

Developing openness in electronic healthcare systems

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Abstract

Electronic data generation and analysis is on the increase. Healthcare is no exception in this matter. Considering the cost and sensitive nature of healthcare, electronic healthcare systems provide a great opportunity to present valuable data when and where it is needed. However there are barriers due to diverse origin and destination of data in healthcare services. This paper presents an overview of these barriers and considers them in the light of an open data ecosystem metaphor. This provides insights into how barriers could be overcome but also leaves some questions that need to be addressed in future research.

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Introduction

Worldwide, the spread of electronic healthcare systems is on the increase. For instance, in 2001 it was reported that U.S. (17%), Canada (14%), Australia (25%), New Zealand (52%), and the U.K. (59%) were using electronic medical records (EMR) systems, while primary care physicians in U.S. (9%), Canada (8%), Australia (44%), New Zealand (52%), and the U.K. (87%) were using electronic prescribing systems (Harris Interactive 2001). With the advent of open government policies and initiatives, health sectors are expected to be among the first ones to offer open healthcare data to different and varied local, regional and national constituencies (Harrison et al. 2012). Alongside this, mobile computing technologies are also providing individuals, patients, carers, researchers and policy makers with valuable data to help them make more effective and efficient decisions about their health and lifestyle habits.

However, the adoption of 'openness' in both the provision of healthcare systems data and its use by constituencies requires careful examination of existing challenges faced by stakeholders, in particular providers and users of these systems. This paper offers an overview of healthcare systems and its associated challenges through the lenses of the ecosystem metaphor (Harrison et al. 2012). The metaphor enables a valuable interpretation of challenges and opportunities and offers some initial considerations for the further development of openness in electronic healthcare systems.

The paper is organised as follows. A descriptive overview of healthcare systems is presented and challenges and opportunities are detailed. The ecosystem metaphor of open government/data is used to examine these and provide further insights on how openness should be further explored in management research and practice.

Benefits and challenges of healthcare systems

Healthcare information systems are a set of software applications aiming to support activities of healthcare performed by different healthcare professionals and in different locations (Prados-Suárez et al. 2012). To date the use of information systems and technologies aims to contribute to reduce errors, increase productivity, provide adequate patient support and make healthcare activity more accountable (Anderson & Balas 2006). The overall benefit of healthcare systems is to contribute to health as an ultimate measure of systems success (Olszak & Batko 2012).

Often, healthcare professionals using systems face a productivity paradox: They

can be required to both perform their 'old' activities whilst ensuring adequate management of electronic data in these systems. The paradox can be better understood in terms of several barriers that continuously are identified by healthcare professionals. Four types of barriers can be generally ascertained:

- **Implementation barriers.** This is a combination of lack of financial resources, inadequate project management by technology implementers, insufficient technical knowledge by people in charge of both implementation and use of systems, lack of strategic planning and lack of leadership (Anderson 2007). On this latter aspect, people in charge of assisting healthcare professionals often forget *listening* to them. Their focus is on ensuring technical implementation of the system rather than adequately supporting health professionals in the *process* of implementation (Lapointe & Rivard 2006).
- **Structural barriers.** There is often a high degree of stakeholders (actors) in healthcare systems initiatives that include not only those contributing to systems implementation but also to the use of data. Actors often include healthcare provider organisations (private, public, independent), hospitals, care centres (ambulatory, long-term), laboratories, radiology centres and pharmacies (Mettler & Vimarlund 2009). In addition, there are other actors that can be called *payers* (public health departments, insurance companies) and who also produce and access relevant systems data (Middleton 2004).
- **Architectural barriers.** Healthcare systems have at their core electronic health records (EHR). These can be generated by different applications and thus data that belongs to a single patient, professional or organisation can reside in different locations. Moreover, applications managing EHRs might not be compatible with each other (Halevy 2011) and this would require designing inter-operability mechanisms to use the records (Halevy 2011, Sunil Kumar et al. 2010) or considering more explicitly their particular context (Prados-Suárez et al. 2012).
- **Personal and ethical barriers.** Users of healthcare services (i.e. patients) are not normally accustomed to access or share their records with third parties (Hillestad et al. 2005). Their consent depends on many aspects including age, illnesses and security of the data (Hassol et al. 2004, Wiljer et al. 2008) as well as the integrity and confidentiality, the availability and utility of the data (Zhang & Liu 2010).

The Open Data 'Ecosystem' Metaphor

In areas like health and partially in response to the above barriers, a metaphor of an ecosystem has been proposed to facilitate joint work between policy makers, government officers, technology vendors, citizens and other stakeholders involved in the design and provision of electronic services (Harrison et al. 2012). This metaphor suggests openness in the provision of data and with it empowerment of users of services. Openness also implies inter-dependence between organisations. Under this metaphor, traditional 'one-way street' approaches to the provision of data (i.e. from governments to the outside world or from one group of stakeholders to another) become multi-way, and data can be made reusable (Pollock 2011).

