Information Integrity and Human Infrastructure in Digital Health Care

Completed Research

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Abstract

Healthcare informatics is undergoing major changes due to new infrastructures like social media that allow patients to proactively bring information to the physician consultation. We use the concept of infrastructuring to describe these changes, referring to the social practice of adapting human infrastructure for specific contexts. This poses informational and social challenges to providers, as they negotiate new boundaries with patients. Information integrity is essential because of risks to both parties. Infrastructuring in this case is the maintenance of information privacy and accuracy, or information integrity. The tasks of vetting information integrity and managing patient expectations add complexity to provider work even as physicians are positive about patients taking responsibility for their own health. The paper addresses infrastructure transformations, the process of infrastructuring, and a concept of information integrity. Using qualitative data from a medical setting, the study illustrates the contradictions physicians face in accommodating social media to their practice.

Keywords

Collaboration, social media, information integrity, human infrastructures, infrastructuring, healthcare.

Introduction

With the arrival of digital platforms, along with social media, healthcare practices are taking on aspects of community. Patients and their friends, providers and their peers increasingly collaborate on patient diagnostics and solutions. While this is overall a positive development, it introduces problems that arise from the requirements of the profession around data privacy and accuracy. Like all virtual practices, healthcare is provided through sociotechnical/sociomaterial infrastructures that evolve both technically and socially even as they are being used (Hanseth and Lyytinen 2010, Aanestad and Jensen 2011). At the same time, the patient-physician role relationship is in a process of transformation. This process is referred to as infrastructuring. In this paper, we examine how physicians cope with the contrast between structure and flexibility as they try to serve patient needs in the new environment.

Transformations in the technological environment set up challenges that affect more than the technical environments or even usage questions. Traditional workplace collaboration technology has dealt with specific packages and tools provided by an organization, whereas private use is based on personal choice or guided by peer groups (Bødker et al. 2017). Mobile platforms and ubiquitous technologies have eroded this boundary between professional and personal use (Harris et al. 2012). Research focus in IS has shifted accordingly (Baskerville 2011; Tilson et al. 2010). CSCW and HCI researchers likewise have refocused from individual or group interactions with single technologies to artifact ecologies (Bødker et al. 2017; Wiberg et al. 2013). Work has become more mobile and decentralized (Jarrahi et al. 2017), formed around flexible teams and projects (Spinuzzi 2015) and new organizational principles (Chudoba et al. 2005; Raguseo et al. 2016). The aggregative possibilities call for critical perspectives on privacy, information security, information integrity (Zuboff 2015) and “decent digital work” (Ens et al. 2018). Thus, it is increasingly important to develop an understanding of information integrity in virtual communities. Jaeger and...
Eckhardt (2018, p. 11) note: “In collaborative working environments, employees are actors in a social network, where its performance is determined by the combination of each individual’s efforts.”

The relationship between technology and the changing nature of work is a persistent theme in IS research. The organizational and practical effects of new platforms and social software on workplaces and work practices (de Reuver et al. 2018; Forman et al. 2014) is the latest in a series of challenges. Much of the research on platforms and infrastructures addresses mature environments in the private sector from a platform owner perspective. More insight is needed into practice-based platforms developed from the bottom up (Islind 2018) and user-driven platform management (Rolland et al. 2018) in public sector platforms. This is especially apparent in the public sector, such as in healthcare. The rise of social media in the public sector has a major impact on the work practice of public-sector professionals (Norström et al. 2017). Patients and caregivers are becoming part of the data creation and editing process. Patients can track much of their diagnostic material, seek information, discuss with peers and make choices about treatment (Neff and Nafus 2016). Challenges include tensions and uncertainties about data quality and consistency, provider responsibility, and control; and finally, the role of patients, not only as consumers but also producers of health care, is a rather formidable and complex cultural change to be addressed (Vallo Hult et al. 2019). Physicians use of social media can lead to virtual collegial collaborations for the benefit of both patients and physicians; but it also introduces uncertainties about privacy and security (Panahi et al. 2014). Layered over this are challenges of working in complex, fragmented and politicized information environments (Aanestad and Jensen 2011) and other consequences of healthcare IT, like technostress (Ayyagari et al. 2011) and workarounds (Koppel et al. 2015).

