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Silent Data, Active Patients

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Abstract. With the wake of digital welfare, governments advocate that patients play an active role in managing their own illnesses. This active role is sustained by access to and use of health data provided by health care authorities through new digital technologies. Stepping into an empirical site where patients log in to their own site, 'MyChart', we inquire their practices reading health care data and their imaginaries about active involvement in their own health care. With this, our analysis focuses on *the active patient* and aims to bring forth local imaginaries in an effort to nuance data imaginaries located in political strategies, which relate data access with active partnerships. Within this, we illustrate how patients are active, while data is silent and in need of work before it vocals meaningful for the patients.

Keywords: Digital health care, Active patients, Sociotechnical imaginaries, Data work.

1 Introduction

Within healthcare, access to health data is imagined to enable citizens play an active role in their own course of diseases and become active partners. The question remains, however, what it means to be active? When reading the Danish national 'strategy for digital health', which couples data access with patients' engagement in active partnerships, we learn that: "Patients should have access to their own data, in order for them, for instance, to have better opportunities for participating actively in their own treatment" [1][1]. While advocating for access to health data, the strategy spends little time clarifying what an active partnership implies beyond proclaiming more involvement and self-service [2][2]. As such, the notion of *active patients* echoes the agenda of patient participation, which the World Health Organization started advocating in the late '70s [3]. While patient participation is linked with the concepts of patient-centeredness and patient empowerment [3], Lupton relates such discourses and the implementation of digital technologies with assumed economic efficiencies [4].

Drawing on Jasanoff, this article argues that discourses of *active patients* in policy-documents start to form a 'sociotechnical imaginary'. An imaginary enabled by digital solutions allowing data access, while, at the same time, also supportive of and

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[1] p. 5
[2] p. 22

sustaining such developments [5]. As we will see below, the imaginary of *active patients* seems to have transgressed onto patients as well.

Taking the patient portal MyChart as an example of a new data infrastructure that provides patients access to their health data, we present empirical examples that illustrate what happens in practice when patients actively engage with their health data through this new digital healthcare solution. Our findings suggest that, while patients welcome the idea of access to their own data, such accessibility can carry with it implications when the data is laborious to understand. Thus, the paper gives examples of how patients perform 'data work' [6, 7] and discusses the potential benefits and pitfalls of their data access. As such, our study brings nuance to the notion of the *active patient* alongside reflections on normativities [8] that such 'imaginary' [5] produces.

2   Digitalization and patient engagement

While we see linkages between data and *active patients* in political strategies concerning digitalization, we have been less fortunate to locate scientific literature concerned with patients' own conceptualizations of being active patients and their experiences with data access. We have found one recent Swedish survey-study, where patients' experiences with access to a national electronic health record are explored. In this study, the authors conclude that access makes patients feel more involved in their treatment [9]. However, one of the few existing studies of MyChart concludes that in its present form, the system might not support patients' active engagement in their treatment, in part because they cannot interpret the information available [10]. Vikkelsø has analyzed four information infrastructures for patient-centered care in Denmark, one of them being online data access. She finds that patients might both need guidance to understand their record, that it can cause worries, and that the language used in the record ought to change [11]. In relation to language usage in patient records, a study of nursing documentation practices in Norway finds that after patients gained access to their record the nurses focused on precise documentation, but with an attentiveness towards avoiding abbreviations and Latin expressions [12]. Similarly, a study of a shared EPR that replaces a client-held record, which pregnant women bring along to visits at general practitioners, midwives, hospitals, etc., found that the women's demand for completeness of the record challenged the care professionals' practices [13].

Several studies remind us that the implementation of new technologies often means redistribution of work rather than minimization of work [14–17]. In studies of telemedicine devices Oudshoorn [15] and Andersen [16], for instance, describe how patients become 'diagnostic agents' and improve their 'diagnostic skills'.

From our methodological standpoint, patients are often the "implicated actors"[3] [19] of new digital healthcare solutions. For this reason, it is paramount to investigate what happens in practice as patients take these new technologies into use.

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[3] While not the focus of this study, clinicians might also be implicated actors, since patients' increased access to their record and new forms of consultations are likely to change current work practices (see [18]).

