THE DIGITAL HEALTH FOREST: HEALTH INFORMATION ECONOMY

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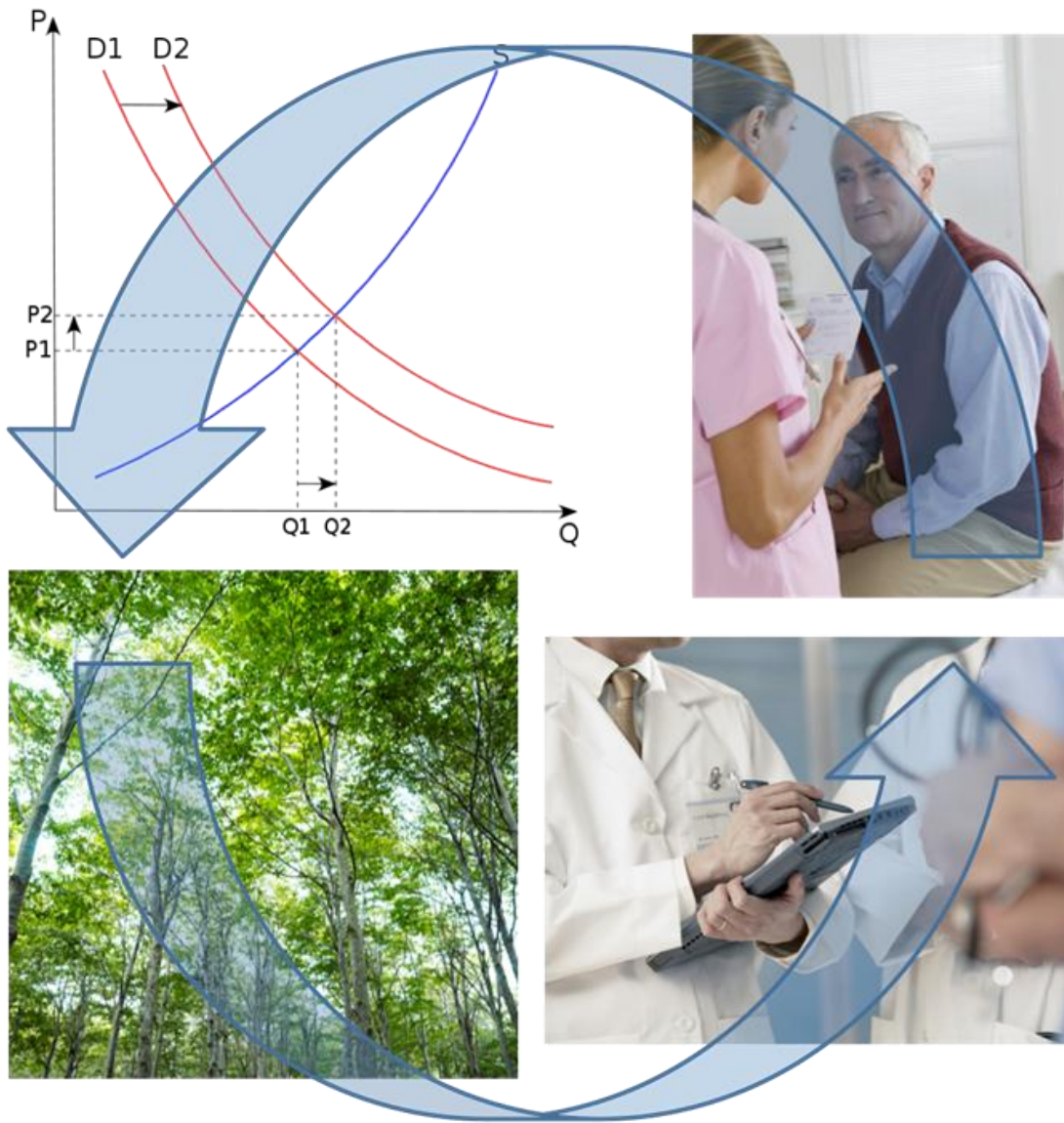
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INTRODUCTION

Every so often, innovation allows for a generational change in human society, changing how our species interacts with the world around us. About 10,000 years ago, the introduction of agriculture allowed humans a steady food supply leading to the development of communities with basic economies. The Industrial Age expanded economic access, created large urban centers, increased populations, and increased the standards of living for select millions around the world. This cyclical process has marked the upward progression of the human race.

During the late 1970s and 1980s, the computer revolutionized how people and organizations worked and processed data. Yet, these early computers had one vital flaw- the information they were managing and collecting was fragmented. The true value of computers was only realized when they started to talk to one another; the Internet was transformational in its ability to exchange information and deliver it instantly between computers. This generational change has been dubbed the Information (or Knowledge) Age.

When historians and anthropologists look back centuries from now at the effect of the Information Age, they will point to its impact on communication, which lead to the creation of virtual communities, development of entirely new markets overnight, and a whole host of other benefits. Perhaps the most important byproduct, however, will be how health information technology (HIT) made a *healthier human race*.

