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## Patient-Generated Data as Intervention into Doctor-Patient Relationships?

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## Abstract

Health data generated by apps and devices are becoming increasingly popular and are expected to affect various aspects of doctor-patient relationships. No longer confined to medically authorised and certified health technologies, a range of biomedical data – from heart rate to blood pressure or oxygen saturation – are captured and processed by consumer health devices. In this article, we compare the practices of physicians and chronically ill patients of integrating, resisting, or neglecting data from popular consumer devices in clinical situations and consider how the data may challenge or reify a doctor's medical authority. Our study is based on semi-structured interviews with doctors and chronically ill patients in Germany between 2021 and 2023. By contrasting cases from general practice, diabetology, sleep disorder, cardiology, and obesity, we explore when, how, and for what reasons different medical specialists and patients with different chronic illnesses consider patient-generated data (PGD) from consumer devices in clinical situations. While some resist PGD that seem to compete with their diagnostic activities, others incorporate the data more readily into their diagnostic practices. This suggests nuanced strategies for navigating the demarcation between expert and lay knowledge, whereby consumer data can either be ascribed health-relevant meaning or not.

*Keywords:* digital healthcare, doctor-patient relationship, lay knowledge, patient-generated data

Von Apps und sog. Devices erzeugte Gesundheitsdaten erfreuen sich zunehmender Beliebtheit und scheinen verschiedene Aspekte der Arzt:in-Patient:in-Beziehung zu beeinflussen. Nicht mehr auf medizinisch zugelassene und zertifizierte Gesundheitstechnologien beschränkt, werden eine Reihe biomedizinischer Daten – von der Herzfrequenz über den Blutdruck bis hin zur Sauerstoffsättigung – von Gesundheitsgeräten für Verbraucher:innen erfasst und verarbeitet. In diesem Paper vergleichen wir die Praktiken von Ärzt:innen und chronisch kranken Patient:innen im Hinblick auf die Integration, Abwehr oder Vernachlässigung von Daten populärer Verbraucher:innengeräte in klinischen Situationen und untersuchen, wie die Daten die medizinische Autorität des Arztes bzw. der Ärztin in Frage stellen oder aber auch bekräftigen können. Unsere Studie basiert auf teilstrukturierten Interviews mit Ärzt:innen und chronisch kranken Patient:innen in Deutschland zwischen 2021 und 2023. Indem wir Fälle aus der Allgemeinmedizin, Diabetologie, Schlafmedizin, Kardiologie und Adipositas therapie kontrastieren, untersuchen wir, wann, wie und aus welchen Gründen verschiedene Fachärzt:innen und Patient:innen mit unterschiedlichen chronischen Erkrankungen patient:innengenerierte Daten (PGD) von Verbraucher:innengeräten in klinischen Situationen berücksichtigen. Während einige Ärzt:innen sich gegen PGD wehren, da diese mit ihren diagnostischen Tätigkeiten zu konkurrieren scheinen, integrieren andere die Daten bereitwilliger in ihre diagnostischen Verfahren. Dies deutet auf nuancierte Strategien hin, um die Grenze zwischen Expert:innen- und Lai:innenwissen zu überwinden, wobei Verbraucher:innendaten entweder eine gesundheitsrelevante Bedeutung zugeschrieben wird oder eben nicht.

*Schlagwörter:* Digitale Gesundheitsversorgung, Arzt-Patienten-Beziehung, Laienwissen, patientengenerierte Daten

## Introduction

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Health data generated by apps and wearable technologies are becoming increasingly popular and are expected to affect various aspects of doctor-patient interactions (cf. Piras/Miele 2019: 116; Lordon et al. 2020). At the same time, debates on the inclusion and usefulness of patient-generated<sup>1</sup> data (PGD) in doctor-patient relationships have a long history. Many medical technologies have been assumed to change the doctor-patient relationship, for better or for worse, from the introduction of the telephone as a diagnostic device in the 19th century (Greene 2022) to genetic testing at the beginning of the 2000s (Webster 2002), internet-based media like search engines (Mager 2009) and social media platforms (Kingod 2020; Kjærulff/Langstrup 2023), as well as data generated by consumer wearables and health apps (Lupton 2016; Ruckenstein/Schüll 2017). The popularisation of these technologies broadens the availability of medical information to the public, fosters public attention, and blurs boundaries between everyday life and clinical situations.

Despite the increase of self-measurement and the widespread generation of biomedical data by patients in the last decade, it is not so clear to what extent this data is also taken into account in medical procedures. Despite their public accessibility and the attention on them, scholars have challenged fears and hopes that technologies substantively alter the doctor-patient relationship and that the availability of medical information challenges the medical authority of doctors (Hardey 1999, 2004; Broom 2005; Oudshoorn 2011). Some argue that internet-based technologies have expanded the domain of professional medicine since people interpret phenomena using professional medical explanations (Fox et al. 2005). Despite this expansion of medical information and interpretations in new areas of life, scholars have argued that doctor-patient relationships remain inherently asymmetrical (Pilnick/Dingwall 2011) and that the use and interpretation of online health information varies by the roles patients and doctors adopt, their pursued goals, and their ability to address a health condition (Henwood et al. 2003; Broom 2005). Consistent with these observations, empirical work on internet-based health technologies and information suggests that doctors and patients negotiate the boundaries of whether they make use of consumer health technologies and internet-based health information in consultations (Benetoli et al. 2018; Kingod 2020; Kjærulff/Langstrup 2023).

