Data as symptom: Doctors' responses to patient-provided data in general practice

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Abstract

People are increasingly able to generate their own health data through new technologies such as wearables and online symptom checkers. However, generating data is one thing, interpreting them another. General practitioners (GPs) are likely to be the first to help with interpretations. Policymakers in the European Union are investing heavily in infrastructures to provide GPs access to patient measurements. But there may be a disconnect between policy ambitions and the everyday practices of GPs. To investigate this, we conducted semi-structured interviews with 23 Danish GPs. According to the GPs, patients relatively rarely bring data to them. GPs mostly remember three types of patient-generated data that patients bring to them for interpretation: heart and sleep measurements from wearables and results from online symptom checkers. However, they also spoke extensively about data work with patient queries concerning measurements from the GPs' own online Patient Reported Outcome system and online access to laboratory results. We juxtapose GP reflections on these five data types and between policy ambitions and everyday practices. These data require substantial recontextualization work before the GPs ascribe them evidential value and act on them. Even when they perceived as actionable, patient-provided data are not approached as measurements, as suggested by policy frameworks. Rather, GPs treat them as analogous to symptoms—that is to say, GPs treat patient-provided data as subjective evidence rather than authoritative measures. Drawing on Science and

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Technology Studies (STS) literature, we suggest that GPs must be part of the conversation with policy makers and digital entrepreneurs around when and how to integrate patient-generated data into healthcare infrastructures.

'The future of health is on your wrist' (Fowler, 2020), or so proclaim the advertisements for the Apple Watch. Yet, the future of *your* health might not be as clear as the crystal display when it notifies that '[y]our heart rate rose above 120 BPM while you seemed to be inactive for 10 minutes starting at 10.06 AM' (Apple Support, 2022). What might you do? You could search for advice through an online symptom and health checker, such as the 'Heart Disease Risk Calculator' (Mayo Clinic Health System, 2022). However, when seeing that you have, for example, a '24% risk of cardiovascular disease within 30 years', you may still want to consult your general practitioner (GP) to make sense of the number, and European policymakers are trying to encourage this. What might your GP do? We do not know.

The number of wearables may have reached 0.9–1.1 billion devices globally (Jin et al., 2020; Mück et al., 2019). The Apple Watch was the first direct-to-consumer medical product of its kind. This type of product contains apps, which might be framed as '"democratising" healthcare' (Shih et al., 2022, p. 6), but also can be viewed as part of the 'rise of the medical marketplace' (Shih et al., 2022, p. 5). From a policy perspective, the European Union (EU) expects that data from the Internet of Things will save the EU health sector 120 billion euros per year (European Commission, 2022b). Moreover, the EU has invested heavily in constructing a so-called European Health Data Space, which—among other things—is supposed to facilitate integration of data from patients' wearables with other types of health data (European Commission, 2020). The goal of the investments is to 'allow *a more effective, accessible and resilient healthcare and better quality of life*, while *giving individuals control over their health data and unleashing the potential of the data economy*' (European Commission, 2022a, p. 4, original emphasis). Health professionals' work 'will be made easier and more effective with more efficient access to health data of their patients' (European Commission, 2022a, p. 14). How do these policy ambitions relate to the use of such data in the everyday clinical work of general practice?

For decades, Denmark has been at the forefront of digital integration in healthcare (Aanestad & Jensen, 2011). The backbone of this is a personal identifier system implemented in 1968 and sustained investments in digitization. In 2016, the Ministry of Health introduced an online Patient Reported Outcome (PRO) system for GPs to replace all paper-based tests and questionnaires (Ølholm et al., 2019). The year before, easy online access to personal laboratory results from hospitals and clinics was introduced via the official eHealth portal, sundhed.dk (Bundgaard, 2016). It is a political ambition in Denmark to replace a third of all GP consultations with digital alternatives (Lose &

Astman, 2018; Regionshuset Viborg, 2020). It is moreover a priority to increase digital initiatives in general practice 'to optimise and facilitate workflows for GPs and their patients. […] to free up time and space for other tasks at the clinic' (Ministry of Health et al., 2018, p. 41). The Danish Digital Health Strategy proclaims how 'there is no real alternative to increased digital cooperation' (Ministry of Health et al., 2018, p. 8). It has been framed as a citizen right to let patients share their information with the health system (Langstrup, 2019). The national data infrastructure aims to include data from patients' own wearables (Finansministeriet, 2022). One purpose is to make the patient 'an active partner' who can 'obtain better insight into their own illness and health data' (Ministry of Health et al., 2018, p. 18). A survey from 2017 found that 50 percent of the GPs had experienced patient inquiries based on self-generated data (Videbæk et al., 2019), and a survey from 2020 estimated that a third of all Danish families own one or more smartwatches (Danmarks Statistik, 2020). Denmark presents an excellent opportunity to study how increased patient participation in the creation of and access to data affect healthcare, and to compare existing practices with the political ambitions.

In the Danish healthcare system, GPs play a key function as gatekeepers for most non-emergency medical services (Forde et al., 2016). This is where people are most likely to bring any self-generated data or online test results. Most patients' inquiries are handled by the GPs without referrals to other specialists or hospitals (Ministry of Health, 2017). Each citizen is on average in contact with their GP seven times per year, and 99 percent of the Danish citizens are registered with a GP. Each GP is on average accountable for 1600 patients and paid through the tax system (Ministry of Health, 2017). Thus, GPs in Denmark can be expected to have a good sense of what data patients wish to discuss with a doctor. In this study, we therefore ask: how do GPs describe their responses to patient-provided data? Which types of data involve which types of work for them and when and how do data come to influence their clinical decisions? How do policy ambitions relate to GP descriptions of their everyday clinical work?

