and spread of data have generated more information than any one person could possibly interpret. However, recent breakthroughs in data science and artificial intelligence (AI) are quickly overcoming this challenge. Medical experts and scientists are now training algorithms that can analyze vast quantities of data and extract insights.

These developments, though recent, have already attracted tech firms to the health care sector in a big way.

Tech companies see opportunity in the need to bring health care into the digital age, and they are investing heavily to address these new markets.

Many roadblocks and inefficiencies that have encumbered this digital transition are gradually being phased out and eliminated. Although we are not yet in an ideal state of democratization, early signs of where we're headed are loud and clear. We must now take steps to address the challenges that stand in the way of that ideal state.

Key Questions Going Forward

- What are the key opportunities presented by democratization?
- How do we realize this vision?
- How do we ensure that the benefits play out equitably for all people?
- What safeguards are necessary?

The 2018 Health Trends Report will examine these questions across three domains that represent some of most important trends taking shape in health care today.

Intelligent Computing
Sharing
Security, Privacy, and Safety

Advances in Digital Health Taking Shape at Stanford Medicine:

- 1. A Stanford-developed AI algorithm for radiology can reliably screen chest x-rays for more than a dozen types of disease, and does so in less time than it takes to read this sentence.
- 2. Stanford Medicine's **Second Opinion** platform, powered by Grand Rounds, allows patients to get a second opinion from a Stanford Medicine doctor without leaving home.



- **3.** Stanford and Apple teamed up on the **Apple Heart Study**, recruiting 400,000 participants in a year with the goal of detecting atrial fibrillation in Apple Watch wearers.
- 4. Stanford Medicine's Center for Clinical Excellence (CERC) is collaborating with Stanford's Artificial Intelligence Lab via the Partnership in AI-Assisted Care, with current pilot tests focusing on computer vision technology.

Three Pillars of Democratization in Health Care

1. Intelligent Computing

Algorithms are fueled by data; the more they have, the further they can go—and the more we can learn. An increase in data is fueling better algorithms, creating a virtuous cycle for the industry. As analytic methods continue to improve, these approaches will have a compounding effect on the industry, in both the near- and long-term: increasing efficiency, improving predictive capabilities, enabling greater personalization, and democratizing access to this enhanced care. As health care leaders adapt to this technology, they must take into account the practical and ethical implications it poses.

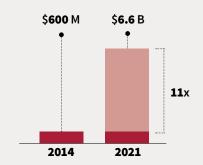
"

[In] the next 2 to 5 years there will be a lot of attention on data analytics and artificial intelligence that will allow us to learn from large observational datasets. It will teach us what we do today which we don't understand, how varied our practices are, and what outcomes we get with them.

- Dr. Paul Tang, VP, Chief Health Transformation Officer, IBM Watson Health

Scope and Scale of the AI Market

The AI and machine learning market is immense and fast-growing, especially in health care, where it promises steady improvements in cost, access, and quality. The size of the AI health market is expected to reach \$6.6 billion by 2021—that's a compound annual growth rate of 40%. That means that from 2014 to 2021, a period of just five years, the health AI



Health AI Market Size 2014 - 2021

Acquisitions of AI startups are rapidly increasing while the health market is set to register an explosive CAGR of 40% through 2021.

Source: Accenture (December 2017). Artificial Intelligence in Healthcare.

market will have grown more than 10x.³ This surge of health data has led to the development of highly sophisticated algorithms that are able to parse information at an unprecedented scale. Image recognition algorithms, for example, can now process hundreds of thousands of images, such as x-rays, photos of skin conditions, or images of tumors and reach a diagnosis in a matter of minutes. And as they continue to do this, they will become more accurate over time. In some cases, these algorithms are already capable of providing diagnoses more accurately than specialists working alone.

The health care industry appears ready to embrace this development. In a survey of senior health care decision-makers regarding AI maturity levels by industry, health care ranks higher than retail and financial services, with pharmaceuticals and life sciences being considered the most AI-ready.⁴

Near-term and Long-term Impacts

AI has significant implications for the health care sector, perhaps more so than other industries. The McKinsey Global Institute estimates that 15-20% of the health care market has the potential to be impacted by AI, making it one of the most affected sectors. ⁵

Intelligent computing has the potential to add a significant amount of value by improving quality of care, specifically by allowing for quicker and more accurate diagnoses, higher quality treatment plans, and new ways of managing processes. Some of the most anticipated advances:

Prediction:

Intelligent algorithms have already shown promise in predicting and identifying public health threats as well as outcomes for at-risk patients in the hospital. As they continue to improve, medical professionals will have a powerful tool to provide patient care that is more precise, immediate, and preventive. The Sloan Kettering Institute estimates that physicians use only one-fifth of available trial-based information when diagnosing and treating cancer patients.⁶ When effectively utilized, algorithms could process vast amounts of data and provide a larger picture of medical evidence to a doctor within seconds.

Personalization:

Physicians will soon be able to customize treatment plans, and even drugs, to individual patients based on a complex interplay of factors such as their genetic makeup, habits, and digitally monitored biometrics, to name a few. As this continues to evolve, standardized health care will increasingly give way to personalization. Research shows that tailored treatments could reduce health expenditures by up to 9% and add up to 1.3 years to average life expectancy.⁷

Access:

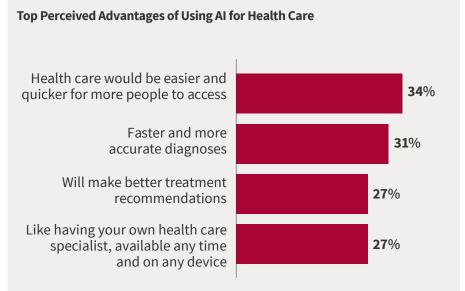
Virtual and mobile care now serve as a primary health resource for many patients. In fact, over the next five years the global mobile health market is expected to have a compound annual growth rate of 29%.⁸ When asked to name the top advantage of AI in health care, over a quarter of consumers cite having their own health care specialist available at any time, on any device.⁹

