Digitized patients: elaborative tinkering and knowledge practices in the open-source type 1 diabetes “looper community”

Bianca Jansky

Angaben zur Veröffentlichung / Publication details:

Jansky, Bianca. 2024. “Digitized patients: elaborative tinkering and knowledge practices in the open-source type 1 diabetes ‘looper community’.” *Science, Technology, and Human Values* 49 (1): 53–77. https://doi.org/10.1177/01622439231170443.

Original Article

Science, Technology, & Human Values
2024, Vol. 49(1) 53-77

DOI: 10.1177/01622439231170443
journals.sagepub.com/home/sth
Sage

Digitized Patients: Elaborative Tinkering and Knowledge Practices in the Open-source Type 1 Diabetes "Looper Community"

Bianca Jansky[1,2]

Abstract

In this article, I explore knowledge practices in increasingly digitized, data-driven, and personalized healthcare settings by empirically focusing on the "looper community" in type 1 diabetes. This community develops and uses open-source automated insulin delivery systems and frequently criticizes slow innovation cycles and data monopolies of commercial device manufacturers. Departing from the literature on patient knowledge, I argue that studying these knowledge practices at the intersection of digitized and personalized health care, open-source innovation, and patient activism calls for an expansion of the theoretical notions of patient knowledge.

---

[1] Institute for Ethics and History of Health in Society, Medical Faculty University of Augsburg, Augsburg, Germany
[2] Institute for Sociology, Ludwig-Maximilians-University, Munich, Germany

Corresponding Author:
Bianca Jansky, Institute for Ethics and History of Health in Society, Medical Faculty University of Augsburg, Universitätsstraße 2, 86159 Augsburg, Germany.
Email: bianca.jansky@med.uni-augsburg.de

Empirically I map out three knowledge practices: technical, including maintenance and repair work; recursive, including the building and maintenance of adjunct care and support structures; and methodological, including scientistic forms of self-experimentation. I propose "elaborative tinkering" to foreground the nuances of when and how patients' different forms of knowledge practices intertwine and when they are kept apart. This approach offers new concepts for understanding what it means to know as patients in spaces of (chronic) self-care, innovation, and activism.

Keywords
ethnography, patient knowledge, open-source, type 1 diabetes, chronic disease, digitalization, digital health technologies, mHealth

Introduction

How individuals know about their (chronic) diseases is an ongoing concern in the social studies of health and illness. Within different healthcare contexts, scholars of sociology and science and technology studies (STS) have argued for respecting the epistemology of how patients engage with their diseases, bodies, medication, and self-care technologies, emphasizing that patients[1] are more than "important epistemic factors" (Falke 2018, 36) within the biomedical sphere (Epstein 1995; Pols 2013, 2014; Rabeharisoa, Moreira, and Akrich 2014). In this article, I explore patient knowledge practices in increasingly digitized, data-driven, and personalized healthcare settings by focusing on the "looper community" in Germany. Here a group of people with type 1 diabetes (T1D) develops and uses an open-source closed-loop algorithm to automate their insulin delivery and with this also improve their "chronic living" (Wahlberg et al. 2021). In their open-source endeavor, they also shed light on slow innovation cycles of commercial device manufacturers, including their data monopoly.

T1D is a chronic illness where the pancreas stops producing insulin so the affected person needs to administer it exogenously. Individuals' illness-related knowledge practices consist of measuring their glucose levels multiple times a day and administering insulin according to those measurements. Contemporary T1D self-care is often described as a burdensome practice of repetitive data work for those affected (Jansky 2021; Forlano 2016). In order to care for themselves, people living with T1D constantly need to know how to mediate between different technical devices in, on, and with their bodies, such as insulin pumps and continuous glucose monitors, and the data these technologies generate (Kingod 2018). For individuals with T1D, creating and interpreting data about themselves is a daily necessity and an integral part of their knowledge practices (Mol 2000; Piras and Zanutto 2014; Danesi et al. 2020; Liggins 2020). Even with new digital technologies, they have to be alert and active in every moment of their lives (Kaziunas et al. 2017; Gottlieb and Cluck 2019). In completing their repetitive data work, they encounter black-box algorithms, limited openness regarding the use of the data generated and collected, as well as limited interoperability (Jansky and Langstrup 2022; Gottlieb 2021).

Dissatisfaction with existing self-care technologies foregrounds the slow pace of technological innovation in T1D, device manufacturers' persistent nontransparency about data-handling, and the associated burdens of living with T1D. In this context, the looper community started to develop and use open-source algorithms to automate parts of the burdensome repetitive data work (Schipp et al. 2021; Lewis 2019).[2] Their critique of current self-care technologies was later also reflected in the community-defining use of the hashtag #WeAreNotWaiting. Loopers are "deliberately non-compliant" (Scibilia 2017) by creating and using automated systems—which commercial providers fail to deliver—in an open-source manner. In practice, this means that loopers created an open-source control algorithm that enables an insulin pump and a continuous glucose monitoring device to communicate with each other and thus take over essential data work (Braune et al. 2021). The algorithm makes small adjustments to the insulin dosage every few minutes as it responds automatically to changing glucose concentrations registered by the continuous glucose monitoring device, intended to keep glucose levels within a predefined target range (Lewis 2019). To set up the systems, loopers need to engage medical devices such as specific insulin pumps and glucose sensors as well as smartphones or smartwatches. They can then access their data on an app, which also graphically represents what the algorithm does and what it predicts. Looping is not a frictionless endeavor and has a material component to it: some loopers tinker with the battery of their glucose sensor to prolong the battery life, others 3D print transmitters. Engaging in the looper community can be interpreted as forms of chronic self-care (Schipp et al. 2021), patient-driven innovation (Demonaco et al. 2019), and activism (Jansky and Langstrup 2022).

Building on seventeen months of ethnographic fieldwork in the German looper community in 2018 and 2019, twenty-eight in-depth interviews and an analysis of public documents, I explore empirically how new patient knowledge practices emerge within this open-source endeavor. I depart from the literature on patient knowledge and argue that the phenomenon of looping points to the need to expand established theories of patient knowledge.

How loopers know is characterized by knowledge practices described in patient knowledge literature, such as tinkering (Mol 2006), practical "know-now" (Pols 2014, 82), and "credibility struggles" (Epstein 1995). Yet, as I explain below, the observed practices are also technical, recursive, and methodological. To account for how these different forms of knowing are intertwined or are kept apart, I suggest the notion of elaborative tinkering. Patients engage in knowledge practices that amount to innovative ways to change their self-care and are characterized by both intimate practices of tinkering for immediate self-care purposes, and practices of scientistic experimentations to build a knowledge base for epistemic legitimacy, for example, by establishing a research project (O'Donnell et al. 2019). Current STS understanding of patient knowledge practices can be improved by empirical accounts of cases situated at the intersection of digitized and personalized health care, open-source innovation, and patient activism.

