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National Digital Infrastructures for Healthcare: A Comparative Case of Estonian and British Healthcare Infrastructure

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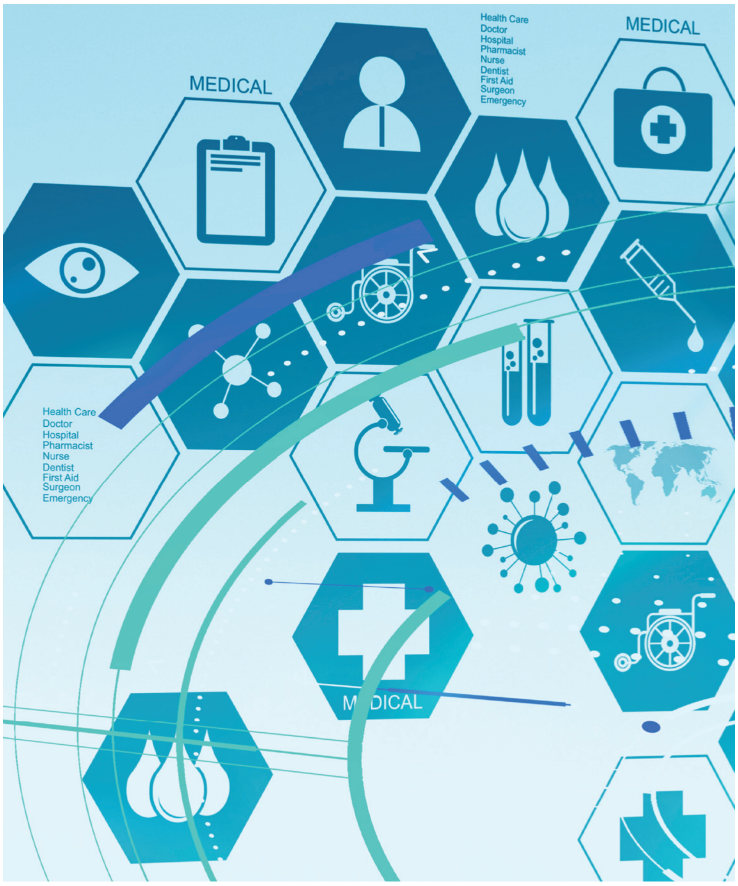

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ABSTRACT

This paper presents a comparative case study between the technological healthcare systems of Estonia and Britain. It describes these two nations' digital infrastructures: socio-technical collections of information communication technologies and networks along with standards, institutions, data practices, policymakers, professionals, support staff, and patients. On this basis, the paper posits three research questions: What are the characteristics of the Estonian and British digital infrastructures for healthcare? How does digital infrastructure for healthcare influence the patients connected to that infrastructure? What are the key factors of digital infrastructures for healthcare?

To examine these research questions, the paper explores seven themes of digital infrastructure as previously defined by Ribes and Lee.[1] In each case study, the following themes are mapped: relationality, integration of heterogeneity, sustainability, standardization, scaling up/extension, the distribution between human work and technological delegation, and the always-ready social characteristic of digital infrastructure. After interpreting the digital infrastructure of each case, the paper presents recommendations for future directions of each respective digital infrastructure, centred particularly on data-sharing, patient-entered data, and governance of the infrastructure.

HEALTH AND INFORMATION AND COMMUNICATION TECHNOLOGY

The hallmark of a modern and successful healthcare system is the ability to use information and communication technology (ICT) in a meaningful way to reduce costs, provide access to information and support, and add value to the delivery of care.[2] Additionally, healthcare is an information-intensive domain for both patients and healthcare professionals.[3] The quest for ICT investment in healthcare is also fuelled by the proliferation of Internet connectivity, mobile computing,[4] online health-information seeking,[5] and overall ease of information access across all age groups.

One application of ICTs in healthcare to address the need for information dissemination to the patient is the personal health record (PHR). PHRs are designed to support patients, increase patient satisfaction, and motivate and empower patients to be involved in their health care. PHRs are tools for patients to use. Typically they are tethered to, or pull data from, an electronic medical record. The PHR only allows patients to see data in their health record and rarely allows them to manipulate or contribute data. The data patients can enter is not stored in the clinical record. An application of ICTs that focuses on health providers is the electronic medical record (EMR). EMRs are clinical tools designed to streamline clinician documentation, serve as a nexus of clinical data and patient information to support decision-making, and act as a modern patient chart. The EMR is the legal record of a patient's health information. As such it contains data gathered by clinical and hospital staff, does not contain patient entered data, and does not allow patients to edit this data. Rather than give patients access to EMRs to see their information, as an EMR is far too clinical, PHRs were created as a patient facing portal to their health data. Aside from these two major systems for providing information to patients and providers, many other ICT systems are found in healthcare, including billing and finance, insurance management, prescription order entry, patient reception management, and so forth. The data that all these systems process and generate creates a need for additional storage, greater network capacity, and more security as they grow.

Research Questions and Design

This paper explores the following research questions:

RQ$_1$: What are the characteristics of the Estonian and British digital infrastructures for healthcare?

RQ$_2$: How does a digital infrastructure for healthcare influence the patients connected to that infrastructure?

RQ$_3$: What are the key factors of digital infrastructures for healthcare?

This paper argues that the collection of these systems in total creates new digital health infrastructures. This study is a comparative dual-case research design.[6] In developing each of these cases, the goal is to enrich the understanding

1 David Ribes and Charlotte Lee, "Sociotechnical Studies of Cyberinfrastructure and e-Research: Current Themes and Future Trajectories," Computer Supported Cooperative Work (CSCW), Vol. 19, Nos. 3–4, pp. 231–244, http://doi.org/10.1007/s10606-010-9120-0, August 2010.

2 Andrew S Grove, "Efficiency in the health care industries: a view from the outside," JAMA : Journal of the American Medical Association, Vol. 294, No. 4, pp. 490–492, http://doi.org/10.1001/jama.294.4.490, July 27, 2005.