Cost and Health Outcomes:

Today, 90% of the U.S.'s \$3.3-trillion annual health care spend is on people with chronic health conditions. ¹⁰

By ensuring that the right care takes place at the right time, and in the right setting, advances in data science and AI have the potential to significantly slow the onset of chronic disease at a population level and prevent some forms of disease altogether. Even small improvements—powered by intelligent computing—could result in large economic savings for all stakeholders in the health care system. This incentive is likely to encourage partnerships and more value-based purchasing models in the future, further bolstering the industry's shift to preventive care.¹¹

By one estimate, AI could help reduce health care costs by \$150 billion by 2026 in the U.S. alone.¹² From a business perspective, intelligent computing creates an opportunity for industry players to optimize savings and profitability while still taking advantage of growth. Various AI applications are expected to bring billions of dollars in near-term value to the economy, the most valuable being robot-assisted surgery (\$40 billion), virtual nursing assistants (\$20 billion), and administrative workflow assistance (\$18 billion).¹³ These applications will only become more accurate and efficient over time, implying even greater value down the line.



Source: PwC (November 2016). Survey: The new imperatives for health.

Stanford Faculty on the Benefits of Intelligent Computing across Specialty Areas:

۲۲

You have these large genetic associations between a phenotype and a certain genotype, and it is very hard for the human eye to figure out which ones are real and what they're telling us. But there have been machine learning approaches applied to genomic data sets that are now suggesting candidate disease teams.

- Stanford Faculty



۲۲

On the more clinical side, there's been a proliferation recently of National Cancer Registry based studies that analyze data from tens or hundreds of thousands of patients. That also has let us ask some questions that we could never have asked with prospective studies. So, I think that big data has been a huge impact.

- Stanford Faculty



۲7

When you look at cells or neurons under the microscope, there are a lot of features going on in those cells and the human eye and brain can only really detect a few of them. There have been exciting developments where machine learning algorithms can detect things and patterns that we can't really see with our eyes.

- Stanford Faculty



Robot-Assisted Surgery Virtual Nursing Assistance Administrative Workflow Assistance Fraud Detection Dosage Error Reduction Connected Machines Clinical Trial Participant Identifer Preliminary Diagnosis Automated Image Diagnosis

\$40 \$20 \$18 \$17 \$16 \$14 \$13 \$5 \$3 \$2

Source: Accenture (December 2017). Artificial Intelligence in Healthcare.

New advances in intelligent computing will reduce the cost of treatments and procedures that were previously seen as inaccessible. The price of genome sequencing continues to fall while at the same time the actionable information available from combining the results of genomic tests with other key determinants of health is growing. Treatments for complex diseases such as cancer are being made increasingly more specific as a result of information obtained from populations of patients with comparable characteristics. Greater specificity typically means less trial and error as well as better outcomes.

Additionally, AI holds the potential to address a significant challenges in modern medicine: physician burnout. A recent Stanford Medicine study found that a majority (55%) of physicians report symptoms of burnout—or, exhaustion, cynicism, and feelings of reduced effectiveness. The study also notes that burnout influences quality of care, patient safety, turnover rates, and patient satisfaction. ¹⁴ Specifically, AI can provide relief to physicians' already hectic work days, six hours (on average) of which are currently spent on electronic health record (EHR) data entry—a task that can be easily handled with automated methods. ¹⁵ By making clerical processes faster and more efficient, AI stands to play a meaningful role in reducing physician fatigue and allowing health care professionals to focus more time on their patients.

AI in the Clinic

Various specialty areas within health care have already experienced the benefits of intelligent computing. For example, AI can be used to assist radiologists in identifying abnormalities such as heart disease and cancer and in conducting image guided procedures and biopsies. The proper deployment of algorithms to such processes has the potential to greatly improve the accuracy of screening and diagnostics.

Neuroscience

International Competition

The United States is not the only market looking to increase capabilities in AI and intelligent computing. China has become progressively competitive with the U.S. in terms of investment in AI applications and solutions. China leads the world in the number of research publications on AI.¹⁶ The country's intense focus on this area has resulted in the rapid development of new health care diagnostic tools.

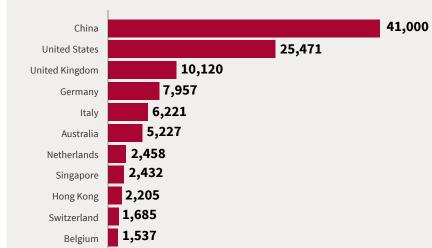
The U.S. leads the global AI sector in many other respects: in average years of experience of data scientists (majority have more than 10 years), number of AI patent applications (15,317), number of workers in AI positions (850,000), and percent of AI investment coming from private sources (66%).¹⁷

Ethics of Automation

Despite the many perceived benefits of AI in health care, public opinion splits on some sensitive questions about its role in delivering care. In a recent global study of consumers, just over half of respondents indicate that they would be willing to let an AI "doctor" perform an eye exam, while the majority say they would be opposed to brain surgery by an AI-driven machine.¹⁸

Less invasive, more routine procedures and processes seem to be more acceptable roles for AI in patients' minds. But when it comes to patients' biggest concerns about AI in health care, nearly half lack trust in robots to make the right decision when faced with an unexpected result.¹⁹

Al causes concern in the job market regardless of industry, with increasing apprehension over labor displacement, worsened income inequality, and a potential rise in unemployment. Apprehension is significant throughout the



Publications on AI Research

Source: The Times Higher Education World University Rankings (May 2017). Which countries and universities are leading on AI research?