Theorizing How Patients Know

To make private and often invisible knowledge practices visible, to show that what patients know should be regarded as a legitimate form of knowledge "amidst the multiplicity of forms of knowledge within medical practices" (Pols 2013, 82), scholars of social sciences have theorized that patients know as an "activity of knowing in a particular situation" (Pols 2014, 82) and termed this *patient knowledge*, first introduced by Jeannette Pols.

The first strand of patient knowledge literature I use in my analysis emphasizes that although patients' knowledge practices are "practical knowing in action" (Pols 2014, 75), they cannot be thought of in contrast to biomedical knowledge, because they draw from the latter. From an epistemological perspective, this way of knowing might be "messy" in the sense that these practices involve "many different techniques, values, and materials" and aim for an immediate purpose (Pols 2014, 75). Pols (2014, 79) retraces this by empirically looking at how patients were using technological aids provided by the clinic at home. With this, she foregrounds that patient knowledge practices involve coordinating and translating knowledge, technologies, and advice from different sources (Pols 2014, 75). This renders patient knowledge practices neither opposite to medical knowledge nor the same (Pols 2014, 79).

Translating different knowledges, information, and techniques from different sources and constantly adjusting, testing, and experimenting with bodies, selves, technological devices, or medication in the care context have been termed *tinkering* (Mol 2006; Mol, Moser, and Pols 2010; Winance 2010; Kingod 2018). This notion also gives a theoretical tool to understand patients' practices of "attentive experimentation" (Mol 2006, 411) in order to live with their disease. Tinkering is not a linear translation process but a constant readjusting, refitting, and readapting of care practices. Tinkering has an important collective component, because it involves more than just the individual affected by the disease: it is always done in (care) collectives (Winance 2010, 102). The collective and distributed aspects of tinkering become even more evident with the emergence of patient communities on social media. These online spaces are essential sites for knowledge production (Kingod 2018, 154).

Looping has a significant health-political component to it, which extends to how people know. The second strand of literature on patient knowledge relevant for my empirical analysis concerns activist ways of knowing in the healthcare sphere. Here, patient knowledge practices are conceptualized as actively engaging in shaping biomedical knowledge. Epstein (1995), for example, reveals how "AIDS knowledge" arose out of what he calls "credibility struggles," between different actors—activists, the media, politicians, and healthcare professionals—and therefore cannot be thought of in strictly biomedical categories. Rabeharisoa, Moreira, and Akrich (2014) coined the term "evidence-based activism" to capture forms of involvement where patient organizations engage, participate, and intervene in biomedical research practices seeking an immediate benefit for the affected. Concepts like AIDS knowledge and evidence-based activism illustrate how activists contribute and create new understandings of their disease, how their knowledge practices can influence and shape formalized biomedical knowledge, and thus account for the epistemic significance of patients within biomedical knowledge production.

These articulations of the epistemology of patients engaging with their bodies and illnesses have allowed a better understanding of the fact that patients know in relevant ways, without hierarchizing different forms of knowing in the medical sphere. I bring theoretical discussions emerged around the Quantified Self (QS) movement to the literature on patient knowledge to better grasp the methodological, innovative, and communal characteristics of loopers' knowledge practices and their engagement with personal health data. The QS movement can be described as "a large group of avid self-trackers" (Sharon 2017, 95) and is not related to a specific health condition. Members of this movement focus on creating and interpreting data about themselves and correlate behavior with somatic aspects (Heyen 2020; Villa 2012).

Within the QS movement, the practice of gaining "self-knowledge through numbers" (Wolf 2010) involves creating and engaging with personal (health) data, in what is described as "$n = 1$ self-experimentation." This points to coexistence of individualization and communality of knowledge practices that I observed in the looper community. On the one hand, "$n = 1$" emphasizes that it only needs one-person testing and gaining insights from an experiment. Best described by early QS proponent Kevin Kelly (2016, 241) as "you are testing the variable X against the very particular subject that is your body and mind at one point in time. Who cares whether the treatment works for anyone else? What you want to know is, how does it affect me?" (Kelly 2016, 241)

On the other hand, Jethani (2015, 39) has noted that "$n = 1$ quantified self-experimentation is only made meaningful in the context of a larger audience." While the QS movement focuses on individual needs, it has a "significant social component" (Crawford, Lingel, and Karppi 2015, 484). Personal data are not just about gaining information about one's body; instead, it "becomes a medium for connecting with others by offering a raw glimpse into one's intimate, private life" (Sharon and Zandbergen 2017, 10). Sharing data and participating in the community and meetups are two defining aspects of the QS movement, with personal data being the language everyone can understand and relate to (Sharon 2017, 111; Pantzar and Ruckenstein 2017, 2).

STS scholarship has variously emphasized that it is not possible to make a clear-cut distinction between biomedical knowledge and what patients know, how they engage with their bodies, with self-care technologies, and with disease. Concepts including "know-now" (Pols 2014, 82), tinkering (Mol 2006), or "credibility struggles" (Epstein 1995) emphasize the practical aspects of knowing, translating, and engaging with different forms of knowledge as patients. All these concepts imply a criticism of the binary and hierarchical notion of knowing common in the biomedical sphere. This skepticism about hierarchical knowledge is a useful point of departure for this article. Yet the contexts and operations through which loopers know are very different from clinical and established healthcare settings and thus lead to new questions. Loopers' knowledge practices are more closely related to social media communities, such as the QS movement, innovation spaces, and the open-source sphere. By bringing together these different strands of literature, we can account for the complexities of the knowledge practices that emerge when patients leave behind their provided self-care technologies and venture into an open-source innovation endeavor.

