

Chapter 2

Patients, Platforms, and Wearables: Co-creating Value from Health Data and Wearables

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In 2002, Venezuelan-born Manny Hernandez received his first diagnosis of diabetes. Living in Arizona at the time, he was 30, overweight, and told he had type II diabetes. Over the next several months he struggled to keep control over his condition and by early 2003 his family doctor ran out of ideas, and the traditional therapies were not working, so he was referred to an endocrinologist. The endocrinologist tested his HbA1c (hemoglobin A1c is an important indicator that measures how well one's diabetes is being controlled) and antibody levels and realized that Manny actually had type I diabetes and immediately prescribed an insulin regime that included long-acting insulin as well as watching his carbohydrate intake levels. In 2005, he received an insulin pump that helped to make his diabetes more manageable. The difference an insulin pump makes for a diabetic is rather dramatic. Rather than requiring 20-30 shots of insulin over 3 days he only required one shot from the pump.

Manny's experience with diabetes for the first several years was rather typical. Typical in the sense that he did not know anyone else with his condition. But this changed in 2006 when he participated in a diabetes patient group in Orlando, Florida, and for the first time met many people like himself. This experience planted a seed for an idea—he and his wife decided to try to replicate this experience and created a new platform for diabetics. TuDiabetes.org was created in March 2007 and a Spanish version, Estudiabetes.org was launched in August 2007. This would become a major online meeting place for diabetics to share their experiences with the disease and insights on how to manage it. Social supports have been well known in public health as important aspects of health outcomes and platforms such as TuDiabetes were becoming a growing force in healthcare

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early on in the so-called Web 2.0 revolution. Their first online campaign was the “Palm of your hand” campaign that asked people to write how they feel about life with diabetes on the palm of their hands. They collected approximately 100 or so “hands” and created a video about their experiences. This campaign caught the attention of LifeScan, a company that makes devices for diabetics, who made a donation that helped Manny to launch the Diabetes Hands Foundation by March 2008.

Since these early days TuDiabetes has developed into one of the most active diabetes patient platforms. TuDiabetes was created on the social networking platform Ning and they have developed a Ning app, TuAnalyze (developed in collaboration with the Centers for Disease Control and Prevention), that has a personal health record (PHR) connected that allows patients to collect their self-care data (A1c levels) that they track and share it with whomever they want. This has become useful in some of the campaigns that TuDiabetes runs such as the Big Blue test that encourages diabetics to exercise and test their blood glucose levels. Diabetics from around the world have participated in the campaign and they also have the ability to share videos documenting their experiences. TuDiabetes, through the TuAnalyze application, also contributes to research through collaboration with the Children’s Hospital of Boston where they have analyzed the data that participants shared. There is a gap in the public health research on diabetes where a lack of understanding of people’s locations and testing behaviors or the impact of social networks on diabetes care. The TuAnalyze platform also makes it easy to create surveys that can be used for additional research. To date the research has shown that engagement with social networks over time can significantly improve consistent testing of A1c levels which in turn leads to better health outcomes.

