Device activism

An ethnography of patient activism at the intersection of chronic (self)care and open-source innovation in Type 1 Diabetes

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Dissertation structure

The dissertation is publication based. This means the findings are written as three separate peer-reviewed journal articles and one additional peer-reviewed anthology book chapter. Each can be read independently and consists of an introduction, a theoretical underpinning, and an empirical argument. In them, I shed light on different aspects of the practices of being engaged in device activism and thus offer a mapping of the complexities of the everyday-life engagement in contemporary digitized health activism. In the synopsis (part one), I first introduce my specific empirical case as well as my research interests (**Section 1**), reflect on the conceptual framework of the dissertation, situate my research within the larger sociological and science and technology studies (STS) literature (**Section 2**) and reflect on my methodological approach (**Section 3**). In **Section 4** I will bring together the overarching themes of the articles and point out how I contribute to the sociological and STS literature on chronic (self)care, healthcare activism, and patient-led innovation. The synopsis ends with a conclusion (**Section 5**).

The publications are presented in part two. In **Publication 1**, I empirically retrace how this case can stand as a *cas d'école* on what pivotal role medical devices play in glocal (global and local) health movements. I also introduce the dissertation grounding concept of device activism. In **Publication 2**, I retrace how engaging in this movement leads to new knowledge practices for the affected. In **Publication 3** I further used my empirical experiences to reflect on the situated knowledge(s) of doing ethnographic research and argue for a focus on accountability when studying health movements where one is not affected oneself. **Publication 4** is an additional publication focusing on the bigger picture of what this case can add to the theoretical understanding of care with algorithmic systems beyond Type 1 Diabetes.

Content

Acknowledgements

Appendix

Deutsche Zusammenfassung

Sample overview

Part One – Synopsis

1. Introduction

> "**#WeAreNotWaiting** while our endocrinologist tries to assemble the disjointed pieces of the data puzzle.
>
> **#WeAreNotWaiting** for competitors to cooperate.
>
> **#WeAreNotWaiting** for regulators to regulate.
>
> **#WeAreNotWaiting** for device manufacturers to innovate.
>
> […] **#WeAreNotWaiting** for the cure."[1] (Healthline 2013)

> "Open-source automated insulin delivery systems, commonly referred to as do-it-yourself automated insulin delivery systems, are examples of user-driven innovations that were co-created and supported by an online community who were directly affected by diabetes" (Braune et al. 2022, 58)

Automated and data-driven digital devices are part of many aspects of our lives. Especially in healthcare settings, discussions about automated systems, machine learning processes, or "algorithmic assemblages of care" (Schwennesen 2019) have gained momentum and turned into "matters of concern" (Latour 2004a). The two above cited quotes deal with data-driven healthcare devices as a matter of concern in the case of Type 1 Diabetes (T1D) (self)care. T1D is a chronic health condition for which the affected[2] cannot abstain from involvement in their own care. Being diagnosed with a chronic health condition[3] changes one's life forever. "Chronic

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[1] This is a quote taken from a blogpost summarizing the points made at "DiabetesMine D-Data ExChange" in 2013 at Stanford University. This is the first time the hashtag #WeAreNotWaiting is used. It was later picked up on Twitter by people with diabetes around the globe.

[2] As this is a dissertation focused on individuals living with a chronic health condition, I only carefully use the term *patient* in relation to the theoretical concepts and not to describe the individuals in my studied case. Language matters greatly when writing about people affected by chronic health conditions, and Schicktanz et al. (2015) have rightfully pointed out that the term *patient* cannot grasp what it means to live with a chronic health condition every day.

[3] In sociology, chronic illnesses have gained much attention, with the focus being primarily on illness trajectories and the everyday life experiences of affected people (for earlier work see for example: Burry 1982; Charmaz 1991; Corbin and Strauss 1988, or Strauss and Glaser 1975). Here, I also want to point out that throughout this dissertation, I use the terms *chronic health condition*, *disease*, and *illness* interchangeably to emphasize the entanglement of the social, medical, and

living”[4] (Wahlberg et al. 2021) means engaging throughout one’s life with different care activities in everyday life practices. Recently automation through the use of data-driven devices has become a vision for a “technical cure” (Heineman 2017, 226). For decades, this waiting and hoping for a “cure” through pharmaceutical interventions or technology has been part of the T1D illness experience (Heinemann and Lange 2020, 1028). The individuals at the center of my ethnographic study did not want to wait for this cure through automation and instead created the needed technology themselves outside of the realm of the clinical and pharmaceutical industry. People living with T1D are—borrowing this term from the computer science discussions around automation—the “human in the loop” (Munro Monarch 2021) of their (self)care and need to mediate between different technological devices in, on, and with their bodies to care for themselves.

T1D, which emerges when the pancreatic cells in the body stop producing insulin, leaves the person affected as the “primary decision-maker” (Piras and Miele 2019, 121) in their (self)care. They have to mimic the functions of the pancreas with pharmaceutical and technical aids. Annemarie Mol (2008) describes this as follows: “What happens automatically inside bodies without diabetes, requires a lot of work on the outside of bodies with diabetes” (Mol 2008, 33). No matter what one does, T1D follows: if you want to exercise, if you want to eat an apple, if you want to travel, or if you want to take a shower (Mol 2008, 36). Even though contemporary T1D technologies[5] have become increasingly sophisticated,[6] people living with T1D have to measure glucose levels multiple times a day and then administer

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technical in studying health. With this, I emphasize that I do not orient my study toward the dualistic idea of a differentiation of illness (as a research subject for social sciences and humanities) and disease (as a research subject for life sciences).

[4] I use this notion of “chronic living” throughout the dissertation to stress that a chronic disease is part of every aspect of the life of a person and also shapes everyday activities such as eating, exercising, working, or parenting (Wahlberg et al. 2021). This phrasing emphasizes that “somatic disturbances inevitably spill over into social worlds and vice versa” (Manderson and Wahlberg 2020, 2).

[5] Throughout this dissertation, I follow the anthropological definition of *technology* that goes “beyond the artifacts and include[s] human bodies, skills, traditions, practices, processes and socio-technical systems.” (Bruun and Wahlberg 2022, 4). I use the term *technology* in an overarching sense, while I use the term *devices* when referring to the tangible, technical devices. I am aware that every technology needs some sort of materiality and acknowledge that every technology also has a material component: “from a stone ax or clockwork to a fighter jet or smartphone. They are made by people, using particular techniques and material that may differ in origins, efficacy or aesthetic value, but are nonetheless material” (Bille 2022, 85). Differentiating between technology and devices gives me an analytical tool to be more precise in my description.

[6] One hundred years ago, being diagnosed with T1D would have been fatal, but through the invention of insulin as a hormone preparation, a life with T1D is possible (Falke 2022).

insulin accordingly. In this repetitive data work, device manufacturers are the ones with power over how the individuals who generated the data through "intimate entanglement with devices" [7] (Forlano 2016, n.p.) access, view, and use the data. Affected people often do not feel adequately informed about how these companies use their data.[8] Furthermore, there is a lack of interoperability between technologies from different manufacturers (Forlano 2016), and the devices cannot be customized (Lewis 2019b). Feminist disability studies scholar Laura Forlano (2020) points to the monopoly of the device manufacturers in the care of people living with diabetes, comparing it with other non-medical commercial technology development: "unlike those who own the latest iPhone, a person who is dependent on a medical device—due to four-year product warranties, near monopolies in the healthcare and medical device industry, and health insurance guidelines—cannot easily downgrade, change device, or switch to another provider when problems do occur" (Forlano 2020, n.p.).

In the early 2010s, a few individuals with T1D, who later turned into a global[9] health movement, started to reverse engineer their T1D devices and shared their frustrations with commercial manufacturers and ideas for customizing and adjusting their devices online with others under the hashtag #WeAreNotWaiting. Initially, the group was concerned with gaining easier access to their data (Kaziunas 2018; Kaziunas et al. 2017) or changing the sound volume of the alarms on their glucose sensors (Lewis 2019b). Later these attempts turned into the idea of developing an open-source algorithm that could act as a communication vehicle between insulin pump and glucose monitor and thus automate parts of the (self)care practices of people living with T1D, creating a hybrid[10] closed-loop system for their insulin delivery. In closed-loop systems a control-algorithm makes small

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[7] I use the notion of *entanglement* throughout the dissertation to emphasize this "complex web of connections" (Latour 1999, 90) in the practices of loopers. As Lindén (2020, 7f.) points out, this notion makes it possible to "attend to the inseparability of the affective, epistemic, material, and temporal dimensions" in an empirical inquiry.

[8] See for example this blogpost: http://type1tennis.blogspot.com/2014/12/abbott-freestyle-libre-something-every.html (latest access: 07.03.2023).

[9] There are no official numbers of how many people are part of this community. Some estimates set the number at 2,700 (Lewis 2022 (July 2022), while others are a lot higher at over 9,000 (Wong et al. 2022). It also depends on how one defines being part of the community. Some also include people interested in using the technology or who are part of the Facebook groups related to the system (O'Donnell 2023). It is also important to point out that the community consists mainly of people living with diabetes in the Global North, with the majority having T1D (Braune et al. 2021).

[10] These systems still require the user to engage with the system and, for example, "enter information and manually dose for meals" (Lewis 2019b, 151). A fully closed loop would mean the users only minimally interact with the system.

adjustments to the insulin dosage every few minutes as it responds automatically to changing glucose levels that the glucose sensor had registered with the aim of keeping blood glucose levels within a predefined target range (Lewis 2019b; Farrington 2017; Weaver and Hirsch 2018, 16). Open-source means that everyone can modify the source code for the algorithm to better fit their individual needs and redistribute those changes within the same open-source infrastructures, turning the source code into a collaborative effort (DeLanda 2001, Par. 1; Kelty 2008, 15). The practice of engaging in the endeavor is also referred to as *looping* by the community members who call themselves *looper community*.