In healthcare infrastructuring must address information integrity issues. The relationship between human infrastructure and information integrity is essential, due to the risks involved to both patient and physician. Shifting the boundary of patient-provider interaction, giving the patient more opportunity to understand and make choices, while more patient-focused, also presents legal and professional dilemmas for the provider. Traditionally physicians met patients in a clinical setting and provided patients with highly standardized information from professional outlets. Now patients may engage physicians in virtual environments, and they bring information to be vetted. This raises the question of the reliability of patient-provided information and entails other sets of relationships including patient-patient, patient-physician and physician-physician. Physicians may now be recorded, discussed or rated by patients, or approached by patients on private social media channels. Physicians’ themselves use social media like blogs, wikis, and social networking sites. Decisions made from these sources affect patient diagnoses, treatments, prognoses, care plans, and quality of life decisions. Unreliable information can become a factor in delayed, inappropriate, mistaken, and potentially fatal care (Brassil et al. 2017).

This paper will examine one aspect of the above: the role of human infrastructures described as the foundations of a system comprised of social relationships, networks and other arrangements that create affordances for work coordination and collaboration in social structures. Human infrastructure is intertwined with organizational, physical and technological infrastructures. Infrastructuring refers to ongoing efforts to align these elements (Pipek and Wulf, 2009) as new workplace cultures emerge entangled with new technological infrastructures. Thus, human and organizational arrangements share properties with technological infrastructures (Lee et al. 2006; Tang et al. 2015). Data were gathered in a regional Swedish healthcare practice to explore the physician perspective on the role of human infrastructures in maintaining information integrity, i.e., accuracy, safety, legality, and privacy. The research question is: How is information integrity dealt with in the everyday digital work practice of resident physicians?

The paper is structured as follows: we introduce the theoretical background and the concepts of information infrastructures (II) and infrastructuring; we describe research methods (study background, data collection and analysis); followed by the research findings, where we conceptualize healthcare-specific dimensions of infrastructuring and information integrity; finally we tie the findings to the infrastructuring literature.

**Theoretical Framework**

The theoretical framing derives from sociotechnical practice-oriented information infrastructure literature (Pipek and Wulf 2009; Star and Ruhleder 1996). Digital infrastructures consist of “portfolios of interconnected systems and related components in contrast to stand-alone systems” (Rolland et al. 2018, p. 6); the idea installed base in the II literature includes the physical and social context of work, existing
technologies and routines, and worker’s skills and beliefs (Aanestad and Jensen 2011). This study addresses human infrastructures as social and material (Fischer and Baskerville 2018; Orlikowski 2007).

**Information Infrastructures and Infrastructuring**

There is an extensive literature on platforms and infrastructures, including sociomaterial treatments on infrastructuring as an activity. Prior research was developed in separate communities that rarely engage each other’s work (Constantinides et al. 2018; Lee and Schmidt 2018). Rolland et al. (2018), drawing on Gawer (2014), summarize how digital platforms have been described in the literature:

- from an *engineering* perspective as “technical artifacts with a modular architecture consisting of a stable core component and many changing peripheral components”;

- from an economic perspective “as markets that disrupt traditional markets and facilitate efficient interactions between consumers and producers” and

- from an *organizational perspective* “as innovation practices in which actors organize and coordinate innovation enabled by technical mechanisms and social arrangements.”

New services and software impact existing systems: “digital platforms evolve within an organization through a dynamic interaction between the digital infrastructure and the platform ecosystem” (ibid p. 5). As digital infrastructures evolve, they come with a history of old systems and programs: “an organization’s digital infrastructure typically consists of one or more digital platforms...[and] a portfolio of more traditional information systems that, together with associated work processes, make up a heterogeneous installed base” (ibid p. 6). The conceptualization of information infrastructures by Hanseth and Lyytinen (2010, p. 4) thus emphasizes that an II is *shared* by different stakeholders and groups of users (generic and specific); is typically not designed for a particular purpose but is instead *evolving* continually; is *open* and *heterogeneous*—comprised of different elements—and *socio-technical*. Research on the design of infrastructures (Bygstad 2010, Hanseth and Lyytinen 2010) captures the relationship between control and innovation, i.e., centralized governance may lead to more control, at the risk of impeding innovation, while decentralized governance may lead to more innovation but is potentially chaotic (Hanseth and Ciborra 2007). Lee and Schmidt (2018) likewise state (p. 19, italics added): “this tradition highlights the tension between *standardization and flexibility*; the tension between *the global and the local*; and the tension between the inertia of *the installed base* and the *dynamically changing technologies and practices* that depend on that installed base”. New research is needed to examine the combination of platformization and infrastructuring (see below) with the need to mediate demand-driven innovation (platforms), and supply-driven innovation (infrastructures) (Constantinides et al. 2018; Tilson et al. 2010).