3 William R Hersh, "Medical Informatics: Improving Health Care Through Information," JAMA: Journal of the American Medical Association, Vol. 288, No. 16, pp. 1955–1958, http://doi.org/10.1001/jama.288.16.1955, October 2002.

4 Aaron Smith, "Nearly half of American adults are smartphone owners," Pew Internet and American Life Project, retrieved from: http://pewinternet.org/Reports/2012/Smartphone-Update-2012.aspx, March 1, 2012.

5 Wayne Buente and Alice Robbin, "Trends in Internet Information Behavior, 2002-2004," Journal of the American Society for Information Science, September 2008; and Susannah Fox, "The Engaged E-patient Population," Pew Internet and American Life Project. Washington, D.C., 2008.

6 Robert K Yin, "Case Study Research: Design and Methods (5th ed.)," Thousand Oaks: Sage, 2014.

of the digital health infrastructure. First, the paper explains patient and provider systems in the context of the overall digital infrastructures. To build each case, interviews were conducted with developers, medical professionals, stakeholders, and policymakers in Estonia and Britain. The aim of the interviews was to discuss not only functionality and features, but also policy, incentives, future visions for the platform, successes, and challenges associated with the work. Also, policy documents, reports, parliamentary documents, white papers, and other literature were gathered and reviewed to enrich each case further. Documents and interview notes were analysed in the computer-assisted qualitative data analysis software Nvivo 11 with a structured coding scheme[7] that consists of the seven themes of digital infrastructures as previously discussed in the conceptual framework.

Table 1 (Appendix) presents a summary of the overall research design. The context of the Estonian case is specifically that the healthcare information technologies, databases, interfaces, and associated systems build on top of the X-Road platform. Though there are many similarities between the electronic health information systems in Estonia and Britain, the Estonian approach is a collective "top-down" development of the infrastructure that starts with a basic technical framework and builds within those specifications. Britain uses a "bottom-up" or open market systems approach to development. Rather than a single vision of a grand infrastructure, Britain represents the notion that many separate systems can connect to make a larger infrastructure. The British approach necessitates a priority on interoperability between different systems.

The paper presents two units of analysis within each of these cases. One unit of analysis is at the individual level, which includes interviews in the areas of Estonian and British technical development, administration, policy, and other stakeholders related to the health infrastructure. The second unit of analysis is at the document level. Documents were included to help develop each case and complement each interview.

There are different approaches to the study of infrastructure. This paper takes a socio-technical approach. In other words, the infrastructure comprises the technical components, but it also contains human components of policymakers, professionals, stakeholders, support staff, and clinicians. There are also methods to study a digital infrastructure. To this end, the paper applies the advice of Ribes and Lee by examination of project-based parts of infrastructure, rather than the entire end-to-end system. Thus, the purpose of this paper is to focus on the healthcare component of the digital infrastructure—whereas banking and telecoms, for example, may be other components of the same infrastructure.

Documents included in the analysis are listed in the Appendix, Table 2. As mentioned in the previous section on research design, documents were selected for their ability to contribute to the detail of each case, not for an exhaustive systematic review.

In the following sections, the paper details the digital health infrastructures of Estonia and Britain. Each case represents a different approach to and outcome for digital health infrastructures. The paper incorporates the literature on cyberinfrastructure, e-infrastructure, and digital infrastructure to construct the notion of "digital health infrastructures." These bodies of literature also inform the analysis and interpretation of the two case studies. I group these terms together because they largely mean the same thing. However, cyberinfrastructure is a term common in the United States to describe this field of study, and the United Kingdom more readily uses the phrase e-infrastructure.

DIGITAL INFRASTRUCTURE IN ESTONIA

Estonia is lauded for its use of national technical infrastructure for e-government. State services are digital and administered through this national infrastructure, including vehicle registration, population registration, PHRs, banking, energy, telecoms, and virtually all interactions a citizen can have with the government. What makes the Estonian system an exemplary e-government infrastructure is not only that every citizen has digital access to government and certain private-sector services, but also that all of these services communicate with each other and exchange data to accomplish complex tasks. For example, Estonia has a programme that automatically queries a person's health record when he renews his driver's licence. The system can look at the health record to see if there are any health issues that might prevent the person from obtaining a driver's licence. This is done entirely through the online system—no printed documents are required to complete this administrative task. This indicates that each of these services is reliant on and thus derives some of its features from other elements of the greater technical system. If this system were to be exported to other countries for use with their own citizens, previous reports conclude that certain factors would be required to scale and export the system to other countries. Key features include the existence of a nationwide data-exchange platform, universal health coverage, and national data standards.

The X-Road platform makes it possible for Estonian governmental services to communicate digitally with each other. The X-Road can be thought of as a container system for data exchange between organizations. It also checks for certificates between organizations to verify authenticity and security. This platform is the foundation of the technical system, and other services are built on top of it. These

7 Johnny Saldaña, "The Coding Manual for Qualitative Researchers (2nd ed.)," Los Angeles: Sage, 2013.

services include databases hosted by each governmental organization, user interfaces that display data, and security servers that introduce an additional layer of protection.

I refer to the national infrastructure that links the X-Road foundation, technical services on top of the foundation, support of the technical structure by developers and IT professionals, use of expert systems by governmental employees, access to web portals by citizens, and service provider interactions with data as "digital infrastructure." This term is part of a growing field of study that includes notions such as cyberinfrastructure and e-infrastructure. Traditional infrastructure refers to cities, road systems, airports and train stations, public water systems, and electrical grids. Digital infrastructure is the purpose-built large-scale networked information and communication technologies that have a scope and reach beyond a single site or practice. They are embedded into organizations, contain standards, and become visible upon breakdown.[8] These digital infrastructures can emerge in different ways. The "top-down" approach, as seen in the Estonian case, is when the government creates a structure and standards and then adopts the technologies that create the infrastructure. Alternatively, the "bottom-up" approach is the idea that networked technologies will give rise to digital platforms,[9] as is the case in Britain. This connection to digital infrastructure occurs in the same way as electrical infrastructure: people plug into it and it allows new possibilities for work and practices to emerge.