In contrast to the expectations articulated in policy papers, GPs we interviewed report that patients relatively rarely bring data from wearables to them, and when they do, they typically see them as of little use. These GPs nevertheless claim to have acquired new forms of data work, not least with respect to other data types also made available to patients through the new digital infrastructures, such as data from online symptom checkers and online access to laboratory results. We analyse this data work and what it takes for GPs to see data as useful. Drawing on work in STS and data studies, we show that when GPs say that data from wearables or online symptom checkers inform their decisions, it is not primarily as the validated measurements seemingly imagined by policymakers. Rather, data operate on par with symptoms. They serve as a type of patient experience. They are used only when actionable. New forms of data therefore involve shifts in the diagnostic process in general practice and these shifts are not grounded in 'best' clinical practice. In conclusion, we suggest that as policy makers seek to change the digital infrastructures, they can learn from the experiences of GPs and adjust their expectations, but also that GPs may need new forms of training to help patients navigate the digital marketplace for health data.

Data work in healthcare

Health data are today produced by actors other than those employed in the health services (Fiske, Prainsack, & Buyx, 2019; Ruckenstein & Schüll, 2017). People are increasingly generating data on their own (Lupton, 2020; Lupton & Jutel, 2015; Nielsen & Langstrup, 2018). It requires work for health professionals to use such data (Pine & Bossen, 2020) and datafication generates a need for new skills and knowledge (Møller et al., 2020). According to Hoeyer and Wadmann (2020), datafication changes the perception of what counts as knowledge. It changes the actual working conditions and creates experiences of meaningless work among healthcare professionals. A focus on data potentially directs the limited resources in healthcare away from patient-oriented work (Hunt et al., 2017). This can lead to burnout (Melnick et al., 2020) or prompt professionals to develop various maladaptive strategies to reduce their data workload (Morrison et al., 2013). Scholars argue that such data developments have created the need for new expertise, changes in professions, and creation of new professions, such as health information counsellors (Bossen, Chen, & Pine, 2019; Bossen, Pine, Cabitza, et al., 2019; Fiske, Buyx, & Prainsack, 2019; Fiske, Prainsack, & Buyx, 2019; Pine & Bossen, 2020; Timmermans & Berg, 2010).

Data require not just work, but also *infrastructures*. Such infrastructures are the technical and organizational systems that facilitate and control data exchanges (Bowker & Star, 2000). They enable information connections, sharing, and assessments of quality and efficacy of services (Bossen & Piras, 2020). Data infrastructures are dynamic because the technologies, systems, involved actors, and purposes are changeable and interdependent. Investments in infrastructure typically 'signal the desires, hopes, and aspirations of a society, or of its leaders' (Anand et al., 2018, p. 19). Infrastructures affect work practices and routines as they make some choices possible and easy and others difficult or even impossible. Morrison (2017) observes that since all innovation by definition arises from an infrastructure, it appears to be rhetorically effective—though not logically necessary—to claim that investments in infrastructure will lead to innovation. As Lee (2015) notes, infrastructural investments can also be politically appealing because different actors can align them with very different hopes. Infrastructural investments carry great appeal and they do not seem to call for careful empirical scrutiny but understanding current data practices could be valuable to inform the ongoing investments in data integration.

Data work in general practice

Gabriels and Moerenhout (2018) have investigated GPs' and cardiologists' responses to patients' self-tracking data. They found that the doctors were concerned about how to interpret and use the new data in a context-dependent and complex everyday medical practice. Further, the doctors described the risk of performing more instead of less work as well as an inability to see the broader picture due to 'data overload'. Fiske et al. (2020) interviewed 15 doctors from various specialties, including GPs, about their conceptual understandings of self-care and two hypothetical scenarios involving new data devices. They found the existence of 'notable frictions between narratives of "e-patients" and

digitally-empowered people in public media and scholarly literature on the one hand, and what doctors reportedly experience in their own practice on the other' (Fiske et al., 2020, p. 1). In a combined literature review and interviews with 13 clinicians, including one GP, West et al. (2018) identified 12 barriers for using patient-generated data, such as insufficient time, expertise, context, and reliability.

If GPs are expected to use patient-generated data, what type of work does it involve? Bossen, Pine, Cabitza, et al. (2019) define data work as 'any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data' (p. 446). It is a comprehensive definition, but not all these activities consume the same amount of time and attention. Fiske, Prainsack, and Buyx (2019) distinguish between three forms of data work in healthcare of relevance to our study: (1) the work of supporting digital data practices; (2) the work of interpretation and contextualization; and (3) the work of inclusion and interaction. With respect to GPs, we interpret supporting digital data practices to include the work of assessing and preparing new digital technologies or online sources that *potentially* could be relevant in a healthcare situation, such as suggesting wearables, apps, and online symptom checkers to patients. The second form, interpretation and contextualization, can be seen as the work of assessing the trustworthiness and relevance of specific data in a specific clinical general practice situation, for instance, when data from a patient's watch reports an arrhythmia. The third form, inclusion and interaction, is the work *with* patients about data, which includes the patients' preferences and ethical concerns. An example could be the GPs' communication with patients when instructing them how to use a data device.

Before data can inform clinical judgment productively, GPs must do something to make sense of the data involving one of these three forms of data work. Of particular interest is the work of interpretation and we draw from Leonelli's (2016) concepts of decontextualization and recontextualization. She suggests that data scholars and data users often consider data as *representational* entities: fixed information, independent of surrounding conditions. Leonelli argues instead that data should be considered *relational*, meaning 'what counts as data depends on who uses them, how, and for which purposes' (Leonelli, 2015, p. 817). When data depend on the context, 'data need to be appropriately packaged to be circulated and used as evidence for new claims' (Leonelli, 2009, p. 737). This process Leonelli terms *decontextualization* and gives the example of librarians classifying books: almost all content of the books is being decontextualized into specific classification labels. *Recontextualization*, conversely, is 'to make it possible for researchers unfamiliar with these data to assess their evidential value and use them for their own research purposes' (Leonelli, 2016, p. 194). Leonelli does not explicitly define *evidential value.* We understand the evidential value of data as the extent to which the data can be used to support a particular claim. For data to gain evidential value, an element of recontextualization is always needed.