Drawing inspiration from ecology and economics, a business model can be developed that allows HIT to realize its potential to help accelerate new cures, develop best practices for patient treatment, and build communities around defined groups of patients or "cohorts." A new healthcare economy requires three main components:

- **Creation of the "Digital Health Forest":** The cultivation of an ecosystem that creates a robust framework for a symbiotic relationship between all stakeholders including patients, providers (which includes physicians, caregivers, health workers, etc.), payers, and researchers.
- **Gatekeeper control mechanism for patients:** A secure, encrypted 'gatekeeper' identity built into each patient record (EHR, EMR, PHR, etc.) that allows a patient the ability to control who has access to their record.
- **Incentive model for all stakeholders:** A valuation of a patient's data based on supply and demand for a given cohort, with the flexibility required to account for a diverse set of interests.

DEMAND

Two converging factors are creating a strong appetite for health data. At one end of the spectrum, the system itself is struggling to provide quality care at sustainable cost levels, particularly as it relates to chronic disease management, the baby boomer population, and the health disparity communities. For instance, the Milken institute estimates that chronic diseases cost the country, when accounting for care and secondary costs associated with loss of productivity is $1.3 trillion. Innovative approaches to reducing costs while balancing the need for continued quality of care are required to place the health system on a path towards sustainable growth.

On the other side, there is an increasing demand for the ability to deliver higher quality of care and new hope for patients. Consider the case of Dr. Keith Flaherty in driving the treatment of melanoma with a drug known as PLX4032. For years, Dr. Flaherty, an oncologist, sought targeted treatments for cancers based on a patient's genetic profile. After reading an article about the increased incidence of a genetic mutation in melanoma patients in a protein known as B-RAF, he sought to focus on treatments that accounted for this variable. In 2006, he was introduced to PLX4032, an early stage drug designed specifically with the B-RAF mutation in mind. Using his approach to targeting a specific cohort, Dr. Flaherty was able to push melanoma into remission for dozens of patients. The promise of tailoring treatments based on cohorts is limitless, but realizing it requires a system that can reduce the logistical burdens of these studies, while harnessing technology to accelerate them.

What if physicians and researchers had the ability to view the population and divide it based on an ever-expanding set of variables? Could we create incentives for participation from all the stakeholders of the health system? Is it possible that a business model combined with the application of technology could have measurable impact on the overall health of our society?

THE DIGITAL HEALTH FOREST

Envision a forest; this ecosystem is the source for a tremendous amount of biologic innovation. At the center of each forest are trees, nature's own platform for value creation. Through modification, trees can serve as shelter, food, or provide nutrients to a host of organisms. How they are used is limited only by the ingenuity of the organisms in the ecosystem. In the Digital Health Forest, the overall well being of our society grows with the overall health and size of the forest.

Trees represent data exchanges charged with aggregating data from patient populations and making it available to qualified groups of health professionals. These actors will likely be new companies built around this new marketplace or existing institutions such as providers and providers that forward integrate. At the roots are factors of compliance, security, and a standards-based approach that includes transparency. Transparency of practices and prices is mandatory for maintaining trust between the exchange platforms and their patient populations. Furthermore, these trees that serve as data exchanges include revenue generated from managing transactions of patient data. The more well developed these roots are, the larger the tree can become, and the more life it can support around it.

Patient information serves as the cellular component of the trees; when linked together they join to form a platform for growth. The diversity of patients, or the cells, in this ecosystem, will create magnificently unique correlations based on genetics, environmental factors, and social/cultural backgrounds. Patient data will be organized into trees, which interact

with the surround ecosystems. The greater the amount of information that can be aggregated into the system, the larger the trees will become.

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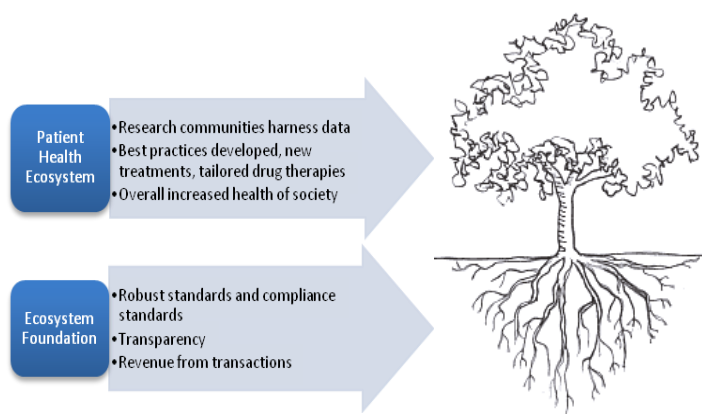
Symbiotic relationships must be formed for the continued growth of the forest. Although data trees can grow over time, they require intervention to realize their full potential. In the context of the health system, this means that researchers, health workers, physicians, and all other stakeholders of the healthcare system will be able to harness the power of data and information to improve overall wellness of society. Within this system, health data would be harnessed to drive towards a system of prevention and tailored treatments, allowing simultaneously for cost reductions and significant improvements in the quality of care.