Top Perceived Disadvantages of Using AI for Health Care



Source: PwC (November 2016). Survey: The new imperatives for health.

health care sector, with studies showing nearly half of patients and caregivers express concern over job losses caused by AI. Similarly, about a third worry that AI will result in humans losing certain abilities or skills, or even losing control over machines.²⁰

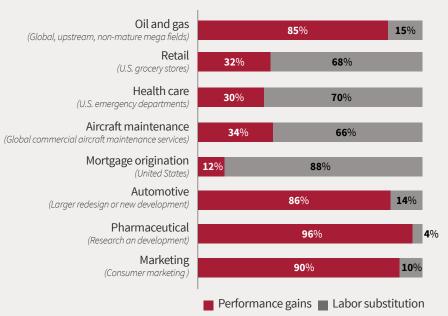
Despite the perceived ability of health

care roles to be automated, studies show that the health care industry itself is the fourth lowest when it comes to job automation potential, suggesting that these fears are largely unfounded. In fact, AI could have a net positive impact on the health care professions. Research shows that performance gains from AI are sizable in comparison to the projected labor impacts.²¹

Intelligent computing and AI should not be viewed as a means of replacing doctors; the human element is an important keystone in the physician-patient relationship. Research supports the fact that most patients are more comfortable with humans managing their health; 56% cite lack of human oversight as a concern about virtual nurse assistants. More than a third of patients are concerned that without human interaction, their health care provider would not know them personally.²²

Automation Improves Corporate Performance in Ways Beyond Simple Labor Substitution

Relative weight of performance gains vs. labor substitution



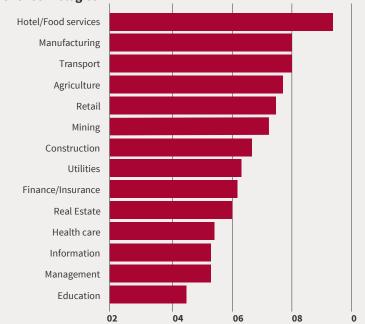
Source: McKinsey Global Institute (December 2017). Jobs Lost, Jobs Gained: Workforce Transitions in a Time of Automation.

Percent of Roles That Can Be Automated by Sector Using Current Technologies

,,

The potential for AI to positively impact our practices and make radiology professionals even more valuable to our patients and health systems is enormous, but to be effective the design and development of these use cases must have substantial input from radiologists.

-Bibb Allen, MD & Keith Dreyer, DO, PhD, Journal of the American College of Radiology



Source: McKinsey Global Institute (December 2017). Jobs Lost, Jobs Gained: Workforce Transitions in a Time of Automation.

,,

When it comes to collecting analysis of data, software can do it better than a human being, but I also still strongly believe in the value of having a human being examine the patient. AI can be incredibly helpful to doctors to really elaborate on this enormous amount of data that we are collecting, but I don't think we will replace our roles.

- Stanford Faculty

Al can also have unintended consequences. Algorithmic bias is becoming a major concern in this critical moment in the evolution of intelligent computing. If biases built into health care algorithms (or those that evolve within the program naturally) go unchecked, they could jeopardize quality of care, and even patient safety.

A seemingly simple test to screen for Alzheimer's disease may boast 90% accuracy but miss the mark for someone from a different country or region than the computer scientists who developed the test. That was the case for Torontobased Winterlight Labs, which develops auditory tests for neurological diseases. After publishing initial research on their technology, they found that their test only worked for English speakers of a certain Canadian dialect.²³ A participant's results might indicate Alzheimer's simply because they are not native English speakers and are slower to respond to test prompts as a result.

Quality and safety checks should be built in well before data is used to inform health decisions. The Framingham Heart Epidemiology Study in Massachusetts is one classic example of health care data potentially being skewed by certain factors—in this case, most study participants were white New Englanders.²⁴ The study remains one of the most famous and influential in cardiovascular disease epidemiology and raises important concerns about data objectivity.

Issues with data objectivity affect more than just cardiovascular epidemiology. Data shows that many psychological and social science studies comprise participants that are overwhelmingly Western and educated, and from industrialized, rich, democratic countries. Further, 67% of American psychology studies are conducted at universities using college students, bringing age bias into the mix.²⁵ As we transition into the age of Alassisted health care, software developers, practitioners, and patients must be on the lookout for subjectivity in the data being used to make life-altering health care decisions. Without inclusivity, there cannot be a democratization of health.

Intelligent computing and AI have the potential to be a major pillar in the democratization of health care, but only if the industry is prepared to address the challenges.

2. Sharing

Intelligent computing will allow health care practitioners to generate and apply insights at a scale that has never before been possible. Yet this potential could be constrained if the health care industry is unable (or unwilling) to share information and collaborate with others. Fundamentally, democratization necessitates openness, which invites technical and cultural changes that must be navigated.

Improving Data Sharing at a Basic Level

For health care to be truly democratized, information must flow freely between and among various participants in the system, including health care providers, patients, technology providers, insurers, and others. While this is happening to some degree, the health care industry has a long way to go in order to reach an ideal state of data sharing, and, ultimately, an ideal state of democratization.

The foremost hurdle, and perhaps the most trying, is interoperability: the capacity of of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of health care data and information for patients, practitioners, and providers.

Health care lags behind other industries when it comes to data sharing and interoperability. We can send text messages between different networks and access our money from mobile devices all over the world but cannot access all our own health data in a central location.

Currently, there is no central, shared database to reference all, or even the majority of, health care data around a specific issue or patient. This limits the quality of care physicians can deliver to their patients, as some of the most essential data points may be shielded behind virtual walls or slow-moving processes. For instance, fewer than one in three hospitals can electronically find, send, receive, and integrate patient information from another provider. Instead, most rely on paper or fax when sending a care summary for patient discharges or referrals.²⁶

A recent study revealed that less than 30% of U.S. hospitals were able to meet the four key metrics necessary for interoperability: data integration, reception, distribution, and funding.²⁷ To realize the benefits of democratization, the industry must make a shift toward increased integration and practices that promote interoperability.

