From Internet to AI Bot: Leveraging Technology to Empower and Engage Patients in Their Health

Daniel Sands, Nancy B. Finn

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Abstract

This paper will view the rise of the e-patient, who is "equipped, enabled, empowered and engaged" through the lens of the evolution of successive digital technology innovations, each building on its predecessors.

We begin with the dawn of the Web and the proliferation of health websites and discuss the use of digital communication tools. We then discuss the adoption of electronic health records which enabled the rise of patient portals. This digitization of health data, along with the rapid adoption of mobile internet access and the proliferation of health-related smartphone apps, in turn, provided a platform for patients to co-produce healthcare by contributing their own health data to their self-care and healthcare. The exchange of health information between patients and providers has also been facilitated by telehealth/telemedicine technology which enables direct care delivery. The use of social networks in health, in use since the early days of the Web, has expanded since COVID, when public health authorities worldwide, as well as patients, sought the use of social media channels to get connected and share information. Most recently, artificial intelligence and large language models have emerged with yet untapped potential to provide patients with the information that could improve their understanding of their conditions and treatment options.

We conclude that innovations in digital health technology have symbiotically evolved with the ascendance of the e-patient, enabling improved communication, collaboration, and coordination between patients and clinicians and forging a healthcare system that is safer and more responsive to patient needs.

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From Internet to AI Bot:

Leveraging Technology to Empower and Engage Patients in Their Health

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This paper will view the rise of the e-patient, who is "equipped, enabled, empowered and engaged" through the lens of the evolution of successive digital technology innovations, each building on its predecessors.

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248 words

Introduction: The Rise of the e-Patient

Until the late 20th century, the concept of an empowered, engaged patient did not exist. Physicians were viewed as experts who, based on their medical education, were supposed to understand every issue or concern a patient presented. The patient was expected to comply and follow their doctor's orders passively. Dr. Tom Ferguson, physician, author, educator, and innovator had a different view.

In his sentinel White paper*, e-Patients: How they can help us heal health,* completed posthumously by the e-Patient Scholars Working Group in 2007, the term e-Patient is defined:

> *e-Patients represent the new breed of informed health consumers who go online to seek information on their own ailments and to find better health information and services for others. They work collaboratively with their doctors and within the system to resolve health issues.*[1]

The e-Patient Scholars Working Group fostered the movement of *Participatory Medicine* in which patients, using digital health tools, become active drivers of their health, leveraging newly developed and available digital health technologies that have changed medicine forever.

The rise of digital health technologies has fueled the emergence of the e-Patient. First the World Wide Web, then the adoption of electronic health records, patient portals, and connected self-monitoring instruments that enable patient-generated health data and facilitate patient involvement in their own care. Additionally, technologies such as smartphones, telehealth, social networking, and finally, recent innovations that include various iterations of artificial intelligence, have fostered engagement of both patients and clinicians in a way that has changed the way healthcare operates. Pressure from patients who want to manage their own health, participate in their health decisions, communicate and collaborate with their healthcare providers, and push back against a healthcare system that does not meet their needs has led to the creation of digital technologies—with their attendant questions about safety and privacy— that have evolved to meet these needs. The rise of the e-Patient and these digital technologies has shaped a new dynamic in health that has indelibly changed the face of healthcare.

The Internet and the World Wide Web

The Internet is a global network of servers and networks originally conceived and developed to meet the demand for automated information-sharing between scientists in universities and institutes throughout the world.[2] The protocols that enabled the evolution of the World Wide Web (WWW) were created by Tim Berners Lee in 1989.[3] By the mid-1990s, the proliferation of websites and the technologies for publishing on the Web had democratized access to information and communication on the Internet. Over the last three decades, there has been significant innovation in the use of the Web as a platform for accessing enormous multimedia information resources and enabling cutting-edge technologies in healthcare, including digital health records, patient portals, remote monitoring tools that enable patient-generated health data, telemedicine/telehealth, social networking, artificial intelligence including AI chatbots. The widespread adoption of these technologies has been facilitated by the development of broadband internet access, Wi-Fi, wireless internet access, and powerful and highly portable mobile technologies.