DIGITAL INFRASTRUCTURE IN BRITAIN

Estonia and Britain both participate in universal healthcare systems. The National Health Service (NHS) healthcare system in Britain, however, involves about 65 million citizens (NHS Statistics, 2016) and data about NHS patients are not stored in a central database. Instead, data about patients in Britain are in fragmented systems across both primary (general practice) and secondary (hospital) care. Estonia, by contrast, has a national, centralized database. The most publicized example of a potential centralized patient database in Britain is the now defunct and widely controversial care.data data-sharing scheme.10 The case of care.data is an indication of Britain's desire to have a single national database, but it shows the challenges in the larger British system in trying to make a single database work. While the countries in this paper may have similar national single-payer healthcare systems, the way that each country handles and processes data is completely different.

The devolved British national health insurance system has resulted in separate NHS entities for England, Northern Ireland, Scotland, and Wales, which are politically accountable to their respective governments. For the purposes of this paper, the scope of digital infrastructure examination is limited to NHS England (henceforth referred to as NHS).

The landscape of healthcare delivery in the NHS is made up of primary care, also known as general practice (GP). The GP health centre is the first encounter all patients have with their healthcare system. Short of accident and emergency services or specialist appointments, patients will be seen first at their GPs. From there, the GP can refer patients to secondary care—larger hospital facilities made up of specialists. The difference between primary and secondary care is relevant to this case study because of how information and communication technologies function in each setting. Primary care can be thought of as individual GP businesses that are contracted by the NHS to perform a variety of health services. These separate businesses can purchase whatever software and hardware they see fit. They often choose to adopt one of four unique electronic medical record systems, along with a handful of other software packages that are required to run a primary care clinic.

The use of information and communication technologies is different in secondary care. Often secondary care includes a variety of legacy systems, expert systems, and specialty systems created for specific medical specialties such as radiology. This is the case with professional-oriented EMRs. When it comes to patient-oriented PHRs, the options are basic and suffer from poor usability and low adoption. Sometimes, the software used for EMRs in primary care will have a patient-facing portal that allows patients to see some of their health data that is tethered to the EMR. There are also websites that individual primary-care clinics develop and maintain. These websites typically offer services to allow patients to renew prescriptions through the website, book appointments, or send a message to their general practitioner. These services, which are hosted on a GP's website, can overlap or be completely redundant with services offered through a commercial PHR.

The EMRs are not all-inclusive of every service, but connect to other systems that specialize in specific tasks. For example, administrative staff will change how they work in the electronic health record with different modules that add functionality, such as adding the ability to create specialized templates, create a protocol that provides context-specific reminders, or changes the user's workflow for a specific task.

8 Susan Leigh Star and Karen Ruhleder, "Steps Toward an Ecology of Infrastructure: Design and Access for Large Information Spaces," Information Systems Research, Vol. 7, No. 1, pp. 111–134, http://doi.org/10.1287/isre.7.1.111, 1996.

9 Geoffrey C Bowker, Karen Baker, Florence Millerand, and David Ribes, "Toward Information Infrastructure Studies: Ways of Knowing in a Networked Environment," International Handbook of Internet Research (pp. 97–117). Dordrecht: Springer Netherlands. http://doi.org/10.1007/978-1-4020-9789-8_5, 2009.

10 James Temperton, "NHS care.data scheme closed after years of controversy," Wired, http://www.wired.co.uk/article/care-data-nhs-england-closed, July 6, 2016.

These EMR systems are also used to share data with other organizations and departments in the NHS. Data-sharing is not done through any kind of system interoperability, but through a series of steps that allow the importing and exporting of data queries and reports. That data is then uploaded to a corresponding website or data portal.

There are three major reasons for the fractured landscape of British digital infrastructure for healthcare. The first is strong resistance to any kind of a national identity card. Estonian citizens have a registry and national identity card that provides them with access to governmental digital services. This approach has never been adopted in Britain, and is in fact actively resisted. For example the Identity Cards Act of 2006 was widely criticized and eventually repealed and the national database was destroyed. Identity card schemes were also introduced after World War I and World War II and abolished in the years following each conflict. The second factor involves multiple public information and communication technology blunders—most recently, the closure of the long-planned care.data project. This was a single database that linked patients' information from primary, secondary, and social care institutions. The demise of care.data is well-documented in the news, on UK government websites, and on NHS websites as the multi-year process moved along. The reasons for its failure are multifaceted, including poor communication with the public on explanations of benefits, privacy issues, and a poor opt-out consent mechanism. The third reason is population. The population of Estonia is about 1.3 million, while Britain has over 65 million residents. The difference in resources required to construct a digital infrastructure for 65 million people versus 1.3 million is quite significant.

These three drivers of Britain's fractured digital health infrastructure lead to the question of why these differences matter and what they mean between two countries with similar overall national health systems, but different approaches to the development and governance of digital infrastructure. Moreover, how can the findings from an analysis of the Estonian digital infrastructure inform similar systems such as the NHS? Much of the data and potential already exists, from the multiple EMRs used in primary care to the variety of digital systems used in secondary hospitals and accident and emergency services. With the availability of many British government services through online portals, it appears the larger e-goverment infrastructure is coming into focus. This may contribute to the further cohesion of a specific digital health infrastructure plan inspired and supported by other sectors of the government. Considering this, much can be learned from the Estonian system, which has been in development since the 1990s.

The following section details the conceptual framework that the paper employs to analyse and report the findings from each case study.

CONCEPTUAL FRAMEWORK

The work of each infrastructure is primarily information-based. These infrastructures influence the healthcare professionals and patients that are part of the social infrastructure. To understand the different technical components of infrastructure and the social actors that connect with the infrastructure, this paper employs a conceptual framework put forth by Ribes and Lee in their work on socio-technical studies in cyberinfrastructure and e-research. They develop seven themes or characteristics of cyberinfrastructure. This paper uses these themes as an analytical framework for the case studies.