Application programming interface (API) technology has the potential to advance interoperability in health care, and by extension, accelerate democratization. APIs, which are commonplace in other sectors of the economy, help to standardize the way applications interact and access data from one another. In health care, APIs have been slower to take hold, but most agree that the greatest opportunity to use APIs in the near term is to foster and enhance data sharing between the various EHR systems that exist in the market today.

One such solution is Health Level 7 International's (HL7's) Fast Healthcare Interoperability Resources (FHIR), a standards framework for data formatting and an API for exchanging electronic health records. The FHIR framework, which is available to the public, has grown increasingly popular.²⁸ In practice, it encourages the transfer of data by reducing the time and effort it takes application developers to connect to EHR systems and exchange health data. Tech companies like Microsoft have already begun integrating FHIR technology into their cloud-computing services.²⁹

EHR data preparation represents an additional hurdle for interoperability. No

two organizations have the exact same standards governing how data is entered into their EHRs, let alone individual departments and clinicians. The result is large disparities in data quality and consistency. This "messy" data makes it extremely difficult to share usable information between organizations that can be subsequently analyzed. Companies like Flatiron Health are working to resolve this by aggregating, cleansing, and anonymizing data from various health care platforms to make it transferable for research purposes.³⁰

77

The biggest problem is that our data are not prepared in a way that allows us to even make sense of it. Once the data are readily analyzable, frankly, the majority of the critical clinical questions can be addressed.

- Amy Abernethy, Chief Medical Officer/Chief Scientific Officer & SVP Oncology, Flatiron Health

Sharing with New Market Entrants

Increasingly, tech partnerships are driving a significant portion of the innovation in

health care. For example, Apple reports that 142 health care institutions now share medical records data with their Health app.³¹ These partnerships promote data interoperability in a way that could lead to more comprehensive and accessible patient records across the board.

A Few of the Health Care Systems Linking Medical Records to Apple Health:

- Stanford Medicine
- Geisinger Health System
- Johns Hopkins Medicine
- Medstar Health
- Cerner Health Clinic
- OhioHealth
- Adventist Health System

From end-to-end, the experience of health care is being bolstered by new and non-traditional partnerships. That includes patient transportation, where a flurry of recent activity has taken place. For example, Lyft has partnered with EHR company Allscripts to provide patients with rides to appointments. Uber similarly gives doctors the option to order rides for patients rather than using taxi vouchers. Even the more traditional automotive companies are entering the health care market. In April, Ford launched an ondemand medical transportation service for non-emergency medical purposes.³² Headlines from the past year announce new collaborations between health care providers and large corporations, with projects ranging from biotech to wearables and transportation.

Comcast partners with Independence Health to create digital health company

Ford launches on-demand medical transportation service

Lyft partners with Allscripts for patient rides

Doctors can now call Uber for patients, ditching taxi vouchers

Amazon, Berkshire, J.P. Morgan partner to cut U.S. health care costs

Apple and Stanford Medicine fire up Heart Study to spot irregular beat, atrial fibrillation Hospitals were once the center of the health care universe. Now, organizations that did not start in health care are becoming increasingly prominent in the industry, with 42 of the Fortune 50 companies engaging in health care to some extent (up from 38 in 2013).³³ Moreover, 20% of consumers in 2018 reported having been treated at a health clinic in a retail setting.³⁴

The continued challenge for the once-cloistered field of medicine will be determining how best to share in the responsibility of patient care with outside organizations and how to collaborate in ways that actually lead to improved outcomes for patients. This is still a relatively new concept, for all involved.

۲7

This can be good for the field and can be good for the society. It will bring attention to health care, the fact that new players come in. It will create interest for investors to engage in the health care system and, hopefully, to engage in a business model that will lower health costs and deliver significant advancements and breakthrough cures for patients.

- Stanford Faculty

Sharing in Discovery

The democratization of medical research could also bring advantages, exemplified by new kinds of organizations entering the field as well as the emergence of "citizen science," enabled by crowdsourcing websites. These developments represent a cultural shift taking place in research toward the notion of "discovered together, deployed everywhere".

Technology companies are increasingly focused on fostering innovation in health care. Alphabet, Microsoft, and Apple collectively filed more than 300 health care patents between 2013 and 2017.³⁵ Recent health care patents by these and other tech companies focus most on data storage and processing-related developments as well as wearable technologies.³⁶

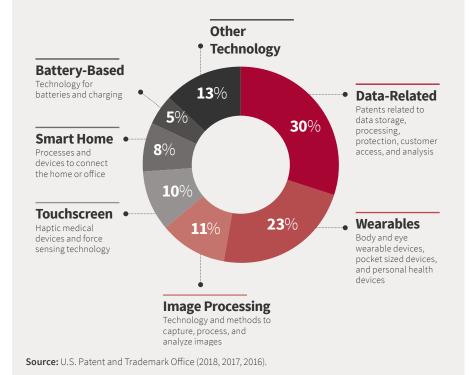
Crowdsourced health research is a powerful example of democratization in health care since anyone can contribute to crowdsourcing studies regardless of background or qualification.

It starts with data—as data becomes readily available online, more information is being shared freely across groups and channels. Kaggle, for example, is a crowdsourcing platform for data science projects, and aggregates datasets for public competitions. The Heritage Provider Network hosted one such competition on Kaggle in which participants used de-identified hospital data to develop an algorithm capable of predicting and preventing unnecessary hospitalizations.

Medical researchers are also beginning to call upon the public to help brainstorm solutions to scientific and medical problems. Eterna, a citizen-science crowdsourcing platform that was codeveloped at Stanford, is another example of such efforts. It challenges users to work through medical issues ranging from the development of a new diagnostic device to detect tuberculosis to improving the efficacy of CRISPR gene editing—all by playing visually based puzzles online.