Equally important as relationships within the ecosystem is competition. The trees themselves will be constantly competing with one another by innovating new ways to present their information through analytics or on definitions of cohorts. Therefore, it is entirely possible that a patient's information would be represented on several different data trees as data collection and analysis improves. Competition will enable growth of the system by seeking new ways for the data to be harvested.

CHARACTERIZING THE PATIENT POPULATION

The Healthcare 2020 Perspectives forecast drafted by the Institute for the Future predicts that society will begin to view biologic metrics as part of an individual's personal identity. With the rise of mobile devices in our daily lives, proliferation of sensors, and increasingly sophisticated (yet subtle) ways to monitor our lifestyle, a collision will occur between our personal lives and clinical ones, creating a 360 degree view for a caretaker into a patient. This cornucopia of data will present tremendous value to the health system as a whole, but the final decision on how that data is shared will rest with the patient. Within the context of the digital health forest, increased diversity leads to new opportunities for growth.

An essential component of health records, including EHRs, EMRs, and PHRs is the ability for a patient to control who can view that data. Currently, these health records have components that facilitate data sharing, but these need to become standardized to allow for information to be harnessed in the development of new treatments. This is termed the patient's *gatekeeper ability*. The patient, through web portals or a mobile device, controls and manages the flow of information. Developing this ability will permit patients to control which data trees they utilize. These trees can then manage millions of transactions annually between research communities and patients. Patients will generally be divided into three categories when it comes to their participation in the Digital Health Forest: the isolated, moderately connected, and highly networked.

On the outside of the system, is the isolated patient population. These patients refrain from sharing their health information generally because of their distrust or wariness of selling health information or due to lack of access. At the very basic level, this group will share information between their own physicians to maintain their own quality of care. As standards improve and market incentives mature, the total size of this group will likely decline.

Next, we have the moderately connected. While these individuals understand the value of sharing health data, their involvement in the data economy exists mainly through third parties. They will realize financial benefits, but never fully appreciate the value that can be derived from interconnecting multiple aspects of their lives into their health record.

The highly networked patient will seek out social communities and virtual networks that can exchange best

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practices, information, and create bargaining power with the research community. In 2010, it was estimated that over 80 million users were using Facebook's Farmville application. By comparison, if Farmville were a European country, it would trail only Russia and Germany in terms of population. Users in the third group will create communities based around social networks, a trend that will continue as they build virtual communities centered on their health. Similarly, the savvy patient of the future will organize into online communities that can self-organize and deal with the research community directly.

Furthermore, individuals in this group are extremely savvy in developing their personal health ecosystems, having grown up using social networking sites, mobile apps, etc. with regularity, generating tremendous value from the amount of data for new treatments and lifestyle-based approaches to patient management. They also will develop strong patient diaries and create data directly related to managing their disease, an invaluable tool for researchers looking to target treatments.

HARVESTING THE DIGITAL HEALTH FOREST

By agreeing to data exchange, there are three tiers of value creation. At a basic, individual's perspective, the advantage of information exchange between caregivers benefits a single patient. At a cohort level, data sharing allows for research and benefits within a patient's own community. Finally, from a societal view, this allows for macro health trends to be identified, enabling the development of new treatments and therapies across different cohorts. As the use of patient data matures through these tiers, their worth expands, resulting in lower costs and premiums.

The size of the population will determine the cost of data from each cohort for use. As the cohorts get smaller and increasingly defined, the price of the cohort will increase accordingly following a basic supply and demand curve. This will encourage patients to aggregate as much data into their record as possible. In addition to costs, these exchanges will compete on size of the data they represent, patient metrics that are available for study, etc. To access these patient cohorts, researchers will likely browse multiple data trees, select one, and pay for either snapshots of data or longitudinal access.

The revenue generated from transactions will go towards pools of money to directly offset the costs of maintaining data trees and patient care. Once these transactions occur, money will be funneled back to the patient through their insurer or as a means of reducing their premiums or co-pays. Furthermore, the data tree itself receives monetary benefit based on the amount of transactions they facilitate. This will allow the ecosystem the ability to sustain and scale itself based on the amount of innovations the system can develop.

For example, in the Digital Health Forest, a physician like Dr. Flaherty could browse different trees that provide different viewpoints on patient populations and easily select those he would like to study. He would be able to scale up his study rapidly, providing new hope for hundreds, even thousands of melanoma patients around the world. Now, magnify and expand this effect for potentially hundreds or thousands of new possibilities for better care. The new process would no longer be ad hoc and anecdotal but rather empirical and efficient. This new world of improved human health can be enabled through the creation of a Digital Health Forest.

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