1. *Relationality* refers to the relations between the technologies and social actors. Large, complex systems require working relationships between interdisciplinary social actors and various networks and servers. The components of a digital infrastructure are relational.

2. The *integration of heterogeneity* refers to the ability to bring together social and technical actors for a shared goal or end product. Overall, the goal of both cases presented here is healthcare delivery. The integration of heterogeneity specifically refers to the professions or social roles that collaborate to reach that end goal. The cases presented here identify methods by which different healthcare professions can come together using the same infrastructure and provide care for patients.

3. *Sustainability* refers to long-term resources and maintenance of the infrastructure. These digital infrastructures become physically large and technically complex. They are built for use over long spans of time; thus, they must anticipate future requirements and needs. Sustainability in this context also refers to the ability of the infrastructures to reach beyond a single site or practice.

4. *Standardization* of digital infrastructure is both a goal and a method. The foundation of standardization is interoperability. The adoption of standards to enable interoperability changes the practices of the users and various professionals who interact with the technologies. Thus, standardization can also create consequences for the social structure.

5. To *scale up* or *extend* the infrastructure is a central characteristic and highly desirable capability. Scaling up and extending relate to both the actual geographic reach of a digital infrastructure and the ability to support additional users. Scaling up also applies to the increase in technical capacity. For example, this may be an increase in the quality of data or processing power from work-related demands of the professionals who use the infrastructure. The ability to scale up presents technical problems and issues in the workflow of the social structure.

6. The preceding themes so far connect to a general concept of *the distribution between human work and technological delegation.* This theme explores work distribution between humans and technologies and directs the researcher to cast an analytical eye on who is doing what. Digital infrastructures typically span multiple agencies or organizations, and any work that happens within the infrastructure transcends the organizations associated with the infrastructure. This is because labour-intensive and tedious tasks require less effort when they are performed by machines. Automation is a key concept because digital infrastructure begins to automate certain work for the human infrastructure.

7. The notion of a human infrastructure or social organization that interacts with a digital infrastructure means there is an *always-ready* social characteristic to digital infrastructure. Digital infrastructures require complex social organization and cooperation to function, be maintained, and make virtually every one of the other themes possible. The point of this theme is to focus on the social organization around digital infrastructures because infrastructure is a social enterprise as much as it is a technological one.

CASE STUDY FINDINGS

Estonia

The central electronic health record system, which was built on top of the X-Road framework, was launched in 2008. Ultimately, the Ministry of Social Affairs is responsible for the digital health infrastructure. The scope and magnitude of this infrastructure also, however, relies on several partners, partial funding from the European Union, and other organizations inside and outside of the Ministry of Social Affairs. One such organization, the eHealth Foundation, was formed in 2005 to lead all of the digital health–based projects in Estonia. Given the network of governmental institutions, policies, routines, and training it takes to render any infrastructure operational it is clear that there is a need for those who work with and within the infrastructure to function across these organizations. This, in part, is key to the integration of heterogeneity because the infrastructure revolves around clinicians delivering healthcare to Estonian citizens. There are also IT departments responsible for technological maintenance and administrators performing billing and other clerical support tasks. All these actors, both governmental and non-governmental, collaborate for the same end goal. They are also a part of the same broad organization.

It is important to note that the seeds for the current digital infrastructure in Estonia were planted more than twenty years ago through the emphasis on the use of technology by medical doctors. Basic decisions, such as use of desktop computers in primary care, set the entire health system toward integration of technology into the system. Future technologies are dependent on current embedded technologies. This is exemplified by one interviewee who discussed some of this history: "We had one kind of ministerial regulation which stated what kind of equipment family doctors should have, and one of these [required pieces of] equipment also include the computer instead of any kind of medical equipment but [a] computer was compulsory for family doctors as well. You couldn't open your practice when you didn't have a computer and later it [a law] was written [that an] Internet connection [was required] so you could exchange information." This straightforward policy set the tone for many future developments. The desktop computer is the core technology used to access, interact with, and build the current digital health infrastructure.

The infrastructure derives its technical relationality from close organizational connections that have in tandem developed policies and coordinated to contribute to the same system. This "top-down" model results in more intentional planning than in "bottom-up" infrastructures, in which new builders of the infrastructure are acquired as time progresses. Estonia's institutional involvement and close governmental oversight filters down into the technical details that have set the digital infrastructure on certain path dependencies. One example is the design decisions for databases in the infrastructure: they all share data with each other to accomplish certain tasks. If a patient wants to look up information in his or her PHR, the task involves data transmission from the population register, health insurance register, and health record service. No redundant information is stored among these systems. Another example of relationality that emerges out of this digital infrastructure is the recent development of a drug interaction database. It is a value-added system that supports the cognitive work of clinicians by delivering alerts if the system detects any issues with medications the patient has been prescribed. As one interviewee explained: "When a physician prescribes a new medication, it doesn't matter where the physician works or is entering the new medication. The electronic medical record or electronic patient record makes a query to the national prescription centre where all patients' prescriptions are stored. If they are valid prescriptions…the response comes with the already existing medication and the new medication and the existing medication ingredients are sent to this drug interaction database…so if there is a contraindication to prescribe this new medication then the physician gets an alert to consider the appropriateness of prescribing this medication. We have seen some initial results, and it is very surprising how many interactions there are." It is an exercise in the principle that the sum is greater than the whole of its parts. The data from the system is used to create additional services and clinical support tools that are integrated into the system. This is possible because of the high amount of relationality built into the infrastructure.

The path dependencies of this infrastructure, however, are to integrate future technologies into the X-Road system and the existing database structure. This means that future technologies that may be more efficient, faster, take up less storage space, or have advanced features are unable to be used due to previous commitments made in the system.