3 Sociotechnical imaginaries and data work

The study has been guided by a theoretical positioning within the field of STS. This implies an attentiveness towards the networked entanglements of humans, technologies, institutions, meanings, practices, etc. [20]. Our analysis particularly engages with the concept of 'imaginaries' [5, 21], which have been an analytical focus for STS scholars within the past few decades [22]. Jasanoff [5, p. 6] describes sociotechnical imaginaries in the following way:

> "collectively held, institutionally stabilized, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology".

In this paper, we proceed with conceptualizing the notion of *active patients* as a collective imagination of a desired future for digital health care, tightly coupled with developments within information and communications technology (ICT). It is an imaginary producing normatives for social life and social order. Drawing on Jasanoff, Felt [23] explores local versions of sociotechnical imaginaries of the internet in a healthcare context. In her study of Austrian citizens'/patients' use of the internet, as an information medium, she shows the transformative power of the sociotechnical imaginary by demonstrating how new patient identities become intertwined with a particular version of the imaginary of the internet. She, for instance, explains how the opportunity to get informed through searches on the internet also creates an "obligation to do so" [23][4], which, simultaneously, caters to a practice where patients participate actively in the collective care infrastructure [23]. In line with Felt [23], this study unfolds local versions of the *active patient* by analyzing how Danish patients conceptualize themselves as active, as well as how they engage with health data made available through MyChart through the lenses of 'data work' [6]. Data work is "any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data" [6, p. 466].

4 Methods and empirical setting

The patient portal, MyChart, which serves as a hub for the ethnographic study presented here, is part of a larger IT-system or, more specifically, of an Electronic Patient Record (EPR) designed by Epic. The EPR was adapted for the Danish market (and called The Health Platform (red. Sundhedsplatformen) and implemented in the Capital and Zealand regions of Denmark during 2016 and 2017. The Health Platform gathers patients' data in one place to be shared across hospitals and hospital units in the regions. Further, the Health Platform is designed to better support clinical staff in diagnosing and planning treatment trajectories [24]. Next to supporting clinical staff, the Health Platform is designed with the integrated patient portal MyChart (red. Min Sundhedsplatform),

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[4] p. 188

which allows patients to have written communication with the hospital, to access their health data, including doctor's notes, test results, and upcoming appointments [25]. According to the Capital Region "The Health Platform makes it easier for the patient to play an active role" [25] and thus, the system supports the line set out in the current Danish strategy for digital healthcare, which couples data access with patients' engagement in active partnerships [1, 2].

The paper builds on an ethnographic study [26, 27] conducted by the first author for her master's thesis [18]. The study includes fieldwork at an outpatient clinic in a Copenhagen based hospital on selected days from December 2017-August 2018, visits in homes/workplace of five patients, document analysis of internal documents from the hospital, system descriptions, and political strategies.

The patients were between the ages of 20-60 years old and affiliated with the outpatient clinic, either because they had a chronic disease, or were in the process of being diagnosed. The patients were interviewed about their experiences with MyChart, how they understand the notion of the *active patient*, and their understandings of being active. The patients were also observed while using the patient portal, which sparked reflections about specific functions in the system. The interviews were semi-structured, conducted in Danish, and lasted on average a little over an hour. The field material used in this paper is translated from Danish to English; the same applies to quotes from various strategies and web pages produced by Danish organizations or governmental agencies.

At the time of the data generating, three of the patients were students, and in their early or mid-twenties: Niels[5] had had his diagnosis since he was a child; Emma was recently diagnosed with a chronic condition; and Astrid was in the process of being diagnosed. The fourth patient, Miriam, was also in the process of being diagnosed. She was in her late twenties and worked in the healthcare sector. The fifth patient, Lisbeth, is a 60 years old woman having two chronic conditions. For this reason, she received treatment at two different outpatient clinics.

All fieldnotes, interview transcripts, and documents were coded and analyzed using Situational Analysis [19].

This paper includes empirical data used in [18] as well as material, which did not make it to the final edition of her master thesis. In addition to a new literature survey on *active patient*s and added theoretical readings, new political documents have been gathered for this particular analysis.

5   Silent data and active patients

In situating the *active patient*, we move into the empirical site where patients are interviewed while accessing their health data via MyChart

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[5] All patients appear with fictitious names to protect their privacy.