The concepts of contextualization and evidential value can help explain how GPs use different types of information in the diagnostic process. During a patient consultation in general practice, a patient may report a symptom such as heart palpitations. A symptom is, however, rarely enough for clinical action. It needs to be contextualized to other

symptoms, family history, and risk factors as well as available options for care. Symptoms can give rise to preliminary diagnosis, which are tested with various measurements. Such measurements come in the form of quantitative data. Measurements are not 'truths', however, but must also be contextualized. A blood pressure reading, for example, can be higher when the patient is in front of the doctor than when home. Armstrong (1995) suggests that notions of illness have changed over time so that measurements—as 'signs'— are given more weight than symptoms. This conceptualization provides a means of examining the sparsely studied ways doctors in general practice work with data from wearables and online symptom checkers.

Methods

Because of the limited literature investigating GPs' engagement with patient-provided data from new technologies, we adopted a qualitative research approach involving in-depth, semi-structured, one-to-one interviews with 23 Danish GPs, 10 men and 13 women. The GPs were between 39 and 75 years old. Haase conducted all interviews. To achieve a rich and diverse range of experiences, we interviewed GPs working with different groups of patients in terms of socio-demographic and dominant health issues in various geographical locations including one large city, smaller towns, and rural areas. The GPs were moreover working in different types of clinics, some in single doctor clinics with a secretary, while others worked in bigger clinics with multiple doctors, secretaries, lab technicians, and nurses. We interviewed all GPs who replied positively to the first invitation, sent by email to 80 GPs. These GPs were, to varying extents, associated with the University of Copenhagen, with employment ranging from external lecturer to sporadically hosting medical students. The protocol for performing the study was approved by the Faculty of Arts and Education's Human Ethics Advisory Group at Deakin University.

Prior to the interviews, we developed an interview guide and tested it on three doctors who were at the end of specialist training in general practice. The guide contained open-ended, situated questions allowing a wide range of different answers. The GPs were asked to follow up with a description of an actual experienced clinical case, with focus being on diagnosis rather than other clinical aspects such as treatment and prevention. An example of a question is 'with data understood broadly, have you had any experience with patients who provide data to you about their health?' The interviews were conducted in Danish and took place between March and May 2021. All the GPs were interviewed while they were in the clinic except one who was interviewed in her home. The interviews lasted between 46 and 96 minutes. They were recorded and transcribed verbatim. We use pseudonyms to maintain confidentiality.

Haase started transcribing and analysing after the first interview. This preliminary analysis aimed to improve the interview questions to ask more open questions and reach deeper into the GPs' experiences with data work. Another aim that transpired at this stage was to unpack the GPs' understanding of normatively laden descriptive words, such as 'good data' or 'quality'. After transcribing all interviews, Haase read and summarized all interviews for an overview of preliminary content of data types, data responses and attitudes to the data, and arguments used by the GPs to explain their responses and attitudes.

The summarized findings were discussed in Danish with Haase, Brodersen, Risor, and Hoeyer followed by discussions in English with all authors. All quotes were translated into English by Haase and checked by the other three Danish speaking authors.

When analysing the material, we performed thematic coding (Madden, 2010) by first identifying inductively the types of data that patients bring to GPs, the frequency, and the GPs reported responses. While GPs mentioned how patients claimed to be measuring their step counts, they also described how this did not seem to be related to specific inquiries and it seemed to have no impact on their diagnostic work. The great majority of reported patient inquiries were about heart and sleep data from wearables; results from online symptom and health checkers initiated by patients; measurements from the GPs' PRO system; and online access to laboratory results.

Looking at these five data types, we were struck by the variable ways in which GPs responded to both different data types and to similar types but from different sources. We therefore began a second set of comparisons between responses to data generated inside and outside the healthcare systems, and then brought by patients to their GPs. Our comparison was inspired by Mills (2000) invitation to explore similarities, contrasts, and contradictions in the material. When interpreting the interviews, we remained aware that doctors may not remember accurately what they did. Our focus was on their impressions and justifications rather than verifying their actual actions.

In the findings, we first provide an overview of the different data types and then compare GPs descriptions of how they responded to these. We include all data provided by patients, irrespective of its point of origin; in this way we can better illuminate the variations and contradictions between how the GPs treated these data. We then draw from the three forms of data work described by Fiske, Prainsack, and Buyx, and from Leonelli's concept of recontextualization, to help us interpret these accounts. We aimed to avoid the terminology and literature of clinical reasoning, clinical decision-making, and diagnostic reasoning (Yazdani et al., 2017), because it involves normative assumptions about how GPs ought to reason. Rather, we broadly considered the GPs' diagnostic approach as consisting of three stages: the *initiation*, the *refinement*, and the *final definition* stage, respectively (Heneghan et al., 2009). Finally, in the discussion, we relate this mundane data work to the policy ambitions with investments in data infrastructures to facilitate creation and access to patient data. Our understanding of the policy ambitions was informed by analysing strategy papers and action plans for data integration from Denmark and the EU and by combining this with attendance at conferences, seminars, and workshops about data integration in Danish healthcare.

