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# When is a lot still not enough?

## Health information, the public good and privacy rights

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THE UNITED STATES HEALTH CARE SYSTEM IS the largest in the world. With annual spending approaching 2.3 trillion dollars in 2009, it eclipses the entire gross domestic product of many other countries. Yet unlike many other industrialized nations, it is a fragmented system that relies primarily on private markets for its provision. This reliance has led to similarly fragmented information about the health of individuals that in turn limits in some cases even a cursory understanding of the health of the population as a whole. Many have argued that some form of collective health information about the population is imperative to the betterment of society, and have called for uniform data collection that links health, socio-economic indicators, indicators of health risks and the like so that future interventions might be better targeted most effectively. Yet others believe that such mandatory data collection is a violation of personal privacy and the basic rights of American citizens. The question remains: what level of information gathering is the appropriate one, and is health information collection possible that serves the public interest while still respecting the privacy of patients and citizens?

### *Health Information and Privacy: A Brief History*

Since the early days of organized medicine, physicians and other providers have collected, stored, and utilized health and personal information to better care for patients. The recording of health histories, presenting symptoms, and other clinically related information has been a long-standing and integral part of the caregiver-patient relationship. Beginning in 1847, certain disease diagnoses have been mandated to be reported to the state and tracked as a public safety concern, although which diseases are tracked vary by state.<sup>1</sup> The list of federally mandated reportable diseases includes AIDS, Lyme disease, meningococcal disease, tuberculosis,

and others.<sup>2</sup> Still other data are collected anonymously through large population surveys, of which there are many. And while broad reaching in their topics and unidentifiable to the individual, they are sample based and have seen a decline in response in recent years as people have switched to cell phone use and are more inundated with information requests.<sup>3</sup> Thus, they present a less than accurate picture of health for some segments of the population.

Our health system is also a predominantly private and fragmented one. It serves many patients, providers, manufacturers, drug companies, and insurers, and personal health information is shared between each. And while much of this information was necessary to carry out the care of the individual (and its payment), many question how that information is accessed and used. Examples of instances for disclosure could include marketing drugs to patients and providers, or disclosure by therapists when potential violence to a third party could occur.<sup>4</sup>

In 1996 Congress passed the Health Insurance Portability and Accountability Act or HIPAA. The law addressed privacy by attempting to extend the provider-patient privacy context to a changing health system. HIPAA does not attempt to put parameters on who may share health information beyond that individuals be involved in the direct care of the patient. The law states that the amount of information shared with those not involved in the care of the patient must be only the minimally necessary amount to accomplish the need at hand. This is an obviously vague and subjective provision and does not extend to those directly involved in patient care. Much of what HIPAA attempts to do is differentiate between what is meant by the *security* of health information and health information *privacy*. The idea of security is largely an information technology issue, and it is concerned with patient and provider identifiers, firewalls, encryption, and the like.

It is important, but its implementation necessitates that some definition of privacy and the parameters of privacy first be defined. The concept of privacy within medical doctrine has primarily concerned itself with the idea that patients' must authorize access to and use of their medical information and also be able to review, correct, and obtain that information.<sup>5</sup> And while HIPAA is an important standard for privacy and information sharing, it is only the minimum federal standard. Many state laws extend beyond HIPAA for certain individuals and in certain states. For example, in New Hampshire, a person's medical information (not the paper it is printed on or database it rests within) is considered their private personal property, not the provider's, as is the case in many states.<sup>5</sup> Many other states have special laws regarding privacy for individuals with HIV or with intellectual disability. But for the majority of individuals, the difficult task related to privacy is to define what is being granted control over; i.e., what constitutes personal health information? And what information is deemed "necessary" for treating the patient. To consider these questions it is important to first define what in fact the goal of the health system is, and what is "health."

### *Understanding our Health*

The idea of "health" and what promotes health has been an issue of long-standing research and debate. In 1990, Robert Evans and Greg Stoddart put forward a now widely cited model of health that suggests that health is built upon a collective foundation of individual values and beliefs, which is modified by our gained experiences and our evaluation of those experiences.<sup>6</sup> Having evidence-based research from medicine and public health is therefore paramount to being able to define our health. The model posits that there are a number of determinants to health, including our socio-economic status, our genetic make-up, our environment, and our access to health care services. In the United States, most of the nearly 2.3 trillion dollars spent on health is funneled through the medical care system, yet research has shown that access to care accounts for less than 10 percent of the variation in our collective health status.<sup>7</sup> In fact, growing evidence suggests that socioeconomic factors may have the most impact in efforts to improve health outcomes.<sup>8–12</sup>

This evidence is increasingly important in the United States, which ranked 37th of world countries in health outcomes by the World Health Organization in 2000 and last among six wealthy nations on dimensions of access, equity, efficiency, and overall health in 2007.<sup>13</sup>

In addition, U.S. health costs continue to rise at an unsustainable rate. Some projections show that by 2019, health spending will rise to near 4 trillion dollars a year or over 20 percent of our national Gross Domestic Product.<sup>14</sup> This would mean one in every five dollars earned by a U.S. citizen would go to health care on average. In addition, we are now realizing epidemics of chronic diseases such as obesity, diabetes, asthma, heart disease, kidney disease, lung disease, dementia disorders, and others that are crippling our country both physically, and in terms of future cost burden.