Community biolabs, like other crowdsourcing platforms, bring members of the public into the world of medical experimentation. These communal labs focus on biotech applications and refer to their work as "do-it-yourself biology" or "garage biology". These efforts have grown into physical operations and facilities across the globe in which members of the community can participate freely.

Health Care Patents Filed by Tech Companies 2015-2017

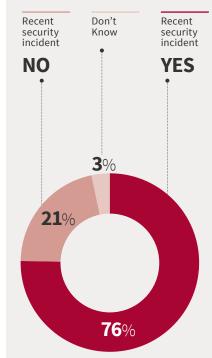




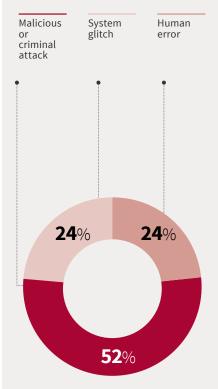


Source: Brookings Institution (October 2017). Do-it-yourself biology shows safety risks of an open innovation movement.

Prevalence of Recent Significant Security Incidents in Past 12 Months



Distribution of the Benchmark Sample by Root Cause of the Data Breach



Source (top): HIMSS (2018). HIMSS Cybersecurity Survey.

Source (bottom): Ponemon, IBM (2017). Cost of a Data Breach Study: Global Overview

3. Security, Privacy, and Safety

In an increasingly democratized world, more data is in motion—and when data is in motion, it is at risk. Patient privacy and safety are, and always have been, cornerstones of health care. As health data becomes more fluid, security practices around that information should be held to the highest standard. In addition to the safety of patients, at stake is health care's ability to benefit from the advantages that digitization has brought to virtually every other sector of the economy.

۲۲

We all benefit [from] the robust sharing of our data, because insights that may benefit all of us can be garnered.

As we all know too well, there are also nefarious forces at play who aren't thinking about how [to] use [data] for insights into human health, but how to use it for [manipulation].

- Stanford Faculty

Ensuring Patient Protection

The health care industry is incredibly complex, composed of large health systems, single physician practices, public and private payers, research institutions, medical device developers, software companies, and a diverse and widespread patient population. With the addition of intelligent computing systems to this dynamic landscape, it becomes increasingly unclear which parties own which data, even if doctors are still the ones providing care.

Uncertainty around ownership brings to light questions of confidentiality. The conventional understanding of confidentiality as it relates to EHRs, for example, requires that a physician withhold information from the medical record in order to maintain doctor-patient confidentiality. Some of the greatest perceived benefits to be gained from AI in health data, however, imply the need to compare the totality of a patient's medical history against large volumes of other patients' data. The concept of confidentiality and ensuring patient privacy and safety will need to be reexamined within this kind of environment.

Patient safety should remain at the forefront of industry priorities, for good reason: if protections erode, trust in these medical advances will dissolve, greatly limiting their benefits.

Data Breaches

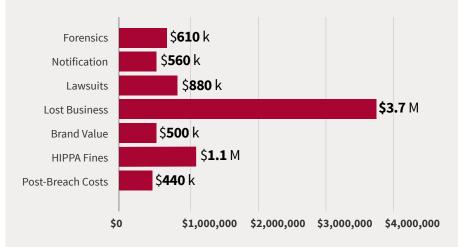
Health information security professionals report a high number of breaches occurring each year, with more than three quarters citing a security incident in the past year.³⁷ Further, a majority of breaches in health care are caused by a malicious or criminal attack (52%) as opposed to a system glitch (24%) or human error (24%).³⁸ Data breaches are expensive and tend to cost more in health care than in any other industry. Health care breach costs surpassed the next industry (finance) by \$135 billion in 2017.³⁹ Breach costs have gone up over time as well, meaning they are likely to only get more expensive.⁴⁰ Data breach costs can be quantified by a variety of factors, including lost business, HIPAA fines, lawsuits, and forensics spend. But this still doesn't reflect the reputational and trust impact side effects of lapses in data security.

Health Care's Current Security Posture—Bright Spots and Current Gaps

The health care industry generally recognizes the need to invest in cybersecurity.⁴¹In a majority of U.S. health care organizations, funds are being allocated specifically for cybersecurity purposes. That being said, more than a quarter of organizations do not have a specific portion of their budgets carved out for cybersecurity. This suggests the need for health care entities to become more intentional about their security practices and preparedness.

As technology companies delve deeper into health care, they, too, are expected to adapt to the additional security risks and responsibilities that come with handling health data. Many companies already understand the significance of these risks: Google, for example, recently expanded its list of HIPAA compliant products. Despite this focus, questions are being raised about whether cybersecurity can keep pace with emerging technology. In a 2017 study, 36% of all U.S. organizations were breached—a marked increase from 26% in 2016.⁴² Although health care organizations are investing in security, they

Seven Potential Costs of a Health Care Breach



Source: Ponemon, IBM (2017). Cost of a Data Breach Study: Global Overview

may not be investing enough. Times have clearly changed with respect to innovation, but security practices have not—in large part due to spending priorities.

۲,

Concerns about data privacy are not being taken seriously enough. The safest health care record was a file in a doctor's office, because no one was going to come in and steal it. Now, with electronic medical records, we know at some point these could be hacked and hundreds of millions of people's health care data will be released.