The data-sharing between databases and organizations has assured the long-term sustainability of the infrastructure within a certain context. The sustainability of the digital health infrastructure functions, in part, through two mechanisms. The first mechanism is the relationship shared by the governmental organizations and database technologies. The close integration of organizational policy and technical standardization has created a singular vision that operates within its own boundaries well. The second mechanism is the incentives and deeply ingrained work practices of the healthcare professionals. This finding is consistent for health professionals' work in any healthcare-oriented digital infrastructure. The work that clinical health professionals perform when interacting with technical infrastructure is routine and structured. They write clinical notes from the patient encounter, which constitute standard documentation of medical issues, patient history, events during the examination, relevant family history, relevant social history, comments, medication, and any follow-up. The medical codes, such as the International Classification of Diseases, are highly structured ontologies, which, along with associated work practices, are ideal for integrating into organizations and large technical systems.

The Estonian system's strengths emerge from standardizations embedded in the infrastructure. The X-Road system is a set of basic standards that has influenced every single technology that is integrated into it. Consider the hundreds of different databases across the entire infrastructure, all in different institutions or departments. For a database to transmit information across the network, it must meet the protocol specifications of the X-Road. Thus, the X-Road can be viewed as a technology of standardization, which produces streamlined data-sharing and reduced institutional friction. Part of this standardization is reached through institutional policies and incentives, in addition to technical specifications. For example, one informant mentioned in an interview that "some things are mandatory; there is a law which specifies that every healthcare provider, whether public or private, must send a certain amount of this information, and it's growing, to the national health information system for secondary use or for use by other healthcare providers to maintain the continuity of care through information being available." While this law facilitates the collection of data for secondary use and public health research, shared information between organizations is also implicit. The frequency of data-sharing is facilitated by standardization.

Collaboration of professions and users is another characteristic of the infrastructure. Standardization encounters challenges, however, including system-wide commitments to that standard. These commitments create a threat to future technologies that may be instrumental to the extension and improvement of the system. Because the X-Road system was first brought online in 2001, no one could foresee the latest state of mobile application development, ubiquitous computing, sensors, and the quantified-self movement. Each of those technologies has its own arrangement of standards, protocols, and policies that may not be compatible with the current Estonian infrastructure. These are what Star and Ruhleder call "second order" issues, which stem from unforeseen or unknowable contextual effects, as opposed to "first order" effects, which are common problems in the infrastructure that can be solved with more resources.

Scaling up the infrastructure, for the advent of new users or additional hospitals, is a relatively straightforward task that requires no new specialized hardware. Additional computers are needed to connect to the X-Road framework and to set up a database, thereby extending the quality of data. Once the new database is configured, the infrastructure has been extended. Inclusion of additional organizations, primary care practices, and hospitals is the basic method by which the geographical reach of the digital health infrastructure has increased. It also increases the reach of practice through creation of additional data sets that allow different occupational roles to function within the infrastructure. There are two challenges to this characteristic of infrastructure. First, because this infrastructure is designed to be modular, the complexity of required technologies can increase exponentially. Second, related to the second order problem, it is challenging to add new technologies or applications designed outside of this characteristic.

Due to the core characteristics of standardization, sustainability within its parameters, and relationality, the system delegates medical work to other technologies with the same level of integration as seen in other services. For the work of the healthcare provider, decision support is one of the greatest delegations of human work onto technical systems. As mentioned above, for example, using shared prescription data, data from the patient's medical record, and pharmaceutical data, a decision-support module looks for drug-drug interactions for a given patient's specific case. Then, the system can deliver an alert to the clinician if there are adverse drug interactions from the use of polypharmacology. This is a clinical task that would otherwise require attention to detail and clinical time of the healthcare professional to detect and prevent drug interactions.

This level of decision support is only possible because of the interoperable and standard data flow between institutions and databases. The digital workflow of prescribing and medication-processing also delegates work that was once performed by an administrator to the infrastructure, thus the technology performs work that was once performed by administrative staff. Similarly, this cumbersome, paper-based, information-processing work is now delegated to technologies in the infrastructure that become responsible for similar administrative workflows, billing, medical coding, and so on. The system also performs work of which the patient would be previously unaware. Specifically, the system auto generating audit logs. These logs show the patient who and which institutions are accessing their information. A level of transparency is added that would otherwise be a laborious and administratively driven process. An infrastructure for digital health is not designed for fast computing or astronomical data storage, something that is the hallmark of science-based infrastructures, but for the demands of information intensive healthcare work.

The digital health infrastructure that is part of a national health system is an investment for the citizens. Inherently the infrastructure has a social component to it. Social buy-in, or social support, is needed to maintain the infrastructure. The approach for social involvement in Estonia employs outreach to different social groups. Social organization around topics like hackathons is used to inform people about the technical aspect of the digital infrastructure, and also to create social networks and support structures around it. As the technical infrastructure is designed and built, the perspectives of different stakeholders are enfolded and embedded into the engineering and architecture.

Great Britain

The approach to digital health infrastructure in Britain is a collection of multiple technologies that slowly became integrated to give the overall system greater agency and capability. Since most of the ICT found in primary and secondary care operates in an open market of software development, much of the relationality is vendor-specific. Certain systems will support limited interoperability functions with other systems. The relationality is robust within each vendor's own EMR, which allows for degrees of expansion and extension through different modules and other plug-ins that, while also addressing other infrastructure themes, add more functions based on relatability. The terrain of the current state of the digital health infrastructure in the NHS is exemplified in an interview with an application developer working in this area: "Interoperability is a really big problem in healthcare; you notice this instantly if you go into acute care, with a million systems all of which—or some of which—need to talk to each other. Integrating them is a problem. That's not a problem we've decided to solve with [this company], but if you don't want to add to that problem, then one thing you ought to be doing is modelling your data in a standard format."

The work required to integrate heterogeneity into the British system requires overhead and greater investment than the Estonian case. Since different systems are used in primary care, secondary care, and social care, there are multiple social and technical barriers to overcome. The technical barriers include interoperability to allow data to be shared across different systems. While this is possible, there are also primary care centres that still use paper, taking them out of the digital infrastructure altogether. If data can be shared across different health centres or hospitals, the second barrier is the training and technical knowledge required to make it possible. Notable record systems in specialized medicine include pathology and radiology. While the systems can be robust for the clinicians, they do not support heterogeneous social actors.