Methods and Setting

This article draws on ethnographic fieldwork carried out in the German looper community in 2018 and 2019, and the regional setting influences people's experiences. Germany is a wealthy Western European country with universal health coverage. And while the cost of much diabetes technology is covered, Germany has also been slow in adopting a digital health infrastructure, compared to other European countries (Bertelsmann Stiftung 2019, 4). For example, Germany is only now discussing electronic patient records. In my fieldwork, I did not remain in one geographic site (Marcus 1995) but followed different actors and stories (Latour 2005, 12). I started my empirical research by participating in a hackathon, and at the same time, I met my gatekeeper, an active community member. I later joined him at a local looper meetup, in which I frequently participated thereafter. I always introduced myself as a researcher and disclosed my research interests (Spradley 1979, 58). I also conducted twenty-eight problem-centered interviews (Reiter and Witzel 2012), predominantly with people who would be considered patients, their relatives, and their healthcare professionals. Participants' age ranged from twenty-two to eighty-one. They had different educational backgrounds, with more or less experience in technology-related subjects, although most participants had a higher education level.[3] Six participants were healthcare professionals, including two who had no T1D. To better understand public and broader negotiations about looping, I included media reports, blog posts, and statements from regulatory bodies in my analysis. Data gathering and analysis were mutually informed, following an iterative logic. Data collected early on in the analysis served as a starting point to direct the strategy of theoretical sampling (Clarke 2015, 101f).

Technical Setup, Maintenance, and Repair Work

> Setting up the system requires determination and technical knowledge. If you don't have the technical know-how at the beginning, you will by the end. (AndroidAPS 2020)

The looper community is strongly tied to the open-source sphere. This means that instructions and source code to set up a closed-loop system are shared online for everyone to access, use, and modify. In interviews, participants gave detailed accounts of the technical aspects when asked about how they started looping. For many, the open-source setting and knowing the technical details and composition of the systems (which I termed technical[4] patient knowledge practices) were central to their looping experiences. However, looping does not mean that people need to program themselves. Many are receivers of code, "cooking" up their own system with recipes. Marcel, a carpenter in his forties, describes the setup process:

> Yes, everything works with the instructions, which you just have to follow step by step. And when you get error notifications when you start and don't know what to do, you can quickly find an answer in the [Facebook] group. Everybody has had some error notifications, and if you just look through the posts in the group, you will find an answer. Or, if you have an urgent problem and write to someone more experienced, you will have an answer very quickly. So, it's a mix of self-work [Eigenarbeit] and feedback from the group.

Looping requires a considerable amount of work before it offers any convenience. Delegating the burdensome data work to an algorithm presupposes that each person has to set up the system on their own and understand its complexities. Detailed instructions are online, and there is a large repository with answers to frequently asked questions (in Wikis and on GitHub), updates, and new features of the systems. Marcel's description is reminiscent of approaches in technology development: experimenting with code, checking online code repositories, and consulting someone personally in case of urgent issues.

In these technical descriptions, healthcare professionals are typically not considered part of the setup practices. Another interviewee, Pascal, a sales associate in his thirties, was reluctant to share information about the kind of technical aid he used, because it did not fit the physician's scope of clinical practice:

> So, in the clinic with my physicians, I wasn't quite as open about looping, because I just think it's none of their business how I manage my diabetes. I think it's not part of the doctor's job.

The practice of looping, with its setup, maintenance, and repair work, is placed deeper into the technical realm than the medical and thus has less immediate connections to the clinic.

During my fieldwork, many healthcare professionals were not yet familiar with the system. Even for loopers who work in the healthcare sector, the technical sophistication of the system is not necessarily easily accessible. Marieke, a diabetes educator and looper in her forties, refers to the distress of having to acquire a technical vocabulary that was new to her:

> just the whole vocabulary that's like a foreign language to me. When I hear sentences like "Have you already booted the 'xDrip'" or something, I am like, "Yes, wonderful. What is he talking about?" And yes, I had support. If I have questions, as I said, it is quite touching how the community takes care of me.

Marieke has biomedical knowledge about her metabolism and a sound understanding of diabetes technology through her professional training. But this is not enough. Others in the community without her background are using these terminologies without hesitation. The technical knowledge practices of the looper community exceed the knowledge held by users of medical technologies, which remain "black box[es], unattainable" (Kaziunas et al. 2017, 3).

Using closed-loop-systems is not set-and-forget—it takes much more than a brief moment to set up the technology, which does not run independently thereafter. These sophisticated technical systems have much practical maintenance and repair work attached to them, as documented in a field note:

> Agnes, Paul and I sit at the lunch table. I sit opposite to them, and we are all eating dessert and drinking espresso; Paul and I are engaging in chit-chat about our morning. Agnes has her insulin pump and her cell phone in her hands. She doesn't listen to our conversation but is busy typing on her cell phone and sighs, "Ohh, why don't I have a connection now? I need to check how that is going." Paul leans forward and says to me with a laugh: "That's also looping, if sometimes something doesn't quite work, you are temporarily in the zone."

Looping involves constant maintenance and repair work that is not done with the initial setup. Paul's remark about being "in the zone" illustrates that this maintenance work can be captivating in everyday life. Agnes is in "the machine zone" (Schüll 2012) of her automated system; she needs briefly to zoom out of our conversation to concentrate on her system. Living with data and systems that rely on and produce personal data is always also a practice of repair and maintenance work, even if the systems are designed to automate parts of the data work for their users. Pink et al. (2018) describe this as “broken data,” emphasizing that data are always situated and temporary and need repair work.

Going beyond the technology received from healthcare providers and engaging in an unregulated open-source endeavor mean loopers begin to cultivate technical knowledge practices. The epistemology of the setup, maintenance, and repair work of the open-source systems shares similarities with the conceptual points made by Pols and Mol. Yet a looper’s way of knowing is far less “know-now” (Pols 2014, 82). Out of necessity, individuals who want to loop become proficient in knowing how their self-care technologies work to a degree that not even trained healthcare professionals have. These systems moved from the open-source and innovation sphere to the homes of individuals, and this is reflected in the ways loopers know.

Recursive: Collectively Building and Maintaining Structures for Care

> You’ll have to build your implementation yourself (no one can/will do it for you!), but . . . [t]here are users in the community around the world, so there is usually someone online . . . who can help answer questions and point you to resources. (OpenAPS 2020)

With the lack of “costumer support service” (as there is no commercial company behind looping setups) and healthcare professionals’ limited familiarity, loopers had to build their own support system (Crocket 2019). Although loopers still rely on the established healthcare system, for example, to access insulin prescriptions, they build adjunct structures of care. Markus, an IT (Information Technology) specialist in his thirties, explains:

> The community is just people who get involved. There are people who can’t program, who can’t do anything, but they can speak [more than one] language. For example, that means they can help with translating or supporting newer members, so the developers and the more experienced members don’t have to answer the standard questions.