In this dissertation, I turn my gaze to the nuanced lived experiences of people engaged in digitized healthcare activism, which I have termed *device activism*, at the intersection of chronic (self)care and patient-led innovation that emerged around the ‘vision of automation’ to reduce the burdensome repetitive data work of individuals living with T1D. Based on more than one year of ethnographic fieldwork (August 2018 to November 2019) in and with the #WeAreNotWaiting movement in T1D, I empirically retrace the health-political aspiration for the epistemic legitimization of one's innovative (self)care practices in a healthcare setting where self-responsibility and the burden associated with it is high. In my study, I was interested in the *practices* of the looper community on both an individual and collective level. I wanted to understand what it means in practice to go beyond the technological aids provided by the established healthcare structures and venture into using an open-source solution that takes over a life-preserving decision instead. I was interested in the ways how narratives, positions, health-political goals and aspirations were negotiated in the everyday lives of people living within these situations.

My ethnographic approach oscillated between the global and the local, the private and the public, as well as the mundane everyday-life practices and the explicitly voiced health-political activism. This led to a thorough understanding of health and patient activism at the intersection of digitized chronic (self)care and open-source innovation. The presented dissertation, therefore, also ties together a broad range of sociological and science and technology studies (STS) discussions around questions of healthcare participation, patient activism, online communities, and knowing as individuals affected by chronic illnesses. With the publications that the dissertation consists of, I contribute to the sociological and STS understanding of healthcare activism in contemporary digitized, data-driven, and personalized healthcare spheres, as well as chronic (self)caring in this context. I offer a nuanced exploration of how people with chronic health conditions can respond with "resilience and creativity" (Pink et al. 2022, 9) to algorithmic care assemblages but how they may also call for more automation and algorithmic mediation of their (self)care. I ultimately offer a sociological and STS understanding of the complexity and ambivalence of chronic living, (self)caring, and advocating with devices in, on, and with bodies in contemporary digitized, data-driven, and personalized healthcare spheres. Epistemically, I situate my study within medical sociology, as well as medical and feminist STS. In addition, I draw on literature from disability studies, anthropology, human-computer-interaction, innovation-studies, economics, and critical data studies.

This synopsis is structured as follows: Firstly, I introduce the conceptual framework for my analysis (section 2). In section 3 I reflect on my methodological approach to the studied phenomenon. Section 4 will give a brief overview over the publications that ground the dissertation and distill the main overarching arguments of the dissertation. I end the synopsis with a conclusion (section 5).

2. Conceptual framework

> "It matters what stories we tell to tell other stories with; it matters what concepts we think to think other concepts with." (Haraway 2019, 10)

To analytically attend to the practices of the looper community, their device activism, and the complexities I encountered in the situation of inquiry, I draw on a variety of different theoretical strands. I, however, want to emphasize that I offer "partial connections" (Strathern 2004) from my empirical engagement to the sociological and STS literature that build the basis to understand the device activism of the #WeAreNotWaiting movement. These connections are bound to my "partial visions" (Haraway 1988, 586) of the phenomenon. Many of these theoretical connection points may also be rearranged and connected differently, and they are all interconnected as well. The triangulation of these different theoretical framings allows me to think of the practices of the loopers as simultaneously both individual and intimate practices of (self)care in increasingly digitized, data-driven, and personalized healthcare settings, as well as a collective and recursive practice of critiquing, rethinking, and redoing technologically mediated care in T1D. Furthermore, it allows me to analytically attend to the #WeAreNotWaiting movement in this global and local situatedness, while not losing sight of the fact that the practices I retrace are always aimed at creating solutions for better "chronic living" (Wahlberg et al. 2021) with devices in, on, and with bodies.

2.1. Setting the scene: Datafication in healthcare and living within data assemblages

The #WeAreNotWaiting movement and the practices of the loopers need to be understood in the context of larger contemporary societal developments related to the increasing merging of humans and technology, as well as the ongoing biomedical and biopolitical transformations in healthcare. Social movements, such as the #WeAreNotWaiting movement, react to the societal settings they are embedded in (Villa 2004, 243). For my sociological inquiry into the knowledge practices and the health-political aspirations of the looper community this situatedness needs to be analytically accounted for. While my ethnographic research was concerned with understanding the nuanced everyday practices of people involved in the #WeAreNotWaiting movement, for a sociological analysis of these practices, it is crucial not to lose sight of the fact that activism in the healthcare sphere "is not practiced in a vacuum independent of political, social, or economic forces" (O'Kane 2016, n.p.) but always situated within and in relation to larger societal processes.

Living with T1D means living with and through data. Human-computer-interaction scholars Elizabeth Kaziunas and colleagues (2017) describe the inherent ambivalence of this as follows: "living with data, […] is simultaneously hopeful and dreadful, empowering and isolating, highly individualizing and dependent on the help of others" (Kaziunas et al. 2017, 5). Often times,[11] living with data means that a person with T1D calculates their insulin dosage from punctual measurements of their blood glucose levels, which are then noted in a blood glucose diary (Falke 2022). In a digitized version of living with data in T1D, this dependency on health data to live with the chronic health condition situates individuals with T1D within "data assemblages" (Kitchin 2014, Lupton 2016a[12]). Originating from the work of philosophers Gilles Deleuze and Felix Guattari (1987) and building on the micro-

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[11] I want to emphasize that these descriptions depict the situation in the German healthcare context, in which digital glucose sensors are part of the national health insurance appliance catalog and can therefore be reimbursed by health insurances (Ärzteblatt 2019). This still does not mean everyone in Germany has access to these devices, which is one of the major inequalities in T1D. In Jansky, Hendl, and Nocanda (2023), I detail these access inequalities and reflect upon the global health justice aspects in T1D and the #WeAreNotWaiting movement.

[12] Sociologist Deborah Lupton also refers to this as *digital data-human assemblages* (2016a).

sociology of Gabriel Tarde (Latour 2005; 2010), *assemblage* is an STS concept that acknowledges the "ongoing flow through which social and material agencies make connections with one another and come to constitute the agential capacities of an entity" (Schwennesen 2019, 179). Assemblages rely on "an understanding of reality as a heterogeneous compound made of diverse elements — material in nature, or semiotic, etc." (Rodríguez-Giralt, Marrero-Guillamón, and Milstein 2018, 8). The notion of assemblages gives a conceptual term to attend to fundamental entangled entities that are not distinct from each other but are intertwined in socio-material networks and are constituted through their relations (Schwennesen 2019, 179).

In the context of digitized T1D (self)care, data assemblages can consist of a system of thoughts, forms of knowledge, people with T1D, practices, devices, algorithms, software, insulin, clinicians, needles and others. Once the body-related data exist in digital form, having emerged from personal and intimate practices of (self)care (such as checking one's blood glucose level), data can easily "travel beyond their place of production" (Langstrup 2019, 569f.). Data thus also have[13] a certain liveliness: they are constantly generated and regenerated, potentially impacting people's lives, and have a commercial and scientific value (Lupton 2017, 1602). Control over the generated data is however gradually lost in the process (Nissenbaum and Patterson 2016, 82). There is an increasing divide between the ones creating the data (individuals engaging with digital technology) and the ones profiting off the data (mainly governments and commercial actors) (Zuboff 2019; Ruckenstein and Schüll 2017, 263; Lupton 2016b, 117f.; Andrejevic 2014, 1673; boyd and Crawford 2012, 666f.). This asymmetry is significant to consider in the #WeAreNotWaiting context. Initially, the primary motivation for people with T1D to reverse engineer their diabetes devices was that they could not access their generated glucose data (Kaziunas et al. 2017; Kaziunas 2018).

In healthcare, "[d]ata have moved to the center stage of […] politics" (Høyer 2023, 2). Critical data studies scholars as well as sociologists have referred to the centrality of data in contemporary healthcare as "datafication in healthcare"[14]

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[13] I use the plural form of data here to further emphasize the multiplicity, liveliness, relationality and distributed nature of data.

[14] This is based on the theoretical concept of *datafication* first introduced by Mayer-Schönberger and Cukier (2013).

(Ruckenstein and Schüll 2017, 261). These processes of datafication are situated in "a political economic regime driven by the logic of perpetual (data) capital accumulation and circulation"[15] (Sadowski 2019, 2). In this logic, data becomes capital (Sadowski 2019, 2) and can be considered the "core feature of 21st century capitalism" (Henne, Shelby and Harb 2021, 2). Economist Shoshana Zuboff (2019) coined the term *surveillance capitalism* to describe the political economy of constant digital surveillance and the associated new modes of power. We live in close relationship with digital data-driven and data-collecting devices, which are created by profit-oriented companies that have identified personal data as lucrative for them. For my sociological analysis of the activism of the #WeAreNotWaiting movement, "the extraction imperative" (Zuboff 2019, 128) of profit-oriented companies and how they make use of increasing digitalization in society is crucial to consider.

In the sociological literature, scholars have introduced nuanced and detailed theoretical and empirical accounts of datafication in the health sphere.[16] Many have turned to Michel Foucault's concept of *biopolitics* as well as Adele Clarke and colleagues' notion of *biomedicalization,* which builds on the idea of biopolitics. Foucault contests how power is increasingly enacted upon the body, both on an individual and population level. He points out that "[f]or capitalist society, it was biopolitics, the biological, the somatic, the corporal that mattered more than anything else" (Foucault 2000 [1974], 137). Biopolitics, at its core, is the politics of "power over life" (Rabinow and Rose 2006, 196). It is a "distinctively modern form of power, 'bio-technico-power'" (Rabinow 1996, 91), which focuses on understanding, controlling, and regulating "the 'vital characteristics' of the population" (Ruckenstein and Schüll 2017, 264). This exercise of power is then no

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[15] In this context, scholars have introduced different theoretical notions to grasp this aspect of contemporary capitalism that is data-as-capital mediated, coining terms such as "Surveillance Capitalism" (Zuboff 2019), "iCapitalism" (Duff 2016), "Datafied Power" (Ruckenstein and Schüll 2017, 263), and "society of algorithms" (Burrell and Fourcade 2021). Henne, Sehlby, and Harb (2021) further emphasize how "digital data bring distinct dimensions of property relations to the fore through cycles of capital accumulation" (Henne, Shelby, and Harb 2021, 3). Similarly, Fourade and Hearly (2017) point out how "contemporary organizations are both culturally impelled by the data imperative and powerfully equipped with the tools to enact it" (Fourade and Hearly 2017, 13).