This finding seems to apply to health information retrieved on the internet, as well as PGD. A study of clinical doctors in Denmark suggests that patients rarely bring data from their consumer health devices into consultations (Haase et al. 2023). Likewise, healthcare providers in Germany have been reluctant to adopt them as shown by a study by Dahlhausen and colleagues (2022); this is also suggested by frequently mentioned concerns over an increased workload due to using health data in clinical consultations (Fiske et al. 2020). Resistance to using PGD in clinical consultations may therefore persist on the side of patients as well as doctors (Weiner et al. 2017). Existing empirical studies on this topic suggest no decline of medical expertise and authority but point to nuanced shifts in work practice. A study by Fiske, Buyx, and Prainsack (2020) documents the opinions

<sup>1</sup> For the sake of simplicity and in line with the established term “doctor-patient relationship”, we also use the term “patient” for people who are chronically ill but do not (permanently) see themselves as patients.

of 15 medical doctors in Germany regarding digital selfcare technologies. Their findings indicate that doctors see benefits in digital consumer devices if they enable directing and controlling medical treatments and existing healthcare goals agreed upon between the patient and doctor. Gabriels and Moerenhout (2018) have studied the response of GPs and cardiologists to patients' self-tracking data and reported concerns about how to interpret the data in a context-dependent manner and how to manage the risk of work overload.

### Patient-generated data (PGD)

The existing literature on the use of PGD in consultations suggests that an important effect of data is not solely their probative value but their ability to shift who or what receives medical attention and with what effects regarding roles and responsibilities. An interview-based study with Belgian medical professionals suggests that the introduction of wearable data in clinical consultations may moderately affect existing hierarchies and roles whereby patients seek a doctor's professional advice on how to interpret the data, thereby affirming traditional medical authority while also demanding increased opportunity to participate in making decisions based on the data (Gabriels/Moerenhout 2018). In exploring how PGD support doctor-patient interactions, Chung and colleagues (2016) describe how patients expect providers to make sense of their data and provide a more personalised treatment plan, while also giving them recognition. Data may thus require the attention of doctors and make them responsible for clinically and legally considering the data (Haase et al. 2023). But in the absence of established protocols, it may also leave doctors in a regulatory grey area (Fiske et al. 2020).

The study by Haase and colleagues (2023) suggests that doctors may accommodate, neglect, or reject wearable and symptom data depending on their ability to ascribe evidential value to the data and qualify the data as relevant for establishing symptoms. This suggests that the inaccuracy and inconclusiveness inherent in many medical measurements are amplified by consumer wearables and health apps, adding to various other "signs" (Armstrong 1995) that physicians gather about a body to qualify a patient's symptom. In the absence of clinical validation, PGD are not readily usable for diagnoses but still require a provider to make sense of them (Williams et al. 2020).

### The informed and involved patient

Today's patients are increasingly well informed but still not on par with doctors (Dieterich 2007: 281). While no longer being the lay people "who unconditionally accept the qualification and advice of professionals" (ibid.), patients nowadays are not only able to acquire sufficient knowledge to make informed decisions about where, when, and by whom they wish to be treated but also to critically evaluate the services provided. At the same time, "[t]he modern patient does not know enough" (ibid.). Anja Dieterich found several statements in the *Deutsches Ärzteblatt*, the largest publication and communication medium of the German medical profession, "assuming that

patients did not have enough knowledge for making independent decisions concerning their health, but required being led by their physician. With the focus on medical expertise, the physician patient relationship is asymmetric and the physician's expert status is further strengthened" (ibid.). Despite the fact that patients questioning their doctors and their expertise is not a new phenomenon (Lupton 1997), the issue arises as to whether patients are actually considered credible, i.e. whether they are legitimately allowed to have a say or not (cf. Epstein 1995: 411). Thus, we are asking: What kind of information are PGD and in what way do they enable patients to be critical or even involved?

Barello and colleagues state that "[p]atient engagement appears to be a fragmented concept that lacks a clear definition" (2012: 3). It comprises either (1) a measurable behavioural marker of patient adherence to treatment, (2) a cognitive (i.e. knowledge and insight into illness) or relational (i.e. the quality of patient-physician encounters) indicator that fosters the patient-physician alliance, or (3) an organisational characteristic that is a critical element in health policy (ibid.: 5). It does not seem to be intended that engaged patients should question the asymmetry between doctors and patients. They are only expected to provide the level of expertise that helps them to manage themselves and their illness.

The same applies to their "extension" – the digitally engaged patient (Lupton 2013a: 258). Digitally engaged patients are lay people who have been "advised that they should use digital technologies as part of patient engagement practices" (ibid.: 259). There seems to be a fine line between being involved and being engaged here: patients need to be active and self-centred but are not allowed to become experts themselves. Since medicine is "a science of the individual" (Crawford 1980: 371), one of digital medicine's central features, the individualisation of detailed data, has increasingly become the focus of attention (Lupton 2013b). Deborah Lupton (2013a) elaborates on the connection between individualisation and digital engagement: "The discourses of the digitally engaged patient suggest that 'empowerment' may be achieved by using sophisticated digital technologies for self-monitoring and self-care" (ibid.: 260). She also adds that "[l]ay people are expected and encouraged to develop routines to regularly assess [...] physiological markers and thus to develop the type of expertise in monitoring their bodies that was once the preserve of healthcare providers" (ibid.). We therefore propose the concept of the involved patient as an intensification: a patient who interferes and wants to (at least partially) compete with the doctor's expertise. Accordingly, it is interesting to see what happens when digitally engaged patients become digitally involved patients through PGD.