Without the requirement for everyone to have the same level of medical or technical knowledge, and without the “safety net” of institutionalized support, division of labor becomes crucial. Markus’s quote illustrates that loopers need to know how to translate competencies they might have into something that can be beneficial to the community. The idea of getting to know something together in a patient community is also prominently discussed by Pols (2014, 81). She points out how patient communities not only connect to "share, but also . . . to create this knowledge in particular situations" (Pols 2014, 82). She refers to this as "know-now" (ibid., 82). Markus also describes a form of knowing together in a community, but the way in which they come together is different. Loopers share the goal of developing and implementing a self-care technology that is not yet available to them in the standard healthcare regime. There is a communal aspect to their way of knowing: the community itself is responsible for further developing the system, and in fact for some it is the only contact for technical problems, which amounts to building and maintaining adjunct structures of support and care. Christina, a social worker in her thirties, retraces this as follows:

> So, it's better than some service you can't get in contact with or one that can't help because the people aren't so deeply involved. Because those in the community usually have diabetes themselves or their children do. And they are so involved in the subject, and they have so much knowledge and I find that extremely important. And I have never received so many tips and help from any manufacturer. You only get so many tips and help from someone who is also affected and truly understands.

For Christina, the shared experiences of being a person with T1D or a caretaker are crucial to the effectiveness of looping. She describes the support from others in the community as essential. Although one needs to set up and maintain the system, there is a high level of understanding and support that community members can give one another as resulting of their shared illness-related experiences. Here, the communal aspect is not just about getting to know one's illness, body, and technological aids together to figure out good ways to deal with the disease. It is about knowing how to create and establish efficient and sustainable support structures.

I interpret the knowledge practices of loopers as recursive. Recursion in programming refers to a function calling on itself during its execution. Knowledge practices in the open-source sphere are recursive in the sense that the software is available for everyone to use without restrictions, as is the source codes that created the software. This means that everyone can modify the code to fit their individual needs and can redistribute those changes within the same infrastructures (Kelty 2008, 15). Hannes, a sales representative in his thirties, explains the open-source aspect of looping as follows:

> And open source simply means that you can adapt the algorithm yourself, if you know what you're doing. I played around with it a bit, but I'm not a programmer myself. That means I don't change much, but theoretically—open source—you can make any modifications you want and then make it available to the group again.

Although customizing the algorithm may seem like a rather personal practice, Hannes points out that if one learns how to change the algorithm, the potential improvement can be passed back to the community so that the group can benefit from it.

Loopers' knowledge practices constantly move between customization/personalization of the technical system and collectively building/maintaining adjunct structures of care in healthcare settings where there are no established support structures. This distance to the clinic reveals how knowledge practices can be defined by a constant "(shifting, dynamic, temporal) assemblage of multiple places, people, and resources" (Trnka 2021, 8). How patients engage with their bodies, self-care technologies, and care infrastructures cannot only be understood "through the interrelation of home and clinic" (Trnka 2021, 8). What makes the knowledge practices of loopers unique is "that code, data, and (digital) devices are their shared concern and the means through which loopers engage individually and collectively" (Jansky and Langstrup 2022, 6). Looping is an inherent individual-in-community knowledge practice that situates the person in feedback loops that involve interacting with peers in an online community, making code and resources available within this open-source community, and ultimately creating adjunct structures of care as part of a broader innovative process in health care.

Methodological: Scientistic Forms of Experimentations for Self-Care Improvement and Epistemic Legitimacy

Looping entails practices of experimenting with bodies, self-care technologies, pharmaceutical aids, and self-care arrangements. My research documents individual loopers explaining their approaches and reconstructing the aspiration of the looper community for epistemic legitimacy, which reveals knowledge practices as methodological and scientistic forms of experimenting for both self-care improvement and epistemic legitimacy.

Jacob, a father of a young child with T1D, explains his experimental approach as follows:

> Unfortunately, we do not have a second dummy child on which we can test and then see if it will work and then we test. What we have is a second pump, but no one is attached to the second hardware. So, we can't test the whole algorithm; we can only test how it behaves under certain conditions. But we can't see what happens if a lot of insulin is suddenly given or not. Or any interaction errors are difficult to test.

Jacob and his wife tinker with their child's self-care technologies to create a good life (i.e., a more comfortable life, with less worries) for their child with T1D—though not necessarily sticking to the medical definition of good care similar to how it is described in patient knowledge literature (Kingod 2018, 164). However, Jacob's remark about not having a dummy for their child and his explanation of testing parts of the open-source algorithm on a second insulin pump (which the parents have for test purposes) cannot be understood in the same terms as people tinkering with their medical technologies, for example, by putting plasters under their continuous glucose monitoring devices (Jansky 2021, 140). In their looping practice, these parents focus on developing and identifying specific methods for providing the best possible and customized therapy for their child, following what resembles specific standards of good practice in academic research and development.

Looping is a practice of constantly optimizing and improving the system and codes, adjusting variables for a personalized and customizable system, and testing and tweaking code, often against the instructions of regulatory authorities and taking the risk on oneself. While not every looper is programming, most of the people I met during my fieldwork did share Jacob's methodological and scientistic approach: using, testing, and modifying the system for personal use, and then if something works, sharing it with the community.

Some of the loopers were deeply involved in the developing and programming aspect, intending to make these efforts available for everyone. Alex, an electrical engineer who started long before the German looper community became as large as it is now, speaks of his involvement in development:

> And then I was one of the first in Germany who soldered the xDrip hardware and implemented it, and that was super, super exciting. Then through that, I met Sebastian . . . . He programmed; I tested like crazy.

Alex is not tinkering with his own medical technologies so they fit better into his everyday life; he is using what he knows from his work as an electrical engineer to help further develop the system. Compared to Jacob's approach, Alex gives more weight to the community, for example, when he states he was one of the first people in Germany to assemble the specific hardware. All the interviewed loopers who were as involved as Alex have regular day jobs and engage in the open-source community after work and on weekends. By contrast, Alex's involvement became so labor-intensive that he reports experiencing burnout. He describes some of the demands:

> You get up and check the chat channel and then there are questions, and you start to answer them and then you sit there thinking: "I've been sitting here answering questions for another hour."

Kaziunas et al. (2017, 57) drew attention to the "hidden work" in developing open-source systems. People sacrificed spare time, time with family, and even savings. They self-experimented with their bodies and had to navigate legal uncertainty, because the systems are unauthorized (Kaziunas et al. 2017, 57). These practices are not captured by tinkering, where the focus is on creating an immediate good life for oneself. Like Epstein's (1995) "treatment activists," loopers' methodological and scientistic knowledge practices are oriented toward the "bigger picture." Loopers seek to build a knowledge basis to establish epistemic legitimacy and challenge commercial manufacturers.