- Stanford Faculty

Earning (and Maintaining) Public Trust

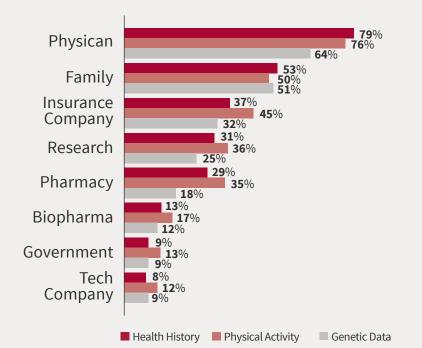
Consumers tend to be wary of sharing their personal data despite the growing desire for more personalized experiences.⁴³ From a health care standpoint, consumers are reluctant to share data with non-traditional health care actors; tech companies rank last among entities with which consumers are willing to share their health data.⁴⁴ Despite being the creators of such technologies, tech companies are less trusted to provide virtual health care when compared to doctors and hospitals.⁴⁵

Although patient data is essential to research and fueling the development of intelligent computing in health care, the industry lacks standardized, explicit permissions or anonymization, processes that would help to mitigate concerns for consumers. Health care providers must work with tech companies and other partners to overcome these barriers and ensure patient trust remains at the forefront of their collaborations because in a highly regulated field like health care, without patient trust, little can be achieved.

Even though patients are wary of sharing data with tech companies, the context of these interactions has an interesting effect on trust. Studies show that more than half of consumers rely on Google searches for health information, with smaller subsets relying on other platforms like Wikipedia and Facebook. ⁴⁶ This points to a divergence between the stated preference of respondents in surveys, and the revealed preference of how tech company platforms are already being used to inform health decisions.

What is clear is that the traditional physician-patient relationship remains a vital component of health care. This existing foundation of trust should be cultivated in congruence with tech partnerships to provide high-quality, high-trust patient care.

Percent Willing to Share by Stakeholder



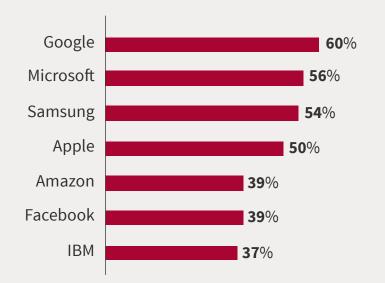
Which Tech Company Would You Share Data With?

Only shown to those who answered 'yes' to being willing to share their health data with a company at all.

۲۲

We want people to feel confident that when they disclose [data] for one thing, it's only used for that thing, and the fact that it is digital doesn't make it riskier to disclose.

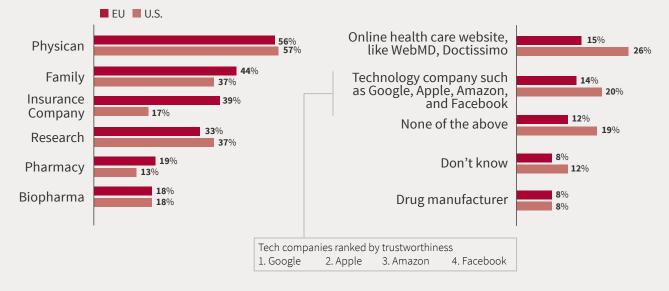
- Lucia Savage, Chief Privacy & Regulatory Officer, Omada Health



Source: Rock Health (2016). Consumer Survey Data.

Trust in Organizations / Individuals to Provide a Virtual Nurse:

Which of the following groups or organizations, if any, would you trust to provide a virtual nurse assistant? How trustworthy do you consider each of the following companies in providing a virtual nurse assistant? (Specific to the four technology companies provided as examples.)



Source: Syneos Health (2018). Survey: Artificial Intelligence for Authentic Engagement: Patient perspectives on healthcare's evolving AI conversation.

Preventing Discrimination and Promoting Privacy

Genetic testing offers many opportunities for improving health. The information from these tests also has major implications for health care ethics with imperatives for protecting privacy and preventing discrimination. While individuals express openness to their employer paying for genetic testing services, for example, the majority (65%) are concerned about whether the results of genetic testing will be used to deny insurance coverage. ⁴⁷

Guidelines and Guardrails

Regulators have enormous influence over the health care industry and its trajectory, and this isn't likely to change on the path to democratization. The regulatory environment greatly affects investment decisions: policy and regulatory factors rank third in importance when making a health care-related investment decision.⁴⁸ The status of tech partnerships or advances in heath, as a result, may be dependent on the decisions of those in government. We see this clearly with the European Union's General Data Protection Regulation (GDPR), a new regulation that fundamentally calls into question previous notions about data ownership in health care. In May of 2018, organizations with business ties to the EU were required to comply to GDPR standards or face fines, prompting any organizations who treat patients from any of the 28 EU nations to gain affirmative consent for any data collected from people who reside in the EU. Now more than ever, health care institutions will need to consider data flows, cross-border data transfer, privacy, and security monitoring to ensure their policies are compliant with the law.

In an attempt to keep pace with the digitization of health care, the FDA has recently taken steps to regulate digital health. The FDA's Digital Health Innovation Action Plan aims to "ensure patients have timely access to high-quality, safe and effective digital health products" by committing to several goals, such as increasing the number of digital health staff at the FDA, launching a digital health software precertification pilot program, and issuing guidance to modernize existing policies.

State regulation is also a factor. California, for example, recently passed a comprehensive consumer privacy law (the California Consumer Privacy Act, A.B. 375) that is likely to significantly affect industries relying on personal data, especially if that data is digital. The law gives California residents the right to be informed about how companies collect and use their personal data, allowing them to request the deletion of personal information, opt out of the sale of personal information, and readily access personal information that is made available to third parties.

What's clear is that proactively engaging regulators and policymakers will be increasingly important to achieve the trust and support needed to push the boundaries of health care while ensuring adequate standards are in place to protect patient privacy and safety.

The Road Ahead

As the trend of democratization continues to develop, traditional health care entities will need to make adjustments to account for new technologies, new ways in which patients will experience health care, and new kinds of partnerships. Perhaps most of all, health care democratization has the potential to recast the patientdoctor relationship, giving patients an opportunity to play a much more prominent role than they have before. If we get this right, it could be a very positive development, for both sides.