[16] There is an ever-growing body of empirical research in sociology that engages the concepts of biopolitics and biomedicalization to understand how datafication in healthcare, both on an individual and collective level, can be described as reformed and datafied modes of control, discipline and surveillance that continue what Foucault has predicted (boyd and Crawford 2012; Lupton 2014, 2016b, 2016c; Ruckenstein and Pantzar 2017; Rich and Miah 2017; Ajana 2017).

longer aimed at the individual but instead focuses on the development, enhancement, and improvement of all vital processes (Folkers and Lemke 2014, 11). A vast number of scholars has engaged in different ways with the concept of biopolitics. Clarke et al. (2003; 2009) pick up the idea that biopolitics is inextricably connected to "the rise of the life sciences, the human sciences [and] clinical medicine" (Rose 2001, 1) and explicitly turn their gaze toward contemporary healthcare settings. By introducing the notion of biomedicalization, they highlight how the prefix "bio", in biomedicine indicates the growing significance of life sciences in biomedicine. This then emphasizes "[f]oucauldian questions of biopower and biopolitics" (Clarke 2014, 1). Biomedicalization offers an analytical tool for understanding the expansion of biomedical knowledge to all areas of life, which is based, among other things, on the activities of profit-oriented institutions that promote the privatization and commodification of the healthcare system. Medical practice is increasingly becoming a "technoscientific" practice. Medicine is no longer only responsible for "normalization" of the body (treating or healing diseases) but also for its individualization and optimization. Thus, bodies and identities are transformed. Biomedicalization is, however, not a linear top-down process: "new forms of agency, empowerment, confusion, resistance, responsibility, docility, subjugation, citizenship, subjectivity, and morality" (Clarke et al. 2003, 184) can emerge within and in response to these biomedicalization processes. This is what I am interested in for my study of the #WeAreNotWaiting movement.

My analytical focus lies with the everyday practices of activism through the engagement with devices in the (self)care of people with T1D, and I understand all of these conceptualizations attending to the ongoing larger societal shifts such as datafication, biopolitics, biomedicalization and surveillance capitalism as conceptual groundwork. However, these notions have trouble accounting for the embodied everyday-life, daily-grind practices of actually living in intimate entanglement with devices in, on, and with bodies—the focus of my dissertation. Donna Haraway (1988, 150) accurately points out that "Michel Foucault's biopolitics is a flaccid premonition of cyborg politics, a very open field." While there are ongoing scholarly discussions on datafication and surveillance capitalism and the potential dangers that data-driven technologies may entail, "people have invited sensors to gather information about them through mobile apps and networked devices, convert this information into electrical signals, and run it through algorithms programmed to reveal insights and, sometimes, inform interventions into their future behavior” (Schüll 2019, 26).

Focusing on the everyday practices of individuals living with and fighting for automated systems in their care allows me to understand how people challenge current modes of datafication in creative and subversive ways, but also how some at the same time call for “an expansion of datafication of their lives” (Pink et al. 2022, 8). Such an inquiry into the everyday-life practices of people living within data assemblages and their health-political activism for more automation in their care then also shows the ambivalence of living with data and data-driven devices as an individual with a chronic health condition in contemporary healthcare spheres. For a sociological understanding of digitized healthcare, this is significant to grasp. In the next section, I go into detail on how sociology and STS scholarship is conceptualizing the collective responses to the political economy of datafication in contemporary digitized healthcare.

2.2 Collective responses to datafication in healthcare

Living within data assemblages does not mean that people are passive subjects to datafication, biopolitics and biomedicalization. Individuals collectively respond in different ways to these “vital politics” (Rose 2001, 2), and digital (patient) communities, new forms of sociality and collective (political) actions may arise (Rose 2001, 134; Gibbon and Novas 2007, 2). A vast array of sociology and STS scholarship has shown that a shared diagnosis or health concern can foster the formation of collectives (see for example, Epstein 2004; Rabeharisoa and Callon 2002; Rabeharisoa et al. 2014; Kingod 2018; Ajana 2017; Li and Wang 2020, Egher 2023). The #WeAreNotWaiting movement ties in with a long list of collectives that formed around their shared health concerns and conditions. Each of these collectives might react very differently to the above-described societal shifts they may resist or align with the ideals of biopolitics and surveillance capitalism. They, however, provide distinct yet entangled perspectives on how contemporary digital patient groups and other health related communities can emerge.

2.2.1 The emergence of digital (patient) communities and new forms of biosocialities

Especially in the scholarly debates around technology and socialities, the term *community* is engaged frequently by scholars to describe processes of forming social collectives with the use of technologies, for example, in social media settings. For the looper community, the term *community* represents an emic term. It is not a concept I brought to the studied group or how I interpreted the studied social formation. Instead, the term was used throughout my fieldwork by the interlocutors. From a sociological standpoint, the concept of community is difficult to define; often it is connected to notions of belonging “rather than actual modes of social interaction or forms of social and economic organization with accompanying power struggles and inequalities” (Bruun and Hasse 2022, 385).

In sociology, collectives that have formed around shared somatic or genetic characteristics[17] that are monitorable and “knowable only through the application of technoscience” (Clarke 2010, 2) are captured in the concept of *biosociality* introduced by anthropologist Paul Rabinow (1996 [1992]). The concept gives an analytical tool to understand the increasing “formation of new group and individual identities and practices arising out of these new truths” (Rabinow (1996, 102). While Rabinow referred to the Human Genome Project in his own research, the concept is easily translatable to datafied healthcare and increasingly technoscience-mediated societies, in which the shared concern might be living with devices in, on, and with one’s body that generate constant data streams. Btihaj Ajana (2017) fittingly points out how online communities, “established for the purpose of sharing health related information and experience, echo […] Paul Rabinow’s concept of ‘biosociality’” (Ajana 2017, 6). Digital and social-media-mediated ways of social exchange also transform the ways in which people relate to each other (Egher 2023, 195).

Especially people with chronic health conditions use social media to connect with people who share their health conditions and to search for information about symptoms and treatments (Kingod et al. 2016, 90). Since the emergence of the Internet and later, social media, patient groups and communities have “found the Internet a congenial host territory” (Rose 2001, 145). There is a growing body of literature that studies how people affected by disease are turning social media platforms to connect with people that are close in experiences and not in geographical distance (Bellander and Landqvist 2018), often to engage in peer-to-peer support, and with this also creating new forms of biosocialities (Egher 2019; Kingod 2018). For people with T1D social media platforms become increasingly part of their everyday lives and care routines, as these platforms give the opportunity to not only acquire knowledge about their disease outside of clinical contexts but to connect with people who have similar illness-related experiences, to share personal feelings, co-create illness-related knowledge, and enact health and illness (Kjærulff and Langstrup 2023; Kingod 2018, Kingod et al. 2016). Online peer-to-peer support groups and communities have “generated a public space in

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[17] It is important to note that biosociality counters dualistic ideas of nature versus culture (Lemke 2015, 193). Instead “the concept of biosociality sought to work against forms of thought which posit a biological basis for society and culture” (Gibbon and Novas 2007, 4).

which issues and concerns relevant to their [the affected] daily lives can be articulated and exchanged" (Kingod et al. 2016, 96).

The looper community not only emerged from their common social media usage to share experiences and relate to each other online, but it grew out of the "sociotechnical imaginaries" (Jasanoff and Kim 2009) of radical open and transparent automated (self)care technologies (Publication 1). These sociotechnical visions of how a technology-mediated future should look "play a crucial role in building new communities and cementing existing ones" (Bruun and Hasse 2022, 384). For example, in my interview with Dana Lewis, one of the first loopers and now the figurehead of the movement, she pointed out that when she and the other initial loopers shared the instructions for the system online, they deemed it as highly important to also initiate an (online) community around this vision of automation.

To fully grasp the emergence of the looper community and their shared sociotechnical imaginaries of radical open and transparent automated (self)care technologies, I draw on the sociological literature on the Quantified Self (QS) movement (Publication 2). This movement has no immediate connection to healthcare;[18] it can, however, be described as one of *the* online communities in which members come together through shared sociotechnical imaginaries. This group shares the vision that with just enough quantified metrics about one's body, one can gain "self-knowledge through numbers" (Wolf 2010). This movement received much attention in sociology and STS in the last ten years (Heyen 2020; Wiedemann 2019; Villa 2012). Authors have critically scrutinized the notion of "body" that QS members have (Smith and Vonthethoff 2017; Abend and Fuchs 2016; Lupton 2013a), the gendered aspects of self-quantifications (Hendl and Jansky 2021; Schmechel 2016), how these practices can be interpreted as another signifier of an increase of self-optimization in society (Villa 2012; Duttweiler et al. 2016; Ajana 2017), and how data becomes biocapital[19] (Lupton 2014). There has also been an increase in ethnographic studies offering nuanced accounts of the lived experiences of the heterogeneous group of people engaged in this movement (Ruckenstein 2022; Schüll 2019; Wiedemann 2019; Pantzar and Ruckenstein 2017; Nafus and Sherman 2014). These ethnographic studies offer a glimpse into the

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[18] For a detailed comparison of QS and T1D datafied (self)care practices, see Wiedemann 2019.

