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Patient-Generated Data as Interventions in Doctor-Patient Relationships? Negotiating (Un)Invited Participation in Medical Consultations

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ABSTRACT

Health data generated by apps and devices are increasingly popular and 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. This article outlines different responses of physicians to patients collecting data with popular consumer devices and considers how the data may challenge or reify medical authority. Based on semi-structured interviews with doctors and chronically ill patients in Germany from 2021 to 2023, we compare cases from diabetes, sleep disorders, cardiovascular conditions, obesity and ME/CFS and explore when, how and for what reasons different medical specialists consider patient-generated data (PGD) from consumer devices in outpatient settings. Their response registers vary: whereas some physicians reject PGD that seem to compete with their diagnostic activities, others tolerate the data (collection), whereas still others more readily include them into their diagnostic practices. This suggests nuanced strategies for navigating the demarcation between accepting or rejecting ‘uninvited’ participation through PGD from consumer apps and devices.

1 | Introduction

The asymmetry between doctors and patients is a frequent finding in sociological studies of medical care (cf. Parsons 1951, 428–479; Lupton 1997, 379; Pilnick and Dingwall 2011): the doctor is the expert, the patient¹ is the layperson. Despite the fact that patients who question medical authority are not a new phenomenon (Timmermans 2020, 264), the issue repeatedly arises of whether they are actually considered credible and legitimate sources of information (cf. Epstein 1995, 411). New medical technologies have often been seen as an occasion for such changes in doctor-patient relationships, from the

introduction of the telephone as a diagnostic device in the nineteenth century (Greene 2022) to genetic testing at the beginning of the 21st century (Webster 2002) or internet-based technologies like search engines (Mager 2009) and social media platforms (Kingod 2020; Kjærulff and Langstrup 2023). Recently, digital health data generated by apps and wearable technologies are expected to affect various aspects of doctor-patient interactions (cf. Ruckenstein and Schüll 2017; Piras and Miele 2019; Lordon et al. 2020). We study to what extent these findings can be applied to the German healthcare system and how this might affect doctor-patient relationships. Following the premise of ‘[w]hat is seen is what is known and what is known

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becomes the space for intervention' (Crawford 1980, 71), patient-generated data (PGD) supposedly represents a more accessible and simpler opportunity for patients to enter into dialogue with their doctors on an equal footing. Biomedical data appear to carry more weight than 'traditional' patient reports of symptoms or complaints (cf. Fiore-Gartland and Neff 2015, 1476), with additional policy expectations for optimising healthcare and increasing cooperation through digitalisation (cf. Haase et al. 2023, 524).

As Pols (2012, 80) states with respect to the engagement of patients in biomedical knowledge production: 'The *production* of knowledge has changed in the process, but not the *object* of this knowledge nor the *methodology* to develop it.' We will take a closer look at the means and modes of producing knowledge through PGD by focussing on doctor-patient consultations and by comparing five different health areas/medical specialities. Our sample encompasses medical fields that are evidently rich in digital data, such as cardiology, somnology or diabetology, as well as domains that remain largely under-researched, where patients must substantiate their condition (long/post-COVID syndrome and ME/CFS) to prove its 'doctorability' (Stevenson et al. 2021, 3), that is the legitimacy of their health issue(s) as warranting medical attention or intervention. Individuals with obesity and/or lipoedema who utilise PGD to validate their claims for coverage of various treatment measures by health insurance companies present yet a different case. As different as these various illnesses or medical fields appear upon first glance, they share the commonality that individuals affected by chronic conditions must constantly engage with their own health status, thereby becoming quite competent in managing their condition. However, this occurs in different ways and for different reasons. The spectrum of patients ranges from 'primary decision-maker' (Piras and Miele 2019) to 'diagnostic agent' (Maslen and Harris 2021) and self-empowered 'activists' (Jansky and Langstrup 2023). We draw on the notion of '(un)invited participation' in biomedical data collection (Weiner et al. 2023), that is whether patients have been instructed by a doctor to monitor themselves (invited participation) or not but choose to do so nonetheless and bring this data to the consultation (uninvited participation). We contribute to this conversation by taking a microsociological look at how patients and doctors negotiate invited and uninvited participation across *different* chronic illnesses and the associated medical disciplines. We study whether and how physicians negotiate, that is accept, tolerate or reject, uninvited patient-generated health data in outpatient settings.