A striking contrast between policy expectations and GPs' everyday experiences

When we asked GPs about their experiences with patient inquiries about data from wearables, some GPs said that, aside from step counts, they hardly experienced any patients presenting data from wearables. Others estimated the frequency to be once every month or second month. Most GPs were reluctant to quantify the frequencies because they experienced it so rarely. The most common type of wearables were smartwatches

followed by smartphones. Most frequent types of data were about the heart, such as pulse, irregular pulse, or electrocardiogram. The typical users of wearables were described as men between 30 and 50 years of age with interest and skills in data and technology. One GP explained how he had almost only experienced patient inquiries of heart data when working on call after normal opening hours. Besides heart data, patients mostly brought data about sleep. For patients mentioning online symptom and health checkers, some GPs experienced it once or twice per month, or described it as twice as often as wearables. Some symptom checkers were about somatic conditions, such as problems with nutrition, but the majority concerned mental conditions. Of these, stress, depression, and anxiety were most frequently described followed by tests of attention deficit hyperactivity disorder, attention deficit disorder, and obsessive-compulsive disorder.

Overall, the reported paucity of such patient-generated data is in stark contrast to the way policy papers suggest a demand of ensuring access to these data (European Commission, 2020, 2022a, 2022b; Ministry of Health, 2017; Ministry of Health et al., 2018). Our interviews, at least, suggest that the announced disruption of the patient role in generating data has not materialized. Thomas, 54, answered the question about how often patients inquired about such data:

> Amazingly little actually. I have wondered why there is not more of it. Well, there are a lot of people who come and tell me how many steps they might take. But beyond that, I think it has been very little.

When describing and reflecting on patient-generated data, the GPs typically spoke about clinical 'relevance' and 'validation'. Interestingly, they did not seem to ever explore whether the wearables actually were 'validated'. In a clinical context, validation is the term used for the extent to which a test measures what it is intended to measure (Guyatt et al., 2015). Relevance relates to what Leonelli describes as recontextualization: data as relational objects that only make sense when the wider clinical context is known. GPs thereby situated the new data sources in their existing analytical frames and in relation to their existing work routines. But this was often not straightforward. For example, Paul, 63, recalled an experience with a patient in the following manner:

> There is actually an elderly woman who has lived in Panama, I think. She is a nurse, and she comes with some kind of watch saying, 'my watch said I had arrhythmia or something?' I wonder if I sent her to a cardiologist. I would think so. Or downplayed it a bit.

The striking element here is that Paul is unsure whether he referred the patient to a highly specialized doctor due to a suspicion of a heart disease *or* if he regarded the data as insignificant and sent the patient home without further actions. Clinically speaking, these two responses appear almost at the opposite end of the spectrum. Still, both responses made sense for him when thinking back on the patient. To understand why oppositional reactions are both plausible to Paul, we need to understand how patient-generated data are situated in the everyday clinical context.

While these patient-generated data are relatively rare when compared to policy expectations, we suggest it is still important to understand how GPs respond when they

experience them. What appears as appropriate reactions to the GPs, as we now describe, very much depends upon the type of data, and who initiated the data production. In the next sections we explore how GPs are more likely to find data from wearables relevant when they relate to heart diseases than sleep disorders, and to data from online symptom systems initiated by healthcare professionals rather than by patients—even when it is the same test in question.

Heart data from wearables: Context enables recontextualization and use

Returning to Paul's contradictory response, we wondered: how could a GP with more than 25 years of clinical experience, and who was aware of national medical guidelines, consider two opposite responses to be equally possible for the same patient based on the same data? Using Leonelli's data distinctions, we suggest that Paul considered data as relational. Rather than taking data as indicative of a singular reality, he thought about them in relation to a purpose. When the patient asked Paul whether they were evidence of an 'arrhythmia or something', the GP could either confirm or reject this specific claim, or do both, depending on recontextualization.

In relation to heart data, the GPs rarely questioned the measurements per se, but some did question the relevance of measuring heart data. Johnny, 64, explained how he was convinced that modern technologies did provide correct data. Yet, for him, the clinical question was *when* the data meant something potentially dangerous:

> I try to investigate if it is something that you actually feel [mærker], do you have any symptoms? Is there something? Do you have any background history or family related cardiovascular diseases or something like that? […] Then I would make my own judgment and say 'well, I don't think this means anything, you do not feel anything, and one can experience this, but this is not abnormal.'

Note that Johnny does not question the validity of the measurement, instead he focuses on the clinical relevance. It seemed that he wanted to assess whether this was a patient for whom measurements were relevant. Johnny therefore asked about symptoms, family history, and risk factors, which are all information to his clinical estimate of a probability for a given condition. If the clinical information did not indicate a heart disease, Johnny suggests he would consider the data from the wearable insignificant or unrelated to this claim for this specific patient: the data could represent just a minor sporadic, benign abnormality. These questions are all about judging the clinical context. Thus, he recontextualizes the data.

Other GPs reported letting heart data play a more decisive role. Data were seen as sufficient to initiate clinical action or, if the data indicated something harmless, the GPs would immediately dismiss any further investigations. Action could involve initiating new measurements, such as electrocardiogram, or making a referral to a heart specialist. Regardless of symptoms or patient history, these GPs generally interpreted heart data as relevant and reliable enough in themselves to initiate further actions. The GP Leif, 46, remembered a particular woman:

> It was an elderly patient that… What can you say? One of those patients who are very self-attentive. A very active elderly lady who had got a watch as a present from one of her equally attentive children, which she had used and been alarmed by and then we took an electrocardiogram, and she did actually have atrial fibrillation.

Note how much Leif's example of a data user sounds like Paul's. In contrast to Johnny, however, who said he would require additional clinical symptoms or information, Leif acted based on the data themselves with less recontextualization work. Leif explained his data response this way:

> I consider it the same way as if they [the patients] come with a sensation [fornemmelse]. I think you should equate it with that. I mean, this is a new way to get a sensation that something is probably wrong […] this has always been a reason for the consultations so I don't think one should, how to say it, pay too much attention that now they come with a watch that measures something.

