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eScience Insights to Inform Infrastructure for Accountability of Healthcare

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Abstract. Healthcare organizations and providers are being held accountable for the care they give and for their processes of improving care safety and quality to an unprecedented degree. In countries around the world, there is a pressing need to develop infrastructure for accountability of healthcare to support performance measurement and reporting activities. Yet, little research exists on the design, development, management, or governance of infrastructure for accountability in healthcare, nor on practices of data sharing and reuse that are central to healthcare performance measurement. This paper draws on literature on data sharing and cyberinfrastructure for eScience to identify key concepts from research on supporting collaborative scienctific practice to inform research on practices and infrastructure for healthcare accountability.

Introduction

Driven by flagging public trust, pressure to contain costs while increasing service quality, and re-organization of healthcare around industrial models, healthcare organizations and the individuals working within them are facing huge pressure to make healthcare practice transparent and accountable to an unprecedented degree (Wiener, 2000). Healthcare organizations and professionals have long been held accountable to acceptable standards for structure, process, and outcomes of their work (i.e. Donabedian, 1980). Yet, the particular form that accountability practices are taking is unprecedented in that they leverage digital information technology, including automated performance measurement

algorithms and expanded capabilities for data storage, retrieval, and analytics (Dickersin & Manheimer, 1998).

The imperative for healthcare accountability has resulted in development of a massive ”machinery” (Wiener, 2000) to support the accountability endeavor. This includes regulatory agencies, processes for vetting and selecting performance measurements, third party vendors who collect and transmit performance data, new hospital personnel and new skill sets for existing personnel, a vast consulting industry, and so on.

A rich body of research has examined design, adoption, and use of electronic patient records (Fitzpatrick & Ellingsen, 2013). Although a major driver of electronic record system adoption is the promise of using data contained within these systems for second-order purposes including retrospective medical research and accountability functions, much of the research to date focuses on how electronic record systems impact clinical practice. Research on accountability functions of electronic records systems focuses on how such accountability functions impact in-the-moment clinical care (i.e. Bossen, 2011; Pine & Mazmanian, 2014). While other applied fields, such as education, have studied the development and unintended consequences of information infrastructure with an explicit focus on accountability functions (see Anagnostopoulos, Rutledge, & Jacobsen, 2013), little empirical or theoretical work focuses on the design, use, and unintended consequences of infrastructure for healthcare accountability and quality improvement.

In addition, at present there is a “problem of infrastructure” (i.e. Colombino et al., 2014) when it comes to healthcare accountability. Data is available—in a sense-- because it is increasingly collected, stored, and extractable via electronic record systems and other IT. Yet producing usable information from stores of potential data is still incredibly difficult. The situation is complicated by the fact that external accountability requirements are rapidly changing (Pine, Wolf, & Mazmanian, 2015) and healthcare systems around the world are implementing payment model reforms, specifically value-based reimbursement (Berenson & Kaye, 2013). European healthcare systems, despite largely providing healthcare through centralized and publicly funded delivery systems, are also struggling with the challenges of infrastructuring for accountability and experimenting with novel accountability practices (i.e. Bossen, Danholt, & Ubessen, 2015).

Insights from Research on eScience

As healthcare performance measurement and quality improvement theory and practice develop, researchers will benefit from drawing on existing research on supporting collaborative eScience. This rich body of work includes studies of ’cyberinfrastructure’ to facilitate the conduct of science: research on cyberinfrastructure for eScience is concerned with creation, deployment, and

maintenance of tools for supporting scientific collaboration across distance. Another key line of research focuses on data sharing and reuse. As leading scholars argue, successfully engaging in data sharing and reuse is essential if science is to reap the rewards of the digital age (i.e. Borgman, 2015).

While there are some differences, the activities of assessing healthcare quality bear much in common with more traditional ”bench” science. Healthcare accountability tools and practices are vast and extend beyond the local, making an infrastructure perspective critical (Monteiro et al., 2013). Performance measurement, the basis of healthcare accountability practice at present, rests upon a supporting infrastructure that enables data to be “…acquired, collected, sorted, analyzed, interpreted, and disseminated” (Ratnayake, 2009, p. 158). While performance measurements for accountability require collaborative data collection, management, sharing, and reuse (Pine & Mazmanian, 2016), the nuanced complexities of these collaborative practices are largely overlooked in design of healthcare information systems and data analytic tools employed for healthcare accountability. Next, I outline some key concepts from the eScience literature on cyberinfrastructure and data sharing and describe how each concept is useful for research on healthcare accountability infrastructure and practice.