We will first elaborate on the concept of patient-generated health data and on the role of consumer apps and devices, the latter being typically uninvited in the field of medicine. We furthermore present our sample in detail, our methodological approach and our methods for data collection and analysis. In line with the Grounded Theory principle of theoretical sampling, we focused on five different health domains, within which we then recruited individual interviewees using a snowball sampling technique based on the logic of the field. The data generated in this way were subsequently analysed, leading us to identify three distinct scenarios of manoeuvring (un)invited participation: negotiating evidence, managing patients and navigating expertise.

Our study specifically speaks to the context of healthcare in Germany: strong data-protection regulations and widespread scepticism with regard to digitalisation currently prevent physicians from directly accessing PGD if done through consumer apps and devices. Whereas patients can grant health insurance apps access to health data stored on their mobile devices to participate in bonus programs (such as their daily step count), there is no indication that a centralised interface similar to the NHS app (Weiner et al. 2023, 64) will be introduced in the near future.

1.1 | Patient-Generated Data (PGD)

PGD can be broadly categorised into the documentation and assessment of symptoms and the measurement of clinical signs. The former involves the translation of embodied experiences into textual or scaled formats, necessitating active patient participation (Torenholt, Saltbæk and Langstrup 2020). This process is facilitated through questionnaires or specific applications and is often employed in research studies as well as in the monitoring of post-treatment care or chronic health conditions. Such patient-reported outcomes (PRO) can be conceptualised as invited participation, where patient engagement is encouraged and sometimes explicitly required (Weiner et al. 2023). In contrast, clinical signs, such as pulse, heart rate variability or blood oxygen saturation, may be collected with consumer apps and devices (e.g. Fitbit, Apple Watch, Samsung Galaxy Watch or the Oura Ring) and without direct order from a medical doctor. If there is no instruction, we consider patients who bring biomedical data from consumer devices to a consultation as cases of uninvited participation. These data are often graphically presented with the aid of applications and not medically certified. In the absence of explicit directives from healthcare providers for self-measurement, this form of 'data work' (Islind et al. 2019) performed by patients on their own occupies an uneasy space of partial credibility. At the same time, eHealth and mHealth technologies suggest that patients are invited as co-producers of data and information (Nielsen 2015, 29). The question therefore remains as to when, whether and how patients will feel invited to participate and contribute their data and when and which data will be welcomed by doctors.

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 whereas also demanding increased opportunity to participate in making decisions based on the data (Gabriels and Moerenhout 2018). In exploring how PGD supports doctor-patient interactions, Chung et al. (2016) describe how patients in the U.S. expect providers to make sense of their data and provide a more personalised treatment plan, whereas also giving them recognition. But in the absence of established protocols, doctors may also be left in a regulatory grey area, as

Fiske, Buyx and Prainsack (2020) report for Germany. The study by Haase et al. (2023) in Denmark 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 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 symptoms. 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).

1.2 | eHealth, mHealth and Consumer Devices

Several scholars have challenged the idea that technologies substantively alter the doctor-patient relationship or undermine medical authority (Hardey 1999, 2004; Broom 2005; Oudshoorn 2011). Doctor-patient relationships remain inherently asymmetrical (Pilnick and Dingwall 2011) and the use and interpretation of online health information varies based on patients' and doctors' roles, goals and their abilities (Henwood et al. 2003; Broom 2005). Consistent with these observations, empirical work on internet-based health technologies and information suggests that doctors and patients need to negotiate the boundaries of whether they make use of consumer health technologies and internet-based health information in consultations (Benetoli, Chen and Aslani 2018; Kingod 2020; Kjærulff and Langstrup 2023). This finding applies to health information retrieved on the internet as well as to PGD. Studies from Denmark (Haase et al. 2023) and Germany (Dahlhausen et al. 2022) note that patients rarely bring data from their consumer health devices into consultations and that providers are reluctant to use them. 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 show little decline of medical expertise and authority but point to nuanced shifts in work practice. The findings by Fiske, Buyx and Prainsack (2020) 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, thus inviting patients to participate. Gabriels and Moerenhout (2018) add to this by noting an increasing opportunity for patients to participate in making decisions based on the data.