Over the past year, we've seen the future of a democratized health care ecosystem move closer to reality. But there is a long road ahead. Here is a summary of the key issues that are likely to influence the course and speed at which we arrive at a more open, innovative, and equitable health care system:

Key Enablers of Democratization:



1. Taking advantage of innovations: Al and machine learning have proven benefits in health care; these and other innovations will not only help the industry progress, but also ensure data is appropriately cleaned, managed, and shared.



2. Collaboration: Working together with tech companies and other health care entities will preempt knowledge sharing and strategic partnerships.



3. Building trust with patients: Adequate data sharing requires that the proper rules and guidelines be put into place to ensure the needs and privacy of the patient come first.

At the Same Time, the Obstacles to Data Sharing in Health Care Are Numerous and Include:



1. Accessibility: Consumers and health care providers are reluctant to share data with tech companies and non-traditional health care actors.



2. Data quality: Most data requires thorough cleaning and structure alignment in order to be referenced and shared between systems; there are not enough processes to ensure cleaning gets done.

3. Physician burnout: Doctors are becoming increasingly frustrated with inputting data into EHR systems and find themselves with less time with their patients.



4. Privacy and ethics: Patients are largely uncomfortable with their data being used for research and other purposes; the industry lacks any explicit permissions or anonymization processes.

If these issues can successfully be addressed, the road to democratization will achieve substantial benefits for patients, providers, and the system as a whole.

References

- ¹ Technology Review (February 2018). 2017 was the year consumer DNA testing blew up. https://www. technologyreview.com/s/610233/2017-was-the-yearconsumer-dna-testing-blew-up/.
- ² American Hospital Association (2016). Annual Survey Information Technology Supplement. https://www. aha.org/system/files/2018-03/expanding-electronic-engagement.pdf.
- ³ Frost & Sullivan (January 2016). From \$600 M to \$6 Billion, Artificial Intelligence Systems Poised for Dramatic Market Expansion in Healthcare. https:// ww2.frost.com/news/press-releases/600-m-6-billion-artificial-intelligence-systems-poised-dramatic-market-expansion-healthcare.
- Infosys (2017). Al for Healthcare: Balancing Efficiency and Ethics – Survey of 1,600 Senior Business Decision Makers. https://www.infosys.com/smart-automation/Documents/ai-healthcare.pdf.
- ⁵ McKinsey Global Institute (January 2018). Artificial Intelligence: The Time to Act is Now. https://www. mckinsey.com/industries/advanced-electronics/ our-insights/artificial-intelligence-the-time-to-actis-now.
- ⁶ Wired (February 2013). IBM's Watson is better at diagnosing cancer than human doctors. https://www. wired.co.uk/article/ibm-watson-medical-doctor.
- ⁷ McKinsey Global Institute (December 2016). The Age of Analytics: Competing in a data-driven world. https://www.mckinsey.com/business-functions/ mckinsey-analytics/our-insights/the-age-of-analytics-competing-in-a-data-driven-world.
- Research and Markets (March 2018). Global Mobile Health (mHealth) Market - Segmented by Type of Service, Device, Stake Holder, and Geography -Growth, Trends and Forecast (2018 – 2023). https:// www.researchandmarkets.com/research/mv6s5d/ global_mobile?w=4..
- PwC (November 2016). Survey: The new imperatives for health. https://www.pwc.com/gx/en/industries/ healthcare/publications/ai-robotics-new-health/ survey-results.html.
- ¹⁰ Centers for Disease Control and Prevention (2018). https://www.cdc.gov/chronicdisease/about/costs/ index.htm.
- ¹¹ McKinsey Global Institute (June 2017). Artificial Intelligence: The next digital frontier? https:// www.mckinsey.com/~/media/McKinsey/Industries/ Advanced%20Electronics/Our%20Insights/How%20 artificial%20intelligence%20can%20deliver%20 real%20value%20to%20companies/MGI-Artificial-Intelligence-Discussion-paper.ashx.
- ¹² Accenture (2018). Al: An Engine for Growth. https:// www.accenture.com/us-en/insight-artificial-intelligence-healthcare.
- ¹³ Accenture (2018). Al: An Engine for Growth. https:// www.accenture.com/us-en/insight-artificial-intelligence-healthcare.
- ¹⁴ Stanford University School of Medicine (July 2018). Medical errors may stem from more physician burnout than unsafe health care settings. https:// med.stanford.edu/news/all-news/2018/07/medicalerrors-may-stem-more-from-physician-burnout.html.
- ¹⁵ Annals of Family Medicine (October 2017). Tethered to the EHR: Primary Care Physician Workload Assessment Using EHR Event Log Data and Time-Motion Observations. http://www. annfammed.org/content/15/5/419.full.
- ¹⁶ The Times Higher Education World University Rankings (May 2017). Which countries and

universities are leading on AI research? https://www. timeshighereducation.com/data-bites/which-countries-and-universities-are-leading-ai-research.