### Doctor-patient relationships in the age of eHealth and mHealth

We assume that changes in the doctor-patient relationship and matters of medical authority are connected to how doctors and patients attend to and evaluate PGD in clinical consultations. How patients and providers interpret self-initiated PGD in existing clinical settings and what practices they devise to give meaning to the data, and the challenges and frictions this may create, have been considered in just a handful of studies (Raj et

al. 2017). Recently, studies have also shown the need to study not only how healthy people quantify themselves but also how chronically ill people customise consumer health technologies to make them fit their illness (Maslen/Lupton 2020; Lomborg et al. 2020). Since chronically ill people require more time than is available to them from their GPs, for example (Østbye et al. 2005), there is a need to study their uses of self-measured data in interactions with doctors. Existing studies have also mostly focussed attention on particular illness types such as diabetes (Fiske et al. 2020; Kjærulff/Langstrup 2023) and selected, broad data types like heart-related data, sleep data, or results from online symptom checkers that are discussed by doctors and patients in consultations (Haase et al. 2023).

We focused our sample on chronically ill people living with heart conditions, type 1 diabetes, sleep disorders, obesity and lipoedema, chronic fatigue syndrome, and long COVID/post-COVID syndrome, as well as on general practitioners, diabeticians, cardiologists, somnologists, and surgeons. We focused primarily on the use of consumer health technologies and the related health data, not on certified medical devices, as well as on those situations in which no established protocols for their use exist. Diabetes is a liminal case here: even though the doctors in our sample repeatedly emphasised that a distinction must be made between medical and lifestyle products, the question arises as to how lifestyle apps that receive data from certified medical devices and are then additionally fed with other data from the patient should be classified.

## About the study

Data generation and analysis was informed by our theoretical lenses, and our methodological framework for this research project is based on Grounded Theory (Strauss 1987). We wanted to examine a range of chronic diseases and medical specialities in order to map the range of PGD use and to contrast and compare the cases with each other. While diabetes research has been done for quite some time (for example: Mol 2000), the state of research on long/post-COVID is still limited due to the novelty of the phenomenon. However, the different levels of implementation of digitalisation in the various medical fields also provided a good basis for contrasting cases.

To address the question of the study, Danny Lämmerhirt collected data from November 2021 until April 2023. Recruitment combined a staged self-selective and purposive sampling strategy that addressed participants with experiences using consumer health devices and data for illness management or interactions between doctors and patients. Following approval by the ethics committee of the university, project details were first sent by email to self-care groups throughout Germany following a self-selective sampling. We interviewed everyone who responded positively to our initial interview request. We contacted patients through the contact persons of self-care groups, regional self-care points of contact who shared the information on mailing lists, and moderators of illness-specific Facebook groups. We also contacted groups of specific illnesses where we expected a higher likelihood that people had experiences using digital devices in



interaction with their doctors. Eligible patients were aged above 18 years and had to have experiences using consumer health devices, regardless of whether they used them for their illness or in interaction with doctors. We included participants if they identified themselves as chronically ill, in spite of their diagnostic status, and if they currently received care from a provider. In total, 21 patients were recruited with health conditions such as lipoedema, heart failure, diabetes, insomnia, sleep apnoea, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and long/post-COVID syndrome. Another five participants were recruited through three focus group meetings.

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To contact health care providers, we purposely selected and approached medical doctors of different specialisations that we found in professional directories. In addition, we approached providers who gave presentations and workshops at annual conferences of their disciplines. Eligible providers had to have expectations or experiences using consumer health devices, regardless of whether they actively prescribe these devices or get approached by patients regarding their use. We included providers 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 providers, including two general practitioners, three cardiologists, three somnologists, one nutritionist, two obesity therapists, one surgeon, and two diabetologists, with the interviews with the obesity therapists and the surgeon being ethnographic interviews that took place during a participant observation as part of a one-week internship in an obesity clinic that were not recorded but reconstructed from memory in the field diary. Another participant observation occurred during a diabetes conference. The interviews were recorded and later transcribed verbatim and pseudonymised in accordance with ethical research conventions. Ann Kristin Augst translated the quotes used in this publication from German into English. Written or oral consent was obtained before the interviews from all participants. Danny Lämmerhirt conducted all interviews.

We followed a qualitative research approach that was based on semi-structured, one-to-one interviews. Due to the COVID-19 pandemic, it was not possible to attend self-care group meetings or visit doctors' offices. The participants were interviewed through online video calls. Provider interviews lasted between 36 minutes and 100 minutes, and interviews with chronically ill people lasted between 46 minutes and 120 minutes. We developed two interview guides to explore the expectations and experiences of chronically ill people and providers using digital health devices and data. Interviews with chronically ill people addressed their usage of digital devices and data, the relevance for their chronic illness, their data-sharing practices, and how they discuss the PGD in clinical consultations. Despite efforts to invite male and female doctors in equal quantities, only 4 out of the 14 interviewed doctors were women. Out of the 21 chronically ill people that were interviewed, 12 were women.