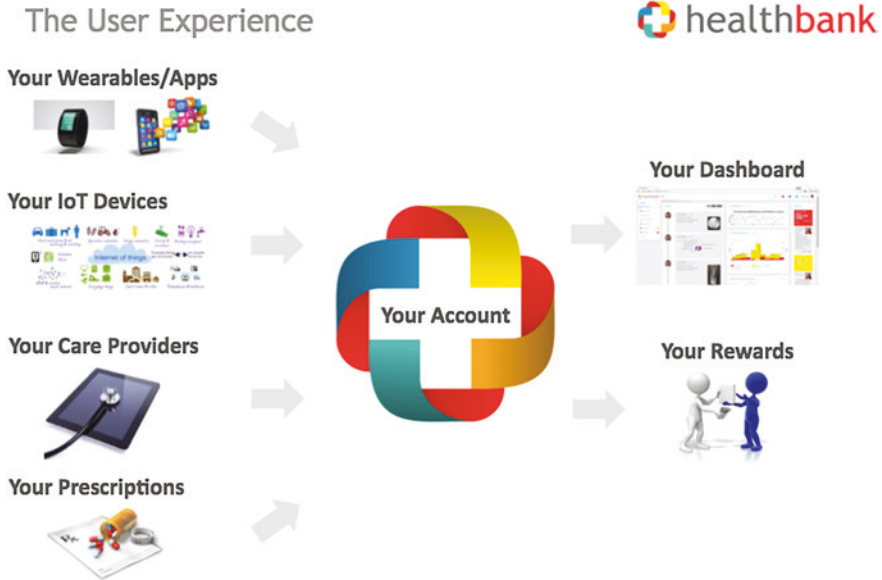
One of the impacts of this type of online community is to amplify the power of patient voices in major policy decisions whether at the FDA or in insurance plans. They now have a platform to aggregate their voices and exert their pressure on health insurers to purchase technologies that are best for the patient rather than make decisions based on the cheapest product. In the past, many diabetics in the TuDiabetes community have viewed purchasing decisions by some health plans as more in the interest of the plan than the patient. They are now becoming experts in navigating a complex health system and advocate for the technology options that serve their needs best. Later we discuss the People Powered Health approach fostered by NESTA in the UK that focuses on building on the knowledge and capabilities of patient groups and communities. We need to think about how new technologies and business models can engage with these practices as part of what we call “innovation.”

Enabling Patient and Researcher Collaborations

The story of TuDiabetes and the collaboration with clinical researchers is a signal of a growing part of the way in which digital health is changing the traditional relationships in research and the practice of medicine. There are numerous efforts underway to augment the role of patients in clinical trials and research efforts through more participatory approaches. Online patient communities have offered new platforms for engaging with patients in the aggregate that can be quite valuable to research efforts. In order to continue to build on these efforts, there are a number of technological and policy issues that can be improved upon to make it easier to connect patients and researchers. It is estimated that only 4 % of Americans are aware of a clinical trial that they could potentially participate in and help further the growth of medical knowledge. Apple's ResearchKit application launched in early 2015 illustrates how new tools and platforms can fundamentally alter the way we design trials when in the first 36 h of its existence the ResearchKit app enabled more new participants in clinical research efforts than would normally have been enrolled if 50 medical centers spent a year in recruiting participants.

One of the missing elements has been a viable way for the consumer or citizen to store the data that are collected from their devices and then have a relatively simple way of exchanging the data with researchers or clinicians in a private and secure manner. Google's early efforts in health via GoogleHealth was an early venture to create a Personal Health Record (PHR) that could store patient-generated data and also have links to research institutions and health providers. The problem was that there was not enough patient-generated data available and the underlying business case was not robust in the mid-2000s to support growth in use of the PHR. Microsoft Vault has been slightly more successful and has enabled integration with a wide range of tracking devices and platforms as well as ways to integrate your prescription data from your pharmacy and other health-related services. There is still a problem of not having a robust enough use case to really create a business providing a "must-have" service to consumers. This has led many observers of digital health to conclude that the PHR is simply not going to work in the current digital health ecosystem. Or, can we rethink the PHR from a passive storage receptacle to become something akin to a patient platform where patients can do things with data and transactions can take place?

This is the novel approach that a Swiss start-up that the author of this chapter is involved with has taken. Healthbank, a Swiss-based start-up, has built a platform that is designed to offer a secure, private storage service for consumer health data but incentivize data sharing and harvesting greater public good from moving data out of silos. Most surveys show that citizens of Europe and the USA are very interested in sharing health data in a private and secure way if medical research and public health can benefit.



Healthbank is a cooperative business model where citizens who become members also are co-owners and have a voting role in corporate governance. In a world where consumers are increasingly concerned with the manner in which companies use their data in unauthorized ways, we feel that a cooperative model can help build trust and become part of a system that incentivizes doing more with data and putting the patient or citizen in control of who gets to use their data.