[19] This is in relation to Rabinow and Rose (2006).

practices of this community of tech enthusiasts that emerged from the San Francisco Bay Area and spread throughout North America and Europe, “drawing in newcomers through a website featuring videos of members’ presentations, a message board where people could discuss tracking tools, and links to local meet-ups” (Schüll 2019, 27). Personal data are the central shared concerns of the QS movement and the “medium for connecting with others by offering a raw glimpse into one’s intimate, private life” (Sharon 2017, 112). The first ideas of the #WeAreNotWaiting movement grew out of the same tech-enthusiastic scene in the San Francisco Bay Area (Healthline 2013), and there are many loopers that are also avid QS self-trackers. Therefore, thinking these movements together is crucial for my undertaking.

Taken from the rich literature on the QS movement, the simultaneousness of personalized and communal characteristics of the QS movement that other scholars have carved out, is especially relevant for my study of the practices of the loopers. Particularly in Publication 2, this literature helped me to understand the methodological and scientistic ways in which loopers know about their illness, bodies and technologies beyond what is discussed in the literature on patient knowledge (which is covered in section 2.4.3). Numerous scholars have explored the social part of this community by focusing on what they refer to as n=1 self-experimentations.[20] On the surface level, the idea of n=1 self-experimenting points to a practice that is done only for oneself. In these n=1 self-experimentations, “devices and data contribute to new ways of seeing the self and shaping self-understanding and self-expression” (Kristensen and Ruckenstein 2018, 2). Some have even “built their own tools” (Choe et al. 2014, 1149) or developed “software programs that could extract data and integrate it into a representation they were happy with” (Whooley et al. 2014, 155). However, “n=1 quantified self-experimentation is only made meaningful in the context of a larger audience” (Jethani 2015, 39). The possibility to meet and discuss experiences is a movement-

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[20] n=1 self-experimentation in the QS context is often used to describe how self-trackers are employing self-tracking technologies to conduct quasi science experiments on themselves, which are then primarily relevant for them, thus n=1. Kevin Kelly (2016), one of the founders of the QS movement, describes this as follows “The subject is yourself. At first it may seem that an n=1 experiment is not scientifically valid, but it turns out that it is extremely valid to *you*.” (Kelly 2016 241, italics in original). It is also often used in the #WeAreNotWaiting movement (see for example: https://medicalfuturist.com/living-with-an-artificial-pancreas/ and https://openaps.org/ (latest access 21.03.2023).

defining aspect, with personal data being the language that everyone in the QS community can understand and relate to (Sharon 2017, 111).[21]

Understanding the practices of the QS movement as forms of self-experimentation opens the space of possibilities to also see the "potentially noncompliant, creative, and reflexive" (Schüll 2019, 28) characteristics of the #WeAreNotWaiting movement and at the same time the emphasis on individualization of responsibility for one's body and health. It is however important to keep in mind that "clinical self-tracking" (Prias and Miele 2017) is a daily necessity for persons with T1D and an integral part of their everyday lives with the chronic health condition (Gottlieb and Cluck 2019, 138). Furthermore, loopers relate differently to the data that they generate. People with T1D need to—in one form or another—rely and act on the data that they generate about their bodies in order to live. It is important to keep in mind that the looper community utilizes self-tracking practices and self-experiments with their bodies and technologies to redesign a care technology that their lives depend on.

To summarize, the rich literature on biosocialites, online patient communities and the QS movement offers a way to see how different digital technologies, the Internet, and social media allow for new ways to form collectives around shared concerns. While some of these collectives and communities seem to be closely related to the looper community and others not so much, they all reveal how people relate to each other, their health concerns and conditions, as well as technologies in different ways and how this can lead to creative and reflexive ways of aligning or resisting current modes of datafication in healthcare.

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[21] Most digital self-tracking devices even have "built-in functions that enable and encourage users to share and compare their findings with others, via social media and specially created platforms" (Sharon 2017, 111).

2.2.2 Health movements digitized: Between evidence-based activism and hashtag activism

What differentiates the looper community from the above-described online communities, that have emerged from shared health concerns and conditions, is that the loopers have a shared and explicitly voiced health-political goal. They organized via a now movement-defining hashtag[22] and grew into a digital health movement: the self-described #WeAreNotWaiting movement. This means that their engagement needs to be situated within the sociological and STS engagement with health movements and patient[23] activism.[24] The formation and political activism of health movements are central research subjects in sociology. In this section I focus on the literature from the medical sociology and medical STS realm. From a sociological perspective, social movements in general can be described as collective actors on a meso-level: They are not organizations with formal memberships or a professionalized division of labor, but they are also not just arbitrary interactions (Villa 2004, 243). Anselm Strauss (1978, 125) emphasizes that they can be found in all social worlds. What social movements share is that they focus on their societal setting, which they want to transform in one way or another. Activism can start with smaller actions and can originate in mundane everyday practices (Schermuly et al. 2021, 2; Dokumaci 2019).

In the rich literature on health movements and patient activism, scholars emphasize how individuals organize around their shared health conditions, how they engage in policy making, how they lobby for the funding research of their health conditions, and with this also challenge medical epistemic authority and expertise (Rabeharisoa et al. 2014; Mazanderani et al. 2013, 420; Rose 2001, 23). Here “patients” take on an “active role in shaping the direction of science” (Rose and Novas 2005, 452). In different health contexts, scholars have repeatedly shown how advocacy groups “develop novel kinds of relations with medical specialists,

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[22] Hashtags are the structuring element of social media discourses and enable individuals to partake in bigger discourses and to share social issues with a broader public (Zappavigna 2015, 274).

[23] Epstein (2008) points out that the term "patient” in patient activism is mostly for proxies for "patients” and can include caregivers, family members, relatives, or partners (Epstein 2008, 504).

[24] I follow Epstein's (2008) suggestion to use the terminologies of patient groups/activism and health movements together instead of using any narrow definition to do justice to the multiplicity in this realm (Epstein 2008, 505). He further emphasizes that patient groups and health movements often have boundary-crossing characteristics and that these groups often are hybrids in which the differentiation between “lays” and “experts” cannot be made (Epstein 2008, 506).

clinics, laboratories, and with medical knowledge" (Rose 2001, 23). Callon and Rabeharisoa (2008) refer to this "intense engagement in scientific and technological research activities" (Callon and Rabeharisoa 2008, 231) by people affected by health conditions as the "emergence of concerned groups." While the formation of biosocial groups or concerned groups highlights how "the scope of medical authority was extended" (Rose 2001, 11), these groups simultaneously challenge medical authority.

Sociologist Steven Epstein (1995; 1998), who ethnographically studied the AIDS Coalition to Unleash Power (ACT UP)[25] movement in the context of HIV/AIDS in the U.S. in the late 80s and early 90s emphasizes how this activism was a fight for "the rights of those affected by biomedical science to participate in its production" (Epstein 1995, 428). He illustrates how AIDS knowledge arises out of "credibility struggles" (Epstein 1995, 3) and cannot be thought of only in biomedical, scientific categories. By asking "who becomes an 'AIDS expert' and by what means?" Epstein (1995, 2) illustrates how people who live with the life-threatening disease are important factors in the production of AIDS knowledge (Epstein 1995, 2). AIDS treatment activists acquired a profound understanding of immunology, virology, and biostatistics and became credible stakeholders in the biomedical context of AIDS "and thereby influenced processes of scientific knowledge construction as well as pharmaceutical drug development" (Epstein 2016, 4).

Over the last decade affected people and their organizations have increasingly ventured into biomedical epistemic networks by documenting their lived experiences with a disease as well as collecting and generating evidence (Akrich, O'Donovan, and Rabeharisoa 2015, 73) and thus have "provid[ed] robust knowledge on how patients' and activists' conditions or situations ought to be understood and treated" (Rabeharisoa et al. 2014, 111). Rabeharisoa et al. (2014) refer to this practice as "evidence-based activism." Akrich, O'Donovan, and Rabeharisoa (2015) emphasize that "[e]vidence-based activism constitutes a powerful leverage which allows patients' organizations to penetrate others' territories, to redefine borders, and to bring in new entities and new issues, so that

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[25] ACT UP forced both the U.S. government and the biomedical community to change the ways in which biomedical research was conducted and paved the way for many other patient activist groups (Hieber 2007; Aizenman 2019).

the whole geography may be turned upside down in some cases" (Akrich, O'Donovan, and Rabeharisoa 2015, 86). This notion gives me lens through which to understand how affected people are making themselves part of the medical epistemic networks around their disease, while at the same time aiming for health-political transformation (Akrich, O'Donovan, and Rabeharisoa 2015, 73). This also fits Latour's (1998) observation that current science policies are characterized by an impetus of "collective experimentations,"[26] in which patient organizations increasingly engage with biomedical research.[27]

The latest example of evidence-based activism can be observed in the collective responses of affected individuals in the context of Long Covid (Callard and Perego 2021, Roth and Gadebusch-Bondio 2022). Here too individuals have formed biosocial groups around their shared suffering from Long Covid symptoms, and as Callard and Perego (2021) point out, "made Long Covid." Often affected have to advocate to have a name for what they are experiencing and subsequently receive recognition and care for their health conditions.[28] Joe Dumit (2006) famously termed this "illnesses you have to fight to get." Roggers emphasizes that "the struggle to gain medical legitimation of bodily experience is precisely a political one" (Rogers 2022, 414). In this context, the notion of embodied health social movements as introduced by Brown et al. (2004) is significant: "Patient" advocacy is highly related to the effort to highlight the significance of "experiential experiences" (Borkman 1976) of somatically experiencing an illness.

For my inquiry into the practices of the loopers, it is crucial to understand, that activism does not necessarily mean that people only fight "for civil rights, freedom from barriers, and [through] intentional and explicit acts targeting public space" (Dokumaci 2019, n.p.). Activist practices can be much more mundane. The majority of loopers did not initiate large-scale political action, but rather, they engaged in local everyday activism by participating in their care in different ways than they are supposed to. They are "deliberately non-compliant" (Scibilia 2017, n.p.) in their everyday care practices, which I cover in greater detail in section 2.4.2. People with chronic illnesses and disabilities often live in "an environment [that]

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[26] This is a notion introduced by Michel Callon (1994).