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 medical consultations 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). Existing studies have also mostly focused attention on particular illness types such as diabetes (Fiske, Buyx and Prainsack 2020; Kjærulff and 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; Lomborg, Langstrup and Andersen 2020).

Our sample consists of chronically ill people living with cardiovascular conditions, type 1 diabetes, sleep disorders, obesity and lipoedema, chronic fatigue syndrome and long COVID/post-COVID syndrome, as well as general practitioners, diabeticians, cardiologists, somnologists and surgeons. We focused on the use of consumer health technologies and the related health data, as well as on those situations in which no established protocols for their use exist. Diabetes constitutes a liminal case in this context: although the physicians in our sample discussed both medical and lifestyle products (and underscored their differences), we closely examined the management of data measured by (non-medical) devices other than the blood glucose metre. Unlike the findings in the study by Danesi, Pralong and Pidoux (2018), the patients with diabetes in our sample manage their type 1 diabetes using consumer devices as well as a blood glucose metre. Whereas the measurement of blood glucose levels is increasingly being embraced as a lifestyle practice within self-optimisation circles and among amateur athletes, indicating a blending of lifestyle with medical technology, our emphasis here is on the additional wearable use.

2 | About the Study

Data generation and analysis was informed by our theoretical interest in the negotiation of medical authority and the digitalisation of doctor-patient relationships. 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. Whereas cases like diabetes have been in the spotlight for a long time (e.g. Mol 2000), the state of research on long/post-COVID syndrome is still limited because of the novelty of the phenomenon. To what extent both are impacted by consumer apps and devices is an empirical question yet to be answered.

Danny Lämmerhirt collected the interview 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, information sheets and project details were first sent by email to self-help 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-help groups, regional self-help contact points that passed on the information via 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. Five participants were recruited through Danny Lämmerhirt's (digital) participation in meetings of three different self-help groups, in which he presented the research project and discussed it with the participants. Eligible patients were over 18 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 receive 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.

To contact health care providers, we 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 for their disciplines. Eligible providers had to have expectations or experiences using consumer health devices, regardless of whether they actively prescribe these devices or are 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 1-week stay 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. Because of the COVID-19 pandemic, it was not possible to attend self-help group meetings or visit doctors' offices. The participants were interviewed through online video calls. Provider interviews lasted between 36 and 100 min and interviews with chronically ill people lasted between 46 and 120 min. 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 emergent findings were discussed in recurring meetings and informed the theoretical sampling, 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 related to 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.

3 | 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 2013a, 3), our results show that the extent to which these data are accepted—or even 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. Most physicians in our sample do not fundamentally question the usefulness of the data or its collection, *per se*; some even favour it.

It became apparent during the interviews that not all collected data actually reaches the physician. Patients engage in complex information management, continually reassessing 'addressivity' (Nielsen 2015, 36), that is, considering which data should be discussed with whom. In doing so, patients undertake a portion of the filtration work (*ibid.*, 41) that is typically part of the medical history-taking process. Because data collection typically happens uninvited, this 'hidden part' does not seem to affect the doctors. For them, the data is usually only relevant if it is made relevant during the consultation. In that case, responses range from outright rejection to mere tolerance to acceptance to even encouragement, almost crossing the line towards invited participation. In the following, we present three different facets of the collection of biomedical data using consumer devices. In 'Negotiating Evidence', we thoroughly elaborate upon the

mechanisms of manoeuvring and shifting between various response registers, which is why this section is the longest. In the subsequent sections, 'Managing Patients' and 'Navigating Expertise', we then provide exemplary depictions of physicians' reactions to PGD.

3.1 | Negotiating Evidence

In this section, we outline how the negotiations between doctors and patients unfold with regard to the (uninvited) participation of patients in the form of PGD. We begin by focussing on 'logics of evidence' and also consider the patients' motivations for collecting their biomedical data, as these appear to influence their consultations with doctors (cf. Stivers and Timmermans 2020; Timmermans 2020). Given that biomedical data seem to hold greater significance than patient reports (Fiore-Gartland and Neff 2015, 1476), especially people with chronic fatigue syndromes 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 chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) 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.