So why is this important now? Cardiologist Eric Topol and Leonard Kish spell this out in a paper in *Nature*, “Unpatients—Why patients should own their own medical data”¹ The authors point out the dramatically lower cost in sequencing whole-genome data and the growth in biological and medical data that is skyrocketing every year. And this is not just the volume of data or big data, but data over the entire life history of individuals leading to “long data” or a longitudinal record of a person that can be analyzed over the life course for predictive or personalized medicine types of care. The problem is that there is no centralized place to bring together EHR data, patient-generated data, and genetic data and this is a problem for actually implementing precision medicine initiatives. We also need to not lose sight of population health approaches as we increasingly personalize care. In most of the USA, the existing legal frameworks empower physicians and hospitals to own the patient’s data. The authors argue that in no other sector of the economy do we see consumers responsible for paying for a good but someone else owns the good afterward. But this is the reality of your health data. The legal status of

¹Leonard Kish and Eric Topol. Unpatients-Why Patients Should Own Their Medical Data. *Nature Biotechnology*, 33(9):921–924, September 2015.

ownership of health data in the USA is actually playing a role in blocking the sharing of data and consequently locking up the value we can generate from our health data as a society. Merely framing the discussion in terms of access to data helps the companies that currently own your data and does little for the consumer. If we want to unlock the value of health data, we need platforms for consumers to store and control their data while also exercising some form of return to individuals and society. This is the *raison d'être* of healthbank.



health bank Interface

The authors also discuss the potential revolutionary impact of bitcoin and blockchain on the current health data ownership models. Blockchain is a distributed cryptographic ledger platform that the cryptocurrency bitcoin is built upon. Blockchain enables greater security for data transactions and has potential applications for envisioning a new, more citizen-centric way of storing health, genomic, and financial data. One of the problems many health systems have, especially in the US context, is the lack of a unique identifier for every patient. Due to a Byzantine political process, this is currently a taboo subject in the US government. The lack of a unique identifier adds to the confusion in health informatics and possible safety issues and misidentification of patients. Blockchain could potentially provide a default solution to this problem while also maintaining high standards of privacy and security. At healthbank, we are actively involved in assembling some of the best minds on clinical research and Blockchain to position ourselves

to play an important intermediary role in providing this type of service to citizens around the world and hopefully change the current ownership model of health data while incentivizing medical research and the pharmaceutical sector's transition to a "beyond the pill" paradigm.

Another component of the transition to a new "beyond the pill" business model for the pharmaceutical sector is the use of wearables and mobile applications that can be used in both clinical trials and disease management. There are some estimates that the costs of clinical trials could be reduced by 50 % through more effective use of these technologies and data analytics that can match patients to the appropriate clinical trials better. Yet the current market for wearables is still rather primitive. For insights into what the future of wearable computing might be we can see many signals of what the future holds by looking at the sector in Finland and move beyond Silicon Valley. This is a story of rethinking how the academic sector is organized and different departments can cooperate more effectively as well as how to create a cooperative ecosystem for innovation in an emerging technology sector.

A Finland Success Story in Wearable Computing and the Future of Innovation with Patients

Wearables are the buzz across just about any technology conference these days and will likely play an important role in managing chronic diseases as well as offer opportunities to conduct clinical trials in less expensive ways. As a part of the Internet of Things ecosystem, there is a tremendous amount of hope that wearables will be an important part of the disruption of healthcare as we know it. Amidst the buzz and hype, however, there are many reasons to question the PR machine behind the buzz as studies show that sustainable use of wearables is questionable with the average user tossing their latest wearable on the junk heap on their desks after 3–4 months. A lot of data is "dressed up with no place to go," that is, in apps or silos with few user-friendly tools to help users make sense of the data. This represents the old way of thinking about data capture which fails to leverage the value of data and engage patients in a more robust way. It is clear we are in the early days of wearable computing making inroads into improving health outcomes or quality of care. Yet, even skeptics admit that the future of healthcare is likely going to have wearables and data analytics as a central component of managing one's health and fitness. But what might that future look like?