Interviews with providers concerned the devices and data patients bring into consultations, data-sharing practices between patients and doctors, and the integration of data into diagnosis and treatment. Both interview guides first inquired into the overall uses and types of digital health devices

and data and afterwards asked the interviewees to follow up with a description of interactions experienced between patients and providers that involved consumer health devices or data.

We analysed all data according to the principles of Grounded Theory (Strauss 1987) once the interviews were conducted. This ensured that the initial interview guide could be adjusted to include relevant questions. The emerging findings were discussed in recurring meetings and informed the purposive recruitment strategy, as well as the identification of similar and contrasting topics to pay attention to in future interviews. Danny Lämmerhirt openly coded the empirical material to identify how and why digital health devices and data are mentioned and interacted with in consultation settings. He grouped codes into categories that derived from a range of “sensitizing concepts” (Blumer 1970), including the salience of devices and data in consultation situations and for illness management, meanings ascribed to devices and data, and changes in the doctor-patient relationship. Ann Kristin Augst joined the research project later on and familiarised herself with the data material in a second round of analysis.

When analysing the data, we were struck by the differences in which patients as well as doctors ascribe value to digital devices and data for consultations. Our coding identified various practices of chronically ill people and doctors to actively draw boundaries against digital health devices and data; to accommodate the data in diagnostic, therapeutic, and self-monitoring practices; or to neglect and not mention devices and data in consultations. The meanings for these findings were discussed and iteratively interpreted following the principles of Grounded Theory (Strauss 1987). We were able to generate concepts derived from the data that systematise these three approaches of accommodating, neglecting, and resisting data and devices and to find reasons that condition these responses to digital health devices and data.

## Findings

Through refining the insight that these devices “offer an unprecedented opportunity to monitor and measure individuals’ health-related habits on the part of not only the users themselves, but also by health care and public health workers” (Lupton 2013b: 3), our results show that the extent to which these data are of interest depends on the medical specialisation and its interconnectedness with digital data. We have found stark differences across doctor specialisations and chronic illnesses regarding the relevance and perception of consumer devices and PGD. The reasons for patients’ use vary from a logic of proof to support in coping with everyday life to vital advice to seek medical help. The doctors in our sample do not fundamentally question the usefulness of the data or its collection, per se, and generally even favour it.

The frequency of “data contact” also varies: a somnologist reported that he is shown data from his patients about once a month that was generated without a specific “medical order”. A cardiologist, on the other hand, said that she is confronted with PGD relatively frequently. Whether, and if so, when and how the data is used by the patients in the doctor-patient inter-



action depends strongly on the disease but also on the doctors or the length and frequency of the consultation. To what extent patients' consultations with their doctor is influenced by making PGD relevant in them is discussed below.

### Generating evidence

For some of the patients surveyed, data from wearables primarily represents "proof" and "evidence" that they actually adhere to their doctors' recommendations (cf. Fiske et al. 2020), e. g. to exercise several times a week with lipoedema, as one patient described:

We lipoedema patients, who are mostly women, are always told by doctors that we are lazy, unathletic and eat the wrong things. That's why we have, let's say, a great potential for self-observation, and we like to use it so that we can really refute this statement. [...] And if you wear a Fitbit or track your calories or something else, then you know, ok, I'm not actually doing it wrong. (IP4)

Obesity patients also have to prove themselves: they must document for the Medical Service of the health insurance companies (*Medizinischer Dienst der Krankenkassen* [MDK], an institution responsible for assessing the severity of illnesses, among other things) that they really tried to lose weight so that the MDK, and therefore the patient's health insurance company, will approve a bariatric stomach reduction operation and its financing. During his participant observation in an obesity clinic, Danny Lämmerhirt was allowed to take part in several admission interviews with patients. This is an excerpt from his field journal:

The initial admission always includes an exercise log for the past 6 months, which must show that people have already tried weight loss with exercise. [...] It is evidence for health insurance companies that you are doing something about obesity and that this is not helping. This evidence must be legally binding, which is why one has to sign it. (FN2)

These admission interviews are conducted by a consultant who must assess the credibility of the patient's statements.

{Name of the consultant} and I then talked about his experiences with people who had sent their data to him. One person had apparently attached his Fitbit to his dog, and another woman had 60k steps a day because she was a postwoman. Here he said that it didn't seem plausible to him at first, but that the woman later said that she was a postwoman and that her route was that long. {Name of the consultant}'s astonishment once again highlights the controversial issue of what exactly counts as athletic activity for whom and how much an individual is really capable of walking. [...] However, this also shows that an exact quantification of the steps does not necessarily lead to objective data, but rather, raises questions as to whether the steps walked are really plausible and possible for the person. I asked Mr. {name of the consultant} how he makes the data plausible, to which he replied that one knows the person and knows that certain values cannot be correct. So the "objective" data must first be made plausible by referring back to the person. (FN2)

After one week in the obesity clinic, Danny Lämmerhirt concluded that

wearable data and nutritional data thus appear to be therapeutically more important for monitoring compliance than for planning therapy and understanding the body's reactions and functions. (FN2)

Rather than their vital signs, the efforts of people with obesity or lipoedema must be made evident here. This is similar for people with diabetes. Here, too, the use of wearables is about proving to the doctor or being able to show him or her exactly that, or how, you are moving.