A recent Pew Research Center survey of 5,733 U.S. adults, published in January 2024, reported that nearly 95% of U.S. adults say they are using the internet; 80% say they subscribe to high-speed internet (broadband) at home. The study determined that large proportions of Americans are connected to the world of digital information while "on the go" via their smartphones and other mobile devices. From these numbers, it is apparent that the Internet is a staple of the 21st century lifestyle and an important way that patients remain empowered and armed with the information and tools they need to make medical decisions. [4]

Email

Email, asynchronous computer-based communication technology, was created in the 1970s and its use proliferated with the dawn of the web in the 1990s. In 1998, Sands and Kane[5] first promoted broad use of email between patients and physicians and offered guidelines for its appropriate use. Prior to the use of e-mail, only synchronous communication in the office or over the phone was used in healthcare interactions.
Common uses of patient-provider email are many and include:

1. Advice regarding new or recurrent medical conditions, including recommendations on the best site of care (home vs. clinic vs. urgent care vs. emergency department), which may include photos or other media as needed;
2. Response to quick questions that should not involve an office visit;
3. Sharing data such as blood pressure and blood sugar;
4. Follow-up on effectiveness or side-effects of medications.

Because of the need for patient privacy, which is not inherent in email, patient portals emerged in 2010 with secure messaging. Many of these messages today are triaged by nursing staff before being sent to physicians.

Social Networking

e-Patients do not rely on medical professional views alone. They actively engage with other patients on social networks to gather and provide information. These patient support groups were a primary source of information during the pandemic. Today nearly 80% of cancer patients regularly connect with peers. There are many web-based peer-support networks that bring together patients who are living with illnesses and healthcare professionals who may be interested in these conditions. For example, Patients-Like-Me (PLM) is an online community health data platform that helps patients find new treatments, connect with others, and take action to improve their outcomes. The network has over 800,000 members who are dealing with more than 2,900 conditions including ALS, MS, and Epilepsy. There is no charge to be a member of PLM.[6]

There are also online communities for many different cancers, neurologic diseases, auto-immune diseases, mental health disorders, and many other conditions. These communities provide emotional support, peer coaching, and medical advice. The advice gathered from these communities has been reported to be life-saving.[7]

Electronic Health Records (EHRs)

Digital health records got off to a slow start when they were introduced in the United States starting in the 1980s. It was not until 2004, when President George Bush set the goal that every American would have an EHR within ten years, supported with funding for demonstration projects and development of common standards that digital health records became ubiquitous.[8] The passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted under Title XIII of the American Recovery and Reinvestment Act of 2009, helped to foster the growth of the EHR. In 2008, only 17 percent of healthcare providers had electronic medical records, but by 2021, 9 in 10 U.S. office-based physicians had adopted EHRs.[9]

Patient Portals

EHRs were adopted to improve the quality and safety of patient care, but they also permitted patients access to their health information through connected patient portals.
Patient portals are secure websites that provide access to EHR information (including sharing access with caregivers), communication with the healthcare team, and convenience transactions such as tools for booking appointments, requesting prescriptions, and paying medical bills. Through these portals, patients can view their entire medical records — including office notes, thanks to the advocacy of organizations like OpenNotes — pulling back the curtain on healthcare decision-making and permitting them to manage and monitor their health issues and collaborate with their physicians to resolve health problems.

The 21st Century Cures Act (Cures Act),[10] signed into law on December 13, 2016, by President Barack Obama, was designed to help accelerate medical product development and bring innovations and advances to patients who need them faster and more efficiently. The Cures Act legislation makes patient access easier and virtually unrestricted by giving them undeniable access to data from their medical records so they can make better choices regarding their care, and experience transparency regarding costs and healthcare outcomes.

The Smartphone

Modern smartphones combine a full suite of mobile tools for patients and clinicians in one compact device that has a large memory, fast processing speeds, wireless internet access, (both through the mobile networks and Wi-Fi), a high-quality camera, an accelerometer, GPS, Bluetooth for connectivity to devices, near-field communication, and, of course, a phone. They provide the ability to manage personal information, streaming music, videos and games, 24/7 access to social media, text messaging, and real-time language translation. The number of tasks that can be accomplished with this platform is almost infinitely expansible through access to applications stores ("app stores"). There are more than 350,000 healthcare-related apps available globally through several app stores and that number is increasing all the time. The average person uses 9 mobile apps per day, 30 apps per month.[11]

Smartphones provide patients with ubiquitous access to health information, including their health records, participation in social networks, connection with their healthcare team, health plan, and pharmacy, as well as access to apps that allow them to track their activity, food intake, blood pressure, glucose, sleep, weight. When combined with connected wearable devices like smartwatches, available apps can also track heart rate and rhythm, oxygen saturation, and

cardiovascular fitness. New apps become available all the time.

