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Old data in new devices? Problematic popularizations of digital health data and consumer devices

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Abstract

Digital health data and devices have become increasingly popular in the last two decades. This resonates with research on the expansion of health data ecosystems, the platformization of health issues, the rise of consumerism in medicine, and the movement of big tech into healthcare. The proliferation of popular health devices, such as activity trackers and smart watches, however, does not simply reinforce existing dynamics of medicalization or economization. The expansion of digital health data opens up a contested space in local settings, such as doctor-patient interactions, where data and devices are evaluated and negotiated, depending on and varying by symptom, medical discipline, and type of patient. We focus on these negotiations by analyzing how popular apps and devices create instances of problematic popularity, where popular devices and personal data conflict with professional authority. We suggest three distinct types of popularization of digital health data and devices - professionalization, personalization, and public attention. Our perspective foregrounds the importance of popularization as a practice for enabling and constraining the expansion of health-related data into local healthcare settings.

Keywords: problematic popularization; digital health devices; health data ecosystems,

1 Introduction

The convergence of medical and media technologies in smartwatches and activity trackers is often conceived in terms of an "expansion of the health data ecosystem" (Sharon and Lucivero 2019): Digital media become (quasi-)medical technologies that circulate data, practices, and knowledge into arenas outside traditional medical settings, similar to the expansion of medical categories in processes of medicalization (Conrad and Potter 2000). As research has shown, this expansion is not a singular dynamic, but a complex and multilayered process. For instance, it can be a source for patient empowerment by taking control of their own data (Maslen and Lupton 2020). However, digital health data can also be inconclusive and messy because of the hybrid status of health apps as being neither purely lifestyle, nor medical devices (Williams et al. 2020). We add to this line of research by analyzing how the expansion of digital health data and devices is negotiated on the micro-level of daily use practices and doctor-patient relationships. Our main focus will be how digital data is made (ir)relevant in doctor-patient interactions and how this can be understood as a case of problematic popularity with respect to medical authority.

We suggest the notion of *problematic popularity* to investigate how the expansion of digital health data through consumer and lifestyle technologies in turn becomes an issue for professional medical authority (Gabriels and Moerenhout 2018). On the one hand, popular devices like smartwatches and activity trackers extend biomedical measures into everyday life, producing ever more digital health data. On the other hand, this patient-generated data is not considered as valuable or reliable as professionally generated data (Wyatt et al. 2013; Haase et al. 2023). We are interested in how the limits of expanding digital health data are negotiated in the relation of experts and laypersons. Research on the persistent asymmetry in doctor-patient relationships (Pilnick and Dingwall 2011) has highlighted how the lay-expert dichotomy is maintained in the face of demands for more participation. Medical doctors may also be reluctant to employ novel technologies, e.g. in case of telemedicine (Greene 2016). In our understanding, problematic popularity emerges in the threefold relation of *popular devices*, *personal data* and *professional recognition*. This understanding allows us to follow the dynamics of expansion while being sensitive to the multiple layers of resistance to expansion. We seek to analyze these resistances as they are being negotiated between physicians and patients, based on how doctors *and* patients pay attention to and evaluate digital health data. We draw on 35 qualitative interviews conducted between 2022 and 2023 with 20 chronically ill patients and 15 healthcare providers in Germany.

The interviews show that personal data created with popular devices does not automatically become relevant as professional data in doctor-patient interaction. The relevance of digital data and devices varies by symptom, medical discipline, type of illness, and other factors. This resonates with previous findings that the widespread availability of health information on the internet and the "end of the medical monopoly over medical information" (Hardey 2001), is not a threat to medical authority per se (Kivits 2004). Despite the growing expertise

of patients and other parties involved (Bellander and Landqvist 2020; Bernardi and Wu 2022), patients themselves may refrain from sharing information with medical professionals. From our Interviews, we see that both patients and doctors are engaging in "boundary work" (Gieryn 1983) to demarcate relevant information from non-relevant information during the consultation.

Our article is structured as follows. First, we will systematize the expansion of digital health data in terms of the popularization of data and devices. We distinguish three notions of popularization that are relevant for our case: the *diffusion of professional knowledge*, the *growing popularity of digital data and devices*, and the *increased personal use for medical purposes*. Second, we investigate these forms of popularization and how they may create tensions between professional, popular, and personalized ways of attending to digital health devices and data. We will do so by drawing on our interview data and closely link the conceptual approach with our empirical findings. This will enable us to relate our research to the growing body of literature on digital health data and devices and to show how private data and popular devices affect professional practice. Third, the discussion section will elaborate on the tensions we have identified and how they can be understood in terms of problematic popularity. We will end with a conclusion of our findings.