Key challenges reported in the literature relate to *tensions, paradoxes, and dualities*, i.e., when it comes to governance, control and flexibility, and integration of end-user perspectives in rapid development/radical change. Rolland and Monteiro (2002) address the need for balancing between sensitivity to local settings and standardization across (global) contexts when designing large information infrastructures. Hanseth and Lyytinen (2010) synthesis of II studies shows a tension between two design problems: (1) the bootstrap problem: IIs must meet early users’ needs in order to be initiated; and (2) the adaptability problem: local designs must recognize II’s unbounded scale and functional uncertainty.

Researchers have used infrastructure as a verb (Bowker et al. 2009; Star and Ruhleder 1996), e.g. ‘to infrastructure’ and ‘infrastructuring practice’ to analyze the processes whereby technologies are integrated with people, materials and tools. The notion that infrastructures tend to emerge, rather than being fully planned is central to Pipek and Wulf’s (2009) theory of infrastructuring.

Mathisen and Nerland (2012, p. 76), drawing on concepts from infrastructure as “a useful way to think about professional work in environments characterized by a range of information and material resources” define professional work as an infrastructuring practice “in which technologies, people and processes come together and make up the working relations that are necessary to perform work”. Thus, in the process of changing platforms, participants must evolve the work practices and standards that suit the goals of their work within the context of new affordances and constraints. In the healthcare domain, the technical part is more straightforward than the social part, due to unique role relations, responsibilities, and consequences.
Analytical Lens: A Typology of Information Integrity Strategies

The typology of information security behaviors outlined by Jaeger and Eckhardt (2018), aligns with the information infrastructure/infrastructuring literature by describing the practices that must develop within a social context, where actions have social meanings. For instance, what strategies do professionals use to gain compliance with formal and informal policies to protect information security? Depending on the threat, relationship to a coworker, and authority, they choose among a set of strategies. The original typology consists of four general types of extra-role information security behavior along two dimensions (see table 1). The first-dimension contrasts whether the behavior would likely strengthen or preserve relationships with others (affiliative) or damage the relationship (challenging). The second-dimension contrasts whether the behavior encourages something to occur (promotive) or to cease (prohibitive).

<table>
<thead>
<tr>
<th></th>
<th>Promotive</th>
<th>Prohibitive</th>
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<tbody>
<tr>
<td>Affiliative</td>
<td>Helping</td>
<td>Stewardship</td>
</tr>
<tr>
<td>Challenging</td>
<td>Voice</td>
<td>Whistle-blown</td>
</tr>
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Table 1. A typology of extra-role behaviors (Jaeger and Eckhardt, 2018 adapted from Van Dyne et al., 1995)

We have used these to sort reflections in our data by health professionals. Whereas the information security research has focused on in-role security behaviors, e.g., compliance to information security policies (ISP), Jaeger and Eckhardt (2018) highlight extra-role security behaviors, e.g., secure actions unspecified in ISP but beneficial to organizations. Since their proposed typology acknowledges the importance of discretionary activities and includes the influence of coworkers' performance in collaborative working environments, it proved an effective framework for our study: to explore information integrity in relation to everyday digital work practice in healthcare (including/with attention to virtual communities and social media).

The patient-physician dimension is the focus of the prior work, and the paper is designed to understand physician practice in the changing context. Our analysis revealed several strategies related to information integrity, such as workarounds (breakdowns, appropriation work), data work (making sense of data), peer learning, work culture and practices (tensions). We adjusted the typology with an iterative process that resulted in a health-specific dimension of patient/physician perspective and four general types of information integrity strategies (see Table 2, further developed in the findings section).