A Pew Research study in 2023[12] found that 90% of adults reported they owned a smartphone, and 4 in 10 individuals polled reported being online "almost" constantly. The study found that smartphones are used across income levels, but those in households earning $100,000 or more annually are far more likely than those earning less than $30,000 per year to use a smartphone (98% vs. 79%). Education level and age also played a factor in the ownership of smartphones. Those individuals with a higher education generally had a smartphone. People over 65 were reported to be about 20% less likely to have a smartphone than those under 50.

Patient-Generated Health Data (PGHD)

According to the RAND Corporation, nearly 60% of adult Americans have at least one chronic disease—including diabetes, cardiovascular disease, such as irregular heart rhythm or hypertension, or lung problems such as asthma or COPD, cancer, arthritis, and kidney disease—and 42% have more than one.[13] These chronic conditions account
for hundreds of billions of dollars in healthcare spending every year. Their estimates suggest that nearly 150 million Americans are living with at least one chronic condition; around 100 million of them have more than one. And nearly 30 million are living, day in and day out, with five chronic conditions or more.

In a 2019 study of 4159 individuals from the Health Information National Trend Survey,[14] about 30% were using a wearable device. Use of wearable devices was more common among those with chronic conditions. They found that 49% of those with a usual source of care had shared data with their provider. This behavior was more common in those with chronic conditions. Both adoption and data sharing have likely risen in the ensuing years.

Since patients only spend a small fraction of their lives in formal medical care, patient-generated health data has increasing potential to help patients with self-care and improve the healthcare of patients with many chronic conditions. In their 2014 paper on the topic, Sands and Wald conclude:

> *"Patient-generated health information, enabled by data transparency and consumer engagement, is not a panacea, but can help address information gaps in important areas, leverage untapped patient experience, and offer information that will improve self-management, provider-directed, and joint decisions made by patients and providers together and facilitate more frequent contacts with patients for better management of chronic conditions."* [15]

Telemedicine/Telehealth

The convergence of the Internet, high-speed telecommunications, video technology, and the availability of patients' digital health records make it possible for real-time video visits between a clinician and a patient to occur over a remote network on a computer screen or smartphone. Telemedicine consultations can be augmented with patient-generated health data to address the difficulty of telemedicine physical exams. With PGHD, and a patient history, the examining physician will have baseline information. This is a viable option for patients in need of medical assistance, and although the physical examination is quite limited, there are guidelines that physicians can use to do physical exams via telemedicine.[16]

For many years, telemedicine struggled with slow adoption, partly due to lack of payment for services rendered remotely and partly due to the lack of infrastructure to conduct such video calls. The COVID-19 pandemic prompted payers to change their payment policies to make it easier during this emergency for telemedicine encounters; telemedicine use increased from 11% to over 60% in a very short time.[17] Post-pandemic, reimbursement for telehealth remains in place. As health care has becomes more digitized, physicians across specialties are integrating telemedicine into their practices. A remaining obstacle is that almost all state medical boards continue to prohibit care of patients within that state by physicians not licensed in that state.[18]

Artificial Intelligence

A few years ago, physicians made medical decisions based on knowledge they accumulated during their training and subsequent experience. Today, the rapid development of artificial intelligence is slowly changing that. Machine learning can process vast amounts of information to identify hidden patterns and replicate clinical thought processes. AI and machine learning are increasingly used in fields such as pathology, radiology, and gastroenterology.[19][20]

Chatbots, such as ChatGPT, Gemini, and Claude, built on large language models, provide an alternative to Google Search for physicians seeking information. However, these same tools allow patients to better understand their health conditions, not only by answering questions but also by helping them understand their medical records.[21][22][23] And these tools have enabled patients to diagnose conditions when their physicians have been unable to do so.[24]

Conclusions

The next 25 years in medicine promise to be unimaginable. Where digital-enabled health will take us and how the e-patient and clinician relationship will evolve depends upon many factors, not least of which is the impact of AI and how AI will change healthcare. Issues about patient safety and quality, as well as the stability of various care models that include equity and inclusion at an affordable cost are all key questions that do not have good answers today. But we anticipate that as digital health technologies continue to evolve e-patients will leverage these technologies to facilitate self-care and improvements in their healthcare experiences, which will in turn spur the evolution of the next generation of digital health technologies.

[2014 words, excluding abstract]

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