As with Johnny, Leif did not question the validity of the data. But differently to Johnny, he considered data equal to patients expressing *symptoms*. In Leonelli's terms, Leif was treating the data as possessing evidential value for the claim of a heart disease. Interestingly, *he did not ask to see the data.* He relied on the patient narrative about them.

Morten, 40, similarly explained how his response could lead directly to a referral:

> And if they [the patients] come and tell me that the watch has stated this and that, and they maybe have had symptoms, then I refer them to a diagnostic investigation at a cardiologist. I cannot diagnose them with paroxysmal atrial fibrillation here.

Morten here relies on what patients say about their data and says that based on such narratives, he is likely having a diagnostic suspicion of a condition that do not necessarily show symptoms. Some GPs described data somewhere in between Johnny's and Leif's position.

Bodil, 55, explained how the patients could find it difficult to tell her what they 'feel' [føler] or 'sense' [mærker] when it is something unspecific. In such cases, data could serve as 'an icebreaker'. Other GPs explained it likewise as 'inspiration' or 'part of abundant information'. In all these cases, the key point is that the GPs did not actually look at the heart data or investigate the quality or validity of them but listened to the patients' description of them, much like the way they handle patients' description of symptoms. In a sense, this placed the data on par with a symptom narrative.

Sleep data from wearables: Limited recontextualization and no use

Sleep data elicited responses very different from heart data. While Leif described how he considered heart data generally reliable and relevant—despite never critically assessing them—he was reluctant regarding the value of the sleep data:

> They [the patients] come and say, 'my phone states that I am not sleeping well enough', then I ask 'well, are you tired?' [the patients answer] 'no I am not' [then I ask] 'do you have a problem

then?' [laughing] […] [The patients'] phone might have informed them of something but how are they? How do they feel? You know, what does the patient experience? Not based on the watch but their own, physical experience about themselves. […] So, it's also about making the patient aware sometimes: what can they use the data for?

We see here that with sleep data Leif approached recontextualization differently from heart data. His interest was limited. If heart data were taken to potentially reveal a 'hidden' state of disease, he did not look for such patterns with sleep, although there are sleeping disorders without manifest symptoms. However, Leif seemed eager to dismiss the data. Asked about how he made a judgment in such situations, Leif explained:

> Well, then it is all about old-fashioned medical work, where you ask for medical history and do a clinical examination and then you make a conclusion.

Leif's response to sleep data was consistently mirrored by the other GPs: the GPs would ask if the patient felt any problems sleeping. Why were the GPs less interested in sleep data as 'symptoms' indicating risk of nonmanifest disease? They described how they had limited opportunity to assess sleep and to compare the data with other measures; moreover, quality of sleep was difficult to assess. As Xander, 40, described:

> Yeah, it is really bloody difficult with people not sleeping. It is really, really difficult to say 'yes you do sleep', right? […] Then I refer some of them [the patients] to a sleep monitoring clinic but they get rejected […] then I tell them that I can see that your app tells you that you do not sleep. I would recommend a period where you try to turn it off to see if you have the same feeling as well. […] I have no clue about it [the data] and that is also what I tell them, I simply have no sense of it, it is so specific that it is out of my field of competence.

Unlike heart data, Xander could neither interpret the reliability or relevance of the data nor make a proper comparative assessment on his own of the patient's sleep. Thus, recontextualization was impossible as he could not create a proper clinical assessment of the context. Furthermore, there was not much he could do ('but they get rejected'), hence there was no point for the GPs in pursuing sleep data in contrast to heart data.

Interestingly, Xander had started using a smartwatch himself. He used it mainly for exercise purposes but also to monitor sleep. When Xander experienced several nights of bad sleep, he used the watch to confirm or refute his experience. Still, directly asked whether he had greater trust in his own experience or the measurement of the watch, he was not sure. He was unable to interpret the data even in relation to himself.

Were they still data then? Using Leonelli's perspective on data, 'any object can be considered as a datum as long as (1) it is treated as potential evidence for one or more claims about phenomena and (2) it is possible to circulate it among individuals' (Leonelli, 2015, p. 817). Thus, it depends on the extent the GPs treat these data *as potential evidence*. To be treated as evidence, there must be someone seeking evidence and, while this might be the intention when patients occasionally bring sleep data to the doctor, doctors are not necessarily looking for evidence for a state of affairs for which they have no or limited solutions. Even when all contributing factors are recognized and behaviourally and pharmaceutically treated, the positive effects on sleeping disorders are often only

partial (Winkelman, 2022). This would explain why the GPs responded to sleep data as having no diagnostic use and no evidential value.

Finn, 67, had a patient suffering from sleep paralysis, a condition in which the patient wakes up from sleep and is paralyzed. The patient showed the data from a digital ring that measured characteristics of his sleep. Asked to describe his own view of the sleep data, Finn explained how they were 'according to the textbook'. Asked if he thought about questioning the validity of the data, Finn explained:

> It fitted very well with what I have been taught about sleep patterns, so in that sense it was all right, you know.

Asked if Finn could have reached any different diagnostic conclusion if the data were different, Finn answered:

> No, if data had been different, then I would have told [the patient] that it was a lousy recording, right? Because what we mostly talked about was his description of how it was to wake up and not be able to move. The truth rests in this experience [of paralysis], no matter how he had slept.

Though being willing to look at the data, Finn found them of little use. They are not used as measurements with clinical relevance.

Why did GPs so often downplay the relevance of wearable data? Work routines may be part of the reason: one feature of routines is the limited amount of time with each patient. Mai, 50, had participated in a three-day medical course about sleep because of her great interest in the topic. Still, she explained, the consultation time was too short for her to properly investigate the patient's sleep data:

> It is difficult to get [the data] squeezed into one consultation. Because, I actually have great interest in sleep […] but when it just turns up during the consultation as 'could you just take a look at this?' […] So, I am trying to educate [the patients] a little more, that is, 'if it's something you really want me to investigate, then hand it in at the reception before the consultation, our fifteen minutes goes fast'.