It is the responsibility of the specific vendors and developers of the ICT to support future technologies and requirements. Because the companies that develop these ICTs are smaller than if a multi-organizational institution such as the NHS were to develop similar technologies, they can respond swiftly to future requirements, technological problems, and changing technical standards. Whereas the NHS would evoke greater institutional friction if it were to develop a single coordinated health information system. The sustainability of each specific vendor's EMR system is high, because each is a dedicated for-profit company that manages the sustainability and maintenance of the code, modules, and product ecosystem. These separate EMRs as a complete digital infrastructure, however, are not entirely interoperable with each other EMR system. Data silos are created that increase, not reduce, institutional friction. While there are layers of policymaking and organizations dedicated to management and coordination of the use of technology, just as in the Estonian case, in Britain they do not orchestrate the development of a single system, but coordinate and regulate many different systems. Each of those systems has its own software engineering methods, user perspectives, design approaches, and priorities.

Standardization is a challenge for the British infrastructure. While considerable time is spent on development of policy in coordination with companies to adopt and adhere to standards, ultimately the vendors are private corporations that produce technologies in a competitive market. The use of their ICTs also varies by geographical area. Thus, one region in the same system has a standardized set of user practices and data standards, but these standards may be different in other regions of the country. The technical mechanisms that would facilitate key characteristics of interoperability face considerable difficulties in this case: for example, the use of an application programming interface (API) could serve this function. One interviewee addressed this situation: "[There were] no APIs that give you healthcare specific functionality. No APIs for data storage in formats that are commonly used for health data exchange."

Extending the number of users in an infrastructure like the one described here involves adding user licenses. Computers, along with subscriptions to EMR services, are paid for by the NHS. The individual health centres do not have to purchase these items, which encourages primary care clinicians to maintain their medical records and conduct administrative work digitally. This piecemeal approach does not, however, connect the separate health centres and hospitals to a larger, seamless system that would create many of the benefits seen in Estonia's digital health infrastructure. Other factors that create a problem for scaling up of infrastructure are long sales cycles for services and solutions, and the fact that each local Healthcare Trust makes decisions for the purchasing of applications and services differently.

The picture of the British digital health infrastructure so far is based on the individual fractured systems that have developed across the landscape. Different experiences and the ability to delegate work between technologies and social actors is variable. The data flow within the same system is frictionless, allowing social actors within the health centre to share data and tasks seamlessly. One clinical system, called EMIS, has a function called GP2GP. When a patient moves from one health centre to another, the first health centre can digitally transfer all of their information into the new health centre's medical record. This functionality, however, only works with GPs that use the same EMIS system.

The social characteristic of British infrastructure is broad; it is not controlled by any specific agency or institution. One of the advantages of this infrastructure is that it is driven by the social organizing associated with all the technologies in use. This means that large and diverse social structures in the form of conferences, outreach by companies, and design and development in the open market influence the infrastrucuture. Although Estonia and Britain use similar methods for including social structures, the design of the digital infrastructure itself influences those social structures. The British infrastructure, being more fractured and diverse, necessitates a more diverse set of social actors that the infrastructure must accommodate.

Table 3 (Appendix) provides a summary of the seven themes used in this analysis, along with the results of each case by theme.

CONCLUSION

To review both cases in the digital infrastructure characteristics framework, here the paper revisits the research questions and summarizes the findings for each of them. The first research question formed the core of the analytical casework: What are the characteristics of the Estonian and British digital infrastructures for healthcare? The paper details the seven characteristics of these infrastructures in the cases above. These two different approaches to digital health infrastructure have their own opportunities and challenges, both excelling in certain areas but weak in others. The Estonian digital infrastructure is ultimately interoperable and designed around data-sharing. This results in development problems years into the future, when new and emerging technologies are developed that are not backwards compatible or that cannot be integrated into the legacy systems. The British infrastructure has little interoperability; it relies on an open market and multiple private companies to develop the infrastructure and work toward interoperability among themselves. This means, however, that Britain can more readily integrate newer technologies and move in an innovative direction with relative ease. These two cases and the strengths of each system show a clear spectrum of possibilities for digital infrastructure—a balance between interoperability and innovation. Figure 1 conveys this idea of a spectrum between interoperability of digital infrastructure and a digital infrastructure that is ready to incorporate future innovative technologies. Both of these cases represent not an extreme on this spectrum, but different points *along* the spectrum.

The second research question places an emphasis on the social component of the infrastructure and focuses it on the group of users that interact with the infrastructure from a different perspective: patients. This research question asked: *How does a digital infrastructure for healthcare influence the patients connected to that infrastructure?* The findings related to the ability to integrate patients' perspectives into the infrastructure, namely having a portal or user interface that translates the medical work to patient information. To evoke the electrical infrastructure metaphor again, this characteristic is the ability for patients to plug into the digital health infrastructure, and it should afford them a new set of practices and possibilities.

Each country achieves this in different ways. Estonia connects patients to a standardized data grid. Information about the patient is integrated across institutions, and the work that is standardized for medical professionals is also standardized for patients. There is no change in this workflow if patients move to a different health centre. In Britain, patients are influenced by the market for PHRs. If a patient moves from one health centre to another, the PHR and associated digital infrastructure could, and likely will,

Figure 1: The Spectrum between Interoperability and Innovation in Digital Healthcare Infrastructures.

Interoperability	Innovation
Characteristics: Integrated systems, data exchange, streamlined training, near-term system sustainability, infrequent social outreach. *Challenges:* Reliance on backward compatibility, slow to incorporate future technologies.	*Characteristics:* Integration of future systems and technologies, ability to develop new technologies, requires long-term system sustainability, frequent social outreach. *Challenges:* Cumbersome training, continuous improvement and maintenance.

be completely different from their previous arrangement. One interesting distinction to mention is portability of the patients' information. In Britain, information must be moved—in some cases via printed documents—from one health practice to the next. Geography is a boundary to information even when that information is within the same healthcare service, such as primary or secondary care. In the Estonian system, there are no geographical boundaries; therefore, the data are portable across healthcare services. Portability has a positive influence on the patients' ability to self-manage, search for information, learn about their health status, and become activated and engaged patients. This can be achieved through the ways in which the system affords concepts such as shared decision-making, providing a satisfactory experience through the interface and interaction of the technology, and even improving health outcomes and medication adherence. Specific outcomes and measurements for patient activation are discussed in the policy implications section.