(Patient 3)

This patient describes that he needs his smartwatch to comprehend his level of energy reserves, employing the device to validate his feelings. This statement aligns with the description by Lupton et al. (2018) regarding data sense as knowing (about) one's body. They distinguish between data that 'show how you feel' and data that 'make you feel' (ibid., 661). Such data thus offer an opportunity to integrate objectified measurements with subjective experience, creating increased awareness about one's own body. But they also generate a 'truthiness' (Fiore-Gartland and Neff 2015, 1476) about a difficult-to-grasp health condition that fluctuates and is often only taken seriously to a limited extent by medical professionals, reflecting the assumption that 'quantitative data are "more objective" and "truer" for health understanding than other types of experience, symptoms or evidence' (ibid.).

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, that is 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 clinic is not meaningful here. Although patients must always decide whether and when to seek medical treatment, meaning they must assess their 'doctorability' and be able to justify it (Stevenson et al. 2021), there is a kind of double burden of proof in this case. The patient must not only demonstrate the need for treatment but also substantiate the

existence of the illness itself. With the data from a smartwatch, the patient has proof that she is not imagining that something is not working as it should. It is noticeable that the less specific or unknown the condition, the more extensively patients autonomously curate their data, as no specific expectations are articulated by healthcare providers (cf. Weiner et al. 2023, 67). In both cases, the PGD appears to be tolerated by the respective physicians: they do not dismiss the data as useless, yet they do not incorporate them into their files or attempt to work with them, which we would consider a form of acceptance. Furthermore, neither patient was encouraged to engage in self-tracking. In other cases, patients experienced that the PGD were ignored, what we regard as rejection, or at least the patients assumed from earlier encounters that they most likely would be.

In cardiology however, 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.

(Doctor 5)

The physician describes how the possibility of constant monitoring of the heart using consumer devices in everyday life brings new opportunities and benefits for the care of patients with heart conditions. These are 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 check 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.

(Patient 12)

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. In this case, the PGD are an accepted form of participation, uninvited at first because of their nature of being *consumer* health data, transforming the patients' involvement into an invited and encouraged assistance. The data provide specific starting points for diagnostics using medical technology and calibrated devices in doctors' surgeries or clinics.

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.

(Doctor 9)

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 observed 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. In cardiology, patient participation seems to be generally welcomed and encouraged. The lack of interfaces for data transmission—patients must send their data as PDFs or often bring printed copies that are then scanned—poses a significant issue (cf. Weiner et al. 2023). Consequently, whereas participation itself is framed as invited, the format in which data is presented can be understood as uninvited, because handling patient data without a suitable interface is described as time consuming (ibid., 69).

In the context of obesity and/or lipoedema, the situation is fundamentally different. Here, the generation of PGD is strongly encouraged from the very beginning by all stakeholders involved. The data from their wearables primarily represents 'proof' and 'evidence' that the patients with lipoedema actually adhere to their doctors' recommendations (cf. Fiske, Buyx and Prain-sack 2020; Fiore-Gartland and Neff 2015), for example 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.

(Patient 4)

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.

(Fieldnote 2)

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

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. 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 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.

(Fieldnote 2)

After 1 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.

(Fieldnote 2)

Rather than their vital signs, the efforts of people with obesity or lipoedema must be made evident here. All the cases presented share the common feature that the device seems to be considered more trustworthy than the patient (cf. Fiore-Gartland and Neff 2015), both by the physicians and the patients themselves. This level of trust varies depending on the illness and the medical speciality, which is why the response registers also differ—ranging from doctors who encourage their patients to

collect biomedical consumer health data about themselves, to those who accept and attempt to work with the data, to those who tolerate it somewhat reluctantly and view it as supplementary evidence to their patient's report and finally to those who reject this type of data, often by simply ignoring it.

3.2 | Managing Patients

The management of patients includes how physicians handle their patients, that is what they know about them and their circumstances and how the relationship between the two parties is organised, but also how compliant the patients are and how the PGD are used to adjust the therapy (Lupton 2013b). Managing patients thus refers to the data work of patients and professionals (Torenholt, Saltbæk and Langstrup 2020) as well as their interaction work accomplished during consultation (Hughes 1982). PGD and, above all, their evaluation and visualisation 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.