5.1   Patients as active interpreters of data

As we have seen, access to own health data is imagined to be one of the key features enabling an active partnership. However, while data can be accessed, its meaning might not be attainable and transparent for patients, especially the test results prove challenging to comprehend. An example of this, we find in Niels's reflections when he accesses his blood test results:

> *He clicks on a result* "Oh there I see my values and the standard intervals. Here I am within the interval." *Opens another result* "Here I am in the high end. (...) Here I am also in the high end. Is my result too high or what? Is it dangerous?".

The blood test results in MyChart are presented both with a standard interval and the patient's results for a specific blood value. When Niels accesses his blood test results, he immediately attempts to make sense of and interpret what he is seeing. Niels compares his results to the standard intervals and reacts when they are outside the standard. He is confused whether a result, which is outside or on the verge of the standard interval, is dangerous, and it sparks a degree of concern and him asking if 'it is dangerous?'. During the interview, Niels googled[6] some of the names of the blood values, such as 'Monocytes', to gain information about the different values and their meaning. The actions Niels takes towards interpreting his results can be viewed as 'data work' [6, 13], which he performs in order to make sense of his results. Niels is excited about the access to his health data even though some of the information is difficult to understand. It, for instance, sparked his curiosity that he is able to see the data forming the basis for the physician's assessment.

The other patients in our study also found it interesting to be able to access the same data as the physician. However, they were unsure of how the data was useful to them since they could not understand it. The participant Emma, for instance, said:

> "I was looking at these 40 new test results because [my physician] said to me, 'I will see you in 2 weeks' (...), and until then, I could go and have a look at my test results in here [MyChart]. And I thought that is fine, but then I logged in, and I don't understand anything of what it says."

It is not only the test results that are difficult for the patients to understand. Also, the physicians' notes from consultations are difficult, since they are written in, what Emma calls, 'medical-lingo'. Emma consults her mother, who is a physician, to understand the information on MyChart. Emma imagines that her physician will teach her to interpret her own blood test results. Astrid, in a similar line, imagines that by hearing her physician explain the results during consultations, she will eventually learn to read the results herself. She says:

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[6] This is the term our participants use for performing searches in Google's search engine, why we maintain this phrasing.

> "Over several years, I might learn what the results mean. I like that thought. If I will learn, that's another story."

These empirical examples of the patients' engagement with their health data show that while the data is accessible, it is not necessarily understandable for them. It also shows how data access does not automatically make an *active patient* who can take proactive steps in her/his patient trajectory.

5.2 Data in need of work

When Niels is asked if he sees MyChart as encouraging patients to take an active role, he says:

> "Is the activity simply keeping yourself up to date, as what I am doing now, then yes. But it is very few Danes who would read their phosphorus value in the blood test results and think to him or herself: 'Wow I really need some phosphorus'. In this way there is not much activity in it [red. MyChart]. (…) I definitely think the test results should be there, but they might fall short. You need to be more than averagely active in order to use it."

In our view, Niels sums up the issues pertaining to data access as an enabler for being an *active patient*. As it is at present, there is no translation process when data is pulled from the clinicians' system in the Health Platform to the patients' MyChart. That is, the data is the same and it proves difficult for the patients to understand the medical terminology and test results without explanation. In line with this, Haraway [28] reminds us of situatedness of knowledges and knowledge production. Likewise, from a healthcare perspective, Berg [29] points to the context-dependent qualities of the information in the patient record and how it is directed towards clinical personnel in order to serve their work. The particularities of the record becomes very visible once it is put in a different context. As a physician in our study stresses; the patient record is a work tool for him and his colleagues, which is why it is written the way it is[7]. However, with the increased patient access to e-records, the current configuration of the data in patient records might be challenged. Vikkelsø [11][8] states that it requires balancing "to ensure that patient records can simultaneously function as professional decision-making tools, legal document and patient-oriented summaries". However, she also writes that, if patients should be able to understand what is written in the record, the writing style must change [11]. The question is whether this will happen, and if it is possible to be as precise without the medical terminology?

In Miriam's opinion, she has no use of the test results due to the way they are presented. She suggests that the results should be presented with comments:

> "I think there should be some comments attached stating that everything is okay, or that there is a lack of something, or something like that".

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[7] Fieldwork 13.04.18.