It is also clear that in both cases, there are opportunities and needs not being met by the digital health infrastructure. Estonia, for example, has a stable digital infrastructure for the processing of information, but it is weak at integrating new and emerging patient health practices using technology that did not exist when the X-Road infrastructure first came into use. Health trackers and mobile sensors are now ubiquitous in mobile phones, jewellery, and even clothing. As the market for these sensors grows, so too does the amount of data generated. Tracking devices started by monitoring only steps and calories based on an estimation of the users' basal metabolic rates, but are now capable of tracking sleep, pulse oximetry, heart rate, and other measures of energy expenditure. These constant metrics can be useful to clinicians in certain situations. The advent of these technologies, however, creates a need for patients to *input* data into the infrastructure because the sensors and health tracker devices are not integrated and interoperable with any system outside of their own ecosystem controlled by the product developer. Thus, the second research question has two aspects to it: first, what is currently possible and how the patient is presently influenced by the infrastructure; and second, the *potential* for future digital infrastructures to provide support, given how patient needs and practices have evolved. While the present affordances of the current infrastructure have been discussed, potential and future directions are discussed in the next section.

The third and final research question asked: *What are the key factors of digital infrastructures for healthcare?* Part of the answer to that question depends on what is being prioritized. If the ability to future-proof or integrate newer technologies and serve a diverse set of uses are desirable characteristics, then key factors are the infrastructure's abilities to incorporate heterogeneous technologies and to distribute work in new ways, from clinical staff to increasingly competent technical actors, artificial intelligences, and decision-support systems. If the population of users is small, such as in Estonia, then scaling up and extension is not a primary concern. As newer technologies become integrated or assimilated into these digital infrastructures, however, the nature of work for both clinicians and patients will change. Changes will occur from the new practices afforded by the infrastructures' capabilities, but also by whether and when technologies become capable of offloading and supporting more human tasks. A key factor moving forward is the ability to audit the work of humans and machines alike to see what changes are made and also how the system is used. The present key factors for Estonia are: availability of data across institutions, the common platform other services are built upon, and sharing clinical data with patients. The potential for this infrastructure, given current and emerging technologies, includes data reuse, assimilating non-clinical data, tracking edits, and decentralized data storage. This points to a future of healthcare work and services that include a greater emphasis on patients working with their own healthcare data, changes in the patient-provider relationship, and the use of healthcare data for other contexts such as public health campaigns, as well as using data for machine-learning applications such as automated diagnosis and advanced clinical decision support. Whereas key factors in the British system of a more open market for competing health information systems are closer to the innovation side of Figure 1. There is greater flexibility and potential to enrol or integrate future technologies into a greater whole, the digital health infrastructure. There is a reduced path dependency when this ensemble of different health information systems provides multiple points of integration through different standards, data models, and protocols. The collection of different companies developing their own health information systems can compete on innovative features that theoretically drive the market forward. However, this potential is curtailed without the key factors already present in the Estonian case: interoperability and cross institutional data sharing.

POLICY IMPLICATIONS

The two case studies presented here show two different approaches to infrastructure, each with its own strengths and weaknesses. In the case of Estonia, it is a highly integrated and standardized system developed mostly in parallel or in modules. In the British case, open market forces shape the infrastructure, leading to more innovation, competition, and development. Each of these infrastructures has different policy implications and indeed, each nation can learn from the other.

When considering policy for the Estonian system, there are multiple suggestions resulting from this study. First, the inclusion of patient-entered data should require an audit log to track edits and understand the integrity of the data. This log should include information about how data are shared and how the data are generated—with what devices and in what contexts.

The future of healthcare will be shaped by the data generated and used in a healthcare system. This necessitates the use of personal health data in secondary contexts; including activities such as analysis, population health, medical research, quality and safety measurement, fiscal research, and business intelligence metrics would be beneficial. A key challenge in this area is the public's lack of understanding about the secondary use of data. In order for a digital health infrastructure to maximize fully the use of the data it collects, its supervisors must engage with the public to show the benefits and outcomes of secondary data use, including advances in health services research and publications. Policies that promote the use of personal health information outside of the initial context in which it was collected should promote transparency and public awareness, give patients total control, create a taxonomy for data specifically for secondary use, and address questions of the commercialization and sale of data outside of the healthcare system. A digital infrastructure of this sort, where consent and data use is prioritized, will rely on the best current technologies of database design and security to house and track that data. One such technology ideal for this application is blockchain, a distributed accounting technology designed to store data and monitor the integrity and history of that data against an encrypted ledger. The key characteristic of this technology that should be emphasized is blockchain's ability to track edits, allowing patients and other users to see which user is changing what data and where one can establish and revoke permissions.

A policy of using open-source software for the creation of digital health infrastructures will help establish an infrastructure that is designed for sustainability over the long term and can readily integrate new technologies. The integration of open-source technologies has the main benefit of allowing for the integration of standardized data formats and agreed-upon methods for technical development. This means that as technology advances, it relies on open standards and common formats rather than proprietary formats, allowing for a greater degree of freedom as the infrastructure ages. Additionally, because open-source software is the product of active and passionate development communities, bugs and problems in computer code are likely to be identified by this community rather than private vendors. This style of community development also addresses the key need for security and privacy through transparency of code.