[27] Latour's remark also fits well to the growing scholarly discourse around citizen science in medicine (see for example, Prainsack 2017; 2014). This is, however, out of the scope of this dissertation.

[28] In ethics this is also described as *epistemic injustice* (Fricker 2007).

fails to provide in the form of built objects, places, and socially recognized gestures" (Dokumaci 2020, 100). This then leads them to improvise, rearrange, or invent in their everyday lives. Dokumaci (2020) terms the practices of "everyday improvisations and DIY inventions […] microactivist affordances" (Dokumaci 2020, 100).

In the context of the looper community, many microactivist affordances happen online, under the movement-defining hashtag #WeAreNotWaiting. Videos are shared on how to exchange the batteries of the glucose sensors to circumvent the factory preset battery life of two weeks, and people with T1D around the globe discuss local regulations and how the community should react. In Publication 2, for example, I describe how the community discussed a warning from the U.S. Food and Drug Administration (FDA) and then issued a collaborative response letter online. The Internet and social media have changed the ways in which health movements work and operate (Petersen et al. 2019, Schermuly et al. 2021, Roth and Gadebusch-Bondio 2022). Sociologists have studied how individuals affected by health conditions utilize online spaces not only to access information about their disease (Mazanderani et al. 2020; Bellander and Landqvist 2018; Kingod 2018) but also to lobby for access to medication or treatment (Mackey and Schönfeld 2016). The looper community is strongly tied to the Twitter hashtag #WeAreNotWaiting, which was first used to air frustration with the pharmaceutical and device manufacturers, as indicated by the quote in the introduction, where it is proclaimed that people with diabetes are tired of waiting "for device manufacturers to innovate" or "for the cure" (Healthline 2013). Dana Lewis, one of the most vocal spokespersons of the #WeAreNotWaiting movement, and her now husband Scott Leibrand were working on reverse engineering her glucose sensor to make the alarms louder (Lewis 2019b, 3) and turned to Twitter, where they connected via the #WeAreNotWaiting hashtag with software engineer Ben West, who had been reverse-engineering diabetes devices himself since 2009.[29] Together they developed the first version of the open-source algorithm and shared the instructions online (Lewis 2019b, 11).[30] This situates their engagement within the growing

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[29] https://myartificialpancreas.net/2020/04/01/ben-west-fixing-diabetes-changing-the-conversation/ (latest access: 25.02.2023).

[30] https://myartificialpancreas.net/2020/04/01/ben-west-fixing-diabetes-changing-the-conversation/ (latest access: 25.02.2023).

scholarly debates around *hashtag activism*[31] (Alcalde and Villa 2022; Jackson, Bailey, and Welles 2020; Ahmed 2018; Williams 2015; Zappavigna 2015). Engaging with one hashtag cannot only bring social issues to the public that might have otherwise not received the attention of the wider public, but it can also create new relations between actors who would not have been able to meet otherwise. Jackson, Bailey, and Welles (2020) counter critical arguments against the idea of online activism by pointing out how the use of hashtags can help "ordinary people and those without access to traditional forms of power [to] create compelling, unignorable narratives" (Jackson, Bailey, and Welles 2020, 185) and with this challenge authority. For a sociological analysis of the health-political practices of the loopers the notion of hashtag activism is crucial to consider as the hashtag #WeAreNotWaiting is not only name-giving it is essential for this movement and it "leads to material effects in the digital and physical sphere." (Jackson, Bailey and Welles 2020, xxxii).

Building on this rich and diverse body of literature, I argue that the #WeAreNotWaiting movement that formed around the effort to transform living with devices in, on, and with bodies as a person with T1D can be partly characterized by classic STS and sociological understandings of patient activism as evidence-based activism. The observed practices, however, at the same time, exhibit traits of newer forms of Internet advocacy such as hashtag activism. Thinking these different forms of (health) activism in digital spaces together offers me a theoretical tool for mapping the complexities of being engaged in this movement.

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[31] The term *hashtag activism* was first used in news coverage in 2011 and it "describes the creation and proliferation of online activism stamped with a hashtag" (Jackson, Bailey, and Welles 2020, xxxii).

2.2.3 Open-source patient-driven innovations: Engaging devices and creating actual existing alternatives

Loopers have utilized the online sphere to an extent that few other patient activist groups did before. They have turned to open-source infrastructures to develop the automation algorithms, to shared instructions, and even invented hardware solutions and, thus, created “actually existing alternatives” (Kelty 2008, 3) to the technologies offered by the standard healthcare regime. This leads to a significant difference between the #WeAreNotWaiting movement and the previously described forms of patient activism and health movements. The goal of the looper community has not only been to bring so far “undone science” (Frickel et al. 2010; Hess 2016) to the attention of actors of the established healthcare system or patients’ efforts to participate in biomedical research. Instead, they have come together to critique the current state of diabetes technology to create “solutions for themselves” (Demonaco et al. 2019). In the social studies of human-technology relations, there is a large interest in the agency of technology users (for example, Oudshoorn and Pinch 2005). Within digitized and technology-mediated biomedicalized healthcare spheres, “patients” have increasingly turned into users and consumers of medical technologies (Hardey 2010), which is also discussed under the term “consumer healthcare” (Garge et al. 2017). Dana Lewis (2019b, 4) describes her role as user as follows:

> “I was living with the problem then, that day, that night, and every night for the rest of my life. And what could I do about it? Nothing. I was "just" the patient and the "user" or "consumer" of the device, with no option to change medical devices to better suit my needs.”

Within the #WeAreNotWaiting movement, people with T1D, loopers, are no longer only “patients” and consumers of a medical product who have no way to influence the technological development; they become developers of the technologies they use for their (self)care. The first loopers shared the source codes and instructions of their developed algorithms online on an open-source platform, and this changes both their activism and knowledge practices. Amongst scholars of innovation studies and economics this is termed as *patient-driven innovation* (Demonaco et al. 2019; Demonaco and von Hippel 2019). Here the #WeAreNotWaiting movement has gained wide popularity challenging the notion that “[v]aluable improvements in health and patient care should come from experts in the pharmaceutical, medical device, and related industries" (Demonaco and von Hippel 2019, n.p.). However, as I describe in detail in Publication 1, these celebratorily descriptions of the #WeAreNotWaiting movements as *the* examples for "bottom-up" user-innovations, overlook the nuanced everyday experiences of the engaged people and the societal embeddedness of the movement (see also, Jansky, Hendl, and Nocanda 2023). Loopers are not all engaged in similar manners in the #WeAreNotWaiting movement. They, however, all share the concern of making their care practices with devices in, on, and with bodies better for them and the community.

To understand this way of collaborative developing and using the technologies that make up the #WeAreNotWaiting movement I turn to the concept of *recursive public* by anthropologist Christopher Kelty (2008). In his ethnography of practices of people involved in open-source projects, he took inspiration from the mathematical concept of recursive functions, which in programming means that a function calls on itself during its execution. He describes a "recursive public [as] a public that is constituted by a shared concern for maintaining the means of associating through which they come together as a public" (Kelty 2008, 100). What differentiates them from interest groups or other forms of organizations, is that they focus on "the radical technological modifiability of their own terms of existence" (Kelty 2008, 3). This notion is a basis for my understanding of the looper community; they too are focused on their own existence and the technical devices that are central to their "chronic living" (Wahlberg et al. 2021). For my understanding of loopers' practices as forms of device activism, the notion of recursive public gives an analytical prism through which to consider not only the health-political activism of the looper community but also their recursive engagement of creating the advocated change and the needed technology themselves. By this they also create a form of recursive public that only exists in relation to the technology that they are re-engineering, developing, and creating (Publication 1 and Publication 4).

2.3 Intermediate summary

To summarize, in order to understand the practices and activism of the looper community, and ultimately to understand patient activism in contemporary digitalized, personalized, and device-mediated healthcare settings, it is crucial to attend to how datafication and digitalization transform the ways in which individuals relate to each other and how communities and collectives are formed. To do this, I draw on a rich and diverse body of sociological and STS literature that illustrates how individuals can react differently to biopolitics and biomedicalization and collectively align, resist, or tinker with datafication processes in healthcare settings. The above-introduced conceptualizations may not be in direct relation to the observed struggles of the loopers; however, they all reveal in what ways individuals form specific biosocialities around their shared health concerns and conditions. They also illustrate how these processes of community building and advocating are transformed through digitalization. Furthermore, they point to an increasing significance of social media for collectives that emerge around shared health concerns.

For my inquiry, I combine theoretical perspectives that specifically center around patient advocacy and (online) patient communities, as well as conceptualizations that focus on collectives and activism in digital spaces. This results in grounding my analysis in three strands of conceptual and empirical studies: studies of biosociality (Rabinow 1996) and (online) community building, scholarship on health movements and patient activism (Epstein 1995, 1998, Rabeharisoa et al. 2014), as well as the conceptualization of the open-source movement as recursive public (Kelty 2008). These different conceptualizations give me analytical tools to retrace that the formation of and the involvement in patient communities and movements, such as the #WeAreNotWaiting movement, is not necessarily a frictionless, straightforward, and inclusive process. For a sociological understanding of the #WeAreNotWaiting movement and its devices activism, it is crucial to consider that "communities do not simply exist but instead come together in various ways that rely on people working together" (Bradley 2021, 545). The previously introduced conceptualizations help me to better grasp the different processes involved in collective responses to datafication in healthcare and how patient activist groups and communities emerge.

In the next section, I continue with the theoretical and conceptual works that guided my analysis and that focus on theorizing the mundane everyday practices of living and (self)caring as everyday cyborgs in contemporary digitalized and device-mediated healthcare settings.