Loopers' efforts led to the OPEN-Project, a research project initiated by loopers and funded by the European Union (O'Donnell 2019). Here, "$n = 1$" refers to unifying knowledge practices that each of these individually setup systems contributes to the common goal, advancing and challenging the seemingly slow innovation cycle in T1D technology development.

Toni, a diabetologist and looper, retraces the relation between knowledge she gained through looping and established diabetology knowledge from her professional training:

> I would say [looping] changed my understanding of diabetology for the better. I now understand the human organism much better; I think much more dynamically. Before, it was always so that one has a blood-glucose level and takes a dose of insulin. Diabetology for most is still measuring one's blood glucose and injecting, even though this is a therapy that is actually already decades old, but that is our reality. But still, for that, I have developed a better understanding through my closed loop. Apart from that, if patients talk to me

> about it, I am, of course, open to dialogue but cannot help practically with setting up the loop, even though I have one myself.

Toni emphasizes that as a diabetologists, she has to stick to the outdated standard therapy. The "$n = 1$ self-experimentation" of using a system where the algorithm is reacting to the changes in glucose values much quicker than a human could leads Toni to understand the physiology of diabetes more dynamically. The conflict resulting from the difference between new knowledge production and established knowledge becomes apparent at this point: on the one hand is the knowledge established in and approved by the medical system as a codified practice, and on the other, the innovative yet unapproved technology used by loopers.

At the time of my fieldwork, concerns were raised by health professionals, legal scholars, ethicists, and regulatory bodies about the risks and safety of using the unauthorized system. In 2019, the US Food and Drug Administration even issued a safety warning:

> Today, the US Food and Drug Administration is warning patients and health care professionals of risks associated with the use of unapproved or unauthorized devices for diabetes management . . . . [T]he agency noted that the use of unapproved or unauthorized devices could result in inaccurate blood glucose (sugar) measurements or unsafe insulin dosing, which can lead to injury requiring medical intervention or even death. (FDA 2019)

This statement caused significant concerns in the German looper community, because loopers already felt they were in precarious situations by using this system and may lose support from their healthcare providers. The warning statement intensified these tensions, and the community felt they had to react. They issued a response statement, posted on different social media platforms, in which they compared the risks of looping to not automated management and stated how they, as a community, are working to make looping as safe as possible. These tensions around credibility were apparent in my interviews. Reacting to legal advice to turn off the automated system when driving a car to avoid liability issues in case of car accidents (Ebert 2019), Katja, a diabetologist explained:

> From a medical point of view this is the worst thing you can do . . . . That's my opinion from my medical metabolic point of view. It's completely wrong and I don't know if a lawyer can even give . . . therapeutic recommendations.

Looping is accompanied by these tensions around expertise, credibility, and legitimate ways of knowing. The OPEN project aims to challenge the "outdated" knowledge practices of standard therapy and safety concerns raised by other actors in the healthcare sphere. With their (individual and collective) engagement, the looper community is issuing political claims. The knowledge practices of the looper community explored here are related to activist knowledge practices retraced by Epstein (1995, 1998), Callon and Rabeharisoa (2003), or Rabeharisoa, Moreira, and Akrich (2014). How loopers "take means of production into their own hands" (Jansky and Langstrup 2022, 11) also adds new dimensions to this understanding. Loopers challenged pharmaceutical and device manufacturers' innovation operations and knowledge practices in biomedicine more broadly.

The literature on patient knowledge is quite clear that care always entails practices of experimenting and tinkering with bodies, technical devices, medication, and human and technical arrangements. Loopers' knowledge practices aim to improve everyday life for people with a chronic health condition and can be personalized. However, looping goes beyond patient knowledge because it is a more deliberate approach to changing variables and code analytically, often with the goal of improving the system for all. This methodological way of knowing in the looper community points to health-political goals. Loopers know by creating a knowledge base where evidence is produced, with the possibility of formalizing what loopers know, for example, through the establishment of the OPEN project.

Discussion: Elaborative Tinkering

In this article, I empirically mapped out three patient knowledge practices (technical, recursive, and methodological) that emerge when people with T1D use and develop an unauthorized automated system for their illness-related repetitive data work. The epistemologies of going beyond commercial self-care technologies and venturing into this open-source endeavor highlight an entanglement of different forms of (patient) knowledge practices that have not yet been addressed in the literature about patient knowledge.

Pols (2013, 2014), Mol (2006), and others working in their tradition note that what patients do and how they bring together different sources, techniques, and knowledges to live with a disease should be respected as knowledge among other forms of knowledge in the biomedical sphere. On the other hand, Epstein (1995) and Rabeharisoa, Moreira, and Akrich (2014) focus on how patients know in activist ways. They documented affected people self-organizing, being vocal in their demands and criticism of established healthcare structures/actors, and challenging and influencing (medical) understanding of their health condition.

These different concepts from STS are a lens to look at loopers' knowledge practices, which have elements of tinkering, as described by Mol (2006) and others, as well as practical "know-now" (Pols 2014, 82) and can also include more activist forms of knowing with a health-political aim. Looping is firmly situated in the realm of open-source innovation. The fact that loopers are experimenting with their bodies in creative, critical, and vocal ways—stressing the importance of personal health data—brings their knowledge practices close to the QS movement. These accounts of how patients know add nuance to descriptions of patient knowledge.

Yet developing and using life-saving self-care technologies while being involved in open-source innovation and activism go beyond tinkering and know-now. With loopers, we are somewhere in between these notions of patient knowledge: loopers are demanding, they want to be recognized, they are vocal, and managed to create "actually existing alternatives" (Kelty 2008, 3) to the commercial systems. Loopers' knowledge practices are technically advanced to a degree that is not conceived of in the current literature on patient knowledge. They know about technical details that even people trained in T1D technologies do not necessarily know. Data repair work (Pink et al. 2018); maintaining devices on, in, and with bodies; keeping data flowing; or navigating the open-source platforms are some of loopers' common knowledge practices, even though they are not part of the established care structures of living with T1D. Loopers experiment with their bodies and self-care technologies, and they engage in innovative ways in a community outside of the clinic, on social media and in the open-source sphere. In the context of looping, knowing becomes a recursive practice of methodologically experimenting with bodies, self-care technology, algorithms, and digital infrastructures—all while staying in feedback loops with others in the community. The focus of the looper community is always directed at establishing a knowledge base and epistemic legitimacy. Looping becomes a continuous moving between deeply individual practices and inherently communal challenges that cannot be undertaken alone. It connects self-care practices with broader negotiations and tensions in the healthcare sphere regarding expertise, credibility, and knowledge legitimation. Similar to the QS movement, loopers do not see technologies and health programs provided by the "traditional" and standard healthcare regime as fitting or good enough, so they take matters into their own hands

(Sharon 2017, 109). They push device manufacturers and pharmaceutical companies like Epstein's (1995) "treatment activists." However, with the establishment of the OPEN project, loopers are beginning to enter (clinical) academic spaces, not invited as "citizen scientists," but by using their diverse professional backgrounds. Evidence is produced within a research project, with the possibility of formalizing what loopers know. Unlike other forms of patient activism, loopers do not stay in the biomedical and healthcare realm, instead moving in and out of healthcare/clinical and open-source innovation spaces, challenging received ideas about patients' knowledge practices.

