Introduction to the Special Issue on 'Information Infrastructures in Healthcare: Governance, Quality Improvement and Service Efficiency'

Claus Bossen[1]* & Enrico Maria Piras[2,3]
*[1]*Aarhus University, Aarhus , Denmark (clausbossen@cc.au.dk); [2]*Fondazione Bruno Kessler, Povo , Italy;* [3]*University of Verona, Verona , Italy*

From the beginning, information infrastructures in healthcare have had at least two purposes: First, the coordination and exchange of information across professions, organizational units and time in order to treat and care for patients, and second, the accumulation and analysis of data in order to improve quality and efficiency of services provided. The duality goes back to Zuboff's call for digitization to not just be used for automation, but also for informating workers, management and organisations (Zuboff 1988): IT would provide information that could be used to 'informate work' by making some activities visible. Such informating can concern workers as part of their ongoing activities (Kristiansen et al. 2018), or management as part of organizing and monitoring organisational work processes (Evans and Kitchin 2018), or state authorities.

The deployment of healthcare infrastructures has been relatively late compared to other domains in the sense that despite numerous stand-alone IT systems one of the core infrastructures, the patient record, has only become digital at scale during the last two decades: In Europe, development of electronic health records took off around the turn of the millennium (Häyrinen et al. 2008), in the USA a couple of years later (Berner et al. 2005; Simborg et al. 2013). However, since then information infrastructures in healthcare have developed rapidly (Fitzpatrick and Ellingsen 2012) and the above mentioned duality of coordinating and informating has become evermore relevant. In the USA, the HITECH act of 2010 launched to spur the adoption of Electronic Health Record (EHR) also aimed at generating data on patients and healthcare service on large scale (Blumenthal and Tavenner 2010) (Sholler, This issue). In Europe, the European Institute for Innovation through Health Data was launched in 2016 to promote semantic interoperability, quality and governance through healthcare data (i ~ HD.eu).

The duality of aims was found to create tensions in and obstacles for the development information healthcare infrastructures, because the wish to generate data for

administrative purposes, secondary to the primary purpose of delivering healthcare, led to more work of creating data for healthcare professionals (Greenhalgh et al. 2009). The increased volume of data work has subsequently led to physician burn-out (Melnick et al. 2019), and the emergence of new occupations such as medical scribes, who shadow and write physicians' entries, and CDIS (clinical documentation integrity specialists), who read and improve patients' records concurrent with admission (Bossen et al. 2019a).

The tensions between the multiple purposes of data have often led to prioritize the development of IT system aimed at supporting clinical practice and internal work processes rather than tools primarily devoted to support governance and overall efficiency of healthcare delivery. Such choice was due, among other factors, to the realization that disentangling information from its production context requires additional work. The idea that a seamless flow of data across different domains is only a matter of technical standards and interoperability has been proven to be naïve. As stated by Berg and Goorman (1999) in their "law of medical information", 'the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production' (Id). Moreover, the actors directly involved in producing the extra documentation or information needed for coordinative purposes often do not benefit from such work (Stisen et al. 2016).

At the same time, the repurposing of data for administrative and governance aims have become more organized over time. To take an example close to one of the authors, in Denmark a new Healthcare Data Board was established in 2015 to strengthen already ongoing monitoring of healthcare and now regularly disseminates information and statistics based on data from EHRs and other healthcare IT systems. In the USA, implementation of EHRs and the provision of data are tightly interconnected, since this a requirement for reimbursement by the crucially important federal Centers for Medicare and Medicaid Services Medicare. In both countries, the accounting of healthcare services is based on ICD-10 (International Classification of Diseases) and the overlaying classification system Diagnosis-Related Group, which bundles treatments with similar diagnoses and resources requirements into groups to which a certain amount of reimbursement is allocated. A system originally invented in the 1980s in the USA, and since applied in many healthcare systems (Busse et al. 2011). Today, EHRs and other healthcare IT systems are expected to provide policymakers and healthcare managers with data that may be used for monitoring of quality, efficiency and inform policy decisions and governance. More recently, similar expectations have extended to patient-controlled data sources and technologies such as Personal Health Records (Piras et al. 2019; Mønsted, Hertzum, and Søndergaard, This issue) and Patient-Reported Outcomes (Langstrup 2019). Furthermore, such data are tied to aspiration of Big Data use to drive

development of new treatments, drugs and efficient healthcare organisations (Galetsi and Katsaliaki 2019).

Turning information infrastructures in healthcare into vehicles for governance in its various forms is taking place, though challenges continue to persist. These include the additional efforts to format, generate, accumulated and interpret data – data work (Bossen et al. 2019b; See also the special issue of Health Informatics Journal, vol. 25, no. 3, 2019), but also the challenges of bias, integration and incompleteness of data (Verheij et al. 2018). While information healthcare infrastructures may indeed be used to further healthcare service quality and efficiency, it requires close cooperation between healthcare staff and technical experts across borders (Holten Møller et al. 2017; Sanner and Øvrelid, This issue). Similarly, developing infrastructures necessitates considerable 'back stage' work in order to scaffold the emerging structures and creating of data (Bødker et al. 2017; Mønsted, Hertzum, and Søndergaard, This issue), and may encounter various forms of resistance by healthcare professionals (Markus 1983; Sholler, This issue).