One interviewee with diabetes answered the question of what motivated him to use the pedometer when he bought it as follows:

I wanted to know how much I was walking. What the distances are. What the distances are, to get an overview of (unintelligible) what you actually walk and what is normal movement. Because I have my appointments in {city name} and I live a bit outside {city name}. I have to take the public transport. And then I have to walk to {city name}, so I have to see, uh, yeah, what does that actually look like? What kind of movement do you have there? And I have the average, so I know roughly how much I have to walk and that's good. (unintelligible) I should have that in the back of my mind. (IP5)

For people with diabetes, however, a double logic of documentation comes into play: on the one hand, the voluntary and usually not prescribed measurement of movement data and, on the other hand, the measurement of blood glucose levels. One of the diabetologists reported that the digitalisation of measurements evokes evidence of “misconduct”. Doctors can now see when a patient is not complying with treatment – and patients are less able to cover this up:

Of course, patients are becoming increasingly transparent via digital data. I get more data from them. If they use a smartpen, I can suddenly see exactly how many units of insulin they inject and when. “You have to inject before your meal!” “Yes, I always do that.” “No, you don't. Five times out of ten you inject during or after a meal.” “Oh well, yes, yes, that's possible.” So, on the one hand, in many cases you get an improvement in the setting. But in some cases, the patient also feels caught out because it always triggers shame. (ID3)

The other diabetologist said the same thing in her interview. The evidence here is therefore rather against the patients, even if in the long term, from the doctors' point of view, it is actually in their favour. The diabetologist that was quoted first also noted that simply looking at blood glucose levels can sometimes lead to the patient's data being more important than the patient him-/herself.

People with fatigue syndromes, on the other hand, such as ME/CFS and/or long/post-COVID syndrome, generate data about themselves as evidence of their own feelings as well as for medical purposes. One patient with CIDP (chronic inflammatory demyelinating polyradiculoneuropathy) told us:

Sometimes I kind of think, that's kind of stupid. I have to look at my watch to know how I *feel*. Actually, I know <laughs> how I feel. Like this, right? That I'm somehow completely exhausted and haven't slept well. So I haven't slept well and I feel like I've been hit by a train in the morning. I know that then. But the watch also confirms that for me. (IP6)

Another patient, suffering from long/post-COVID syndrome, reported that her heart behaves “strangely” during physical exertion and does not adapt to the corresponding setting, i.e. either the heart rate does not decrease at rest or does not increase during exertion. However, as this is not the case on a regular basis, a classic ECG in the practice or clinic is not meaningful

here. But with the data from the smartwatch, the patient had proof that she is not imagining that something is not working as it should.

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In cardiology, specifically rhythmology, this possibility for patients to record data in situ with their smartwatch is very welcome. A cardiologist who works at a hospital described a scenario in which PGD are very helpful:

One scenario is when patients come to us in the outpatient clinic, say they have symptoms, and we want to objectify these symptoms. In other words, we want to know whether a cardiac arrhythmia is really the problem or whether it is perhaps something completely different. And for this objectification we ultimately need a symptom-rhythm correlation, as we call it, which means we also need an ECG. And it used to be the case that people would say, well, take regular ECGs from your GP or perhaps do a long-term ECG over the course of a day. Today, there is a completely different perception in this regard thanks to these wearables. This means that we have completely different options. This means that patients can make a recording exactly when they have symptoms and then send it to us in the end. (ID5)

This is also confirmed and welcomed by patients. A patient with heart disease described how the data measured by the wearable can serve as evidence and how it becomes useful in the interaction with her doctor:

The nice thing is that if I have a bad day, e.g. a day where I think my heart is restless today, then I write it down and then I can go to the doctor with this date and time and my doctor can read out the device and look at the date and time to see if there really was something there. So I think that he can really look at it retrospectively. (IP12)

The aim here is to objectify and validate past events and perceptions and to correlate them with the patient-generated health data. The cardiologist that was quoted above also explicitly pointed out the function of the devices to provide evidence of past medical conditions. The PGD provide specific starting points for diagnostics using medical technology and calibrated devices in doctors' surgeries or clinics:

What we always have, of course, are patients who have complaints from time to time and then perhaps look at their data at that moment and think, is this something or is it nothing? And that's something I'm noticing a lot right now, that patients are now very good at recognising this. So if it's something that they can see for themselves from the data and then come up to you and say, "Hey, something's strange, can you have a look at what it is?" And the nice thing is, with the wearables I *can* look it up. (ID5)

One of the somnologists also sees PGD as an indication of something that needs to be checked:

So the oxygen saturation, if it is also measured, that is relevant. Right? Because if someone now says "Well, somehow, I've turned on my Apple Watch and it somehow shows me that I'm running out of oxygen 20 or 30 times a night," then that's a great mini-screener for sleep apnoea. (ID9)

PGD are not treated as "hard evidence" here but as an indication of a medical problem that needs to be investigated. What all the medical conditions and specialities that we have examined have in common is that they attribute an evidential character to PGD. This varies in degree and ranges from indications to measured values that are almost as good as those obtained with medical equipment.