[8] p. 345

Lisbeth, on the other hand, has no expectation of such. She is used to using another health data platform, which has a small dictionary embedded in the website and instead she hopes that a similar dictionary will be integrated into MyChart, allowing her to look up medical terms she doesn't understand.

It seems beneficial to implement some sort of translation process between the data used by clinicians in their daily care work and the data presented to patients. But then again, who would carry out this work and at what cost? Currently, the work is somewhat delegated to patients in the form of data work, which they engage in, in order to make sense of their data. As described, patients try to interpret their health data by looking up test results or unfamiliar words on Google, or they ask relatives to explain their results. The work that patients carry out in an effort to understand the data available can be viewed as cultivating diagnostic skills, as Andersen [16][9] describes:

> "The possibility to remotely question and achieve increased information (...) prescribes patient work of improving diagnostic skills and developing ways to deal with information that is not easily understandable".

The patients' possibility to remotely access their individual health records activates them in performing data work, particularly in terms of interpreting data that is not easy to understand.

If the patients learn to understand the meaning of their test results, is it then desirable to act on the results on their own without consulting their physician? The specificities of what constitutes an active patient remain unclear, but in the following section, we unfold local enactments of *being* an active patient.

5.3 Being active does not necessarily involve ICT

All patients in our study expressed the importance of being active in their own patient trajectory. As such, one could say that the sociotechnical imaginary of active patients, which has been established by discourses in policy-documents, has transgressed onto citizens. For instance, Miriam says she thinks it is a good idea that people take care of themselves and take responsibility for their treatment to the degree they are able. However, she also stresses that it is important for clinicians to accept and help the ones not capable (Interview with Miriam). Since imaginaries shape social lives and social orders and produce visions of the collective good [5], it is unsurprising that all five patients perceive themselves as active patients. Lisbeth, Niels, and Emma emphasize that one part of being an active patient in one's own trajectory involves asking questions and asking for further explanation from their physicians:

> Lisbeth: "I would say that I am active in my own disease. I ask – until they are on the verge of losing their minds. And I keep asking. And eventually, if I cannot allow myself to ask any more questions, then I wait till next time, and then I'll ask again".

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[9] p. 154

The two other patients, Astrid and Miriam, relate being active to seeking information on their own. Both of them had not received a final diagnosis during the fieldwork, whereby they sought information related to their symptoms and how they could feel better. Astrid, for instance, used Google to look up dietary suggestions, and she asked relatives, with similar issues as hers, for advice.

The above examples show that the patients are active in regard to asking questions and seeking information. However, these local imaginaries and enactments of *active patients* make no linkage with data access and the use of ICT, which are central to the national imaginary of active patients performing different acts of self-service. Instead, the patients' conceptualization of being *active patients* relates to taking some degree of responsibility in their own trajectory.

Arguably, from what these patients tell, they are active and take responsibility for the management of their illness. Several of them also describe how they engage in discussions with their physicians about their treatment. In our opinion, this constitutes an active partnership. However, it seems to be a partnership that also demands more from the physicians, since the patients ask critical and clarifying questions to the instructions. In addition, as we have seen, the information available at MyChart is not easily understandable, and for this reason, patients can have a need to consult their physicians about the information they have retrieved online. In this way, digital health technologies might change the roles and responsibilities of both patients and clinicians [11, 30].

6   Concluding discussion

In line with previously mentioned studies on digital health solutions, our research shows how patients become activated [13, 15, 16] when interacting with MyChart. That is, they become activated to perform data work [7], specifically in the interpretation of information in MyChart. We believe that when the data available in MyChart is not easily understandable for patients, it entails some risk. For instance, patients might misinterpret the data, and additionally, the lack of comprehension can provoke worries among some patients. The organization Danish Patients is aware of this risk, but state that even so, the benefits of knowing, counterbalance cases of worry. However, Danish Patients [31] acknowledges the importance of patients having easy access to a physician when questions are present. Thus, rather than leading to cost reductions and self-service, data access may, in some cases, bring patients to reach out to their hospital for dialogues about the data provided. In this way, MyChart constitutes new forms of work for both patients and clinicians [18]. While we acknowledge the record's role as a work tool for the clinicians [11, 29], our study suggests that a modulation of the documentation practices, similar to that of the Norwegian study [12] might be beneficial. Accommodating the needs of both clinicians and patients would be a delicate balancing act [11].