This special issue of the *Journal of Computer Supported Cooperative Work* is the outcome of the 6th International Workshop on Infrastructures for Healthcare held in 2017 in Aarhus (DK), a series of workshops that have been held biannually since 2007 (The latest in Vienna in 2019: https://infrahealth.eusset.eu/). Each of the three papers addresses a crucial and significant aspect of how information infrastructures in healthcare can serve the purpose of providing tools for "Governance, quality improvement and service efficiency", the theme of 2017 workshop.

The papers extend prior knowledge on the ramifications of development and adoption of healthcare infrastructures aimed at supporting governance quality improvement and service efficiency. Each paper reflects on these issues at a different scale (local/hospital, regional, national).

Healthcare organization such as hospitals often favour intra-organizational (within a department) over inter-organizational coordination (among departments). Terje Aksel Sanner and Egil Øvrelid, drawing on a case study at a Norwegian general hospital, reflect on the tensions and conflicting goals among different departments arising from the redesign of the hospital procedures of patient admission, transfer, and discharge through the use of workflow information obtained integrating several clinical and administrative information systems in a single healthcare infrastructure. The case study shows how an higher degree of interdepartmental coordination is achieved by the implementation of new organizational procedures, which require not only the implementation of a new technical infrastructures, but also the *legitimation* of the information shared obtained through dedicated face to face meetings. Sanner and Øvrelid note how the increased efficiency gained by the hospital is the result of the unfinished business of the collaboration among departments with new

organizational actors, the data analysist and dedicated coordinators, and how the legitimation of workflow information triggers the requests of additional information by the clinicians.

Troels Mønsted, Morten Herzum, and Jens Søndergaard's study investigates the issues arising from the piloting of a regional preventive health infrastructure, which integrates data from medical records and self-reported by patients to stratify citizens into risk groups and channel them to general practitioners (GPs) or municipal health. The study follows the piloting of the infrastructure illustrating how the new governance model for preventive health is achieved, if only for testing, on the one hand aligning concerns of the municipalities and GPs, and on the other establishing the legitimacy of the new technical systems. The authors show the issues regarding the use of data for purposes different from the ones that led to their collection in the first place. In the case presented, for instance, GPs feared that automatic bulk extraction of patients' data from their repositories could turn into a tool for regional government to control the GPs themselves, leading to an overall readjustment of the project. Moreover, Mønsted and colleagues reflect on the cascade effect of implementing the infrastructure at a larger scale observing how this would entail significant readjustments to reimbursing schemes and organizational models.

Dan Sholler addresses the issue of resistance to large-scale governance initiatives drawing on the analysis of the initiatives of professional associations to shape the development and implementation of a nationwide EMR program aimed at capturing, storing and processing data to shape both organizational and clinical practice. The case under analysis, in sharp contrast with the studies presented above, describes a government-led, top-down initiative that renders futile localized actions of resistance. Sholler argues that the implementation of policy-driven infrastructures should consider the underestimated role professional organizations can play in contrasting and reshaping both technical systems and its policies. The study illustrates how, despite a strong alignment of interests of US federal government, the main IT vendors, the healthcare managers and the medical professional association managed to channel the localized frustration in an 'organized resistance' targeting the political level and successfully stalling the program and regain some agency in its redesign.

The papers in this special issue provide a multifaceted illustration of the complexities in designing or repurposing healthcare infrastructures to support governance, quality improvement and service efficiency, paving the way for future research in the field.

References

Berg, Marc; and Els Goorman. (1999). The contextual nature of medical information. *International journal of medical informatics,* vol. 56, no. 1-3, pp. 51-60.

Berner, Eta S.; Don E. Detmer; and Donald Simborg. (2005). Will the Wave Finally Break? A Brief View of the Adoption of Electronic Medical Records in the United States. *Journal of American Medical Informatics Association,* vol. 12, no. 1, pp. 3-7.

Blumenthal, David; and Marilyn Tavenner. (2010). The "meaningful use" regulation for electronic health records. *New England Journal of Medicine,* vol. 363, no. 6, pp. 501-504.

Bødker, Susanne; Christian Dindler; and Ole Sejer Iversen. (2017). Tying knots: Participatory infrastructuring at work. *Computer Supported Cooperative Work (CSCW)*, vol. 26, no. 1-2, pp. 245-273.