2.4 Caring with devices in, on, and with bodies: Chronic (self)care in datafied, technologized, and device-mediated healthcare spheres

This dissertation, at its core, is concerned with “chronic living” (Wahlberg et al. 2021) and consequently also with practices of (self)care. Device activism is not an abstract tech utopian idea of human enhancement through automation. Every observed practice in my empirical work is in one way or another aimed at (self)care: Be it sitting at the computer debugging code, writing up statements for clinicians or posting experiences on Twitter under the hashtag #WeAreNotWaiting. I put self in parentheses to emphasize that “there is no ‘self’ in self-care since the ‘self’ is an actor who is thoroughly dependent on and ineluctably interconnected with other actors and entities in infrastructures in order to become a self-caring subject” (Danholt and Langstrup 2012, 514). (Self)care can be described as a social practice that refers to a collective (Mol, Moser and Pols 2010). Care is relational, and care practices are fundamental to all relations in the world (Villa 2020, 435; Pols 2012, 71; Puig de la Bellacasa 2010, 164; Mol, Moser and Pols 2010, 7). This emphasis on relationality becomes clear in Fisher and Tronto’s often-cited definition of care as:

> “a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, selves, and environment, all of which we seek to interweave in a complex, life-sustaining web” (Fisher and Tronto 1990, 40).

For my ethnographic exploration of the practices of the #WeAreNotWaiting movement, it is essential to grasp this. Looping is inherently a collective, recursive, caring and relational practice with devices in, on and with bodies. I use the expression of devices in, on, and with bodies to highlight the entangled and intertwined nature of the relationship of people living with T1D and the devices mediating their care. These devices can be mundane everyday devices such as smartphones that are used with bodies. They can be insulin pumps and tubes worn on bodies, and the devices can reach into bodies, such as catheters or sensors. There are many dimensions to these care practices with devices in, on, and with bodies in looping: caring for bodies, caring for the technological devices, caring for relationships, caring for other loopers. Therefore, this section consists of a contextualization of chronic (self)caring in datafied, technologized, and device-mediated healthcare spheres and a mapping of the specificities of diabetes (self)care.

2.4.1 Everyday cyborgs and the intimate entanglements of bodies, data, devices and care

How individuals with T1D are living with and by injecting insulin, and how they live with and through the entanglement with technological devices such as sensors and pumps in, on, and with their bodies is paid a significant amount of attention in the sociological, STS, and anthropological literature (for example Pals et al. 2021; Liggins 2020; Danholt 2012; Mol and Law 2004; Mol 2000). To theoretically grasp living as a person with T1D as living as "a hybrid of flesh, bones and blood along with sensors, tubes and external devices" (Forlano 2016, n.p.), I draw on feminist technoscience scholarship and disability studies. Their theoretical engagement offers a view on human-machine relations, that focuses on the inextricable entanglement of humans and technology and subverts the understanding of singularity of bodies and humans. These notions give me a lens through which to understand that "mundane everyday life is comprised of complex inter-relations of humans and non-humans" (Forlano and Jungnickel 2015, n.p.) in T1D and to go beyond the idea that "the demarcation of materiality as body or thing is […] predefined" (Villa and Schadler 2015, 181). Rather, these differentiations always happen within practices.

Firstly, I draw on the theoretical notion of *cyborg*.[32] This concept, in feminist scholarship, made famous by Donna Haraway (1991 [1985]), describes "a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction" (Haraway 1991, 150). It is increasingly used to theorize how "humans had become so thoroughly and radically merged and fused with technologies that the boundaries between the human and the technical are no

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[32] The term *cyborg*, which is an abbreviation of *cybernetic organism*, was first introduced by Manfred Clynes and Nathan Kline in 1960. Oudshoorn (2020a) points out that "[t]hey introduced the term to describe the reconstruction of humans needed to enable them to live in space, for example, by changing the human bodily functions involved in breathing" (Oudshoorn 2020a, 16).

longer impermeable" (Oudshoorn and Pinch 2005, 7). For Haraway, cyborgs exist at the crossroads between the organic and the mechanical. Human bodies and selves are not stable or "natural", but rather, people are always multiple bodies and selves, dependent on the context in which they are situated. Neither can human bodies be easily categorized in static binarity, nor can technologies be thought of as entities separate from humans (Lupton 2016a). Haraway understands nature and culture not as an irreconcilable dichotomy but as being continuously mutually constituting. The cyborg metaphor offers a way to "question that which is taken as 'natural' and 'normal' in hierarchic social relations" (Haraway 1991, 149).

Scholars in medical sociology and STS have drawn differently on the notion of cyborg to grasp the hybrid bodies that biomedicine produces and enacts (Oudshoorn 2020a, 17). For my inquiry, the conceptualization of the "everyday cyborg" (Haddow et al. 2015, 2021; Oudshoorn 2020a, 2020b; Quigley and Ayihongbe 2018[33]) is crucial for understanding the relationships between technical medical devices and human bodies. Gill Haddow et al. (2015) introduced this notion to grasp the difference between the science-fiction cyborg metaphor and those living with technological devices in, on, and with their bodies every day of their lives. The everyday cyborg notion "adds to previous versions […] a recognition that a willingness to become cyborg is contextually dependent, for example, to avoid cancer" (Haddow et al. 2015, 486), or in the case of the loopers, to live with a chronic health condition. Oudshoorn (2020a) further reminds scholars to attend to "the cyborgs who have lived among us for several decades already, bodies kept alive and active" (Oudshoorn 2020a, 11f.) by technologies such as pacemakers. Loopers, and individuals with T1D, too are "practical cyborgs with T1D" (Garfinkel 2021, min 13:39). Similarly, feminist disability studies[34] scholar Forlano (2019) coined the term *disabled cyborg* in an autoethnographic account of living with T1D. She suggested the notion of the disabled cyborg to draw attention to "the ways in which networked medical devices offer to extend and repair the capabilities of [her] body while at the same time suffering their own breakdowns" (Forlano

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[33] Quigley and Ayihongbe (2018) emphasize the question of responsibility and ownership of medical devices in, on, and with cyborg bodies. These questions are important to consider in the context of the loopers but are beyond the scope of this dissertation.

[34] The notion of the cyborg is frequently used within disability studies (see for example: Reeve 2012).

2019, 40). This then leads to practices of “maintenance, repair, and care of the devices that were ostensibly taking care of [her]” (Forlano 2019, 40). For my understanding of the experiences and practices of loopers. the cyborg notion helps to go beyond the idea that looping merely means that loopers are using technologies to “normalize” their bodies; rather, the entanglement of bodies and technologies may allow for rethinking these categories, or at least allow for the possibility of constant renegotiation (Spöhrer 2015, 310f.; Villa and Schadler 2015, 183). Further, it makes it possible to critically reflect on what new burdens can occur for loopers, while not losing sight of the relationality of the observed practices.

The notion of cyborg also gives a prism through which to understand the specific becoming and enactments of cyborg bodies. To understand everyday cyborgs and the intimate entanglements of bodies, data, devices, and care in the context of the #WeAreNotWaiting movement it is important to go beyond the theoretical argumentation for the existence of cyborg bodies, and also attend to their becoming and enactment. Cyborg bodies can only “materialize in a network of relations with others” (Oudshoorn 2020a, 20). This leads to an understanding of “the body [as] always in the making, […] always constitut[ing] in relating” (Haraway 2008, 163).Throughout her work Haraway emphasizes that “the world is a knot in motion” (Haraway 2003, 6), which highlights the volatile nature of being in the world and its relations: “To be one is always *becoming with* many” (Haraway 2008, 1, italics in original).

In relation to the diabetes “cyborg body” (Forlano 2016; Hatch et al. 2020), Mol’s (2002) conceptualization of “the body multiple”[35] offers another theoretical lens for my understanding of the specific relations of bodies and technologies in the practices of the looper. With her concept of the body multiple, Mol points out that a body with diseases is enacted differently in different situations, with different technologies, and with different perspectives on it: there is not one body, rather different practices and technological approaches to diseases also create multiple and

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[35] Mol (2002, 129f.) points out that the question of boundaries of organisms is also subject to one of the first studies of medical knowledge by Ludwik Fleck (1980 [1935]). Here the physician and philosopher raises the question that of if we define the bacteria inside the human intestines as part of the human organism, and these bacteria can also merge with other humans, then this would lead to the conclusion that “the entire ecosystem of which humans form a part may well be designated as a viable whole—an organism—in its turn” (Mol 2002, 131).

fragile body realities. However, this also does not mean that "there are many divergent and unrelated bodies; for the various modes of ordering, logics, styles, practices, and the realities they perform do not exist in isolation from one another" (Law and Mol 2002, 10). Mol and Law (2004, 45) propose that in order to deconstruct the dichotomy of *Körper* (the body we have) and *Leib* (the body we are),[36] we should analytically attend to the body we do, and how we enact the body in practice (Lutz 2016, 11). With this perspective, the body does not become the result of specific (medical) discourses; rather, it is constantly enacted through specific practices. Loopers bring together many different spheres of negotiating what "doing diabetes" (Wiedeman 2016; 2019) and having and being everyday cyborg bodies can entail. With the concepts of (everyday) cyborg and enacting the body multiple, these partial connections can be attended to.

2.4.2 Tinkering, repair work, and mundane everyday-life practices of un/invited material participation

Care practices are constant maintenance and repair work (Fisher and Tronto 1990; Mol 2008; Puig de la Bellacasa 2011, 2017). With her concept of *matters of care,*[37] María Puig de la Bellacasa (2011, 2017) highlights that care is "an affective state, a material vital doing, and an ethico-political obligation" (Puig de la Bellacasa 2017, 42). She introduces "matters of care" as a theoretical proposal to engage with "matters of facts" in ways that allow for caring relationships to emerge (Puig de la Bellacasa 2017, 66). "Matters of care" is not a fixed normative vision of how the world ought to be, but rather, a "speculative commitment to think about how things would be different if they generated care" (Puig de la Bellacasa 2017, 60). Her notion "matters of care" foregrounds that maintenance and repair work in care also

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[36] This differentiation is originally from Helmuth Plessner: "Ein Mensch ist immer zugleich Leib […] und hat diesen Leib als diesen Körper" (Plessner 1970 [1941], 43).