Key eScience concepts applied to healthcare accountability infrastructure and practice

Data provenance. Provenance refers to the chain of custody of data and the transformations that data undergo as they pass through different hands. Tracing custody and transformations makes datasets more useful (Borgman, 2015). Performance measuremens for healthcare typically utilize data elements drawn from administrative sources such as billing data or birth certificate data. Such data is often already a transformation of clinical data, and is not collected with performance measurement in mind. Billing data, for example, maximizes financial gain rather than clinical truth (Pine, Wolf, & Mazmanian, 2015). As accountability infrastructure develops, it should support custodians of healthcare data in recording and easily tracing the data’s lineage.

Background and foreground data use. In the process of doing research, researchers do a number of activities which may include calibrating instruments, assessing site conditions, or verifying measurements. Such activities often involve existing data from archives or repositories, but data reuse is often in the “background” of research (Borgman, 2015). Researchers of healthcare quality and accountability would benefit from paying explicit attention to background data reuses. At present the various sources of data that are reused in the process of calculating performance measurements are poorly understood, particularly by those that are being evaluated according to the measurements. Making the background data reuses part of the everyday discourse about performance measurement in

healthcare organizaions and healthcare quality research would improve quality science and transparency of the accountabilty practices themselves.

Interpretation & trust of data is a crucial component of assessing the potential of a data resource for reuse (Faniel & Jacobsen, 2010). Successfully reusing data is largely dependent on social relationships rarher than technical tools, as users need to understand what data is available, the curcumstances under which data were collected, and the trustworthiness of the data (Faniel & Jacobsen, 2010). In healthcare, breakdowns occur when social relationships do not exist between key players in the lifecycle of data. For example, low-paid clerks may not have mechanisms to query questionable medical chart data or opportunities to discuss documentation practices with clinicians even though the data they record based on medical records produces key data elements for performance measurement (Pine & Mazmanian, 2016). There is a need for research on the social relationships and organizational structures that would support data reuse for healthcare performance measurement.

Knowledge infrastructures. Knowledge infrastructures (i.e. archives, collections, data systems, databanks, information systems, repositories) are considered common pool resources by Borgman (2015). Common pool resources require governance relating to collection development policies, rules for contribution and access, classification standards and data structures, and plans/structures for sustaining the resource over time. Investments in governance are crucial; infrastructure for accountability for healthcare requires investments in human and technical governance structures. This will be particularly important as the stakes of healthcare accountability increase—a crucial question facing healthcare organizations is how good must data be in order for it to be used to sanction a healthcare provider?

Bridging communities of practice. A challenge of data sharing is imposed by the difficulty of communicating the meaning of data and understanding what is happening in another's dataset when data is being shared across different communities of practice. A "community of practice" (CoP) is a group of practitioners who have a shared passion or engagement in something and engage regularly over time (Lave & Wenger, 1991); in the domain of work, communities of practice can refer to different occupational groups. Healthcare accountability infrastructure and practices must bridge multiple CoPs: clinicans, educators, administrators, regulators, etc. Cyberinfrastructure for eScience literature offers a number of useful concepts ripe for study in infrastructure for accountability of healthcare, such as boundary objects (objects that inhabit several communities of practice and satisfy the informational requirements of each of the communities they inhabit) (Bietz & Lee, 2009). Further, it is incumbent on researchers and other stakeholders to place explicit attention on CoPs to understand which of multiple

CoPs perspectives, interests, and values are prioritized in healthcare accountability infrastructure and what the potential consequences of these decisions will be.

While there is much to be gained from looking to the eScience literature, there are some aditional considerations that researchers must take into account. Since performance measurements are tied to systems of reward and sanction and embedded in organizational and national policy, the social and political stakes of healthcare accountability are quite high. Also, most stakeholders of healthcare accountability are engaged in clinical practice or support services as their primary activity—quality science is a shadow of this primary work and can all too easily interfere with it (Bossen, 2011; Pine & Mazmanian, 2015).

Conclusion

Healthcare organizations are facing huge pressure to make healthcare practice transparent and accountable to an unprecedented degree. Yet, little empirical or theoretical work focuses on carrying out data-intensive healthcare performance measurement on the ground. Existing literature on conducting large scale eScience, including data sharing and cyberinfrastructure for supporting scientific collaboration, offers valuable insights for healthcare accountability stakeholders (i.e. researchers, managers, designers). Specific concepts drawn from eScience literature that could be fruitfully applied to healthcare accountability and quality science include: data provenance, background and foreground data use, interpretation and trust, knowledge infrastructures, and bridging communities of practice.

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