Bossen, Claus; Yunan Chen; and Kathleen H. Pine. (2019a). The emergence of new data work occupations in healthcare: The case of medical scribes. *International journal of medical informatics*, vol. 123, pp. 76-83. https://doi.org/10.1016/j.ijmedinf.2019.01.001

Bossen, Claus; Kathleen F. Pine; Federico Cabitza; Gunnar Ellingsen; and Enrico Maria Piras. (2019b). Data work in healthcare: An Introduction. *Health Informatics Journal*, vol. 25, no. 3, pp. 465-474. https://doi.org/10.1177/1460458219864730

Busse, Reinhard; Alexander Geissler; Wilm Quentin; and Miriam Wiley (Eds.). (2011). *Diagnosis-related groups in Europe*. New York: Open University Press.

Evans, Leighton; and Rob Kitchin. (2018). A smart place to work? Big data systems, labour, control and modern retail stores. *New Technology, Work and Employment*, vol. 33, 1, pp. 44-57. https://doi.org/10.1111/ntwe.12107

Fitzpatrick, Geraldine; and Gunnar Ellingsen. (2012). A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. *Computer Supported Cooperative Work (CSCW)*, vol. 22, no. 4-6, pp. 1-57. https://doi.org/10.1007/s10606-012-9168-0

Galetsi, Panagiota; and Korina Katsaliaki. (2019). A review of the literature on big data analytics in healthcare. *Journal of the Operational Research Society*, https://doi.org/10.1080/01605682.2019.1630328.

Greenhalgh, T.; Henry W. Potts; Geoff Wong; Pippa Bark; and Deborah Swinglehurst. (2009). Tensions and Paradoxes in Electronic Patient Record Research: A Systematic Literature Review Using the Meta-narrative Method. *Milbank Quarterly*, vol. 87, 4, pp. 729-788. https://doi.org/10.1111/j.1468-0009.2009.00578.x

Häyrinen, Kristiina; Kaija Saranto; and Pirkko Nykänen. (2008). Definition, structure, content, use and impacts of electronic health records: A review of the research literature. *International Journal of Medical Informatics*, vol. 77, no 5, pp. 291-304. https://doi.org/10.1016/j.ijmedinf.2007.09.001

Kristiansen, Kristian Helbo; Mathias A. Valeur-Meller; Lynn Dombrowski; and Naja L. Holten Moller (2018). Accountability in the blue-collar data-driven workplace. In: *CHI 2018. Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems. Montreal, Canada, April 2018*. New York: ACM Press, pp. 1-12.

Langstrup, Henriette. (2019). Patient-reported data and the politics of meaningful data work. *Health informatics journal,* vol. 25, no. 3, pp. 567-576. https://doi.org/10.1177/1460458218820188

Markus, Lynne. (1983). Power, Politics, and MIS Implementation. *Communications of the ACM*, vol. 26, no 6, pp. 430-444.

Melnick, Edward R.; Liselotte N. Dyrbye; Christine A. Sinsky; Mickey Trockel; Colin P. West; Laurence Nedelec; Michael A. Tutty; and Tait Shanafelt (2019). The association between perceived electronic health record usability and professional burnout among US physicians. *Mayo Clinic Proceedings*, vol. 95, no. 3, pp. 476-487. Elsevier.

Holten Møller, Naja L; Pernille Bjørn; Jonas Christoffer Villumsen; Tine C. Hansen Hancock; Toshimitsu Aritake; and Shigeyuki Tani (2017). Data tracking in search of workflows. *CSCW 2017. Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing. 25 February – 1 March 2017, Portland, Oregon*, pp. 2153-2165.

Piras, Enrico Maria; Federico Cabitza; Myriam Lewkowicz; and Liam Bannon. (2019). Personal Health Records and Patient-Oriented Infrastructures: Building Technology, Shaping (New)

Patients, and Healthcare Practitioners. *Computer Supported Cooperative Work (CSCW),* vol. 28, no. 6, pp. 1001-1009. https://doi.org/10.1007/s10606-019-09364-x

Simborg, Donald W; Don Eugene Detmer; and Eta S. Berner (2013). The wave has finally broken: now what? *Journal of the American Medical Informatics Association*, vol. 20, no. e1, pp. e21-e25.

Stisen, Allan; Nervo Verdezoto; Henrik Blunck; Mikkel Baun Kjærgaard; and Grønbæk, Kaj. (2016). Accounting for the invisible work of hospital orderlies: Designing for local and global coordination. *CSCW 2016. Proceedings of the 2016 ACM Conference on Computer Supported Cooperative Work and Social Computing. 27 February – 2 March 2016, San Francisco, CA*, pp. 980-992.

Verheij, Robert A.; Vasa Curcin; Brendan C. Delaney; and Mark M. McGilchrist (2018). Possible sources of bias in primary care electronic health record data use and reuse. *Journal of medical Internet research*, vol. 20, no. 5, e185.

Zuboff, Shoshana. (1988). *In the age ofthe smart machine*. New York: Basic Book.