- ¹⁷ Science Magazine (February 2018). China's massive investment in artificial intelligence has an insidious downside. https://www.sciencemag.org/ news/2018/02/china-s-massive-investment-artificial-intelligence-has-insidious-downside.
- ¹⁸ ARM, Northstar (June 2017). AI Today, AI Tomorrow: Awareness, Acceptance and Anticipation of AI: A Global Consumer Perspective. https://www. businesswire.com/news/home/20170627005941/en/ Robots-Enhance-Replace-Humans-Jobs-ARM-Survey.
- ¹⁹ PwC (November 2016). Survey: The new imperatives for health. https://www.pwc.com/gx/en/industries/ healthcare/publications/ai-robotics-new-health/ survey-results.html.
- ²⁰ Syneos Health (2018). Artificial Intelligence for Authentic Engagement: Patient perspectives on healthcare's evolving Al conversation. https://syneoshealthcommunications.com/uploads/articles/972/ Syneos_Health_Communications_2018_Artificial_Intelligence_for_Authentic_Engagement.pdf
- ²¹ McKinsey Global Institute (December 2017). What the future of work will mean for jobs skills and wages. https://www.mckinsey.com/~/media/mckinsey/ featured insights/future of organizations/what the future of work will mean for jobs skills and wages/mgi jobs lost-jobs gained_report_december 2017.ashx.
- ²² Syneos Health (2018). Artificial Intelligence for Authentic Engagement: Patient perspectives on healthcare's evolving Al conversation. https://syneoshealthcommunications.com/uploads/articles/972/ Syneos_Health_Communications_2018_Artificial_Intelligence_for_Authentic_Engagement.pdf
- ²³ Journal of Alzheimer's Disease (August 2015). Linguistic Features Identify Alzheimer's Disease in Narrative Speech. http://www.cs.toronto. edu/~kfraser/Fraser15-JAD.pdf.
- ²⁴ National Institutes of Health (September 2014). The Framingham Heart Study and the Epidemiology of Cardiovascular Diseases: A Historical Perspective. https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC4159698/.
- ²⁵ Slate (May 2013). Psychology is WEIRD. https://slate. com/technology/2013/05/weird-psychology-social-science-researchers-rely-too-much-on-western-college-students.html.
- ²⁶ Healthcare Finance (October 2018). Interoperability remains limited, according to the National Academy of Medicine. https://www.healthcarefinancenews. com/news/interoperability-remains-limited-according-national-academy-medicine.
- ²⁷ HealthAffairs (October 2017). Progress in Interoperability: Measuring US Hospitals' Engagement In Sharing Patient Data. https://www.healthaffairs.org/ doi/pdf/10.1377/hlthaff.2017.0546.
- ²⁸ Health Level Seven (February 2014). HL7 Fast Healthcare Interoperability Resources Specification (aka FHIR[®]), Release 3 (STU). http://www.hl7.org/ implement/standards/product_brief.cfm?product_id=449.
- ²⁹ HealthIT Analytics (November 2018). Microsoft Azure Releases Open Source FHIR Server for Health Data. https://healthitanalytics.com/news/microsoft-azurereleases-open-source-fhir-server-for-health-data.
- 30 Flatiron Health. https://flatiron.com/
- ³¹ Apple (2018). Institutions that support health records on iPhone. https://support.apple.com/en-us/ HT208647.

- ³² TechCrunch (April 2018). Ford Launches On-Demand Medical Transportation Service. https://techcrunch. com/2018/04/18/ford-launches-on-demand-medical-transportation-service/.
- ³³ PwC (2018). The New Health Economy in the Age of Disruption. https://www.pwc.com/us/en/industries/ health-industries/health-research-institute/ new-health-combinations.html.
- ³⁴ PwC (2018). The New Health Economy in the Age of Disruption. https://www.pwc.com/us/en/industries/ health-industries/health-research-institute/ new-health-combinations.html.
- ³⁵ Ernst & Young (2018). When the human body is the biggest data platform, who will capture value? https://www.ey.com/Publication/vwLUAssets/ ey-when-the-human-body-is-the-biggest-dataplatform-who-will-capture-value/%24FILE/ey-whenthe-human-body-is-the-biggest-data-platform-whowill-capture-value.pdf.
- ³⁶ U.S. Patent and Trademark Office (2018, 2017, 2016). https://www.uspto.gov/patents-application-process/ search-patents.
- ³⁷ HIMSS (2018). 2018 HIMSS Cybersecurity Survey. https://www.himss.org/sites/himssorg/files/ u132196/2018_HIMSS_Cybersecurity_Survey_Final_Report.pdf.
- ³⁸ Ponemon Institute, IBM (2018). Cost of a Data Breach Study. https://www.ibm.com/security/data-breach.
- ³⁹ Ponemon Institute, IBM (2018). Cost of a Data Breach Study. https://www.ibm.com/security/data-breach.
- ⁴⁰ Health IT Security (February 2018). How Much Do Healthcare Data Breaches Cost Organizations? https://healthitsecurity.com/news/ how-much-do-healthcare-data-breaches-cost-organizations.
- ⁴¹ HIMSS (2018). 2018 HIMSS Cybersecurity Survey. https://www.himss.org/sites/himssorg/files/ u132196/2018_HIMSS_Cybersecurity_Survey_Final_Report.pdf.
- ⁴² Thales (January 2018). 2018 Thales Data Threat Report. https://dtr.thalesesecurity.com/.
- ⁴³ Retail Systems (September 2018). Consumers wary of data-sharing despite personalization trend. http:// www.retail-systems.com/rs/Consumers_Wary_Of_ Data_Sharing_Despite_Personalisation.php.
- ⁴⁴ Rock Health (2016). Digital Health Consumer Adoption Survey. https://rockhealth.com/reports/ healthcare-consumers-in-a-digital-transition/.
- ⁴⁵ Syneos Health (2018). Artificial Intelligence for Authentic Engagement: Patient perspectives on healthcare's evolving Al conversation. https://syneoshealthcommunications.com/uploads/articles/972/ Syneos_Health_Communications_2018_Artificial_Intelligence_for_Authentic_Engagement.pdf
- ⁴⁶ Syneos Health (2018). Artificial Intelligence for Authentic Engagement: Patient perspectives on healthcare's evolving AI conversation. https://syneoshealthcommunications.com/uploads/articles/972/ Syneos_Health_Communications_2018_Artificial_Intelligence_for_Authentic_Engagement.pdf
- ⁴⁷ Wamberg Genomic Advisors (November 2017). Wamberg Genomic Consumer Survey. https://www. prnewswire.com/news-releases/65-of-employeeswould-pay-for-genetic-testing-from-their-employersponsored-health-account-wamberg-genomicsurvey-300560945.html.
- ⁴⁸ Brunswick Insight (January 2018). Global Investor Views on Healthcare. https://www.brunswickgroup. com/global-investor-views-on-healthcare-i6917/.



med.stanford.edu/healthtrends