The evidence suggests societal changes could promote a decrease in these trends, yet that evidence is incomplete. While the argument can be made on a population level that how you live, where you live, how much you earn, your level of education, and the comfort, safety, and amenities of your neighborhood matter to your health, it is unknown which of these contributes to health, how, and to what degree. This is partially because they are all intrinsically linked, and partially because there is no one source of data that pulls together an identifiable individual, their sociodemographic and socioeconomic information, and links it with their health information and experience. The research questions are clear; however, the type of information we collect and how we collect it simply does not allow us to answer them.

### *A Need for More Information?*

From a population health perspective, the need for better information is apparent. The need to slow health spending and improve quality has led many in government and the private sector to promote the use of electronic and linked health information as a potential first step in this solution. In 2004, the government formed the Office of the Controller for Health Information Technology, whose job it was to promote policies around data sharing, a concept known as interoperability, to this end. They list the following as rationale. Enhanced medical information interoperability will serve to:

- \* Complete, accurate, and searchable health information, available at the point of diagnosis and care, allowing for more informed decision making to enhance the quality and reliability of health care delivery.
- \* More efficient and convenient delivery of care, without having to wait for the exchange of records or paperwork and without requiring unnecessary or repetitive tests or procedures.

- \* Earlier diagnosis and characterization of disease, with the potential to thereby improve outcomes and reduce costs.
- \* Reductions in adverse events through an improved understanding of each patient's particular medical history, potential for drug-drug interactions, or (eventually) enhanced understanding of a patient's metabolism or even genetic profile and likelihood of a positive or potentially harmful response to a course of treatment.
- \* Increased efficiencies related to administrative tasks, allowing for more interaction with and transfer of information to patients, caregivers, and clinical care coordinators, and monitoring of patient care. (<http://healthit.hhs.gov/portal/server.pt>)

In 2010, President Obama signed the Patient Protection and Affordable Care Act, or what has come to be known as health care reform. In it are many provisions that are contingent upon a broader proliferation of information technology and data sharing in the health sector. Some relate to paying for quality of care, some around what prices are actually charged and paid, and some are related to tracking disease and its correlates. All of them require the collection and sharing of personal health information between providers of care, those paying for care, researchers, and others in ways we currently do not. Yet many would say we currently collect too much information and are resistant to sharing that information from fear of discrimination due to health status or genetic disposition.

### *Personal Privacy and the Public Good*

A perceived right to privacy is core to American values. In health care, it is rooted in the Hippocratic Oath and tradition which supports the privacy of the patient-provider relationship.<sup>4</sup> But as discussed, the need to disclose personal information has been justified to protect third parties and for the public good in some cases. The idea of privacy has since evolved primarily around the principal of informed consent. Anyone who visits a provider's office for the first time has no doubt signed an informed consent form, or more recently perhaps a privacy notice document, which typically stipulates that the patient has control over his or her health information and that the provider will not divulge that information except for certain purposes (dealing with health insurers for payment being one). Modern health care and its complexities now challenge the notion of a one provider-one patient record holder given that

our health information is stored, recorded, and shared between so many entities. Infants are screened at birth and often before birth on a growing number of genetic conditions, many which get recorded with a state entity. Blood samples rest with genetic registries. Pharmacies hold prescription records, labs store and transmit test values to specialists who may fax them to primary care doctors, and the list goes on. These data are used first for care purposes, but also secondarily in determining the supply of services (vaccines, new technologies, growing trends), for payment, and for research. The question then, is to what did the patient give consent for? Does the consent for care at the time of care also carry forward to secondary uses? Erring on the side of caution, however, is not without implication. For example, is it feasible that researchers investigating genetic medical innovations re-contact all of the children who were sampled at birth for their consent, and does this impose undue cost to new learning? Further, if the type of information collected becomes broader to include socioeconomic and sociodemographic information as so many claim is necessary to answer our pressing health questions, then how does informed consent fit, and is patient privacy truly an achievable idea?

### *Concluding Statement*

We are living in a world witnessing exponential growth in technology and information. Data is being collected in more places, across more people, and about more things than at any time in our history. Yet from a health perspective, we still know very little. Doctors know a little about the health of their patients. Insurers know a little about the health of their enrollees. And overall we know very little about the health of our population or the care being delivered. Yet in the U.S. we spend more on that care than any country in the world, get less for it, and risk crippling our ability to function economically by doing so. Future policy efforts need evidence-driven information to reverse these trends. So, in a world of too much information, is it possible that too much is still not enough? And are we willing to forgo some level of personal privacy for better health and to enhance the public good, or is there a way to accomplish both yet undetermined?

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