If Malcolm Gladwell's observation that you need 10,000 h of practice to become an expert holds true, Finland undoubtedly has the highest number of wearable computing experts in the world, as Christian Lindholm of Koru Lab and HealthSpa, two Helsinki-based organizations focused on catalyzing innovation in the wearables arena, explains. Few observers of the emerging wearables market realize that Finnish entrepreneurs and technologists have been in this business for more than 30 years. That is just a year less than Apple. From heart rate monitor maker Polar Electro

(<http://www.polar.com/en>), to the maker of one of the most important sources of innovation in battery design for wearables Suunto (<https://en.wikipedia.org/wiki/Suunto>), Finnish companies have been innovating in this space for well over a decade and also have a similar university–industry nexus similar to what we find in Silicon Valley. As the digital world fragments, the Finns unite and build bridges across the silos. Aalto University combined the premier design, engineering, and business schools to better support an innovative economy for Finland. Combine this with the University of Helsinki’s reputation in public health and medicine and one finds a pretty robust academic test bed for innovation in digital health. Many will point to the demise of Nokia in recent years as perhaps indicating a weakness in the “culture of innovation” in Finland, but that fear may be misplaced. Many of the engineers from Nokia who lost jobs in recent years left with some intellectual property and a substantial severance package. Often this was just enough to launch a new start-up. Some of the older technology companies that are not focused on wearables have been around long enough to have alumni who have launched their own start-ups as well. What one encounters is an emerging innovation hub for one of the technologies that is predicted to become a \$70 billion dollar market by 2024 by IDTechEx (<http://www.idtechex.com/research/reports/wearable-technology-2015-2025-technologies-markets-forecasts-000427.asp>).

HealthSpa: Launching the Next Generation of Wearables, and Globally

In 2012, Lindholm and partners launched HealthSpa (<http://www.healthspa.fi>), a health & happiness ecosystem to accelerate innovation in the health, wearables, and Internet of Everything computing domain where Finland has developed a comparative advantage in talent. Open innovation is the key word here. Early on they recognized that one of the problems in the digital health and wearables space is the silos within the ecosystem and that breaking down the silos between these companies and building opportunities for collaboration would help grow business opportunities for everyone. You can now find Beddit (<http://www.beddit.com>), the sleep sensor company working with Wellmo and PulseON (<http://www.pulseon.fi>), two data analytics companies, collaborating to offer feedback loops to users to improve sleep outcomes. These collaborations help the younger start-ups build up a customer base. This makes even more sense from the perspective of a small country that needs to build links to external markets to become financially sustainable.

HealthSpa includes both early stage start-ups and some of the more mature companies that have been designing wearables and related technologies for the past decade or more. Suunto has been developing dive computers, heart rate monitors, and other wearable technologies since 1997 with the Spyder watch diving computer. Their first GPS on the wrist the G9 was introduced in 2004 and they can claim ownership of the innovations that have extended the battery life of GPS devices from 8 h a decade ago to nearly 80 h in 2014. On the algorithm side, Firstbeat (<http://www.firstbeat.com>) develops heart rate variability algorithms that can be used