Considering the three primary pillars of diabetes management—diet, physical activity and medical treatment (Danesi, Pralong and Pidoux 2018, 119)—people with diabetes encounter a dual logic of documentation: on the one hand, the (semi-automated) measurement of blood glucose levels, and, on the other hand, the voluntary and usually not prescribed measurement of movement data. In contrast to the findings described in the study by Danesi, Pralong and Pidoux (*ibid.*, 126), the individuals with type 1 diabetes in our sample do not merely retrospectively correlate their physical activities based on memory with their glucose levels. Instead, they track their physical activities with an additional consumer device to proactively manage their glucose levels and prevent comorbidities. These data are discussed with diabetologists, providing supposedly more precise and deeper insights into patients' daily lives. As a result, the patient's narrative account of recent weeks may recede in importance as the values measured by devices gain increasing significance (*cf.* Fiore-Gartland and Neff 2015, 1476). The diabetologists in our sample express a generally positive attitude towards the additional data collection conducted by their patients using consumer devices. However, they criticise the lack of interfaces that would facilitate effective engagement with the PGD, such as correlating blood glucose metre records with the activities documented by the smartwatch. Whereas they are keen to utilise the data effectively, it can be argued that they ideologically accept their patients' data-generating efforts, that is their uninvited participation; yet, in practice, they merely tolerate the data because of their inability to process them efficiently.

PGD can be used as a tool for better understanding a patient's (living) circumstances and getting to know the patient better as an individual—but also for saving time. 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 the doctor. 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 (respectively their data) 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.

(Doctor 5)

This demonstrates that the personalisation through PGD not only occurs at the level of data collection but also that the collected data can lead to a more intimate relationship between doctor and patient. In these cases, our data suggest that in already highly digital and outpatient areas of medicine physicians tend to respond to PGD with acceptance or even encouragement. They perceive PGD as an opportunity to enhance the doctor-patient relationship, as the data obtained through consumer devices not only provide contextual information but also offer an opportunity for brief discussions between consultations, which typically occur only a few times a year.

Nevertheless, 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. 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 apps therefore represent the doctor's watchful eye 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.

(Doctor 1)

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.

(Doctor 2)

In order to check whether patients are adhering to therapy and behavioural recommendations and to manage treatment more precisely, some physicians prefer to collect and receive their patients' body data on a regular basis (cf. Lupton 2013a). Accordingly, their response registers range from mere acceptance to encouragement, even though they cannot prescribe a smartwatch to their patients. What we can observe in the context of patient management is that there is a confluence of transparency and personalisation occurring (cf. Fiore-Gartland and Neff 2015, 1478). In the context of patient (self-)management, their participation is more often invited than uninvited, as it does not challenge medical authority but rather adheres to a biomedical logic.

3.3 | Navigating Expertise

When we take a closer look at how patients and physicians navigate expertise, the situation appears quite different, with physicians being less affirmatively inclined towards PGD. The premise of participating patients suggests they are well informed (cf. Timmermans 2020) and possess significant knowledge about themselves, enabling them to question medical professionals' expertise (cf. Stivers and Timmermans 2020). This raises important questions about the negotiation of expertise when patients generate (biomedical) data through wearables and apps and present it to their doctors (cf. Akrich and Rabeharisoa 2023).

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 accepted 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.

(Doctor 5)

It is notable that there is an emphasis on the benefits of patients acquiring a certain level of expertise, yet a degree of dependence on doctors remains. Although their participation is generally accepted or even encouraged (thus invited), this occurs only under specific conditions. Consequently, some patients seem to

expect their physician 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?

(Patient 3)

So there seems to be a clear difference here between the competences of the doctor and the competences of the device. Hence, 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. We found it intriguing that medicine itself was never criticised; rather, patients adhered to a medicalised logic. In this context, they positioned themselves (cf. Lupton et al. 2018) and/or the apps and devices as experts on their own bodies (Fiore-Gartland and Neff 2015, 1478). 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 get 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.'

(Doctor 9)

This 'parrying', as Timmermans (2020, 260) describes it, reflects a rejection of patient participation in the form of PGD. The physician questions the quality of data obtained from the consumer device, asserting that data from a sleep lab is more 'professional' and thus superior. In doing so, he seeks to reaffirm medical authority (cf. Stivers and Timmermans 2020).

Another somnologist 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, that is medical expertise, could prevent these false-positive and false-negative measurements and their possible consequences. What we find particularly interesting is that sleep research, like cardiology and diabetology, is a highly data-driven field of medicine, yet it remains very critical of PGD. The sleep specialists in our sample all respond negatively to data generated by consumer devices, fundamentally questioning its quality. They tolerate PGD in their practice only as indicators for 'real' diagnostics, administered by them and through their medical technology.