[37] "Matters of care" builds on Bruno Latour's (2004a) concept of "matters of concern," which represents an analytical tool to criticize and analytically scrutinize matters of facts as social scientists, beyond just "moving away from them and directing one's attention toward the conditions that made them possible" (Latour 2004a, 231). Matters of concern are dynamic and complex and "their mode of fabrication and their stabilising mechanisms [are] clearly visible" (Latour 2005, 120), they are simultaneously both real and constructed, as well material and discursive. In relation to activism and social movements, Rodríguez-Giralt and colleagues (2018) state that 'matters of concern' is not about criticizing the notion of evidence, but rather about capturing "the enormous amount of work and affect it takes to assemble and sustain any entity – including, of course, activist formations" (Rodríguez-Giralt, Marrero-Guillamón, and Milstein 2018, 5).

includes non-humans “to probe further into the meanings of care for thinking and living with more than human worlds” (Puig de la Bellacasa, 2017, 4). Similarly, Mol and colleagues (2010) remind scholars that “good care” is a “persistent tinkering in a world full of complex ambivalence and shifting tensions” (Mol, Moser and Pols 2010, 14). Constant adjusting, testing, and experimenting with bodies, selves, technological devices, medication and care arrangements, engaging with different knowledges, and employing logics from different realms can be understood as practices of *tinkering* (Mol 2006; Mol, Moser, and Pols 2010; Winance 2010; Kingod 2018). Tinkering shifts the focus to affected people (as well as caretakers) and how they adapt care practices, technologies, and infrastructures to their bodies and lives (Kingod 2018, 14). It gives a theoretical perspective through which to look at the material practices of “attentive experimentation” (Mol 2006, 411) to live with health conditions. In Publication 2, I use the notion of tinkering to analytically attend to the emerging knowledge practices of the loopers and suggest the concept of *elaborative tinkering* in order to better grasp how loopers can know in technical, recursive and methodological ways.

In T1D (self)care, this tinkering is often in relation to the vast amount of data generated through the entanglements with devices in, on, and with bodies. To attend to the practical everyday-life aspects of living with data and devices in, on, and with bodies while looping the situatedness and fragility of data (Haraway 1988, 581) needs to be in focus as well (Publication 2 and Publication 4). Data is lived, and data needs to be understood as “an integral way of living, collectively produced and engaged with” (Kaziunas et al. 2017, 1). Attending to “broken data” (Pink et al. 2017; 2018) as part of this maintenance and repair work is central to (self)care with an open-source automated insulin delivery system. Pink et al. (2018, 2017) underline the situatedness of data with their notion of *broken data*. With this concept the authors argue for the need to critically “account more fully for the incomplete, contingent and fractured character of digital data” (Pink et al. 2018, 1). In this context, it is significant to recognize the “digital as material itself” (Dourish 2016, 31). Oftentimes data are thought of as something abstract, stored somewhere “up in the clouds.” They always have a material component and can therefore be “flawed/incomplete” (Pink et al. 2018, 3). There is a lot of “‘repair work’ needed to enable algorithmic systems to work in practice” (Schwennesen 2019, 176). In relation to automation in T1D, sociologist Lisa Wiedemann (2021, n.p.) also stresses that no matter how sophisticated automated algorithm-based systems for insulin delivery become, those affected still need to engage in this repair and maintenance work, which she refers to as “being on stand-by.”

Chronic (self)care involves the participation[38] of those affected in aspects of their therapy that in other diseases would be reserved for clinicians (Corbin and Strauss 1985). People with T1D, are “invited to participate” in their own therapy (Nielsen and Langstrup, 2018). Scholars from a variety of disciplines have inquired into the material[39] conditions of these forms of participation (Nielsen and Langstrup 2018; Marent and Henwood 2022; Weiner et al. 2022). With an empirical focus, researchers have retraced the roles of specific things, technologies, and infrastructures in chronic disease (self)care and their relationships to people affected by diseases (Langstrup 2013; McDougall et al. 2018; Bagge-Petersen, Skovdal, and Langstrup 2020). I interpret the practices of loopers as forms of un/invited material participation in their care (Publication 1). People with T1D *are* invited to participate in their care to a certain extent by, for example, engaging with devices that generate health data, interpreting data, and accordingly injecting insulin. Loopers, however, use this "invitation to participate" and not only uninvitedly rethink and redo algorithmic (self)care, by automating parts of their (self)care in an open-source manner, but also critique and challenge the ones that invited them in the first place—device manufactures and healthcare professionals.

To attend to the materiality of engaging with health data, bodies, and devices when looping and how “everyday things, devices and environments may […] acquire the capacity” (Marres 2012, 2) to enable people to engage in public affairs, I build on Noortje Marres’s (2012) concept of *material participation*. Material participation gives a lens through which to explore how “the specification of participation in material terms is accomplished in practice” (Marres 2012, 5). Marres emphasizes that objects can enable novel forms of political participation

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[38] I do not use the term *participation* without critical reflection; rather, I situate my analysis of how individuals with chronic health conditions participate and engage with and in biomedical spheres in the realm of sociological and STS scholarship that have engaged with the power relations of different modes of participation (Kelty 2019; Marres 2012). That, however, also leaves space for thinking of creative, critical, subversive, and innovative ways of participating in the biomedical sphere where the focus is set on inviting patients to participate (Nielsen and Langstrup 2018, 261).

[39] I use the term *materiality* as an umbrella term to refer to everything that is tangible, such as things, technical devices, spatial elements, and bodies (Cleeve et al. 2019, 128). This leaves room for an empirical openness and follows the advice of Mol et al. (2011) and Pols (2013) to focus on openness in inquiries, rather than precipitous definitions.

and underlines that in order to "apprehend the public's engagement with politics" (Marres 2012, cover page) scholars need to take material[40] conditions seriously. A device-centered perspective on participation "then makes it possible to attend to the different, contending modalities of the co-articulation of participation, and of its materialization" (Marres 2012, 81). Building on the idea of material participation, Nielsen and Langstrup (2018, 263) emphasize the significance of material artifacts in participatory healthcare and call out that "everyday situations at home, where people act with participatory technologies, are inherently 'messy': They involve a range of concerns, practices and devices that will influence how participation in this context is enacted" (Nielsen and Langstrup 2018, 263).

To summarize, I am interested in the health-political aspects of these mundane, daily-grind practices of participation in care. Oudshoorn (2020a) points out that there is a "tendency to neglect the mundane" (Oudshoorn 2020a, 12) when attending to the entanglement of humans and technologies in healthcare. In order to understand the device activism of the loopers, practices of everyday repair and maintenance work, as well as tinkering, and mundane practices of un/invited material participation are crucial. The shared matters of concern of the loopers are their engagement with medical devices to change their (self)care, and a lot of this engagement happens in mundane everyday-life practices. Centering my inquiry around the mundane everyday-life practices of tinkering, repair work, maintenance, and other practices of un/invited material participation in care offers a way to investigate how "[p]olitical participation always takes place in a material location" (Marres 2012, 1) and makes it possible to open up the analytical space to attend to mundane and daily-grind aspects of this political participation. I use this perspective to understand and map out the nuanced and complex positions and narratives that people engaged in the #WeAreNotWaiting movement can have, which can be more or less aimed at the bigger picture of collectively challenging epistemic authority in healthcare (Publication 1). This approach also helps me to always understand the encountered practices of the loopers as matters of care.

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[40] This does not mean that this perspective excludes linguistic and discursive aspects of participation: "material participation does *not* involve stripping participation of its informational, linguistic or discursive components" (Marres 2012, 6f., italics in original).

2.4.3 More than epistemic factors – Knowing as a person with a chronic health condition

As in the previous section described, the entanglement of bodies, devices, and data while living as an everyday cyborg demands the increasingly active participation of affected individuals in their care. And while these transformations may discipline patients, demand more self-responsibility of the affected, and govern parts of their intimate/private everyday lives with the disease, they also foster expertise and knowledge for the affected (Gottlieb and Cluck 2019, 141f.).

In my study of the #WeAreNotWaiting movement, I was particularly interested in the *practical* dimensions of knowing as loopers, which I detail in Publication 2. Georges Canguilhem’s distinction between knowledge in the laboratory and the clinic was foundational for the theoretical conceptualizations in which I situated my study. Through analyzing the 19th-century medical practice in France, he established that the categories of what was considered to be “normal” and “pathological” were not objective but rather influenced by their societal embedding. In “Le normal et le pathologique” (1991 [1966]), the philosopher and physician points out how pathologies are mostly thought of in quantitative statistical deviations. However, he argues that pathologies can only be understood if studied “with reference to the dynamic polarity of life” (Canguilhem 1991, 227). What is classified as normal or pathological is then defined by qualitative measures: “Every empirical concept of disease preserves a relation to the axiological concept of disease. Consequently, it is not an objective method which qualifies a considered biological phenomenon as pathological. It is always the relation to the individual patient through the intermediary of clinical practice, which justifies the qualification of pathological” (Canguilhem 1991, 229)[41]. Building on this differentiation of laboratory and clinical practices, Mol (2002, 123) emphasizes that “[t]he normativity that matters is clinical: laboratories can establish facts, not norms.” She also points out that for Canguilhem “knowledge is not only *about* the world, but *in* the world as well.” (Mol 1998, 278, italics in original).

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[41] Canguilhem emphasizes that there is a difference between the clinic and the laboratory and only in the clinic pathologies can be retracted: “Pathology, whether anatomical or physiological, analyses in order to know more, but it can be known as pathology, that is, as the study of the mechanisms of disease, only insofar as it receives from clinical practice this notion of disease, whose origin must be sought in the experience men have in their relations with the whole of their environment.” (Canguilhem 1991, 88).