to inform behaviors that mitigate stress or improve fitness. Formed in 2002 their products are now found in Garmin, Samsung, Suunto, and Bosch devices and have been used for professional athletes as well as occupational health applications for workplace wellness. Omegawave (<http://www.omegawave.com>), another company focusing on the algorithmic side of wearables, offers performance management software for athletes and teams to optimize performance based on the data gathered from ECGs, for example. UnderArmour (<http://www.underarmour.com>) recently conducted a competitive analysis of technologies in this space and Omegawave came out on top of the competition. Their technology was originally used in Russia and the USA bought back to Finland for consumerization and now includes clients such as the US Navy Seals, professional soccer teams, Olympians, and Seattle Seahawks. Heia Heia (<http://www.heiaheia.com>) also provides insights into the ways that data and design are likely going to work in the space in coming years. They have several years' worth of activity log data for everyday activities such as house cleaning and walking with the dog, which seems to be the 5th most done activity logged. One of the gaps in the current wearables space is insights on actual use of the devices that can lead to insights on why sustainability of use is so low. These activity logs may unearth a number of opportunity spaces for designers in the future. Heia Heia provides a service that is increasingly common—activity trackers linked to apps that can utilize various gamified or motivational modules to improve health outcomes in employee wellness programs. Already deployed in 140 countries, they may not be well known in the USA but include one of the largest fitness chains in Europe as a client. Heia Heia also demonstrates the power of collaboration within the local ecosystem. Hints Performance was developed by neurosurgeon Aki Hints, the senior physician for Finland's Olympic Committee, to aggregate data from neurological tests and through tracking sleep and other vital signs that can indicate general fitness and performance levels of athletes. Formula One racing team, McLaren, has been using the system to monitor Formula One drivers for years and finds it one of the most important forces behind selecting drivers who will compete in any given week. Heia Heia and Hints Performance are now collaborating to digitalize the service for a much wider customer base in the coming years.

One application that is currently focused on the fitness market and the posture of athletes may have many occupational health applications for those of us stooped over desks all day. MyonTec (<http://www.myontec.com>), listed by the New York Times (http://www.nytimes.com/interactive/2012/06/03/magazine/innovations-issue.html?_r=0) in 2012 as one of the innovators likely to change the future, utilizes a wide range of sensors found in many other fitness applications with the addition of sensors that monitor muscle load and posture. These sensors can do gait analysis, muscle training monitoring, analysis of movement disorders, and analysis of form in various activities. Users of the new Adidas wearables and smart watches might note that Metawatch and Elektrobit are two Finnish firms that are involved in a joint venture with Adidas wearables.

Koru Lab, Breaking the Mold for Interface Design and Wearables

Lindholm's own company, Koru Lab (koru means "jewelry in Finnish), and its trajectory over the two short years of its existence are an interesting case study in what may become of wearables in the next phase of innovation. Asked by a major technology platform to come up with the "killer app" for wearables, Lindholm spent a year working on an answer to this question and decided it was too early to frame the question in this manner. Instead, after thinking about the big challenge on the radar right now, curve fatigue or lack of sustainable engagement, a number of questions emerged from how to convey data collected via wearables and what new representational paradigms beyond the medical model could emerge to user-interface design for wearables. Also, how to move the price point down while maintaining a smooth iPhone-like experience on a microcontroller is a big technical issue. If devices have to be worn 24/7, they have to be beautiful, small, fast, and their battery cannot run out halfway through the second day. The current market for wearables is bifurcating with those devices that run on a microcontroller versus those that run on a CPU. This has profound implications for users and business models based on the traditional hardware and software paradigm where the manufacturer maintains control over the user interface. Just take a look at Apple and the degrees of freedom a user has in modifying the device, Zero. Koru has developed an incredibly small and flexible platform that runs on XML leveraging the SVG standard, not Java. This makes it easy to adopt by anyone familiar with HTML5. The most unique property is that any manufacturer can design their own experience from a set of more than 60 readymade components. This turns the traditional hardware and software model on its head by allowing manufacturers and even users to modify the device. Koru is the software platform that glues the technology and fashion industry together. Fashion meets technology, but with much more under the hood than meets the eye. Users will be able to modify the device to match outfits in the same manner you can change shoes based on the weather. Their devices can also run across Apple, Google, Samsung, and Microsoft's platforms. This is a big deal when you look at the global market and preferences across regional markets where some companies and consumers may not want to be tied to Google or Apple, for example.