2 Popularization of digital health data and devices

The expansion of health IT in society has many facets. It can be seen as increasing informatization (Nettleton 2004), datafication (Ruckenstein and Schüll 2017), algorithmization (Henriksen and Bechmann 2020), platformization (Williams et al. 2020), technization (Semel 2021) or personalization (Vicari and Cappai 2016), and, no doubt, several more. In this article, we focus not on specialized medical technologies, but on consumer technologies such as smartwatches and activity trackers that patients use for purposes of self-monitoring (Lupton 2013). We seek to understand how the convergence of medical and media technologies in wearable devices and software apps pushes back on the established authority of the medical profession because of the popularity of these apps and devices. Popularization can be, on the one hand, a counterpoint to professionalization. On the other hand, professional biomedicine was itself popularized during the 19th and 20th century (Hansen 2009) and now has become part of popular culture (Görgen, Nunez, and Fangerau 2019). While professional medical technologies may have an alienating effect on patients (Williams and Calnan 1996), the popularization of digital health technologies can foster emancipation (Maslen and Lupton 2020). The multiple interrelations of popularization and professionalization shed new light on how the expansion of digital health technologies in society is brought about and we will elaborate on our understanding of popularization in the following paragraphs. We understand the popularization of digital health technologies in three distinct yet related aspects: 1) the circulation, diffusion, and contestation of knowledge claims over health, raising the question of who counts as an expert and a lay person; 2) the distribution and access to objects through which body data and medical knowledge is accessed (gatekeeping of what constitutes a good source of knowledge and who

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should be listened to; and 3) new ways of measuring documenting and analyzing health-related phenomena, thus raising attention to bodily phenomena that were formerly unaccounted for. We will outline each aspect of popularization in relation to digital health data and devices, before exploring their relations and differences.

2.1 Popularization as the diffusion of professional knowledge

One aspect of popularization lies in the *simplification and diffusion of expert knowledge* to address lay publics (Myers 2003). The "dominant view" (Hilgartner 1990) of this concept assumes a sender-receiver model of communication whereby expert knowledge is simplified and communicated to a mass audience. Critiques of the dominant one-way model have argued that popularization is better understood as a nuanced, bi-directional process in which experts as well as lay people develop claims of expertise (Scavarda and Ariel Cascio 2022). Through processes of popularization, knowledge is not only simplified (ibid.) or translated to become understandable by lay people, but also appropriated by "lay experts" (Epstein 1998) who may challenge, or draw attention to phenomena otherwise unattended by professionals. The rise of professional medical dominance (Freidson 1970) is strongly related to the popularization and control of biomedical knowledge, leading up to concepts such as "medicalization" (Conrad 2007), focusing on the expansion of the jurisdiction of medicine into manifold areas of everyday life. Similar to the diffusion of expert knowledge, medicalization can be driven by multiple actors, including medical professionals, technological and pharmaceutical industries, patient advocacy and self-care groups, and other interested parties.

Digital health devices and their data are part of a longer list of information and communication technologies that act as "popularization tools" (Anesa and Fage-Butler 2015) to negotiate claims of expertise. Rather than being mere conduits of expert knowledge, they participate in the creation, circulation, and contestation of expert claims. Digital media like online forums (Frank 2012), algorithmic recommender systems like "Dr. Google" (Mager 2009), or health apps circulate and make debatable what counts as medical knowledge. For instance, studies of online media have discussed how patients use forum communication to propagate and debate medical expertise vis-a-vis their identity and self-diagnostic practices (Campbell 2021; Glumbić, Đorđević, and Brojčin 2022). Studies on diagnostic technologies suggest that they may promote, but also hinder medicalization, if they prove to be unable to capture a medical condition (Rafalovich 2013). Our interviews suggest that apps and data become objects to discuss claims of expertise, for instance when patients actively hide or show certain data, or when doctors and patients collaboratively interpret the results of apps. We see that the struggles over professional expertise influence the acceptance and meaning of patient-generated data in our cases.

2.2 Popularization as increased public attention

The second aspect of popularization lies in *measurable public attention*. In contrast to the simplification and diffusion of expert knowledge, the claims for importance and attention derive from whether someone or something

is being noticed by many (Werber et al. 2023). Professional medical knowledge may still receive attention, but its status as certified expert knowledge no longer guarantees this. Instead, public attention may be attached to objects of popular culture as well as biomedical knowledge and both may affect and mediate one another in a variety of ways (Görgen, Nunez, and Fangerau 2019). The notion of the "lifestylisation of health" (Lucivero and Prainsack 2015) describes this hybridization of health devices and data in between medicine and consumer culture (Nettleton 2004; Saukko 2018). Wearables and apps use bio-physical measures (Williams et al. 2020), claims of efficacy (Larsen et al. 2019) and discourses of individual empowerment (Ochs, Büttner, and Lamla 2021; Maslen and Lupton 2020) to garner public attention. As Williams and colleagues argue, health apps, data, data visualizations, and instructions inscribed in apps balance a difficult tension being objects of popular culture that shall appeal to a broad public, while also being objects of medicalisation that offer quasi-medical knowledge to their users without being vetted as such. Often, this hybridity is discussed as a discrepancy between popular device features that receive attention by many, and their clinical utility for doctors and other providers (Haase et al. 2023).

Public attention does not only refer to popular health data and knowledge, but also to the consumer health wearables and apps themselves. Public attention is documented by download statistics and sales figures, engagement metrics (via monthly active users), and opinion (via app ratings and reviews) that are associated with different understandings of popularity. Aside from offering different criteria of attention, measurements of public attention also affect the distribution and visibility of health devices and data. Within the medical context, this is often discussed in connection to a reorganization of gatekeeping functions over relevant information. Scholars debated how health influencers (Hendry, Hartung, and Welch 2022), Google search algorithms (Mager 2009), or app stores (Dieter et al. 2021) render certain health information more visible than others and how people consult such information. The interlocutors in our study did not directly address the popularity of apps and devices as a dominant factor. However, the sheer availability of data was a central concern to some of them. Being able to use popular consumer technologies to generate personal health data was seen as a novel way of creating relevant knowledge, even though the epistemic value of the data remains in question.

