

MedDigX: Week 3 Key Concepts

3.1 | Pre-History of the e-Patient

e-Patient: As defined by Tom Ferguson and the e-patient working group, e-Patients are individuals who are equipped, enabled, empowered, and engaged in their health and health care decisions.

e-Health: The use of the Internet and World Wide Web as an information resource and connection hub in medical practice, personal health management, and healthcare decision-making.

ACT-UP: An HIV/AIDS advocacy group that, in the 1980s, organized public demonstrations, staged civil disobedience, and produced videos to persuade the media and healthcare establishment to recognize the interests of HIV/AIDS patients. ACT-UP is a notable predecessor of the modern e-patient movement.

3.2 | Evolution of the e-Patient in the Internet Era

e-Patient: See 3.1.

Peer-to-peer healthcare: The use of social networks, often online, by patients to exchange information and experiences related to personal health management. Examples of peer-to-peer healthcare networks include Patients Like Me, Crohnology, and Smart Patients.

Peer-to-peer healthcare stands in contrast to the traditional, top-down methods by which patients obtained information almost exclusively from their healthcare providers.

3.3 | Evolution of the e-Patient in the Big Data Era

Quantified Self: A movement in which participants observe and measure aspects of their lives, analyze their data, and conduct self-experiments to improve their lives.

Self-quantification has existed since before digital technologies became widely available; over 80% of self-tracking is done with *pen-and-paper*. However, the trend is now becoming more popular and powerful because of *mobile technology*, *sensors*, and *big data*.

Ambient monitoring: The passive collection of data by sensors and mobile technologies.

Active monitoring: The manual measurement and recording of data by a patient, sometimes with the use of digital and/or mobile devices.

Information immediacy: The availability in health information in real time, made possible through self-tracking.

The challenges of patient-generated data in healthcare include:

- Patients may not know how to use the data they collect.
- For many conditions, the relationship between self-tracking and health outcomes remains unproven.
- Healthcare providers and information systems are not equipped to handle large inputs of patient-generated data.

Emerging platforms like Patients Like Me allow patients to share and aggregate their health data with those of others, creating large sets of observational data for clinical decision-making, disease management, and medical research.

3.4 | Personalized Medicine for Patients

Precision medicine: The diagnosis, treatment, and management of disease through individualized, evidence-based care that considers each patient's biomedical data, psychosocial characteristics, environmental context, and personal preferences.

23andMe: A biotechnology company selling direct-to-consumer genomics tests that give patients gene reports on their medical conditions, disease risk, and potential medication interactions.

23andMe is a notable example of the *democratization of medical information*, a model in which patients can access health testing and data directly as long as they can afford to pay for the service. This is a distinction from the traditional model of healthcare, in which patients could only obtain tests and access their results through healthcare providers.

The questions that direct-to-consumer genetic testing raises include:

- Will testing be regulated as a consumer product, or a medical diagnostic tool?
- Should patients be able to access and interpret data without physician involvement?
- How informative and clinically applicable is the data from genetic testing?
- What if patients don't want to 'know everything' about their disease risk profile?
- What are the ethical limits to application of this data?

3.5 | Rise of mHealth and the 'No Smartphone' Patient

'No-smartphone' patient: A patient who, due to constraints such as *socioeconomic status, network connectivity, functional ability, or technology literacy*, is unable to use digital health tools and e-health resources.

As digital health becomes more mainstream, some providers, scholars, and patient advocates have expressed concern about health disparities related to limitations in technology access and use.

Half of all U.S. adults have a chronic condition. Data from Pew suggests that chronic disease patients are more likely to engage in self-tracking, which creates an opportunity for them to engage with digital technologies for tracking and sharing data.

As digital health technologies take on a greater role in health and disease management, questions about how these devices will be regulated, as other medical devices or medications are, will have to be addressed.

3.6 | Patient-Driven Communication with Doctors

Digital technologies: These technologies allow providers and patients to communicate beyond the bedside. They include *email, social media, text messaging, and electronic health records*:

Email is easily accessible, but can seem impersonal and may not be secure enough to exchange patient-specific information.

Social media is public and interactive, and allows doctors and patients to understand each other's day-to-day experiences. However, public networks and privacy concerns do not allow for patient-specific conversation.

Text messaging is simple to use and common, especially for dialogue among providers, but is not Health Insurance Portability and Accountability Act (HIPAA)-secure; it does not meet legal standards of patient privacy and data security.

Electronic health records are secure, and compliant with privacy law. EHRs can be less mobile-accessible or user-friendly than channels like email or text messaging.

With new technology, barriers to patient engagement include:

- The trade-off between communication technologies that are convenient and accessible, versus those that are private and secure.

- The physician payment structure, which compensates doctors for office visits, but not for remote communication.
- The social and professional obligation to respond to communication when it is both constant and ubiquitous ("time creep").