## Managing patients

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Managing patients has two different meanings: on the one hand, it is about how patients manage their everyday lives and their illnesses – with the help of wearables or apps and the health data they generate. On the other hand, it is about how doctors handle their patients, i.e. what they know about them and their circumstances and how the relationship between the two parties is organised (cf. Freidson 1988 [1970]), but also how compliant the patients are and how the PGD are used to adjust the therapy.

With regard to self-management (of patients), one of the GPs pointed out that some patients can be better kept in line by using wearables and/or apps outside of the consultation. The devices and programmes therefore represent the doctor's extended arm and can – so the interviewee hopes – ensure successful treatment.

The patients can perhaps monitor themselves better or perhaps be reminded a little to look after themselves, or perhaps be shown again with colours or whatever or visualised, where they are better or where they can do something for their health and that the overall health of one or the other can be improved. Or if you have formulated a specific goal and an app supports you in structuring it to achieve this goal or perhaps also collects additional data that you can use to perhaps achieve the goal faster or better. (ID1)

The other GP echoed a similar sentiment; he emphasised the objectifying and thus distancing function of health apps, which makes it easier for some patients to recognise (trigger) patterns in the protocols the devices (can) generate.

Experience shows that the patients who understand their illness, i.e. these patterns and also certain therapy effects, are the ones who show a certain degree of compliance, right? Those who don't understand it find it difficult to change their behaviour, find it difficult to take medication, and immediately then they have a lower level of compliance. (ID2)

From a somnologist's point of view, visualising environmental influences or behaviours can also help to make patients aware of what they are doing wrong (or right) and to manage their behaviour or everyday life differently accordingly:

A very important part of behavioural therapy often is sleep restriction. Where people are told to choose a different window for sleep, i.e. not to go to bed at 9 and stay in bed until 8, but perhaps to go to bed at 12 and get up at 6. And with a tracker like this, the tracker can measure that well. My tracker can see when I'm calm and when I'm active. So I can validate that quite well with a tracker like this, of course. (ID8)

PGD and, above all, their evaluation and graphical processing by artificial intelligence can therefore lead to learning effects which, at best, increase the health literacy of chronically ill patients and result in them being able to better manage their illnesses and/or better understand their doctors.

In the case of ME/CFS and/or long/post-COVID syndrome, self-management mainly takes place in private – and is apparently only of indirect interest to doctors. A patient with long COVID reported how she organises her medication intake with the help of an app:

I also have to use the tablet management [app] every day. I'm also glad that I have it, otherwise I would have completely forgotten. Especially now with my cognitive problems. (IP8)

And the pacing that chronically exhausted patients do with the help of smartwatches and their “body battery” or similar functions is also apparently not generally an issue that patients bring to the practice.

However, our research not only focused on patients' self-management but also on what digitalisation does to doctors' management of patients. In particular, this is about better understanding a patient's circumstances and getting to know the patient better as an individual. One diabetologist reported that this is possible through digitalisation. If the measured data no longer has to be discussed in detail at every consultation, but can be viewed between appointments and is already available before the doctor-patient consultation, the “saved” time can be used to get a more accurate overall picture of the person sitting in front of you:

Um, let's say the conversations are shifting. [...] They're shifting away from “inject half a unit more.” They're shifting more towards overall life management. Which I think makes much more sense. [...] How do I manage exercise, shift work, uh problems with my wife, how do I react to emotional stress? Things like that have often been overlooked. In the past. Because in the time, in the time window that you have available, you've paid more attention to the diabetes data. With the AID systems, this is largely no longer the case. You can discuss completely different problems. (ID3)

But it is not just the small talk that helps doctors to get to know their patients better – and therefore manage them more effectively. One of the cardiologists said that, in her view, the frequent contact with patients between consultations changes the doctor-patient relationship:

I have patients who have these wearables, and I have patients who don't have them. And the ones who don't have them, I don't know their names. And the ones who do have them, I know every single name, because they write relatively often <laughs>. That has advantages and disadvantages, but you can tell that the patient-doctor relationship has really intensified. Um, and I think that's almost exclusively positive for the patient. So if you ask them, I think they think it's very good. And um, that's what you want, of course. (ID5)

So here too, the focus is primarily on the interactions that take place outside the doctor's surgery or clinic – on the part of the patient with the device and/or the doctor, on the occasion of the transmission of data generated by the device.