Loopers' knowledge practices are complex and multifaceted and, I suggest, best understood as forms of *elaborative tinkering*. Downloading instructions, maintaining a technical system that immediately can improve one's own "chronic living" (Wahlberg et al. 2021), or the engagement in online and offline peer communities for support are all practical ways of knowing and tinkering with self-care arrangements. Loopers' knowledge practices are closely related to pushing and criticizing commercial device manufacturers and regulatory bodies, deliberate scientistic self-experimenting for "the greater good," and being engaged in building a knowledge base for epistemic legitimacy. Loopers are engaging within the open-source innovation sphere and using and developing this automated system with the aim to improve one's personal life with the chronic health condition while at the same time having in mind that they need to generate evidence that these automated systems are efficient.

Loopers create complex knowledge and make it explicit by sharing it with others in methodological, organized, and scientistic ways. Their emerging knowledge practices reveal loopers radically changing their own treatment, while also challenging "the political economy of health device innovation" (Jansky and Langstrup 2022, 18). If we stay only within the literature about how patients know in practical ways, or if we only see the emerging knowledge practices of the looper community through the prism of activist ways of knowing as patient, or as niche self-experimenting as patient innovators in the realm of the QS movement, we lose sight of the nuanced entanglement of these ways of knowing in practice. Focusing on *elaborative tinkering* captures how knowing as a patient in these spaces of innovation, activism, and digitized (chronic) self-care can and is a constantly moving between and combining different ways of knowing. Understanding that patient knowledge practices in the looper community and similar health communities are made up of different ways of knowing offers a way not to lose sight of the fact that intimate practices of tinkering with self-care arrangements and "know-now" (Pols 2014, 82) can also be entangled with activist and innovative ways of knowing, and how both might be interrelated. With an increase of digitized, personalized, and data-driven healthcare settings, where technologies do not only "travel . . . from the clinic to the home" (Langstrup 2005), but from open-source innovation spaces to the home (and later to the clinical context), we will see more and more that patients can know in technically advanced, recursive, and methodological and scientistic ways. Turning the gaze toward *elaborative tinkering* allows us to carefully explore when and how different patient knowledge practices might come together and when they are kept apart.

Conclusion

Although the case presented in this article is rather specific, from a history of high involvement in one's care in T1D to the uniqueness of the technology and community, similar technologically advanced, recursive, and methodological ways of engaging with technologies can be observed in other healthcare settings, such as sleep apnea (Schultz 2019), epilepsy (Bogataj et al. 2021), and hearing loss (O'Kane et al. 2019). These communities might not be as organized as the looper community currently is—yet the proposed notion of *elaborative tinkering* may help other researchers to gain a deeper understanding of the complexities of knowing as a patient at these intersections of digitized and personalized health care, open-source innovation, and patient activism. The empirical reports above show that patients can have highly complex and sophisticated technical knowledge about an innovation that far exceeds current commercial self-care technologies. I have also illustrated that healthcare professionals can draw upon their own illness-related experiential knowledge, combined with biomedical knowledge. How this can unfold in other areas of increasingly digitized, data-driven, and personalized healthcare settings calls for more empirical exploration.

Acknowledgments

Firstly, I want to thank the looper community, the regular meetup group, and the participants I interviewed for sharing their experiences and lived expertise with me. I am sincerely grateful for all of it. I also want to thank my PhD supervisors Paula-Irene Villa Braslavsky and Henriette Langstrup for their feedback and comments on my manuscript and their continuous encouragement. In addition, I want to thank Verina Wild, Tereza Hendl, Jasmine Schipp, Ayush Shukla, the two anonymous reviewers, and the *Science, Technology, & Human Values* editorial team for their helpful comments on earlier versions of the manuscript. For editorial help, I want to thank Fabian Linder. This article is part of my PhD in sociology at the Ludwig-Maximilians-University, Munich.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This article is funded by the German Federal Ministry of Education and Research (grant number 01GP1791).

ORCID iD

Bianca Jansky https://orcid.org/0000-0001-8180-645X

Notes

1. While the theoretical focus of this article is patient knowledge, I will restrain from using the term "patient" to describe the individuals in my empirical case because it is inadequate to describe the experiences of individuals living with chronic health conditions every day (Schicktanz 2015).
2. During my fieldwork, one commercial system was approved for the European market (Medtronic 2019).
3. Most people I met during my fieldwork were new to this way of knowledge sharing. I also want to acknowledge the class, gender, and race-related power imbalances in the open-source sphere: most people involved with open-source work are in better-positioned socioeconomic spaces and conditions (Dunbar-Hester 2020), which is also the case in the looper community (Braune et al. 2021).
4. I use the term "technical" in a similar manner to Pols's (2014) use of the term "medical," knowing that the technical sphere is as heterogeneous and diverse as the medical one. In my argument, technical is an umbrella term to describe the broader aspects of the technical spheres without going into much detail.

References

AndroidAPS. n.d. "What Is a Closed Loop System?" Accessed April 6, 2020. https://androidaps.readthedocs.io/en/latest/EN/Getting-Started/ClosedLoop.html.

Bertelsmann, Stiftung. 2019. “#SmartHealthSystems. International Comparison of Digital Strategies.” Accessed April 17, 2023. https://www.bertelsmann-stiftung.de/fileadmin/files/Projekte/Der_digitale_Patient/VV_SHS_Europe_eng.pdf.

Bogataj, Monika, Aleksander Hrastič, Jaka Jemec, and Timon Kalagasidis. 2021, May 31. “Epilet—Bracelet for Epilepsy Attacks.” Accessed April 17, 2023. https://www.hackster.io/epilet/epilet-bracelet-for-epilepsy-attacks-25a922.