Despite being more specialized in handling sleep issues than most GPs, data were provided to Mai in ways that were impossible for her to assess under the current clinical working conditions. The data were considered useless because of lack of time, just when Leif said he would have his patients rejected from the sleep clinic anyway. In 2020, Danish GPs manage on average 52 patient interactions per day, half of them face-to-face, the other half mainly by email and phone (Praktiserende Lægers Organisation, 2021). Work of recontextualization and interpretation requires extra time for the GPs. For this data work to make sense, it needs to lead somewhere: it needs to help close the consultation.

GPs aimed to recontextualize patient questions about laboratory results

As mentioned, Danish citizens have had online access to their laboratory results, including results from tissue investigations such as suspected cancers, since 2015. These data

are generated by healthcare professionals and integrated in the data infrastructures within the healthcare system. The GPs can then look up the results from their systems. When patients look at the laboratory results, the results are further classified by the online portal in various ways to explain the numbers, for instance, as 'below', 'within', or 'above' normal thresholds. The patients inquired with their GPs when they had noticed such low or high results. The GPs mentioned these data because the patients asked about them much more than data from wearables and online self-diagnosis and health tests. Further, the GPs described some interesting differences in how they thought about these data compared to data from wearables and online symptom checkers.

In contrast to the data patients bring from wearables, the GPs explained how they felt legally and morally obliged to assess the laboratory data and inform the patient if the data were abnormal. They would look at the actual data, not just rely on a patient narrative about them. As Paul explains:

> Yes, I am reading what there is [of data]. You are obliged to, I guess. You cannot just push it away […] The moment when I have just noticed it, it is on me.

Paul felt accountable for assessing the data, even when he felt uncertain of their meaning, and he had not been involved in what Heneghan et al. (2009) called the initiation stage of the diagnostic process.

The GPs described how the number of patient inquiries about these data have been increasing every year and especially since a new national health app 'Min Læge' ('My Doctor') was launched. Lotte, 41, summarized it like this:

> Now, we are being bombarded with blood samples from dermatologists for example. And all kinds of other specialists who are seeing the patients, and then they take blood samples and then we get a copy of the results without knowing why they were taken because we have not yet received the discharge file.

The GPs reported the importance of the discharge file to respond meaningfully to these data because they often would base their response on why the hospital took the blood sample and how the potential afterwards reacted to the data. They needed the file to recontextualize. Without this additional information, the GPs explained, it could be difficult—if not impossible—to assess why a blood sample was taken and what the data meant.

Nevertheless, the GPs described overall positive attitudes towards the ability of patients to look up online laboratory results and electronic health records from the specialized health sector. The GPs further found it 'smart' or 'really good' that they could look at the data together with the patients. They described this data work as 'sorting information', 'assessing the data', 'refuting dangerous conditions', and 'guiding the patients to find the right information'—all in line with the three forms of data work Fiske, Prainsack, and Buyx (2019) identified. Yet, the GPs also explained how data could sometimes be 'working against us'. Morten mentioned the work that follows with easy data access for patients:

> Now, anyone can pretty much keep up with most things. You can at home or on the phone get access to your laboratory data. One can see what a scan showed at the moment it was written. You can almost instantly see the doctor's medical record note, right? So, the patient's own data are very easily accessible to them. Not necessarily easy to understand, but easily accessible. And it does generate some insecurity for some patients. It also sometimes generates more work for the hospital system and for the general practitioners, because it often raises a lot of questions and doubts, where a need for clarification is then created before it might become necessary. Or where one can say that the patient has no benefit from having that knowledge at this time.

The GPs found it challenging to convince patients that it could be 'normal' (non-pathological) to receive 'abnormal' (beyond certain thresholds) test results. In such cases, Morten felt that the patients did not benefit from the easy access. Similarly, Finn, described how access to data can affect the patients' perceptions on health, and said this about his own response:

> Then the time is spent on explaining that everything is fine and there is no reason to be worried. So, there is a lot of information that unnecessarily medicalizes the patient [sygeliggør], where it would have been better if they either knew something about it or did not know anything about it at all. And it is expensive, creates illness, and steals time when we have to inform the patient about so much that does not matter.

Patient questions about data from online symptom and health checkers: GP responses depend on who ordered the test

Patients provided data from online symptoms and health checkers, but these could be from either their own searching of the internet or it could be by the GPs request from the GPs' own PRO online system. For the GPs, data from online symptom and health checkers had different evidential value—even when the test was exactly the same—depending on who initiated the test and on which platform it was performed. Moreover, and in contrast to wearables data, the GPs could consider the fact that a patient initiated an online test relevant, but its *results* useless. We suggest that the GPs could do so because of relational aspects of the data.

Mia, 39, explained why she—as the other GPs—had no confidence in the online symptom and health checkers results provided by patients:

> There are no validated tests out there [online]. And you have no clue who has posted something on their blog.

Mia was convinced that the tests were not validated, having as little evidential value as anything else anyone could post online. For her, the test results were useless. However, Mia described how it could still be useful to know that the patient had performed a test. Regardless of their thoughts about the validity of the actual test results, the GPs investigated the reasons *why* the patient had conducted the test. Although the test might be

invalid, the inclination to test might reveal some valuable information. Lene, 49, who had also worked as senior psychiatrist, described is as:

> I use them as a springboard for a discussion about 'but why did you take it?' It is fair enough if one… If they have actually tried to do something themselves, then it is fair enough to say 'what have you done?' and then find out what I can offer. […] It depends on why you took the test, right? If I make a depression score on a bad day, it could also be that I am scoring for depression. It is more to say, 'why did you take it'?