4 | Discussion

The study explored the varying impact of PGD across different medical specialisations and physicians' responses to them. We

specifically focused on how (un)invited participation (Weiner et al. 2023) with PDG is negotiated in medical consultations. Patients use PGD from wearables to monitor their health status and—for example in the case of chronic exhaustion—validate their symptoms, which enhances their autonomy in managing their illnesses. Patients not only doing this privately but also bringing these data into the medical consultation may impact the doctor-patient relationship. This form of participation appears fundamentally uninvited at first glance because the patient was not advised to produce these data. In this paper, we differentiated the distinction between invited and uninvited participation further and presented four response registers of physicians towards PGD. The first register occupies a position at the boundary between invited and uninvited participation, transforming initially uninvited participation into invited participation. We distinguished between encouragement, acceptance, tolerance and rejection, showing that in some cases challenges such as data-format compatibility and integration with medical systems seem to be more of a problem than the uninvited participation itself.

Patients with conditions like obesity and/or lipoedema are encouraged and able to utilise PGD to prove compliance with treatment recommendations, challenging stereotypes and validating their efforts in managing their health. In this case, PGD provides evidence of lifestyle changes, which are crucial for obtaining medical approvals like bariatric surgery. But these patients are not just invited to participate; they are coerced by healthcare providers to track and manage themselves. Patients might be pictured as active agents managing health and illness: people with type 1 diabetes, for example see themselves as managers of their own life and might find it intrusive if doctors have access to their data (cf. Piras and 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.

Our data suggest that there is a link between an advanced level of patient (self-)management and accepting reactions to PGD. In cases such as type 1 diabetes and chronic heart conditions, physicians tend to support or at least accept the (additional) self-tracking with consumer devices and make efforts to incorporate the data into their patients' treatment. In contrast, general practitioners tend to view PGD with greater scepticism or outright rejection. When they engage with the data, it often means they look at the printout or digital display, but generally consider them as supplementary to the patient's account, attributing limited independent value to it. At the same time, for patients with ME/CFS and/or long/post-COVID syndrome, these data often represent the only means of 'proving' that they are truly (chronically) ill. Still, these data are frequently dismissed as insufficiently meaningful or ignored altogether. In the case of sleep medicine, the data are often devalued as not professional enough. This reinforces both the superiority of certified medical devices and the expertise of the physician.

As patients become more knowledgeable about their conditions through PGD, there is a shift in the traditional roles where doctors are viewed as the sole experts. This dynamic challenges medical professionals to navigate and negotiate (un)invited participation within the medical system of some of their

patients. 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 the future, more and more patients will attend doctor's appointments with their PGD. Because sales of wearables are on the rise and patients are using them increasingly, doctors acknowledge 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. Our findings show that the response register is quite broad: it appears that the more researched a condition is and the more established patient self-management becomes, the more positively physicians respond to their patients' (initially) uninvited participation through PGD. In contrast, conditions that are more complex to diagnose seem to provoke defensive reactions or at least reluctance from physicians when patients attempt to introduce their PGD into the consultation. The question remains as to how these negotiations will proceed with physicians who are less adept with technology and what role PGD will play in fields less technologically advanced than cardiology or somnology (besides those we studied). Additionally, it continues to be unclear what impact political changes at the international level will have on German health and data policies.

Author Contributions

Ann Kristin Augst: conceptualization (lead), formal analysis (equal), writing—original draft (lead), writing—review and editing (equal). **Danny Lämmerhirt:** data curation (lead), formal analysis (equal), methodology (lead), writing—original draft (supporting). **Cornelius Schubert:** conceptualization (supporting), funding acquisition (lead), writing—original draft (supporting), writing—review and editing (equal).

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Ethics Statement

Ethical approval for the study was received from the University of Siegen's Ethics Committee, which complies with the Code of Ethics of the German Sociological Society (DGS) and the Professional Association of German Sociologists (BDS). Participants provided informed consent prior to data collection in written or oral form, were assured their data would remain anonymous and were aware that they were free to withdraw from the research at any time.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are not available because of privacy or ethical restrictions.

Endnotes

¹ 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.

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