The future of continually evaluating and improving healthcare services will rely on establishing a streamlined feedback loop within the digital health infrastructure—for example, administering user feedback, satisfaction and quality surveys, and other metrics that are integrated into the infrastructure for continuous quality improvement. Also, design decisions should be made using data that gather usability and user experience information in real time as both clinical and patient users interact with various parts of the infrastructure. Measuring how users interact and navigate the infrastructure, as well as how they use data, can have ramifications for face-to-face medical consultations. Surveys conducted after medical appointments should be used in tandem with digital data collection to improve utilization, access, and efficacy of healthcare delivery.

The last recommendation concerns the role of automation and pace of efficiency in digital health infrastructures. As these infrastructures grow, there will be increasing demands on all occupational roles to engage with data entry, analysis, system maintenance, and decision support, as well as governance, storage, and data-processing. Therefore, the appropriate application of automation within these infrastructures will be necessary to deal with these growing needs. Policy guidance in this area requires the review of a thorough taxonomy of current technological capabilities to understand future trends and areas for research; this taxonomy was created by the MGI group in a report analysing the scope and impact of automation (James Manyika et al.,[11]). The five categories for automation opportunities compiled in the report are:

Sensory perception. Machine vision, tactile and auditory sensing, integration of multiple sensors in the world.

Cognitive capabilities. Machine-pattern recognition and machine-learning approaches. Logical reasoning and problem-solving, contextual information support, decision support, and information retrieval.

Natural language processing. The ability to generate human language in an auditory format from textual information, and the ability for humans to use natural language to interact with computers.

Social and emotional capabilities. Social and emotional sensing through the identification of changing emotional states. The production of emotional responses for an appropriate response.

Physical capabilities. Gross motor skills, fine motor skills, mobility, and navigation.

These five categories are relevant because they describe aspects of work that are performed in healthcare and patient self-management. While not every category is relevant for the work described in this report, the areas of natural language processing, sensory perception, and cognitive capabilities are clearly required in healthcare and should be integrated into digital health infrastructures so the benefits of automation can be realized.

Much of the speculation on the Internet of Things involves basic sensors and other potential data inputs. Additionally, the "quantified self" and patient data-tracking activities rely on sensory perception capabilities; future health infrastructures should be designed to support and exploit these capabilities. The key feature among each of these technical capabilities is their reliance on data to automate tasks, and the data that will consequently be generated by the automated system. This is why policy should support the use of audit logs and other tracking methods as the ability to automate decision-based tasks and cognitive work increases. Integrating these taxonomies into the design and development of digital healthcare infrastructure will support future expansion and scaling up as new areas of research and healthcare work are added to the infrastructures.

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APPENDICES

Table 1: Summary of case study contexts and units of analysis

	Case 1	Case 2
Context	Estonian X-Road platform and associated health information technology	British PHR and EMR systems and connected systems
Unit of analysis 1	Estonian policy experts, developers, and other stakeholders	British policy experts, developers, clinicians, and other stakeholders
Unit of analysis 2	Documents of policy, development, and evaluation of the context from Case 1	Documents of policy, development, and evaluation of the context from Case 2

Table 2: Summary of Documents Used in Analysis

Case	Document Title	Organization
Estonia	An Electronic Health Record for every citizen: a global first	Foundation E-Health
	Stairway to Excellence Country Report: Estonia	European Commission joint research commission science and policy report
	Estonian EHR Case Study	Empirica
	Estonia: Health system review	World Health Organization
	Assessing the Economic Impact/Net Benefits of the Estonian Electronic Health Record System	Digimpact
	Family policy: increased child benefits, continued reform of child benefits	Estonian Reform Party and Social Democratic Party coalition Policy Paper
Britain	Data Science Ethical Framework	UK Cabinet Office
	UK Digital Strategy	Department for Culture, Media, and Sport
	Memo of understanding between Health and Social Care Information Centre and The Home Office and The Department of Health	The Home Office
	National Data Guardian for Health and Care Review of Data Security, Consent and Opt-Outs	National Data Guardian
	NHS Digital Corporate Business Plan 2017/2018	NHS Digital
	Electronic Health Records	Houses of Parliament Parliamentary Office of Science and Technology

Table 3: Summary of Digital Infrastructure Themes by Case

Cyberinfrastructure Theme	Definition	Estonia	Britain
Relationality	Interdisciplinary relations and connections between social and technical actors	Single “top-down” platform, governmental approval and adoption, challenges for applications outside of system, relational databases	Vendor-specific, works across systems, junction work, commissioner choice from small market, move from national IT to provider choice
Integration of heterogeneity	Bring together technical and social actors for shared goal/ end product	Wide support required, training for professionals, no training for patients, focus groups, policy focus on different perspectives	Training per system, flexibility of configuration, specialization-specific systems
Sustainability	Long-term resource, reach beyond a single site/ practice, incorporate future requirements, maintenance and breakdown	Data-sharing, layers of policymaking to address both standards and sustainment, policy incentives and requirements for providers	Data silos, duties to share information
Standardization	A goal and method solution to the integration of heterogeneity, foundation of interoperability	Common foundation (the X-Road), eHealth Foundation started to create standards, data-exchange standards, data about the person belongs to the person, default opt-out policy, formal database processes	Vendor-specific, varies by geographic region, national standards, opt-out policy for all identifiable health data-sharing but no technical solution to apply this
Scaling up/Extension	Increasing number of collaborators, quality of data, geographic reach, future growth	Adding additional X-Road servers, creation of new databases, technical limitations and complexity, challenges to connecting new applications and technologies	License-based, often intra-product only across organizations; national interoperability programme to build apps onto EHRs, but limited functionality and slow progress
The distribution between human work and technological delegation	Reduces effort of labour-intensive tasks, data flow between institutions and reduces institutional friction	Cross-institutional data-sharing, audit logs, decision support, drug interaction support, digital prescriptions, administrative workflow	Intra-product data-sharing, junction work, features and usability depend on vendor and product
Always-on social aspect	Everyday impact on work, users of the system	Outreach to groups outside of the system, hackathons, inclusion of user perspectives through social outreach, inclusion of patient-entered data a social process	Conferences for users, social outreach by companies, minimal user involvement in technology development

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