As with wearables, Lene did not ask to see the data; her focus remained on the patient narrative, not the actual test result. Most GPs described the tests as a starting point for diagnostic considerations Thus, in contrast to heart data from wearables, the GPs would not rely on the reported test results, but only inquire into the reasons for performing the test. The act of taking a test acted on par with a symptom.

With this attitude to scoring data from online symptom and health checkers, it may seem surprising that online test results are frequently used, for some GPs every day. However, those test results were from the GPs own online PRO system. Almost all GPs described positive experiences using digital tests and questionnaires from this system. The GP would digitally send the patients previously paper-based forms or questionnaires about mental conditions, such as depression, anxiety, stress, or somatic conditions, such as blood pressure, urine output, blood sugar, and headache. The tool automatically calculated basic measures, such as overall scores of points in a depression score or average urine output and so on; the patients' digital response was digitally integrated in the GP's clinical software. The GPs said they use the results from, for example, the Hamilton Rating Scale for Depression to compare the patient's results over time in combination with the GPs' own impression of the patients. Other GPs said they use the tests to prepare the patients before talking about it during the consultation. Others, to remind themselves to ask all the questions.

Interestingly, some of the tests were exactly the same as those initiated by the patients, such as the Hamilton Rating Scale for Depression and the Major Depression Inventory. The GPs dismissed the validity and relevance of data from patient-initiated tests with tests but used those from their own PRO system. We contend that this approach saves them the data work of recontextualization. Furthermore, data from the PRO system come to feature in the GPs' everyday routines and therefore appear as the GPs' responsibility, just as we saw with the laboratory results. According to Leonelli, the medium in which data are circulated affects the evidential value of the data (Leonelli, 2015). We may add: it shapes the moral obligations accompanying the data. The medium is part of providing data with evidential value. Thus, the same tests can become agents for action when integrated into the infrastructures of the healthcare system but are 'symptoms' when initiated by the patient.

The attitude toward the PRO system was unanimously positive. Importantly though, choosing to use the system was voluntary. Some GPs described how they had never figured out how to use it and therefore continued the paper-based tests instead. The experience of a data workload interacts with the sense of gained evidential value. 'Validated' or not, a test is not just a test. The same score can be seen as clinically relevant when

authorized by the doctor and irrelevant and time consuming when initiated by the patient. Whether data contribute to reaching a diagnosis does not depend on the data alone.

GPs recommended apps to close the case

While the GPs clearly feel more obliged to deal with data generated by the healthcare system, they were not all against the use of apps and devices. So when do they recommend apps? The GPs described their recommendation of apps to their patients first and foremost as a way of wrapping up the consultation. Moreover, the GPs spend little or no time judging the quality of an app before suggesting it to the patients. Asked why she suggested a specific app for headache, Lene, 49, explained:

> Because I have tried to download it and it seems manageable. Ehm, and it is purely random. If someone has come and said 'now I have tried these two and this one is much nicer' then I could end up finding it, trying it and see if it was much nicer. For a lot of patients, it is important that it is free.

Note how Lene suggested apps when the interface was nice and the app 'free', not based on an assessment of clinical relevance and validity. Benedicte, 52, explained how she suggested a particular app that tells you when to sleep:

> […] it doesn't matter whether you use one or the other or the third app. It completely doesn't matter. I don't spend time finding out which one, they [the patients] must find out by themselves.

Despite suggesting a specific app, Benedicte apparently considered the sleep apps on the market as equal. She did not want to spend time on analysing apps, and she was not paid to do so. We interpret that apps could be recommended, not based on evidence, but to offer patients *something* in the consultation.

In addition to the limited time, all GPs declared issues such as data rights and data privacy to be the patients' own responsibility. It was not part of their work. One GPs explained how he had 'no idea' about where data end. Or as Annemarie, 59, explained to the question if she had considered data rights and if she knew who owned the data from the apps she suggested:

> No. There are some who are very sceptical about such a thing. And there I feel like, 'You know what? That's not what I think is important.' I think people use Facebook, Snapchat, and all sorts of other things. So, all that data, they will for sure be collected somewhere. So, in that way, I'm confident that there is someone like the Data Protection Authority, or whoever it is, who is doing something so that it does not completely run away.

In Annemarie's situation, data rights were not her responsibility. She suggested apps, but she expected the 'authorities' to handle data safety issues. What mattered from her perspective was that the app was easy to access and free. She was not paid, nor was she trained, to assess data entitlements and safety. Thus, apps were recommended when they helped closing a case.

Discussion: policy ambitions versus everyday usability

The most striking finding in our study is that the everyday GP experience is far from the policy expectations outlined in the introduction. There are few patients bringing data to the clinic and when they do, data are not analysed as measurements. Rather, they feature on par with patient narratives about symptoms. In most cases, the GPs do substantial recontextualization work before they ascribe them clinical relevance. In only a few cases had the GPs looked at the actual data. Some cases related to heart disorders led to detection of otherwise undiscovered disorders, but if this had positive outcomes for the patients, we do not know (Brodersen et al., 2018).

The way that GPs report different responses to heart and sleep data suggests that they do not necessarily base their responses on insights into the validity of data or the devices from which they stem. Data primarily affect clinical decisions when they can serve as agents that can close a case, provide guidance on action, or bring comfort to the patient within the defined time frame of a consultation. Data then operate more on par with symptoms than as measurements of disease. We can discern three ways in which GPs relate to data as symptoms: they can represent 'sensations' (as when a device has captured a heart anomaly); indications of patient 'concerns' (as when GPs ask *why* a patient has used an online symptom and health checker rather than using the actual test result); or being clinically irrelevant 'noise' from physiological measurements (as when GPs try to make patients feel comfortable about sleep data without initiating any action). The clinical data work turns out to be less about working *with* data and more about working *in and around* data. They are not entities for analysis, but actants in the consultation flow. In some ways, this study raises questions about how symptoms themselves are regarded as having evidential data. It challenges the binaries of objective data versus subjective symptoms, by introducing notions of relationality, contextualization and decontextualization. And objective data assumptions appear to underpin the optimistic visions for a patient-driven digital healthcare system.