2.3 Popularization as personalization of data and expertise

Next to the diffusion of professional knowledge and the popularity of apps and devices, popularization can also entail the *personalization of healthcare and medicine* (Jain 2002) by means of datafication. While some argue that medicine has historically always been personalized in the form of "bedside medicine" (Jewson 1976; Prainsack 2017), nowadays personalization means an expansion of data types and measurement frequencies that results in individual-level longitudinal datasets. With the arrival of new individual-level (or n=1) datasets, personalization assumes an expansive understanding of health (Jain et al. 2015; Vayena and Gasser 2016) that considers various data as "health-related" while also introducing new measurements that use population-scale averages to establish health claims, but that rely on relationships between data related to an individual person.

Scholarly critique of personalization as a new biomedical cosmology points to the increasing range of potentially health-related data without offering conclusive diagnostics (Roth and Bruni 2022). Personalization is often related to medical settings in the form of personalized medicine, but also consumer devices for non-medical self-tracking promote personalized datasets (Lupton 2013). In recent times, index measures such as the "readiness scores" indicate if vital signs like heart rate deviate from personal "baselines" (e.g. with the Oura Ring). Rather than using established medical norm values that rely on population-level averages (such as the Body Mass Index) these readiness scores individualize health by referring to health changes within the individual. In contrast to public attention, popularization through personalisation does not necessarily make digital health data publicly visible, but instead operates by mere availability of personal digital health data through the popularity of digital health apps and devices. Indeed, our interviews indicate that this aspect of popularization is relevant for negotiating the status of health data during consultation and thus for maneuvering the distinction between experts and laypersons.

3 Popularization of digital data and the shifting of professional authority

Each of the aspects of popularization mentioned above has the potential to push back on professional authority and thus may be a source of problematic popularity. To understand how they become relevant in doctor-patient relationships, we draw upon an ongoing study of the usage of popular consumer health devices and data by doctors and patients. We interviewed doctors and patients (n=35) about their use of these technologies in daily settings and in interactions between doctors and patients. In total, we recruited 21 patients with health conditions such as lipedema, heart failure, diabetes, insomnia, sleep apnea, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and Post-Covid. Another five participants were recruited through three focus group meetings. We also included doctors working in outpatient clinics and hospitals in order to increase the breadth of providers, care practices, and clinical settings in which consumer health devices and data may play a role. This resulted in interviews with 14 doctors, including two general practitioners, three cardiologists, three somnologists, one nutritionist, two obesity therapists, one surgeon, and two diabeticians. The cardiologists, one somnologist, and the surgeon worked in a clinic. With the exception of two interviewed providers, all had experiences with consumer health devices in their consultations.

We draw on this data to answer the following questions: 1) How do doctors and patients use consumer health devices and data in the context of (chronic) illness and what is their perceived relevance? 2) How and why do patients share data with doctors? 3) How are devices and data integrated into doctor-patient interactions and into the treatment of (chronic) illness? We developed interview guides for both groups to inquire first into the overall uses and types of digital health devices and data, followed by questions on the actually experienced interactions between patients and providers that involve consumer health devices or data. Both guides used a closing question on how the use of digital data and devices changes the doctor-patient relationship. Interviews

were recorded and transcribed verbatim. Quotes here have been translated into English and we use interview codes to maintain anonymity. Written consent has been obtained before the interviews and the study received approval from the ethics committee at the University of Siegen. The interviews were discussed within the project group and iteratively interpreted through principles of abductive analysis (Timmermanns and Tavory 2012). We organize our findings with respect to three distinct modes of engagement: accommodating, neglecting, and resisting consumer data and devices. We reconstruct the reasons and interpretations that condition these responses to digital health data and devices.

Specifically, we emphasize that different types of popularization require the negotiation of professionalization, public attention, and personalization. Our main argument is that the simultaneous expansion and boundary management of medical knowledge through consumer health devices and data is an important tension that emerges through interactions between different *types of popularizing* health devices and data. As a result, we hypothesize that the expansion of popular health devices and data results from the management of tensions between different actions, interpretations and interests in these devices and the associated understandings of health and illness. To give an example, popular devices may promote simplified biomedical knowledge, but may not be approved by, or shared with professionals, thereby escaping professional control while at the same time expanding biomedical measurements through the medium of a health app.

In the following sections, we will examine and discuss the various practices of chronically ill patients and doctors to actively expand or draw boundaries towards digital health devices and data and to accommodate the data in diagnostic, therapeutic, and self-monitoring practices, or to neglect and not mention devices and data in consultations. We will explore the relations between personalization, professionalization, and public attention to elaborate on processes of *bridging* between these types of popularization (leading to expansion and hybridity of digital health data), as well as forms of *boundary-making* and *distinction* (limiting the expansion of digital health data).

Patient-generated data in the form of personalized measurements, are generated outside of clinics, and possibly do not abide by medical standards, yet they are used to *establish knowledge claims about the body*. Bridges as well as boundaries arise from the general possibility to use data from consumer devices in professionalized practices, such as treatment planning, (self-)diagnosis, or screening.