<table>
<thead>
<tr>
<th>Affiliative</th>
<th>Assisting (teacher/guide)</th>
<th>Appropriation work and learning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging</td>
<td>Patient safety/confidentiality</td>
<td>Professional privacy/security</td>
</tr>
<tr>
<td></td>
<td>Patient perspective</td>
<td>Practice perspective</td>
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</table>

Table 2. Types of information integrity strategies

Research Methods

The research uses interview data from a study of a regional Swedish healthcare practice investigating how new digital platforms and social media impact the work practices and professional roles of resident physicians (Vallo Hult 2017; Vallo Hult et al. 2016; Vallo Hult et al. 2019). This paper comprises a reanalysis of previous findings using the literature on information infrastructures and infrastructuring. We reviewed statements from resident physicians interviews that reflect the strategies outlined above.

Residents practice as physicians but are also engaged in clinical training (min 5 years) towards specialist competence. They come from several medical fields, working across departments and between specializations in a knowledge-intensive practice where quick and easy access to correct information is critical. The information environment consists of multiple tools. Various documents and frameworks constrain physicians to seek new information. Evidence-based medicine is now integrated into clinical work. Before EBM, medical decisions were left to individual physicians’ practice and previous experience.
with some peer consultation. This process has been accelerated, with evidence being essential and collegial advice available both locally and on the Internet. The digital infrastructure, defined as the portfolio of IS and their interconnections (Rolland 2018), include the healthcare infrastructure (e.g., patient records, medical systems), the digital workplace (e.g., intranet, collaboration spaces, e-mail, e-learning), individual information systems (social media, smartphone, private email, etc).

This study revisits data from three qualitative studies, where the original studies are based on explorative approach and grounded theory inspired methods. Interviews and observations elicited data on the digital work (including collaboration, knowledge sharing and workplace learning) of resident physicians. An overview of data collection methods and studies is presented in Table 3.

<table>
<thead>
<tr>
<th>Study</th>
<th>Time period</th>
<th>Empirical data</th>
<th>Reference</th>
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<tbody>
<tr>
<td>Study 1</td>
<td>2015</td>
<td>15 semi-structured interviews with individual physicians</td>
<td>Vallo Hult et al. (2016)</td>
</tr>
<tr>
<td>Study 2</td>
<td>2016-2017</td>
<td>2016: 1 focus group, 6 participants</td>
<td>Vallo Hult et al. (2019)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2017: 1 focus group, 6 participants</td>
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<td></td>
<td></td>
<td>1 focus group, 5 participants.</td>
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Table 3. Overview of empirical data and related studies

All data was read several times, coded and analyzed using deductive content analysis (Graneheim and Lundman 2004) to distinguish activities that contribute to the emergence of infrastructure (Pipek and Wulf, 2009). Tensions and uncertainties related to physicians’ everyday digital work, collaboration, and social media were categorized using descriptive case-ordered display (Miles and Huberman 1994) and mapped to the information security behavior typology described by Jaeger and Eckhardt (2018). Based on this descriptive categorization, key characteristics were summarized in a conceptually-ordered display as patient or practice-oriented, on healthcare-specific dimensions of infrastructuring. We identified and mapped information integrity strategies (helping, stewardship, voice, and whistle-blowing) to this schema.

Findings

The findings are presented according to the themes identified in the analysis, describing information integrity strategies from physicians’ everyday digital work. The typology characteristics are summarized in table 4, illustrated with quotes from the participating physicians. We used the Jaeger and Eckhardt (2018) categories, adding explanations to invoke the healthcare context, which has different social relationships than information security in an organization. For a more healthcare appropriate use of this model, we reconfigure the categories according to whether they are patient-focused or practice-focused, summarized in figure 1 and briefly discussed below.

<table>
<thead>
<tr>
<th>Typology</th>
<th>Physician description</th>
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| **Affiliative and Promotive** | • “it’s good to have a layman’s language […] refer them and sometimes also read together with the patient […] to be able to help them in the best way, not because I am afraid that the patients will be more knowledgeable”.  
• “Previously, we were the almighty doctor in some way; now the patient says that I have read … we must be humble with it, I think because otherwise, we will not be able to connect with the patients…”  
• [Tell them] “where to find information… forums and focus groups for patients that can help, who also have your diagnosis...” |
Affiliative and Prohibitive

Suggestions on how to improve information practices, make new practices conform to standards

- “it’s interesting, but you almost have to do this because it’s fun, not to have to stay updated… listening to podcasts, joining international discussions and lectures.”
- “I use my camera on my mobile if I need … we’re not allowed, so I have to delete it, cannot have patient images on my camera…but we have no way to save photos to the electronic patient record.”
- “…easiest would be a Dropbox folder where you put memos so that it is available … difficult on the hospital computer… easier to have your own folder somewhere. But then it may be the other way around, that it is blocked from the hospital instead, so you can’t access it from work.”