Our analysis of the difference between data from wearables or symptom checkers and data generated within the healthcare system has potential implications for the policy ambition of integrating new types of patient data into the GP digital systems. It might make GPs respond to such data—not because the data are correct, validated, or useful for helping the patient, but because the GPs now feel obliged (both clinically and legally) to act on the data. Therefore, we suggest that such integration can redirect the GPs' attention, but not necessarily ensure better diagnosis. Furthermore, the GPs will have to do recontextualization work, but without being formally trained for this.

Concerning limitations of this study, most importantly, the interviews provided insights into what the GPs recalled and thought of their data experiences, not what they de facto did. Secondly, this study cannot say anything about how new data types affect patient choices. The patient may *not* have mentioned all relevant types of data to their GPs. Neither does our study indicate if socio-economic or other demographic differences between patients affected the GPs' responses to patient data. Furthermore, the selection of respondents, who all had affiliations to a university, could potentially affect their thoughts or answers on the topic compared to other GPs. Most of the interviewed GPs, however, were only associated with having medical students or resident doctors working

in their clinic, which is also common among doctors without associations to the university. Future research could consider how different specialties work with data, and how patients themselves regard the provision of data within consultations.

In accordance with the mentioned Danish surveys, most of the interviewed GPs had experienced patient inquiries about wearable data, albeit rarely. Ziebland et al. (2021) found that digital technologies in primary care can create paradoxical consequences, such as more workload instead of less, and the creation of disempowerment instead of empowerment. In our study, it seems unlikely that these new forms of data empower patients in the way that policy makers imagine. Gabriels and Moerenhout (2018) found that the GPs were sceptical towards seeing data as empowering the patients. Like us, Gabriels and Moerenhout also found that the GPs have few experiences with patients bringing wearable data, and concerns about the need for context to interpret data, the risk of extra instead of less work, and concerns about medicalizing patients unnecessarily. Similar to other studies, we found that health professionals are not formally trained to do data work (Møller et al., 2020; Pine et al., 2018). Within the field of psychiatry, in the response to Covid-19, Skorburg and Yam (2022) argue that the evidence of using digital technologies is weak and may increase health inequalities. These aspects are part of the longstanding discussions of the need to integrate health informatics training in medical school and creation of new data-based medical professions (Fiske, Buyx, & Prainsack, 2019; Strauss, 2010).

Our study adds that GPs often make judgments about data in isolation and this means that further research and education is a pressing need, not least if new infrastructures facilitate easy patient upload of data. We found that none of the GPs were well prepared for handling these new kinds of data. Based on their current training, GPs may use new types of data to initiate unnecessary diagnostic procedures and treatments. Our results show how some GPs are referring patients to heart specialists based on patients' impressions of the data from their wearables. This creates extra work for several professionals throughout the healthcare system. This risk may be small for the individual patient but significant and relevant when accumulated on a societal level, not least because every diagnostic procedure may identify additional reasons for prevention or treatment, irrespective of whether the patient would ever have suffered any symptoms.

A different dimension of preparedness for a digital age goes beyond the clinical relevance and relates to data security and the political economy of online data. It was not clear for the GPs to what extent they could be held accountable for the advice they provided about apps. However, most of the GPs interviewed for this study did not assume responsibility for data security issues. They have very limited training in this field. In the current drive towards datafication of health, questions are raised: where can GPs seek help? How much time are they supposed to spend on uncertain data work?

If the policy ambitions for the investments in data infrastructure are to be fulfilled, frequently updated policy frames and clinical guidance for GPs are needed now. Companies often brand the functions of the wearables as free and some studies suggest that many consumers have trust in these tech companies (Lupton & Jutel, 2015; Shih et al., 2022). While policy frameworks to improve decision-making of clinical apps and wearables are under development in many countries (Essén et al., 2022), new data are currently introduced faster than the introductions of frameworks and guidelines. More than 325,000 health apps were available in 2017 (Research2Guidance, 2017).

Our study therefore holds important lessons for policy makers and digital entrepreneurs currently subscribing to the conviction that '[d]igital technologies can make daily workflows easier, reducing administrative burden and freeing up time for more patient-focused care. Above all, they can add value in clinical practice, helping achieve better health outcomes for patients' (European Commission, 2022a, p. 14). Our study does not support such claims. Instead, we find that the usefulness of the new digital data types is strikingly limited. Moreover, our study suggests that working with the data can be costly for the individual GP, and therefore, communities.

Accordingly, there is reason to question the rationale for major investments in data infrastructures to facilitate upload of patient data. Investments in integration of patient data into clinical systems might not be worth the money. Why not focus on investigating what works in the present before investing in the future? Policymakers in the EU argue that 'the limited use of health data puts limits on making more efficient and effective healthcare and public health policy' (European Commission, 2022a, p. 6). This is ironic, when they pay so little attention to current data practices before investing in new ones (Hoeyer, 2019).

An alternative approach to more efficient and effective healthcare and public health policy could be to invest in a grounded understanding of what health professionals need and find useful. Indeed, we believe there is an important role for STS in helping to rethink how data operate in medical work. There is no doubt that data in healthcare have had and will have increasing diagnostic value, but this value does not spring from data alone. Realizing the positive potentials requires more than optimism.

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