Making lifestyle devices medically relevant by including them in clinical practices
First, the difference between lifestyle and medical technology depends on measurement and usability for therapeutic or diagnostic purposes. Several doctors, including a GP, a clinical cardiologist and a somnologist, considered consumer devices to be lifestyle products who nonetheless afford measurements that go beyond lifestyle applications. Somnologists in particular were skeptical about sleep-related measurements from lifestyle devices such as hypnograms. Respondents positioned themselves against these measurements as limited measurements.

"And of course such a measurement on the wrist cannot replace sleep diagnostics, it cannot. Because ultimately it measures very limited things, heart rate, movement, etc. And we can attach 30-40 electrodes directly to the body and we monitor that too. [...] One has to distinguish, there are lifestyle instruments and medical instruments. And these are entirely different areas one moves in." Somnologist (B25)

At the same time, this somnologist also argues that some measurements are useful, but that they remain non-medical as long as the doctor does not use them in a "medical program."

"What these devices can do well, I think, is that they measure heart rate, definitely and that they of course measure movements and that they may also draw conclusions about oxygen saturation and that you might see a screening like that. That I say, um, suspected sleep apnea, do that for a week and then you look at the curves and then you say, OK, well, now let's get into the medical program." Somnologist (B25)

Interestingly, the data is considered to be partly relevant. Somnologists make clear distinctions as to which measurements are relevant as long as they can be used to invite a patient to follow-up and as long as the measurement itself is relatively clear and easy to perform with a smartwatch. The somnologists we interviewed said that wearables are good tools for measuring blood oxygen. The doctor's clear demarcation disappears when he thinks about the individual measurements in more detail and as long as the somnologist can "get his recognized medical device" to do further measurements.

The 'medical program' that somnologist (B25) spoke of delineates the boundary between lifestyle measurement and professional measurement. It describes the process of initiating diagnostic procedures and 'professional' measurements that are done with 'professional' equipment that are validated by clinical tests and compared with established medical standards. A hospital cardiologist shifted her perspective on consumer cardiological devices. As long as she prescribes the device for a certain period to ask patients to collect ECG data for limited-time monitoring, the device is considered a reliable source. If people use it in their free time, it is a lifestyle product, but this boundary is not clear-cut:

"Now I call it a lifestyle product, but probably it is… It's actually a bit more, because... I mean the patient learns what it [the ECG measurement] means while using the app with us and secondly how I [the patient] can integrate this [measurement] in my own treatment." Hospital cardiologist (B14)

For the hospital cardiologist, the educational effect is what creates the difference to a pure lifestyle product. Consumer measurements can identify possible problems and symptoms that need further validation and can lead to treatment. Doctors make a distinction between measurements that resonate with their therapeutic and diagnostic practices, and measurements that are not usable.

Consumer data are (inconclusive) trends and indicators

Popular consumer devices often provide inconclusive data that requires further interpretation. The somnologists we interviewed reported that trend data can provide useful clues to identify problems and symptoms. Although the data is not perfectly accurate, it can be a clue when the measurements indicate possible anomalies. Doctors and patients value the ability of consumer data to show "trends" (long COVID patient B15), "tendencies" (long COVID patient B18), "rough directions" (general practitioner B8), or "cues" (somnologist B29). A difference is whether doctors and patients assess this characteristic of data as helpful, or as a problem.

A general practitioner said that some patients do not want to do longitudinal measurements, for instance if the measurement device for 24 hour blood pressure changes is uncomfortable. In this case, he asks the patient to use a less accurate consumer device whose data give him an indication whether his treatment plan brings a patient in the right direction:

"You can gauge your way through it a bit. Of course, it's not calibrated in terms of quality and not quite as, er, meaningful. I don't have the night values, but it's much better than flying blind." General practitioner (B8)

This doctor takes a pragmatic approach to gather measurements that are meaningful enough but also possible to measure, considering the preferences of the patient. He told us that he still has the option to take professional measures if these trends show him problematic values. Several doctors and patients shared this approach to consumer device measurements. However, not all consumer device data can indicate relevant trends. Doctors need data that are compatible with their diagnostic practices. All somnologists we interviewed said that they find oxygen saturation levels from smartwatches a relevant trend or indication of a sleep apnea symptom that could help these doctors "screen" patients for an illness that may otherwise remain undetected. In comparison, somnologists said that personalized sleep scores or hypnograms were not relevant because they were too inaccurate and simplified compared to professional sleep monitoring devices. The acknowledgement of consumer data as useful trends is therefore not universal but seems to depend on the complexity of measuring certain biomedical values, as well as whether these values are readily meaningful for a doctor's diagnostic and therapeutic practice.