While MyChart and the access to own health data are optional for patients, the system constitutes a new care infrastructure that fuels the sociotechnical imaginary of a future where patients are part of consolidating this infrastructure by way of being active and engaging in data work. In this way, the Danish government's increased focus on

digital health solutions and the strategies promoting *active patients* might create "normativities" [8] about what a good patient is – i.e., one who reads and are informed by health data and who performs actions of self-service [2]. As such, the option of accessing health data might create a sense of obligation to be knowledgeable about the information provided. This is similar to the patients in Felt's [23] study who feel obligated to perform internet searches. In addition, others have shown how digitalization initiatives can create "patterns of exclusion" of some citizens [32]. With this we could ask: who might be forgotten in the digital healthcare initiatives and who have access to and can maneuver ICTs? Since patients are the implicated actors in strategies concerned with *active patients*, it is important to explore and voice their local imaginaries and enactments of being active, in particular with respect to the new digital solutions, such as MyChart, which are imagined as enablers of active engagement.

We are not opposed to data access, new digital solutions, and the benefits they can bring. Rather, we invite to careful considerations of normativities that are embedded in the technologies and policy documents as well as considerations of new patient identities and roles for clinicians, which come about with normativties embedded in such. We especially find it imperative to unfold whether access to health data caters to patients in a way where they feel obligated to access it *and* to learn to understand it. More research is necessary in order to further understand how and if patients wish to be involved in their treatment *and* what roles ICTs, data, and patients' maneuverings with such come to play in the very formation of digital care infrastructures. As it is now, while the patients are active, the data is silent.

References

1. Sundheds- og Ældreministeriet (2018) Sundhed i fremtiden juni 2018: Ansvarlig brug af data til gavn for patienten. http://sum.dk/Aktuelt/Publikationer/~/media/Filer%20-%20Publikationer_i_pdf/2018/Sundhed-i-fremtiden-juni-2018/Sundhed-i-fremtiden-juni-2018-2.PDF.

2. Sundheds- og Ældreministeriet, Finansministeriet, Danske Regioner, KL (2018) Ét sikkert og sammenhængende sundhedsnetværk for alle - Strategi for digital sundhed 2018-2022. http://www.regioner.dk/media/6588/digital-sundhed-publikation.pdf.

3. Holmström I, Röing M (2010) The relation between patient-centeredness and patient empowerment: A discussion on concepts. Patient Education and Counseling 79:167–172. https://doi.org/10.1016/j.pec.2009.08.008

4. Lupton D (2013) The digitally engaged patient: Self-monitoring and self-care in the digital health era. Social Theory & Health 11:256–270. https://doi.org/10.1057/sth.2013.10

5. Jasanoff S (2015) Future Imperfect: Science, Technology, and the Imaginations of Modernity. In: Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power. University of Chicago Press, pp 1–33

6. Bossen C, Pine KH, Cabitza F, et al (2019) Data work in healthcare: An Introduction. Health Informatics Journal 25:465–474. https://doi.org/10.1177/1460458219864730

7. Langstrup H (2018) Patient-reported data and the politics of meaningful data work. Health Informatics J 1460458218820188. https://doi.org/10.1177/1460458218820188

8. Singleton V (2007) Training and Resuscitating Healthy Citizens in the English New Public Health - Normatives in Process. In: Asdal K, Brenna B, Moser I (eds) Technoscience: the politics of interventions. Oslo Academic Press, Unipub Norway, Oslo, pp 221–246

9. Wass S, Vimarlund V, Ros A (2019) Exploring patients' perceptions of accessing electronic health records: Innovation in healthcare. Health Informatics Journal 25:203–215. https://doi.org/10.1177/1460458217704258

10. Kensing F, Lomborg S, Moring C (2017) Evolving relations between the practices of nurses and patients and a new patient portal. European Society for Socially Embedded Technologies (EUSSET)

11. Vikkelsø S (2010) Mobilizing information infrastructure, shaping patient-centred care. International Journal of Public Sector Management 23:340–352. https://doi.org/10.1108/09513551011047233

12. Berglind FS (2018) Patient Accessible Electronic Health Records: Impacts on Nursing Documentation Practices at a University Hospital. Studies in Health Technology and Informatics 14–18. https://doi.org/10.3233/978-1-61499-872-3-14