Braune, Katarina, Katarzyna A. Gajewska, Axel Thieffry, Dana Lewis, Timothée Froment, Shane O’Donnell Shane, Jane Speight etal. 2021. “Why #WeAreNotWaiting-Motivations and Self-reported Outcomes among Users of Open-source Automated Insulin Delivery Systems: Multinational Survey,” *Journal of Medical Internet Research* 23 (6):e25409. doi: 10.2196/25409.

Callon, Michel, and Vololona Rabeharisoa. 2003. “Research “In the Wild” and the Shaping of New Social Identities.” *Technology in Society* 25:193-204. doi: 10.1016/S0160-791X(03)00021-6.

Clarke, Adele E. 2015. From Grounded Theory to Situational Analysis: What’s New? Why? How?” In *Situational Analysis in Practice: Mapping Research with Grounded Theory*, edited by A. Clarke, C. Friese, and R. Washburn, 84-119. London, UK: Routledge.

Crawford, Kate, Jessa Lingel, and Tero Karppi. 2015. “Our Metrics, Ourselves: A Hundred Years of Self-tracking from the Weight Scale to the Wrist Wearable Device.” *European Journal of Cultural Studies* 18 (4-5):479-96.

Crocket, Hamish. 2019. “Peer Mentoring in the Do-it-yourself Artificial Pancreas System Community.” *Journal of Diabetes Science and Technology* 14 (6): 1022-27. doi: 10.1177/1932296819883876.

Danesi, Giada, Mélody Pralong, Francesco Panese, Bernard Burnand, and Michèle Grossen. 2020. “Techno-social Reconfigurations in Diabetes (Self-)care.” *Social Studies of Science* 50 (2):1-23. doi: 10.1177/0306312720903493.

DeMonaco, Harold, Pedro Oliveira, Andrew Torrance, Christiana von Hippel, and Eric von Hippel. 2019. “When Patients Become Innovators.” *MITSloan Management Review* 60 (3):15.

Dunbar-Hester, Christina. 2019. *Hacking Diversity: The Politics of Inclusion in Open Technology Cultures*. Princeton, NJ: Princeton University Press.

Ebert, Oliver. 2019. “Closed-Loop-Eigenbau. Loopen: Was ist aus juristischer Sicht wichtig?” *Diabetes Online*, October 18. Accessed April 17, 2023. https://www.diabetes-online.de/a/closed-loop-eigenbau-loopen-was-ist-aus-juristischer-sicht-wichtig-1994440.

Epstein, Steven. 1995. “The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials.” *Science, Technology, & Human Values* 20 (4):408-37.

Epstein, Steven. 1998. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.

Falke, Oliver. 2018. "Der Patient als epistemische Größe: Praktisches Wissen und Selbsttechniken in der Diabetestherapie 1922–1960." *Medizinhistorisches Journal* 53 (1):36-58.

FDA (Food and Drug Administration). 2019, May 17. "FDA Warns Against the Use of Unauthorized Devices for Diabetes Management." *FDA News Release*. Accessed April 17, 2023. https://www.fda.gov/news-events/press-announcements/fda-warns-against-use-unauthorized-devices-diabetes-management.

Forlano, Laura. 2016. "Hacking the Feminist Disabled Body." *Journal of Peer Production*. Special Issue on "Feminist (Un)Hacking" Special Issue 8: Feminism and (un)hacking. Accessed April 17, 2023. http://peerproduction.net/issues/issue-8-feminism-and-unhacking/peer-reviewed-papers/hacking-the-feminist-disabled-body/.

Gottlieb, Samantha. 2021. "The Fantastical Empowered Patient." In *Healthcare Activism. Markets, Morals, and the Collective Good*, edited by Susi Geiger, 198-223. Oxford, UK: Oxford University Press.

Gottlieb, Samantha, and Jonathan Cluck. 2019. "'Going Rogue' Re-coding Resistance with Type 1 Diabetes Digital." *Culture & Society* 4 (2):137-55.

Heyen, Nils. 2020. "From Self-tracking to Self-expertise: The Production of Self-related Knowledge by Doing Personal Science." *Public Understanding of Science* 29 (2):124-38. doi: 10.1177/0963662519888757.

Jansky, Bianca. 2021. "Warum stechen, wenn man scannen kann? Zum Einsatz sensorbasierter Glukosemesssysteme in der Typ 1 Diabetestherapie." In *Digitale Patientenversorgung: Zur Computerisierung von Diagnostik, Therapie und Pflege*, edited by J. Inthorn and R. Seissing, 127-48. Bielefeld, Germany: Transcript.

Jansky, Bianca, and Henriette Langstrup. 2022. "Device Activism and Material Participation in Healthcare: Retracing Forms of Engagement in the #WeAreNotWaiting Movement for Open-source Closed-loop Systems in Type 1 Diabetes Self-care." *BioSocieties*:1-25. doi: 10.1057/s41292-022-00278-4.

Jethani, Suneel. 2015. "Mediating the Body: Technology, Politics and Epistemologies of Self." *Communication, Politics & Culture* 47 (3):34-43.

Kaziunas, Elizabeth, Mark Ackerman, Silvia Lindtner, and Joyce Lee. 2017. "Caring Through Data: Attending to the Social and Emotional Experiences of Health Datafication." *The ACM Conference on Computer Supported Cooperative Work and Social Computing*, February 2017, New York, pp. 2260-72.

Kelly, Kevin. 2016. *The Inevitable: Understanding the 12 Technological Forces That Will Shape Our Future*. New York: Viking.

Kelty, Christopher M. 2008. *Two Bits. The Cultural Significance of Free* Software. Durham and London, UK: Duke University Press.

Kingod, Natasja. 2018. “The Tinkering m-Patient: Co-constructing Knowledge on How to Live with Type 1 Diabetes through Facebook Searching and Sharing and Offline Tinkering with Self-care,” *Health* 24 (2):152-68.

Langstrup, Henriette. 2005. “Linking Healthcare: An Inquiry into the Changing Performances of Web-Based Technology for Asthma Monitoring.” PhD diss., Copenhagen Business School.

Latour, Bruno. 2005. *Reassembling the Social. An Introduction to Actor-network-theory*. New York: Oxford University Press.

Lewis, Dana. 2019. “History and Perspective on DIY Closed Looping,” *Journal of Diabetes Science and Technology* 13 (4):790-93.

Liggins, Arlena Siobhan. 2020. *Making Diabetes. The Politics of Diabetes Diagnostics in Uganda*. Bielefeld, Germany: Transcript.

Marcus, George. 1995. “Ethnography in/of the World System: The Emergence of Multi-sited Ethnography,” *Annual Review of Anthropology* 24 (1):95-117.