Interestingly, notions like trends or indicators are also used by doctors and patients to consider consumer device data as not medically useful because the data are not accurate enough, or because it is unclear how to respond to them. For doctors, this inconclusive data can also be a problem in cases of emergency. Data is a "signal" or a "clue" and this can create problems for doctors if there are no clear guidelines on how to handle it. A diabetician uses the example of blood pressure alerts:

"And then there are programs [...], yes, then it flashes red when the blood pressure is elevated. We also had this in the Advisory Board, that we consider what happens then? Do I have to look into this as a doctor today and then react? [...]

and it was clearly stated that it was just an indication, right? [...] So I don't think I'm obliged to do that, but I think you have to define that, of course." Diabetician (B10)

A diabetes consultant says that providing personal measurements also blurs professional boundaries because you are dealing with measurements and diagnoses that no longer fall within your own area of expertise:

"So, that's really difficult. Because some things are not my area of responsibility. No? You always have to filter out a little bit, what can I [emphasized] actually change. And what it's worth. And then she told me about an app where she documents her cycle and an app where she looks, the nutrition app, the nutrition app. So some people get lost in there too." Diabetes consultant (B11)

For this diabetes consultant, the solution lies in establishing "rules of the game" with patients to filter out what kinds of data a diabetician can work with. Filtering out relevant data from irrelevant data is a common practice that other doctors reported to us, often to manage the production and analysis of data.

Data are interesting, but not necessarily medically relevant
The inconclusive nature of consumer data leads several patients to speculate about the usefulness of consumer devices and data. Several respondents refer to the type of device when asking about the accuracy of their measurements. A person suffering from ME/CFS said that "naturally, so a pulse watch, you don't know if the measurements are correct" (B22). A common response from patients was that the novelty of the device and curiosity about its possible usefulness made them engage with it. Several long COVID patients used an app that interprets heart rate variability data to create a score for the day in order to help these people pace their energy. These people were unable to assess the medical usefulness but wanted to support the app. Other respondents spoke about consumer devices being "a nice toy". One patient explains that they use a device for informative reasons, but that the indications of the data are not medical because they are not accurate:

"I just find it interesting, even if you get a rough idea. So I don't have the need that this would be of high medical quality when it comes to topics like O2 saturation in the blood, or sleep monitoring, but as an indication, as a hint, I find it interesting." Patient with stutter (B1)

Some patients thus connect accuracy to medical quality. Similarly, a patient with long COVID argues that their Garmin device is a "trend meter", but not a measurement device that reflects with perfect accuracy how one's heart beats. Another common approach to interpreting consumer device data is to consider them as guidance for everyday life that confirms one's feelings of a symptom, but that is considered not to be able to accurately reflect a complex chronic illness. A person suffering from Chronic Fatigue Syndrome illustrates this when she speaks about the use of the Visible app, an app that wants to help patients to pace themselves by analyzing,

among others, the heart rate variability (HRV) as an indicator of exertion levels:

"So reading something from a value [note: HRV], that's not what I expect from this app. For me, it's a practical symptom diary where I can see for myself how things are going. And the HRV, that's just a feature that I think is exciting. [...] It is also difficult to put a value on this whole disease." Person suffering from ME/CFS (B22)

For this person, HRV is not the key value she considers during her day. Rather, she uses a mix of heart rate timelines in combination with everyday situations to make decisions about what activities to pursue during the day. This shows that some patients do not expect accurate measurements from consumer devices and rather use it as another piece of information for everyday decision-making. It also shows that some data is used mostly for personal use and may not be shared with doctors during consultation.

Patients and doctors both create boundaries and distinguish personalized data from medically relevant information. That has the effect that patients do not see certain personal data as meaningful for others and therefore do not communicate them with doctors. This could explain why doctors often tell us that only a minority of patients bring personal data from consumer devices to the consultation. In addition, chronically ill people consider personal data to be interesting without being relevant for their illness or medical uses. Notably, the data respondents deem irrelevant include data that some doctors find relevant (e.g. movement profiles). This supports the argument that health data must be made clinically relevant and is not relevant per se (Haase et al. 2023).

Generally, most interviewees who were members of self-care groups told us that they do not share data publicly, be it in a Facebook group, or within an offline self-care group. With exception of one lipedema group, no respondent told us that their group is actively discussing measurements from wearable devices among each other. In addition, most respondents with chronic illness told us that they rarely share data with the doctor. The responses by patients show us that they bring their data to the (public) attention of other patients and seek professional interpretations from doctors if they perceive data as relevant for others.

We find different reasons why patients consider data to be relevant or not: prioritizing what symptoms to discuss in consultations; perceptions of doctor's time and interest; and perceptions that doctors should see professional patterns where patients as lay people can see none.

Patients expect a professional interpretation of their data

Several patients said that they are unable to assess if their measured data is medically useful, but that they expect doctors to be able to interpret data from consumer devices. Some respondents assumed that collecting different kinds of data, like activities, blood pressure, heart rate variability, or others, can contain meaningful correlations that doctors would be able to see. Other respondents assumed that the data from consumer devices ought to be relevant for doctors, because their measurements resemble what doctors measure with professional devices.

"And so I first bought the blood pressure monitor and then a little later the scales because I thought, if you add the scales, then at least you'll have more data that can be related to each other." Blood pressure patient (B3)

Some patients understand data to carry possible meanings that doctors as experts ought to be able to see. In this case, patients put themselves in the role of the layperson and share data with doctors to receive an interpretation.