13. Winthereik BR, Langstrup H (2010) When patients care (too much) for information. In: Care in Practice: On Tinkering in Clinics, Homes and Farms. pp 195–214

14. Svenningsen S (2004) Den elektroniske patientjournal og medicinsk arbejde: reorganisering af roller, ansvar og risici på sygehuse. Handelshøjskolens, København

15. Oudshoorn N (2008) Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology. Sociology of Health & Illness 30:272–288. https://doi.org/10.1111/j.1467-9566.2007.01032.x

16. Andersen T (2010) The participatory patient. In: Proceedings of the 11th Biennial Participatory Design Conference. ACM Press, Sydney, Australia, pp 151–154

17. Finken S, Mörtberg C (2014) Performing Elderliness – Intra-actions with Digital Domestic Care Technologies. In: Kimppa K, Whitehouse D, Kuusela T, Phahlamohlaka J (eds) ICT and Society. Springer Berlin Heidelberg, Berlin, Heidelberg, pp 307–319

18. Laursen CS (2018) My Health Platform and Changing Relations of Care - An ethnographic study of a new Danish patient portal. Master's Thesis, IT University of Copenhagen

19. Clarke AE (2005) Situational analysis: grounded theory after the postmodern turn. Sage Publications, Thousand Oaks, Calif

20. Felt U, Fouché R, Miller CA, Smith-Doerr L (2017) Introduction to the Fourth Edition of The Handbook of Science and Technology Studies. In: Felt U (ed) The handbook of science and technology studies, Fourth edition. The MIT Press, Cambridge, Massachusetts, pp 1–26

21. Marcus G (1995) Introduction. In: Marcus G (ed) Technoscientific Imaginaries: Conversations, Profiles and Memoirs. Chicago: University of Chicago Press., pp 1–9

22. McNeil M, Arribas-Ayllon M, Haran J, et al (2017) Conceptualizing Imaginaries of Science, Technology, and Society. In: Felt U (ed) The handbook of science and technology studies, Fourth edition. The MIT Press, Cambridge, Massachusetts, pp 435–464

23. Felt U (2015) Sociotechnical imaginaries of "the internet," digital health information and the making of citizen-patients. In: Hilgartner S, Miller C, Hagendijk R (eds) Science and democracy: making knowledge and making power in the biosciences and beyond. Routledge, London

24. Steno Diabetes Center Copenhagen (2019) Nyt IT-system - Sundhedsplatformen. https://www.sdcc.dk/undersoegelse-og-behandling/sundhedsplatformen/Sider/Nyt-IT-system.aspx. Accessed 11 Aug 2019

25. Region H Sundhedsplatformen - én samlet patientjournal. https://www.regionh.dk/sundhedsplatform/om-sundhedsplatformen/Sider/en_samlet_patientjournal.aspx. Accessed 19 Mar 2018

12

26. Crang M, Cook I (1995) Doing ethnographies, Online version. Norwich: Geobooks. Durham Research Online, Durham University. United Kingdom

27. Forsythe DE (1999) "It's just a matter of common sense": Ethnography as invisible work. Computer Supported Cooperative Work (CSCW) 8:127–145

28. Haraway D (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. Feminist Studies 14:575. https://doi.org/10.2307/3178066

29. Berg M (2000) Lessons from a Dinosaur: Mediating is Research Through an Analysis of the Medical Record. In: Baskerville R, Stage J, DeGross JI (eds) Organizational and Social Perspectives on Information Technology: IFIP TC8 WG8.2 International Working Conference on the Social and Organizational Perspective on Research and Practice in Information Technology June 9–11, 2000, Aalborg, Denmark. Springer US, Boston, MA, pp 487–504

30. Hult HV, Hansson A, Svensson L, Gellerstedt M (2019) Flipped healthcare for better or worse. Health Informatics J 25:587–597. https://doi.org/10.1177/1460458219833099

31. Danske patienter Journaladgang. In: Danske Patienter. https://danskepatienter.dk/politik/det-mener-vi/journaladgang. Accessed 7 Apr 2019

32. Schou J, Pors AS (2019) Digital by default? A qualitative study of exclusion in digitalised welfare. Social Policy & Administration 53:464–477. https://doi.org/10.1111/spol.12470