Medtronic. 2019. “Minimed 670G System ist in der Regelerstattung.” Accessed December 1, 2019. https://www.medtronic.com/de-de/diabetes/home/service/news/neuesten-nachrichten/MiniMed-670G-Regelerstattung.html.

Mol, Annemarie. 2000. “What Diagnostic Devices Do: The Case of Blood Sugar Measurement.” *Theoretical Medicine and Bioethics* 21 (1):9-22.

Mol, Annemarie. 2006. “Proving or Improving: On Health Care Research as a Form of Self-reflection.” *Qualitative Health Research* 16 (3):405-14.

Mol, Annemarie, Ingunn Moser, and Jeannette Pols. 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Bielefeld, Germany: Transcript.

Shane, O’Donnell, Dana Lewis, María Marchante Fernández, Mandy Wäldchen, Bryan Cleal, Timothy Skinner, Klemens Raile, Adrian Tappe, Tebbe Ubben, Ingrid Willaing, Bastian Hauck, Saskia Wolf, and Katarina Braune. 2019. “Evidence on User-led Innovation in Diabetes Technology (The OPEN Project): Protocol for a Mixed Methods Study.” *JMIR Research Protocols* 8 (11):e15368 doi: 10.2196/15368.

O’Kane, Aisling Ann, Abdinasir Aliomar, Rebecca Zheng, Britta Schulte, and Gianluca Trombetta. 2019. “Social, Cultural and Systematic Frustrations Motivating the Formation of a DIY Hearing Loss Hacking Community.” *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, Association for Computing Machinery.

OpenAPS. 2020. “OpenAPS.org.” Accessed April 6, 2020. https://openaps.org.

Pink, Sarah, Minna Ruckenstein, Robert Willim, and Melisa Duque. 2018. “Broken Data: Conceptualising Data in an Emerging World.” *Big Data & Society* 5 (1). doi: 10.1177/2053951717753228.

Piras, Enrico, and Alberto Zanutto. 2014. “One Day it Will Be You Who Tells us Doctors What TO do!” Exploring the “Personal” of PHR in Paediatric Diabetes Management.” *IT & People* 27 (4):421-39.

Pols, Jeannette. 2013. “The Patient 2.Many: About Diseases that Remain and the Different Forms of Knowledge to Live with Them.” *Science & Technology Studies* 26 (2):80-97.

Pols, Jeannette. 2014. “Knowing Patients: Turning Patient Knowledge into Science. ” *Science, Technology, & Human Values* 39 (1):73-97.

Rabeharisoa, Vololona, Tiago Moreira, and Madeleine Akrich. 2014. “Evidence-based Activism: Patients’, Users’ and Activists’ Groups in Knowledge Society.” *BioSocieties* 9 (2):111-28.

Reiter, Herwig, and Andreas Witzel. 2012. *The Problem-centred interview*. Los Angeles, CA: Sage.

Ruckenstein, Minna, and Mika Pantzar. 2017. “Beyond the Quantified Self: Thematic Exploration of a Dataistic Paradigm,” *New Media & Society* 19 (3): 401-18.

Schicktanz, Silke. 2015. “The Ethical Legitimacy of Patient Organizations’ Involvement in Politics and Knowledge Production: Epistemic Justice as Conceptual Basis.” In *The Public Shaping of Medical Research*, edited by Wehling Peter, Viehöver Willy, and Sophia Koenen, 246-65. Oxon, UK: Routledge.

Sharon, Tamar. 2017. “Self-tracking for Health and the Quantified Self: Re-articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare,” *Philosophy of Technology* 30:93-121.

Schipp, Jasmine, Timothy C. Skinner, Edith Holloway, Renza Scibilia, Henriette Langstrup, Jane Speight, and Christel Hendrieckx. 2021. “How Adults with Type 1 Diabetes Are Navigating the Challenges of Open-source Artificial Pancreas Systems: A Qualitative Study.” *Diabetes Technology Therapy* 23 (8):546-54.

Schüll, Natasha Dow. 2012. *Addiction by Design: Machine Gambling in Las Vegas*. Princeton, NJ: Princeton University Press.

Schultz, Marvin. 2019. “DIY Sleep Apnea Screening”. *Medium*, October 28. Accessed April 17 2023. https://medium.com/swlh/diy-sleep-apnea-screening-7e03c607c7e.

Scibilia, Renza. 2017. “Deliberately Non-compliant Diabetic.” *Diabetogenic*, October 25. Accessed April 17 2023. https://diabetogenic.wordpress.com/2017/10/25/deliberately-non-compliant-diabetic/.

Sharon, Tamar, and Dorien Zandbergen. 2017. “From Data Fetishism to Quantifying Selves: Self-tracking Practices and the Other Values of Data,” *New Media & Society* 19 (11):1695-709.

Spradley, James. 1979. *The Ethnographic Interview*. New York: Holt.

Trnka, Susanna. 2021. “Multi-sited Therapeutic Assemblages: Virtual and Real-life Emplacement of Youth Mental Health Support,” *Social Science & Medicine* 278: 113960. doi: 10.1016/j.socscimed.2021.113960.

Villa, Paula-Irene. 2012. “Die Vermessung des Selbst. Einsichten in zeitgenössische Formen der Körperarbeit”. *AVISO* 3:14-19.

Wahlberg, Ayo, Jieun Lee, Anna Mann, Arseli Dokumaci, Kingod Natasja, Svensson Marie, and Laura Louise Heinsen. 2021. “Chronic Living: Ethnographic Explorations of Daily Lives Swayed by (Multiple) Medical Conditions.” *Somatosphere*, February. Accessed April 17 2023. http://somatosphere.net/2021/chronic-living.html/.

Winance, Myriam. 2010. “Care and Disability”. In *Care in Practice. On Tinkering in Clinics, Homes and Farms*, edited by Mol Annemarie, Moser Ingunn, and Jeannette Pols, 93-117. Bielefeld, Germany: Transcript.

Wolf, Garry. 2010. “The Data-driven Life.” *The New York Times*, May 2. Accessed April 17 2023. https://www.nytimes.com/2010/05/02/magazine/02self-measurement-t.html.

Author Biography

Bianca Jansky is a PhD candidate in sociology at the Ludwig-Maximilians-University, Munich. As a research associate at the Institute for Ethics and History of Health in Society, University of Augsburg, she works in the research project “mHealth: Ethical, Legal, Social Aspects in the Technological Age” funded by the German Federal Ministry of Education and Research.