"I went to my GP as a blood pressure patient and said that I had some [blood pressure] data, but they weren't really interested in it. They might have looked at it once in a while when I presented something, but they didn't ask for a proper list [of data] and perhaps at what intervals [to collect it] to see if there was anything recognizable about why my blood pressure was higher at some times than at others. Or what has actually improved with the medication. You could perhaps read that from the data. As a layperson, I might be able to do that superficially, but I think an expert might be able to do a bit more with it. But it doesn't happen." Blood pressure patient (B3)

The quote exemplifies a common experience of patients sharing data with doctors. Datasets make visible the distinction between expert doctors and lay patients, because patients assume that datasets can include patterns inaccessible to patients. According to the respondents, the value of patterns can derive from more variety of data assembled and related, or from longitudinal time series of one measurement. Several times, respondents criticized the 'quick glance' of doctors as opposed to a systematic assessment of data. They argued that consumer devices provide systematic and comprehensive analyses, but that these personalized cardio points and sleep scores do not provide medically relevant information, whereas doctors could do.

"With the blood pressure, I said I have the data here on my smartphone and so on, you can take a look. She looked 'Yes, aha, yes, ok, you had something higher there, then something lower there and so on'. But it's more like saying that what Google itself does here in part, here Google Fit, is that they say we'll evaluate it and make cardio points out of it and you should achieve so and so many cardio points in the week and so on. And, uh, that's bad and that's good, the systems do that almost automatically. But, uh, an individual one... I expect a doctor who does that to link the situation to my illnesses, of course. Google Fit doesn't do that. Google Fit doesn't even know that I have CIDP or high blood pressure or something." Blood pressure patient (B3)

For this respondent, a systematic assessment of medically relevant data from consumer devices requires an intervention by doctors who can provide systematic assessments. Another person suffering from long covid criticized the temporal nature of professional measurements used by doctors to make treatment decisions. This person measures sleep quality and stress levels with an Oura Ring. The respondent pays less attention to personalized data, such as the "readiness score" or stress levels that her Oura Ring calculates, but goes "a level

deeper" to look at individual measurements like heart rate or her heart rate variability. For this person, longitudinal data from her Oura Ring could enable doctors to give more proactive advice on health issues, based on the theory that heart rate variability, and the level of physiological stress it measures is an indicator of long term health. Two respondents suffering from ME/CFS and Longcovid, for instance, said that they wished cardiologists would use pulse and ECG data from their Apple and Garmin watches. One of the respondents makes this clear:

"So I think I'd particularly like to see that with cardiologists. Or perhaps internists, who also look at the heart. That they also look at the data, i.e. pulse and ECG data. Because my daughter recently had a 24-hour ECG that wasn't right at all. But she knows from her watch that it's not okay anyway. The cardiologist only ever gave her the 24-hour ECG. And theoretically, he could also use her watch or look at her app. That then and then, or at least once a week, she has an incident where her heart is not OK." Patient with ME/CFS (B6)

These respondents distinguish between medically relevant data and consumer data and they assume that doctors can use data because it provides measurements similar to a doctor's professional devices.

Shifting relationship due to patterns - from small measurements to big picture
Several doctors see the ability to create data patterns from consumer devices as an opportunity. For doctors, personal records are not new, but the amount of records produced in private settings can help doctors see patterns in data. A general practitioner gives the example of a food intake app that can create an overview of behavioral patterns that the doctor can discuss:

"Well, you can often recognize patterns in these logs. So pattern recognition. This is something that always plays a very important role in such protocols and patients often don't see this. They are too caught up in their own situation, so to speak, to have a neutral view of the situation from the outside. And a presentation like this is of course very helpful in recognizing certain patterns." General practitioner (B9)

The ability to see patterns and to move from individual situations to a larger behavioral patterns was also mentioned by diabetologists and cardiologists. These doctors create longitudinal data about measurements they deem relevant to educate patients about their health. As a result of using longitudinal data from consumer devices, several doctors argue, the topics of a consultation are "shifting slightly". Both doctors report that there's a shift in the topics one discusses. Both doctors educate patients about their illness through data visualizations. For a diabetician, conversations shift away from "inject one unit here and there" and allow him to discuss broader questions of life management with a patient, while educating them about measuring and supervising themselves through continuous monitoring. Another diabetic patient argued that discussions with his diabetician changed from measurements to the "tough nuts to crack" that this patient considers outside of his

expertise. The doctor becomes important not as a daily helper, but as a conveyor of expertise.

Data are not important enough besides other symptoms

Upon the question why patients do not share data with doctors, several patients tell that they weigh which symptoms they are disclosing with the doctor. Particularly patients with ME/CFS and long COVID say that one must think how many symptoms one mentions during a doctor visit. These patients perceive doctors as "too busy" and mention a "flood of concerns" or a "list of 5 [topical] points" that leaves no room during a consultation to discuss data. Personal data are only disclosed when patients can relate them to a symptom they perceive as important enough to discuss. Particularly, interviewees who suffer from Postcovid or ME/CFS told us that they ruin their reputation with the doctor if they share too many symptoms. One patient argues that they share data if it is connected to a clear symptom that they perceive can be treated. This suggests that patients judge if data is relevant enough compared to other symptoms.

Patients perceive a lack of interest on the side of doctors

Another reason not to share data with doctors is the assumption of patients that doctors are simply not interested in patient-generated data. They attributed this either to a lack of a doctor's time or to a lack of expertise to interpret data. A person with heart disease said:

"No one has ever come to me and said, 'I want to see some data'. I don't think they care, or they don't, they don't think so far ahead that this possibility would theoretically exist. Certainly also out of ignorance. I've hardly seen any doctors who have an Apple Watch, at most a nurse." Patient with congenital heart defect (B18)

In opposition to patients who imbue their data with potential medical value, other patients see no value in communicating data with doctors and others due to lack of proactive solicitation for self-generated data (patient with Long COVID, B15):

Interviewer: "You don't have a doctor with whom you share this self-measured data. Why?"
B15: "That doesn't affect them."
Interviewer: "Do you share your information with anyone, online or otherwise?"
B15: "Nope. I do not do that. I also have to say, I don't have anyone who would be interested in this."