However, it is not always just about the curious and interested contact with patients or the improvement of the doctor-patient relationship. At one point or another it is also about control. During his internship at an obesity clinic, Danny Lämmerhirt spoke with a surgeon and his colleagues about PGD as part of an ethnographic interview, which he paraphrased in his field notes:

I then asked Dr {name of the surgeon} and his colleagues present directly whether they saw any particular benefit in wearable data and data from health apps. He replied that it would be good if he could have “objective measurements” to see whether people were following instructions to exercise more, for example. In this context, he again mentioned the problem of shame and stigmatisation that many obese people are exposed to. This often means that patients do not always make honest statements about their everyday lives. (FN2)

Following on from the “search for evidence” (see above), this is about the search for the “truth”. In order to be able to check whether patients are adhering to the clinic’s therapy and behavioural recommendations, but also to be able to control treatment more precisely, internists would like to collect and receive their patients’ body data on a regular basis. This can also be seen in the example of the Zanadio app, which in this case is used by a patient with lipoedema, but whose target group is actually people with obesity:

They [the Zanadio app employees] have an idea of your progress, what you’re currently doing, and what you’ve already tried out for yourself. And they write to you three to four times a week and ask how you’re doing. At the beginning, they write a lot. But there’s also this observation factor, you have to track your food a bit. (IP4)

Here, too, the initial focus is on maintaining relationships and establishing a “baseline” with regard to the lifestyle of the patient or app user. But it is also about monitoring.

### Negotiating expertise

The concept of involved patients (see above) implies that they are well informed. In this case, the point is that they know a great deal about themselves in particular – and are therefore able to question the professional knowledge of doctors (cf. Freidson 1988 [1970]). This raises the question of the extent to which expertise is negotiated when patients generate (bio-medical) data with the help of wearables and apps and confront doctors with it.

In cardiology, patients who measure themselves and bring data collected with their smartwatch, for example, are framed as capable and informed. Patients’ skills in reading (their own) ECGs seem to be welcomed in principle. One cardiologist told us:

So what patients can see very well are regularities, for example. In other words, does my heart beat regularly or is it irregular? They can recognise that very well. If my heart is beating too fast or not, they can also recognise that very well. What the patients can’t recognise, and that’s a good thing, is what type of cardiac arrhythmia it is at the moment. They tend to recognise whether something is strange or not. And if something is strange, then you still need the doctor and that should remain the case so that you can make a diagnosis. (ID5)

It is noticeable that there was an emphasis on how it is good that patients acquire a certain level of expertise, but that a certain dependence on doctors still remains. The doctor as a (knowledgeable) authority can also be found in other medical specialities. One of the diabetologists emphasised that lay interpretations of everyday life often have little overlap with the medical explanation of certain fluctuations in blood glucose levels:

Every blood sugar level that deviates is interpreted somehow, and a causality is sought. Um, and the moment you’ve found a causality, you tick the box in the back of your mind, and the patient says “Everything is fine.” Or their subconscious says “All good.” But now they sometimes give explanations for certain values that have nothing at all to do with reality. Er... “So my sugar level was bad because I ate ice cream three days ago.” Hey, three days later nothing happens. Yeah? “I had hypoglycaemia because I took ten more steps than usual.” Nah, you injected too much. So, um, and that’s, of course, if they have the wrong reasons for data or deviations, they draw the wrong conclusions, if they draw any conclusions at all. (ID3)



Implicitly, it is made clear here (and in the situation described) who knows (more). At the same time, some patients also seem to expect their doctors to know or be able to do more than the app or the wearable. A patient with CIDP and high blood pressure, among other things, stated the following in an interview:

I expect a doctor [...] to naturally link the situation to my illnesses. Google Fit doesn't do that. Google Fit doesn't even know that I have CIDP or high blood pressure or anything like that. Yes, high blood pressure, but for what reason? Or what is the effect? (IP3)

So there seems to be a clear differentiation here between the competences of the doctor and the competences of the AI. At the same time, it does not seem to be a question of pushing the doctor into a corner with the help of PGD or wanting to move on an equal footing at a medical level.

In sleep research, this is sometimes different. However, it is not necessarily the doctor who is questioned but the data generated by their medical technology, or the PGD are used to counter this. One somnologist reported that patients argue with him from time to time:

They [the patients] just have it [the wearable]. And then they show it. And sometimes they go, they try to go into the ring here too. Then I show them our original, awesome polysomnography data. And then they start rivalling me with "Yes, but mine shows..." "Yes, but my..." or, also in this direction, "But my app always shows that I have very little oxygen." And then I say "But look, this is professional data." (ID9)

Another somnologist felt called upon to defend his profession in the interview. There seems to be a general assumption among somnologists that their current measurement technology will be obsolete in around 10 years' time and will be replaced by handy devices that people can wear at home. At the moment, however, this is not yet the case:

Of course, such a measurement on the wrist cannot replace sleep diagnostics, it cannot. Because it ultimately measures very limited things, heart rate, movement, etc. And we can attach 30–40 electrodes directly to the body, and we also monitor this. So it can't do that. (ID8)

Like many patients, he also sees the added value of medical measurement in its framing:

The danger would be that such a device measures any abnormalities that don't even exist. Or that it misses something. So that someone comes along and says "I'm not going to the doctor, my device tells me everything is great." And I don't believe there are any validations or indications. It's a nice gimmick but I can hardly imagine that it really replaces, let's say, sleep medicine as it is practised now, with dialogue, with measurement. (ID8)

On the one hand, he problematises the fact that patient-generated health data can convey a form of false security, but can also cause anxiety, and that both precise measurement data and a correct classification in the everyday context of the patient as well as the medical context, i.e. medical expertise, could prevent these false-positive and false-negative measurements and their possible consequences.

Although patients with lipoedema often endure long periods of time searching for and changing providers until they are correctly diagnosed and

are often better informed about their condition than many of their doctors, body data does not play a central role here.