Koru and HealthSpa have both attracted the attention of large Asian investors who sense the growing need for scalable digital health technologies over the next decade. China has over 10,000 villages that over the next decade will be virtually emptied of inhabitants under seventy. Telemedicine, sensors, and wearables are likely going to play a major role in providing remote healthcare opportunities for both the government and the consumers whose families are dispersed geographically. These large investors are taking note because this innovation cluster is likely going to have a major impact in how we think about wearables, health, and the business of hardware and software in the future. While we hear a lot these days about software eating the world, we may be on to something a bit different here.

Lindholm refers to “omni-platforms” that will emerge as the big players such as Google, Samsung, Apple, and Microsoft offering linked hardware and software services. Design and fashion loom large but need to be linked to a data service or as one Frog Design lead has commented, “design may include algorithms wrapped in nice shiny boxes in the future.” Our current approach to serving up medical data in pretty graphs will need to migrate more into the realm of service design where products are merely avatars for an underlying data service. A glimpse of where this is going can already be detected in Suunto where the community and hobbyist have published 10,000 different apps, and another 5000 that are implemented for the individual. This is mass customization for the twenty-first century. These technological innovations when combined with the social technology of social supports, peer pressure, and behavioral economics-driven design and coaching engines are where we may see the wearables market going in the coming years. The Finns use of open innovation models to bridge the silos across an incredibly fragmented race to the market that we find in other parts of the globe, may make for a powerful test bed for wearables to actually live up to the hype.

Returning to Diabetes and the Concept of “People Powered Healthcare”

We began this chapter with a look at how patients have been self-organizing to create social supports and play a more active role in the research process through sharing data with clinical researchers. Our overview of healthbank demonstrates another aspect of platform creation that can support this overall move into incentivizing participation in research and rethinking ownership of health data away from the traditional model where hospitals and health IT companies own the patient’s data. An important tool in this emerging network of people and things is the growing role of wearables and new zones of innovation and practices that may drive the next generation of wearable technology that can become more user friendly, provide better feedback to users in a way that can sustain engagement. There is another piece of this puzzle that could be brought into play with the components described above that addresses the social infrastructure of communities and innovation in healthcare delivery or just the production of good health, but outside of the traditional focus on medical care.

We now turn to the experience of the UK and an innovative approach to addressing chronic diseases and aging in place that the UK-based think tank NESTA developed from 2011–13. The People Powered Health program offers a valuable tool and way of thinking about design and co-creation in health that could be pulled together with the platforms and networks listed above to create innovative ecosystems of cooperation that are capable of generating new technologies, but most importantly, better health outcomes at lower price points.

The People Powered Health (PPH) program was launched in England in spring 2011 with a call for ideas. In total 106 teams applied and after a three-stage selection process, six teams from across England took part in the program. The local teams were each awarded a £100,000 grant and provided with a range of non-financial support to develop their capacity in fields such as co-production, service design, business case development and commissioning. We established a peer network between the teams to enable them to learn from one another as well as from external experts.

So what makes the People Powered Health approach?

The People Powered Health approach offers a vision for a health service in which:

- the health and social care system mobilises **people** and recognises their assets, strengths and abilities, not just their needs.
- the ability to live well with long-term conditions is **powered** by a redefined relationship, a partnership of equals between people and healthcare professionals
- the **health** and care system organises care around the patient in ways that blur the multiple boundaries between health, public health, social care and community and voluntary organisations

This vision is grounded in innovations that have emerged in health and social care over the last 20 years. It demands an urgent effort to make those innovations a normal part of our health and care systems. This will require a new balance between health provision for people, active health management by people, and mutual support with people.