This resonates with findings that people share health-related data if they can imagine its value for the other person (Ajana 2020). Another chronically ill patient (B3) mentioned the doctor's lack of expertise to interpret data more generally.

You have to offer something for everyone: Consumer devices are old data in new media

A key question for patients and doctors is the quality of measurements in relation to a consumer product like a "pulse watch". Here, the type of product (a consumer product like a watch) is connected to its measurement capabilities. Public attention to a consumer device becomes relevant on the level of consumer preferences (General Practitioner, B9) and patient needs (hospital cardiologist, B12), as well as the recognition by several doctors – regardless of whether they support these devices or not – that devices "will come" (somnologist, B25) in the future.

Two GPs, one cardiologist, and one somnologist said that consumer devices become relevant due to patient's different media preferences to document data, often in relation to their abilities for self-tracking (B8, B9, B12). The interviews indicate that doctors consider popular consumer devices as new media to document biomedical measurements. Two GPs argue that patients share data such as blood pressure or activity data in multiple ways, including paper-based diaries or apps. Doctors have to engage with consumer devices to adjust to the preferences of patients who document their activities or track biomedical measurements such as blood pressure. One GP says that apps do not change work, they still collect the same data. But the data collection through a new medium is more timely. To service patients, doctors have to be ready to adjust to these media and offer patients different means to collect data:

"You have to weigh things up a bit, of course. It's not for everyone. But it's simply timely. [...] And food tracking, that's the group for whom it's clear that when they do something, they write a protocol. With A-4 paper and a ballpoint pen. And others use an app and add photos of their food and can then also add photos of their food and can then also calculate the calories directly, so to speak, and send it digitally. That's different. You just have to have something for everyone. Both are possible. One is not necessarily better than the other. But perhaps the digital version is simply a bit more up-to-date for 2022." General practitioner (B9)

For this GP, consumer devices are merely a different medium for biomedical measurements. Upon the question, if consumer devices also challenge professional expertise of doctors, the GP answers that popular consumer devices may display biomedical data in clear ways to increase compliance:

"Yes, in principle it is, it's the same thing at the end of the day, it's just that you have a really nice and clear overview and can then in principle see things really quickly. [...] And the idea is of course also that it is hoped that such a digital health application will result in a higher level of compliance on the one hand, right? And ultimately also reduce the number of unplanned contacts." General practitioner (B9)

It is important to stress that GPs refer to consumer health devices that align with their treatment practices. In the case above, the GP used a food diary app as another medium for patients to track their food intake. A respondent suffering from epilepsy told us that he shares movement profile data as well as data of sleep and

wake time with a doctor to discuss the reasons of epileptic shocks. The following quote shows that this data is meaningful because the doctor can glean patient behaviors from movement data that may have caused a past epileptic shock:

"Well, I have a neuropsychologist, we have him on board and he tells you, 'Before I work neuropsychologically, I want to work out a daily and movement profile first'. And he says he wants everyone to have a movement tracker to accompany the therapy. Because neurological diseases affect cognitive things, so that you really don't remember what you were actually doing. Technical feedback about the movement sequence is essential." Patient suffering from epilepsy (B2)

Another GP argued that he invites people to use consumer devices to measure, capture, and share blood pressure data if the patient would otherwise not collect the data. He mentioned the example of patients who are uncomfortable using a 24-hour blood pressure measurement device:

"And before I don't get any values, yes, 'then we'll do it this way, you have a device at home, or get a cheap device somewhere, at the pharmacy, that's usually enough for such home measurements to get a rough overview'. [...] And then some patients use some apps of their own accord to document this and so that they can do it everywhere." General Practitioner (B8)

This shows that the type of measurement and documentation device does not matter as much, as long as the data is good enough for him to understand the general tendency of blood pressure changes. In this case, the GP balances the need for data with the preferences of his patients to collect data.

Doctors do not actively popularize consumer devices because they do not resonate with their professional identity

Many doctors and patients still do not use wearables and health apps for medical purposes or at least do not discuss these in consultations. Most doctors we spoke to informed us that they have no knowledge or overview of existing consumer devices and that there are also only few patients who actively bring devices to the consultation. A general practitioner said that GPs still do not prescribe medical apps and other consumer grade apps are rarely used too. Several doctors told us that they are either not aware of products themselves, or think that their colleagues have no experience with these devices.

Even if doctors are familiar with these devices, they do not actively promote consumer health devices. Two doctors who were experienced with digital consumer health devices said that some of their patients approach them to ask for brand recommendations and that professional reasons prevent these doctors from recommending these. A cardiologist informed us that they are not supposed to recommend consumer devices to patients at all, unless it is part of a treatment plan, while a general practitioner said that it is not part of their professional

responsibility, because they are not a patient's "fitness advisor".