Challenging and Promotive

Worrying about bad data that patients bring and its effects

- “always the risk of inaccuracies and flawed information ... It can be risky ... random opinions”
- “It is, of course, a big challenge that we are facing, and how should we handle this? ... in the future? Will this improve health? ...there will be more and more of this, this discussion on digitization going forward”.
- “asks questions about their own illness there [on Facebook]”
- “And yet, the patients still want, even if they used a secure login, they still want a paper copy.” ... we have not provided enough information about it to make the patients feel secure [to trust the digital].
- “I don’t know about forums, social media for doctors... online, you never know... so it does not feel right, to discuss patient cases even if you completely deidentify them...it needs to be a very closed forum”.

Challenging and Prohibitive

Worrying about negative effects and challenges to practice

- “…misunderstandings that can be difficult to solve in these social channels, it’s better to solve it internally in the clinic with the judgment it touches.”
- “you don’t discuss anything medical ... the barrier is that you consider social media as somewhere where you can relax, not to discuss the job.”
- “I think that is great, but it is also, it is based on having the time... it’s not like you can step aside and watch a YouTube film.”
- “I have forgotten my password, so I try a few times and have to ask for a new one, and it takes a lot of time, and so I forgot to next time/laughter/ ...”
- “[social media] if you are going to use it for work then it must be a safe system ... now, it’s like they just pushed all of this out and no support ... and then we have a lot of restrictions...clearly, healthcare is lagging here”.

Table 4. Summary of typology characteristics and physician descriptions

Affiliative and patient-oriented: Assisting (responsibility). An information integrity concern raised by physicians is that patients bring their health data to consultations--information found on the Internet, and from other patients. It was not seen as problematic that patients come prepared. Even when patients’ information or opinions differ from the physicians’--for instance information from other countries or alternative medicine--it need not be a conflict. Physicians described recommending trustworthy sources or patient forums, to vet information. In these quotes, we see physicians addressing information integrity with focus on the patients’ perspective. They highlight the positive aspects of media and collaboration (patient-patient and patient-physician) and the value of patients becoming more knowledgeable. While aware of risks from social media and platforms they maintain that the development is beneficial. Strategies include taking on the responsibility as professionals to suggest information search strategies to the patient.

Affiliative and practice-oriented: “making work, work”. Physicians see the potential of digital platforms and social media, especially if it comes from the practice (bottom-up). They are aware of policies and integrity risks, yet would often, for practical reasons find a solution to a problem at hand, such as using private smartphones and shared passwords. They also make simple rationalizations and practical explanations, such as that the systems provided in healthcare are old fashioned and time-consuming and need to be more like everyday technologies. The quotes illustrate positive attitudes towards new platforms (digital collaboration/social media). Only minor attention is placed on information integrity issues and the focus is on the benefits from the perspective of the physicians. The rationale is “to make work, work”, turning to strategies for solving the problem at hand, e.g. care for the patient (appropriation work).
Challenging and patient-oriented: safety and confidentiality. Physicians are concerned that online consultations and health platforms may not be secure enough for sensitive issues. Fake (medical) news can spread rapidly in social media channels and forums, especially when no healthcare professionals are involved. It was noted that patients might prefer traditional paper documents, for confidentiality reasons, considering it the safer choice. Social media commercial interests pose risks; patients might post sensitive information on a public Facebook page, and it is still unclear if digital channels replace oral communication; can chat conversations be saved as knowledge archives? Quotes like these illustrate a skepticism towards evolving new platforms. The focus is on risks and challenges (for patient privacy), pointing to the need for more evaluation and knowledge. Commonly adopting “wait and see” and “better safe than sorry” strategies.