The NHS in England could realise savings of at least £4.4bn a year if it adopted these People Powered Health innovations that involve patients, their families and communities more directly in the management of long term health conditions. These savings are based on the most reliable evidence and represent a 7 per cent reduction in terms of reduced A&E attendance, planned and unplanned admissions, and outpatient admissions.²

In a way, we can think about the NESTA approach as a “People as Infrastructure” approach to producing better health outcomes. Most of our digital health conversations focus purely on the technology components and data analytics that can drive change but neglect the so-called soft components. We talk a lot these days about patient engagement but in most cases this is lip service or a marketing slogan to go along with the latest trend in health IT. To add substance to the marketing slogans, we need to build more robust methodologies and take advantage of co-creation in the actual development of technology tools further upstream versus the traditional way of rolling out new technologies in the name of patient “empowerment” and “engagement” with a wish and a prayer assuming that the technology will play the magical role of making these things happen.

The PPH program is heavily focused on co-production of services and how peer-to-peer networks and co-design methodologies can be used in conjunction with rethinking of where and how care is delivered. Some of the examples used over the years included:

- A good case study of redesign is NeuroResponse (<http://launchpad.youngfoundation.org/node/252>); a social enterprise incubated by the Young Foundation’s Launchpad (<http://launchpad.youngfoundation.org/>) that addresses the unmet

²<http://www.nesta.org.uk/project/people-powered-health#sthash.rPqW223E.dpuf>.

needs of patients with neurological disorders through the use of existing telecommunications infrastructures so that more patients can receive treatment at home, that is, moving from an acute care model to community care. The cost of a diagnosis of MS currently costs the system £17,000 per person or a total of £400 million of which the majority is for in-patient, hospital-based care. Telemedicine has the potential to save millions.

- The Expert Patient program (<http://www.expertpatients.co.uk/>) is another example of how self-care is being used to improve outcomes and patient satisfaction. Hospital admissions have been reduced by 50 % and visits to GPs reduced by between 40 and 69 %.
- Community-based initiatives tend to be better for behavioral change than top-down approaches. The Knowsley Primary Care Trust (<http://www.invmeduk.com/nhs-health-checks/articles/nhs-health-checks---knowsley-health-and-well-being-partnership-71/>) created a partnership for well-being that focuses on cardiovascular disease prevention at the community level and works through pubs, bingo halls, and shopping centers. The result has been a 28 % reduction in cancer morbidity rates and 32 % decrease in smoking.
- Well London (<http://www.london.gov.uk/welllondon/>) is a consortium of health, environmental, education, and arts organizations that invests in community projects for health behavioral change. This includes projects like Healthy Spaces that transforms open spaces into greener, more attractive places. Community mental health is one of the focus areas.
- Transforming Innovation: Perhaps the most difficult challenge is changing the way organizations think about innovation. The US public health sector is in dire need of this change in mindset. Getting funders AND organizations to take risks, experiment, move beyond dated ways of thinking about technologies and community is a challenge. One of the platforms they have used in the UK is Patient Opinion (<http://www.patientopinion.org.uk/default.aspx>), a platform that enables users of the NHS to provide feedback and develop networks of user citizens to provide the essential feedback that innovators within the system can use to improve services.
- Open Innovation for behavioral change: The Big Green Challenge (<http://www.biggreenchallenge.org.uk/>) is another initiative designed by NESTA focusing on climate change and how communities can reduce their carbon emissions. The program is essentially a platform that crowdsources ideas for innovative strategies and provides awards for the best proposals. The concept has been extended into the obesity/diabetes space through the Healthy Community Challenge Fund (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/DH_085328) to test and evaluate ideas that make activity and healthier food choices easier.

The underlying business case for the PPH approach was relatively inexpensive and ranged from approximately \$150–700 per patient annually. NESTA has published a number of case studies and an overview of the overall business case for co-production of healthcare delivery.