"What patients often ask me now is indeed: 'Which wearable should I use at home?' 'How often should I do this?' [...] And you can tell that they also want digital expertise from us. So what should I do now, which company do you recommend? Where, of course, we are not allowed to make any statements or don't want to. No? That's one thing. Sometimes you have to think about what to say, especially when it comes to wearables. Because there is simply no such thing as perfect, it always depends a bit on what the patient likes, what they would like to do and so on." Hospital cardiologist (B12)

4 Discussion

Digital consumer health devices and data are potentially relevant for medical decisions, bodily self-knowledge, and doctor-patient interactions. This depends on what aspect of a consumer health device one considers, since hardware like wearables and software such as apps may incorporate different features – from clinically validated medical features to novel consumer health features – as well as data categories, their computational style, and the way they are measured (Williams et al. 2021). As we will argue with the data from our interviews, it is not merely a digital health device that receives attention, but also more specific data points or features and how well they align with the clinical work of a doctor, and the relevance for life with chronic illness that shapes its use. Our study suggests that the delimitation of health through digitization is not all-encompassing. Boundaries (Gieryn 1983) are managed carefully through practices of accommodation and resistance. These boundaries have different degrees of stability and they revolve around different questions. Accordingly, different lines of tension arise from popular health data devices, depending on the specific situation of the patient and their engagement with their own patient-generated data.

Empirical studies in different countries have shown that personal and public health data indeed rarely enters the doctor-patient relationship and that biomedical data often is not being communicated to publics, communities, or doctors. The few existing studies on the topic suggest that people rarely share self-tracked, personalized health data with their doctors (Haase et al. 2023) or if so, then only specific types of data, such as diabetes-related data, in specific circumstances (Kjærulff and Langstrup 2023). The key insight is that people are selective about who they share data with and how, and only sometimes share with doctors, but not with a public audience. Studies found similar insights with regards to data sharing between patients and doctors, arguing that online health information is not considered relevant for professional notice.

Personalized measurements connect to professional interpretations in at least two ways. Consumer health devices incorporate established and validated biomedical data that are readily understandable by doctors or that can be validated by doctors. In their study of how consumer health platforms expand into the medical system and beyond, Williams et al. (2020) have studied how consumer health devices incorporate medical standards into their technologies to give their technologies medical value and incorporate themselves in medical and non-

medical settings, while also avoiding to frame these technologies clearly as regulated medical devices. The authors draw attention to different technical objects, such as data fields to document one's body mass index (BMI) or blood pressure (BP), how companies frame these objects along (quasi-medical) quality standards of validity and accuracy, and how they are regulated as medical-grade devices or not. Consumer health devices and their component parts may adopt medical standards in different ways, for example, by incorporating norm values into measured data (e.g. determining "good" or "bad" threshold values for BP).

But novel personalized measurements that rely on new measurement technologies such as optical heart rate measurements, or that create personalized scores, are often of uncertain value for doctors and need validation. Studies on doctors' use of self-tracked, patient-generated personalized data suggest that doctors consider these measurements if they can increase compliance (Fiske, Buyx, and Prainsack 2020). But often, rather than being self-evident objective data, as their promoters argue (Engelmann 2022), self-tracked personal datasets require significant interpretative labor to be useful for doctors, and that the usability of data ranges by data type and illness (Haase et al. 2023). Personalized records such as heart rate variability or baseline measures may be subject to tests and medical doctors conducting research have only begun exploring how metrics from consumer health context, such as sleep scores can be useful. Due to their novelty, new metrics may not be usable for doctors. And professional bodies such as cardiological societies argue that personalized measurements such as alerts are often only indicative, inhabiting a gray area. In addition to uncertainties with data, doctors also consider that people do not know how to self-diagnose. Existing literature therefore suggests that the use of personalized metrics, despite revolutionary claims by promoters of personalization, faces various boundaries and uncertainties in practice.

Particularly on a micro-level of doctor-patient interactions, social studies of digital health have painted a more nuanced picture as to how internet and communication technologies reorganize gatekeepers, social relations, and medical expertise. Lay people may access health knowledge through these media, but this information may not reach doctor's consultations and lead to "parallel worlds" (Kjærulff and Langstrup 2023) between digital self-care and doctor-patient interaction. If people bring their self-generated data to consultations, doctors may integrate, resist, and neglect it for different reasons. One reason for this is that medical knowledge and the technologies circulating them often operate outside the traditional settings of medicine. This requires medical experts to establish boundaries that may assert their expertise, qualify knowledge and technologies

Doctors may consider consumer devices as relevant for their practice because patients, as consumers, increasingly use these devices. Yet, there are also tensions because public recognition of consumer health devices and health data does not abide by professional quality criteria of a good device, or a reliable measurement. The relation between public attention and professional knowledge is therefore one of careful gatekeeping.

5 Conclusion

In this paper, we have tried to make the case for problematic popularization of digital health data and devices as a heuristic frame to explain how patient-generated data gains relevance: for whom and in which situations. Instead of focusing primarily on the problem that health data is a public and private object, or concerns that data would undermine expertise, we argue that an empirical and interpretative concept is needed that can explain if and how digital data gains relevance for the purposes and practices of personal health care and professional medicine. Because data is an ambivalent object, actors may attach different interests and meaning to it and interact through data in different ways. Thus, the question of when data and devices become popular and how they become problematic, can give more empirical clarity into otherwise well-rehearsed critiques of the health data ecosystem.

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