Challenging and practice-oriented: privacy and legality. Social media afford new opportunities and access to a large network of specialists. Blending private and work-related (digital) communication, information overload and constant notifications (nudging) creates stress and possibly lower quality of care. Transparency relates not only to the risks connected to sensitive information or patient data but also becomes a barrier for sharing information and posting online. Communication in social media is difficult and can lead to misunderstandings. As well, there is simply no time for social media when at work, even for work-related purposes. Finally, it was regarded as important in this theme that the technical solutions are sanctioned and secure, for instance, shared medical records for example. We see a skeptical attitude towards evolving new platforms. The focus is on risks and challenges related to information integrity from the physician perspective, highlighting aspects of privacy and legality, professional role, practical and technical barriers, and increased administration and workload. Strategies include “not my responsibility” and the separation of private and work domains from administrative and medical, clinical issues.

Figure 1. Typology of information integrity strategies, reconfigured for healthcare
Discussion

The strategies found in the analysis illustrate the dual, paradoxical nature of work technologies in a context, as described in early information infrastructure literature (Pipek and Wulf 2009; Star and Ruhleder 1996). The contradictions are exacerbated by the variety of new platforms and social media and their lack of boundedness, potentially compromising information integrity. Information flows are diverse, and the ability to navigate and make sense of them has become crucial. The dual view on digital work as both a burden and a blessing is a challenge that requires attention in order to gain benefits and avoid pitfalls, such as information overload and digital stress (c.f. Ens et al. 2018). The typology points to concurrent approaches among the physicians, highlighting this point. For example, the physicians separate the formal, often administrative systems from informal tools for finding information or collaboration online. The administrative systems are described as unreliable and time-consuming. The informal system is described as modern (towards patients) and "how you work nowadays". Although the administrative and informal systems aren't comparable in terms of complexity, the different ways physicians describe them is illustrative.

The infrastructuring perspective provides a structure to analyze tensions and challenges when different perspectives intersect in the everyday work of physicians. In the case of patients bringing their own data from social media, there is a tension between wanting to be modern (and go to Google), but on the other hand, being hesitant to discuss a medical issue in a Facebook group. This conforms to propositions in the literature about the simultaneous need for customization and standardization and to a duality--not a dualism--between “top-down and bottom-up approaches” (Aaenstad & Jensen 2011; Rolland 2018). Thus, the information integrity typology strategies can be described as infrastructuring work, for instance where a physician describes trying to solve the “tension between local, customized, intimate and flexible use on the one hand, and the need for standards and continuity on the other ... [as] a member of multiple communities of practice which use technologies differently, and which thus have different demands on their flexible standard requirements” (Star and Ruhleder 1996, p. 112).

The interview results can be sorted into both the infrastructuring and the information security frameworks from prior literature. They illustrate problems in healthcare where lives are at stake and patient privacy is a requirement. Participants confirmed asking a colleague for advice prior to turning to IT support, and the interviews provide examples of inappropriate learning, in the form of workarounds related to perceived inflexibilities around digital technologies and policies (Koppel et al. 2015). Similar infrastructuring activity surely occurs in other settings where people must use existing infrastructure, adopt emerging platforms that change the nature of the work, and incorporate outside media that lack the constraints of organizational IT. At the same time, they must navigate social relations not accounted for in the platforms, but that are essential features of functioning successfully in professional environments. For resident physicians, this means accepting input from patients, and assessing how it fits into standard practice while trying to accommodate the patient as a human being.

While these findings are a preliminary attempt to use an information security framework in medical practice, it proved useful to sort physician reactions in this way. The conceptual framework lends itself to further research studies where there is a tension between client and practitioner as they navigate infrastructuring projects. It is too early to create guidelines from this work, but this is a promising path for exploration into practice guidelines, red flags, and recommendations. For these new data practices to succeed, participants need pathways to data integrity even as they create new social infrastructures.

Conclusion

These findings highlight that human infrastructures are part of information integrity in healthcare. Information integrity efforts are human infrastructuring: trying to make new forms work without sacrificing core values. Faced with the challenges of working in complex and fragmented information environments, participants may create workarounds with unintended consequences (appropriation work). The infrastructuring and information security strategies frameworks shed new light on the previously analyzed data, showing how physicians perform infrastructuring work to make the new healthcare platforms work for them within the context of accommodating patients while maintaining core standards of medical practice.
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