An ecosystem is defined as a 'system of people, practices, values and technologies in a particular environment' (Nardi & O'Day 1999). Within this system there are key groups of people (mediators) who perform vital functions of boundary spanning across institutions including the development of platforms of data and services to be used by other people within the system (Harrison et al. 2012). Mediators introduce innovations in the ecosystem and therefore can contribute to add value to the services provided by it.

The metaphor suggests three key drivers for an ecosystem and can therefore facilitate co-ordinated and inter-dependent action between stakeholders. These drivers are: *Intentionality, values and sustainability* (Harrison et al. 2012). Intentionality is reflected in policies aiming to generate an adequate data environment vision in which different stakeholders could develop their thinking and action. Values refers to whether open data initiatives enable people to solve problems and meet important needs of individuals, communities, or society at large (Harrison et al. 2012, p. 912). Finally, sustainability means continuous assessment of what works best and should continue to be funded and supported. In practice, this requires both government and non-government organisations responsible for data maintenance to develop long-term arrangements in order to ensure the adequate preservation, storage and reuse of the data that is generated throughout an ecosystem.

Many benefits could be derived from using the ecosystem metaphor to guide policy making and implementation in healthcare. Data could be made accessible to different stakeholders and be used for a variety of purposes. Data can also be recycled, reused and its quality can be improved. Data can be used to inform both diagnostic and treatment of health conditions by third parties and thus it can boost commercial and technological innovation.

However, the following issues require further attention:

- The provision of 'open' data per se cannot ensure that such data is going to serve marginalised communities. A distinction between data access and data use needs to be made so that support to such communities is given to gather, interpret and use it effectively and meaningfully (Gurstein 2011).
- Data that is currently held by government might not be data that is wanted by citizens (Harrison et al. 2012). The context of such data needs to be carefully analysed and re-defined in terms of what users and other actors are to do with it.
- Data that is to be integrated into centralised databases for analysis and decision making might play against people's privacy or confidentiality (McLoughlin & Wilson 2013).
- Diversity of methods of analysis and dissemination of data to the end user (citizens) need to be tested so that any inaccuracy could be redressed whenever possible (Dickenson 2014).

Developing openness in electronic healthcare systems: Preliminary considerations

Applying the lens of an open data ecosystem to healthcare systems can help overcome some of the issues identified and open up new opportunities whilst also generating additional (and possibly more complex) ones. Openness and interdependence would bring a less technology dependant and more innovation focused approach to healthcare systems. New actors (for instance communities or citizen groups) might play advocacy and mediating roles which could then contribute to generate new goals to the management of healthcare data. The imperative for centralisation of electronic information (i.e. EHR) can be reviewed in the light of alternative possibilities for federated, contextualised and participative use and design of mechanisms of data provision (McLoughlin & Wilson 2013). Joined up thinking with a view to provide long-term value and sustainability can also contribute to focus on delivering better healthcare services.

However, the ecosystem metaphor can exacerbate issues of privacy and confidentiality of data. If data is to be open on the name of 'transparency' or 'accountability', shifts in the balance of power can occur which might undermine the interests of some of the actors of the ecosystem. These actors can be marginalised communities but also healthcare professionals (Gabe et al. 2012) which will have to find

ways to protect their integrity and interests from data abuse by others.

The ecosystem metaphor can bring together different groups of stakeholders and its features can help addressing barriers to implement healthcare systems. It might help establishing better possibilities for conversation between actors so that intentions of designers and policy makers can be matched with user expectations and the extensions afforded by technologies (McLoughlin & Wilson 2013). However the metaphor alone might not help in supporting conflict resolution among people. Neither could it enable a critical analysis of the goals and implications of healthcare systems initiatives. In this regard a less service-oriented systems view and more people-oriented view can be of value also to enable further discussion of the societal impact of initiatives.

Further research

Using Nardi and O'Day (Nardi & O'Day 1999) work on information ecologies we intend to explore how the ecosystem metaphor could help us understand a recent initiative related to the use of electronic health records (HER) in the UK under open government policies. The properties of information ecologies (system, diversity, co-evolution, keystone species and locality) and the ways to investigate them (i.e. using ethnography) will be used to enquiry about the initiative and identify problem or dysfunctional areas as perceived by the initiative's stakeholders. Systems thinking methodologies will also be used to facilitate joint inquiry and possible design of improvements in both policy and practice of the initiative.

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