From these components, we can also imagine how health data platforms, patient networks, and wearables (and/or sensors) may be assembled in the future to manage chronic conditions. Some of the scenarios envisioned by NESTA include the following:

- **Health Knowledge (Data) Commons:** With greater sharing of knowledge and improvements in biometric authentication and security, we may see greater transparency in how data are used and be able to more clearly see how it benefits others as well as receive feedback on how our own actions impact our health and the populations. If we drive our cars more, for example, we may worsen our own asthma as well as others. Wearables that can connect to platforms enable us to track data in more sensitive ways and encrypted but also see the data in aggregation or in analyzed form for our neighborhood, city, or region, for example.³
- **Health Data Markets:** Markets for personal health data emerge where the citizen maintains control and can bargain and barter for new products and services with their own data. Data for special conditions become more valuable and citizens can negotiate prices. Higher-quality wearables can authenticate and certify the reliability of your personal health data set.⁴
- **Health Data Provenance Systems:** Privacy breaches damage trust and citizens begin to set up their own provenance systems for health data that encourage sharing. This is where cooperative structures such as healthbank could also play a role as the Consumer Reports for health data provenance, accuracy, insurance, and financial transactions.⁵
- **Health Data Markets Explode:** When people realize the value of their health data, they find the means and devices to track and integrate many types of data and explore the meanings and analytics. Machine learning tools become more user friendly and enable both individual and collective analytics commons and cooperatives. Investment of your data in the market is automated.⁶
- **Surveillance Fears:** People are becoming distrustful of how data analytics can be used against them or without their consent, security breaches are increasing, and engagement with wearables is weak because users are not receiving useful feedback that can engage behavioral change. Devices such as Medi-Bloc have emerged to block tracking and collection of personal data due to the fears listed above. Devices such as Medi-Bloc emerge to block tracking and collection of personal data.⁷
- **Co-produced Service Society Emerges:** Networks of citizens–patients have digital infrastructures to enable co-created/produced services to proliferate and devices to support the underlying analytics and communications needed to

³<http://www.nesta.org.uk/health-knowledge-commons-innersense>.

⁴<http://www.nesta.org.uk/personal-data-ecosystem-medihex>.

⁵<http://www.nesta.org.uk/health-system-shutdown-analogue>.

⁶<http://www.nesta.org.uk/data-makers-cumulus>.

⁷<http://www.nesta.org.uk/still-nation-medibloc>.

coordinate care, provide transparency and incentivize data sharing. New wearables help people to engage in peer-to-peer support programs that have feedback loops to technology companies and designers.⁸

- **Blockchain-enabled health records:** Blockchain (distributed, cryptographic, transaction ledger that bitcoin is built upon) matures and becomes the standard for storing encrypted health data and serves as the underlying infrastructure for distributed, peer-to-peer systems of support as well as the lynchpin of the health data economy that rewards sharing of data for the collective good. Healthcoins reward data sharing and peer-to-peer healthcare delivery programs and are used as payment for health services. A mature healthbank has become a platform in the true sense of the word that offers transparency in health data transactions and the foundations for robust data sharing while putting citizens in control and providing a socially responsible way to use data ethically but also drive innovation in wearables, sensors, and new health services.

I have taken the scenarios offered by NESTA and mashed them up with the ideals behind our company healthbank, to show how we can envision a more innovative economy based on data sharing with greater citizen control and through the use of innovative wearables. We also see that no single technology or business model alone can realize a better future but assemblages of different approaches, policies, and platforms when outfitted with the tools for cooperation may lead to more effective uses of data in the future while still protecting privacy and security. A lead role for patients as active participants in shaping these futures will be necessary and later in this book we discuss the potential for networks of patients and their data to influence policy innovation as well as technology innovation. A key piece in this future we have not discussed is the growing importance of algorithmic ethics. As more parts of the health system become automated and machine learning tools proliferate off of our data sets, we will need to be vigilant in addressing how new forms of discrimination and inequality may emerge from the reliance on algorithms and develop policy tools and business practices to avoid these cases.

⁸<http://www.nesta.org.uk/health-and-care-system-alt>.



<http://www.springer.com/978-3-319-40978-8>

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