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## Discussion

In principle, the divergence of perspectives between doctor and patient and the asymmetry between the two is a cornerstone of social science concepts of medicine (cf. Dieterich 2007: 281; Lupton 1997: 379): the doctor is the expert, the patient is the layperson. At first glance, this hierarchy seems to be challenged by the use of wearables and health apps by patients. However, the situation is not quite so simple: although the doctor is no longer the only source of information for patients, doctors are demonstrating strategies to defend or re-establish their authority and autonomy as professional experts or to prevent their authority from being questioned in the first place.

Following the medical sociological premise of “[w]hat is seen is what is known, and what is known becomes the space for intervention” (Crawford 1980: 371), PGD supposedly represent an opportunity for patients to enter into dialogue with their doctors on an equal footing. Biomedical processes in the patient’s body are visualised and thus become a bargaining chip. Patients become lay experts (Pols 2012: 80; cf. Epstein 1995) – at least for themselves. In doing so, the patients approach a genuinely medical perspective (cf. Epstein 1995, 429) or commit themselves entirely to a biomedical view of their bodies. Jeannette Pols (2012: 80) states that “[t]he production of knowledge has changed in the process, but not the object of this knowledge nor the methodology to develop it.” She emphasises that “[i]n the life of chronic patients [...], medical knowledge is everywhere, in the form of devices, medication, lifestyle rules and so on” (ibid.). The fact that chronically ill people know a lot about themselves, their bodies, and their illness is hardly new. Only the ways in which they acquire this knowledge have changed, and the possibilities for documenting this knowledge have expanded. “Medicine as a therapeutic or clinical science locates the problem of disease in the individual body” (Crawford 1980: 371). The patients do not generate any of their own expert knowledge but perpetuate this biomedical perspective on the individual, which is “both the locus of perception and intervention” (ibid.).

This often involves liberty: “For someone with diabetes who is engaged in self-regulation it is no longer necessary to follow “doctor’s orders” which means that a lot of autonomy vis-à-vis professionals is gained” (Mol 2000: 18). Robert Crawford concludes that self-care aims to reduce reliance on physicians and enhance medical self-competence (1980: 374). Patients might be pictured as active agents managing health and illness (Dieterich 2007: 82): People with diabetes, for example, see themselves as managers of their own life and might find it intrusive if doctors have access to the data (cf. Piras/Miele 2017). At the same time, an automated data exchange leaves more time for the doctor and the patient to get to know each other – or at least for the doctor to better understand the patient’s living circumstances. Whether patients share data depends on the roles negotiated between doctor and patient (ibid.) and the interests, needs, and requirements of the patients.

Does this all mean that medicine basically stays the same? There are three resonance registers available to medicine in the face of the intrusions of popular health apps and devices, i.e. the dissemination of patient-generated biomedical data: resilience, resistance, and accommodation (cf. Werber et al. 2023: 5). (1) Resilience here indicates ignoring what is popular and being ostentatiously unimpressed; (2) resistance means actively objecting to the terrain gained by what is popular, e.g. quality erosion and success metrics; and (3) accommodation refers to the efforts of established orders to adapt to the demands of what is popular, to integrate it or even adapt to it.

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1. The resilience of the field is demonstrated by the low number of patients who actually submit their self-reported health data to the practices. Outside of cardiology and private somnological practices, lifestyle wearables and the data generated with their help play only a minor role. The lack of interfaces between non-medical wearables and doctors' software and specific data-protection requirements also play their part. Some doctors have also reported having a majority of less tech-savvy, or even tech-averse, colleagues. Resistance can also be found here, which is rather noticeable by its absence in our sample.

2. Resistance in the field is evident in the attempt to assert the interpretative sovereignty of medicine. The dangers of self-measurement for patients are used here to make it clear that a professional classification and interpretation of the data is required. Neither the collection of biomedical data by patients is rejected in its entirety nor the fact that patients collect (or have collected) these values, but reference is made to medical supervision as a necessary framework.

3. Accommodation tends to be the exception; only cardiology (and rhythmology in particular) is genuinely open to consumer wearables and the data they generate. The somnologists we interviewed find the use of these devices useful, at least as a pointer to problems that need to be medically examined, due to the affordability of long-term measurements, which would compensate for errors to some extent over time. The situation appears to be different in those disciplines that are inherently less data and measurement oriented or where there are no lifestyle products that come close to being medical devices (diabetology).

In sum, the role of doctors seems to be shifting "from professional expert (instructing and deciding) to guide (supporting, advising, and navigating)" (Greenhalgh 2009: 629) and adapting to the circumstances, albeit prophylactically: it is anticipated that in future more and more patients will attend appointments at the practice or hospital with self-reported data. Because sales of wearables are on the rise and patients are using them increasingly, doctors say that they themselves and their colleagues should engage with wearables. But still, wearables appear infrequently in doctor consultations as of now. The assumptions and preparation for this moment seem to be more hypothetical in nature – and derived from the popularity of wearables and health apps per se, rather than an actual increase in encounters with the devices in practice. Piras and Miele (2019) state that technological devices shape and limit the range of possible interactions if they "become the cornerstone of the patient-provider relationship" (ibid.: 118). This is a scenario we do not see coming about in Germany in the foreseeable future.

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