To better understand these entangled and overlapping knowledge practices of people engaged in rethinking and reworking their care practices, I firstly turned to Jeannette Pols notion of patient knowledge, which she conceptualized in relation to Canguilhem's description of the clinical, as "a form of practical knowledge that aims to improve the daily life of individual patients" (Pols 2014, 78). She retraces how the laboratory, and the clinic can be understood as two epistemes, that both come with their own logics, practices and methods (Pols 2014, 78) and with this they can both be understood without hierarchical order or as contrasting. What patients know is then conceptualized as "knowing in action" (Pols 2014, 75) and cannot be thought of in contrast with medical knowledge, as it draws upon the latter. Patient knowledge is a form of knowledge "that patients use and develop in order to relate to medical knowledge and live their daily lives with disease" (Pols 2013, 80). Knowing can then involve different forms of coordinating and translating knowledge, technologies and advice from different sources (Pols 2014, 75). Similar to Pols, Mol and Law (2004) argue, by empirically focusing on hypoglycemia in T1D, that knowing one's disease is related to everyday-life practices of (self)care. In this context, recent STS scholarship has highlighted how different sensory experiences, such as tasting, hearing, and touching are relevant but mainly overlooked practices of knowing for people affected by diseases (Oudshoorn 2020a, Pinch and Bijsterveld 2012; Rice 2010; Shapin 2012). Sensory experiences are significant ways of knowing: experiences with bodies and technologies cannot just be understood as linguist or discursive but need to include the understanding of the sensory experiences (Oudshoorn 2020a, 21). Being entangled with devices, in, on and with bodies involves penetrating the skin with needles, involves blood, and may cause rashes and other bodily reactions that need to be part of the analytical equation as well.

What is also significant to my understanding of the knowledge practices of the looper is the collective nature of the way loopers know. Pols (2009) already points out that knowing as patients "requires patient *collectives* rather than individuals who share and develop [knowledge]" (Pols 2009, 192, italics in original). In digitized healthcare social media interactions play a significant role in the "development of illness understanding and adaptive self-care practices" (Kingod 2018, 4) and the way people know about their diseases. Kingod (2018) foregrounds how social media groups can be spaces in "which knowledge about how to self-care become co-constructed by peers" (Kingod 2018, 1). In relation to online patient communities Akrich (2010, 2) proposes that these can become epistemic communities, a concept mostly used to describe networks of professionals in policy making that "produce policy-relevant knowledge about complex issues in their area of expertise" (Haas 1992, 16). It is, however, also important to consider that the simple act of sharing experiences online does not make it knowledge or make the sharer an expert (Mazanderani et al. 2020, 272) "[r]ather, experience comes to be seen as knowledge through practices and technologies that differ between interactions, groups and communities" (Mazanderani et al. 2020, 272). What is also important to consider for the analysis of the #WeAreNotWaiting movement is that some loopers transitioned into opinion leaders[42] within the online community; often these were loopers that were part of the community early on or that had some sort of professional background that was important to the community, e.g., medical or technical. These opinion leaders were then also active in developing their own research projects, acting as looping advocates in policy making or even founding startups around the system. In this context the OPEN project was also established (O'Donnell 2019). Some of the members of the #WeAreNotWaiting movement, who were also already in academia, applied for a European research grant to generate evidence and study the lived experiences of loopers themselves (Publication 1). Out of this project stemmed multiple journal articles pointing out the clinical (Braune et al. 2021) and the psychological (Schipp et al. 2021) benefits of the use of an open-source closed-loop system. They also engaged in sociological studies, for example, by mapping usage barriers and access inequalities (O'Donnell 2023).

To summarize, in my analysis I differ from the literature in which the knowledge of individuals affected by disease is conceptualized along the lines of expert and lay, with patient knowledge labeled mostly as lay in contrast to healthcare professionals. While concepts such as "lay-experts" (Arksey 1994), "experience-based experts" (Collins and Evans 2002, 238), or "experimental knowledge" (Borkman 1976) acknowledge the capacity of individuals with health conditions to be knowers of their own health condition and their daily efforts to

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[42] Mazanderani and colleagues (2020) define that one becomes an opinion leader "through a combination of sharing their own experiences, engaging with medical research and terminology, being active in online communities and supporting others." (Mazanderani et al. 2020, 273).

acquire scientific knowledge about their illness, they follow the epistemic notion of differentiating between knowledge that is formal or propositional and knowledge that is informal, embodied, or tactile (Collins 2004, 125) and with this implicitly follow a hierarchical dichotomy. I take another route for my empirical inquiry. Building on the above-introduced conceptual works in the tradition of Georges Canguilhem, I focus on the practical and entangled aspect of knowing as loopers in their life with this open-source (self)care technology and illustrate that people affected with illnesses can know in technical, recursive, and methodological ways that cannot be categized in binary hierarchizations (Publication 2).

2.5 Intermediate summary

To summarize, the above-described rich and varied body of research has shown how relational, practical, multiple, and fractured care, bodies, technologies, and knowledges within the biomedical sphere are. The previously introduced notions contribute to my understanding of the multiplicity of individuals' lived experiences and how these different experiences with technology, care practices and human relations can enact different selves, bodies, knowledges, and illness experiences. People with T1D and respective loopers are invited to participate in their care; they are and constantly are becoming everyday cyborgs and, with this, enact everyday cyborg bodies. Their care practices consist of constant tinkering, improvisation, shuffling, maintenance, and repair work. Focusing on the mundane everyday-life practices of engaging with medical devices for one's care practices and how people are un/invited participating, tinkering, and repairing in and with their care then enables me to go beyond the view that there are only specific premeditated ways in which "patients" can and need to participate in their care. Rather, focusing on un/invited material participation and mundane practices of tinkering, as well as repair and maintenance work can reveal how people with chronic health conditions engage in their everyday-life care practices in multiple ways. This perspective helps to understand that care entails "practices for holding together that which does not necessarily hold together" (Law 2010, 69). For my analysis, understanding the entanglement of bodies and technologies and multiple and fractured bodies, (health) data and knowledge practices in the healthcare sphere constitutes an epistemic basis for grasping the knowledge practices of loopers and their health-political activism.

Centralizing looping as (self)care practices allows me to think *with* the individual and collective practices observed in the empirical study. Puig de la Bellacasa (2011, 99) puts it like this: “transforming things into matters of care is a way of relating to them, of inevitably becoming affected by them, and of modifying their potential to affect others.” For studying the #WeAreNotWaiting movement, I translate this as a commitment to approach the practices of this community “not only as recipients of the academic gaze, but also as knowledge-making agents in their own right” (Rodríguez-Giralt, Marrero-Guillamón, and Milstein 2018, 6). In the next section I go into detail on what this commitment meant for my empirical approach to the #WeAreNotWaiting movement.

3. Methodology and methodical approach

> “[A]n ethnographic attitude is a mode of practical and theoretical attention, a way of remaining mindful and accountable. Such a method is not about ‘taking sides’ in a predetermined way. But it is about risks, purposes, and hopes – one’s own and others’ – embedded in knowledge projects” (Haraway 1997, 191)

I now attend to the methodological[43] framework that guided my empirical approach, my concrete empirical approach, and the reflection of the research process. My main empirical approach is an ethnographic one and has been guided by the practical research principles of a constructivist Grounded Theory Methodology (Charmaz 2006). I further utilized the mapping strategies of the Situational Analysis (Clarke 2005) to map out the complex human and non-human relations in the studied situation.

3.1 Ethnography and the #WeAreNotWaiting movement: Research process and fieldwork

> “At some point in the interview (I later realized while transcribing it), we started to switch from the formal form of address “Sie” to the more informal form “Du,” and I started to detour from my beforehand carefully prepared interview guideline. Markus asks if he can use my laptop because it is easier to show me how he loops instead of just telling me about it. I agree and get out my laptop, we each sit at the corner edge of a table, and I move my laptop to his side so that I can still see the screen. He now starts to tell the story about how he started being engaged in the looper community, narrating me through different technical interfaces, graphs, values, and data. He takes my laptop, quickly opens the browser, and types in the address for a server, he explains, on which his glucose data is stored. He tells me proudly that he is also the host for the server and now hosts over 1,000 other loopers. He types in his password and moves the laptop closer to me. I slide forward

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[43] In English the terms *method* and *methodology* are often used interchangeably (Crotty, 1998). In German there is a very distinct understanding for methodology as the theoretical underpinning of a method, which is the practical execution. In this section, I follow the German distinction.

> with my chair and stare at the screen. A chart taking up the whole screen shows up. Markus walks me through the interface and explains the numbers that define his life with the complex chronic health condition now that he loops. He fumbles in his pants pocket, gets out his phone, and shows me the mobile version of the screen. He laughs and points to his smartwatch: "I can also get alarms directly on this one." Back to the laptop screen: In bright green appears his glucose values on one corner of the screen and a trend arrow next to it. On the other side, there is an overview of what happened in the last 5 minutes, the indication of how much battery his cell phone (which serves as a controller) has and what his insulin pump is doing. The curve that takes up most of the space on the screen shows his blood glucose levels over the last 12 hours. What makes up the "closed-loop" is that after the point in time we are at right now, the one curve branches into three. These are the algorithm's estimates of what might happen to the blood glucose values in the future: "The algorithm then takes over what I would have normally done myself and decides," explains Markus." (Summary of a postscript/field note)

When I decided to study the #WeAreNotWaiting movement my initial plan was to conduct interviews with loopers and analyze public documents with a Situational Analysis (SitA) approach, as introduced by Adele Clarke (2005). I soon realized that it was not as easy as I had thought to just ask people who were (at the time) involved in practices that were situated in a legal gray area to participate in my study. After writing to a few T1D bloggers who were also writing about looping one person replied that he would be interested in helping me with my study. Markus[44] had great knowledge about the different systems and (as I later learned) was incredibly engaged in the community and in the online peer-to-peer support. During our interview (the above-cited postscript), we had a good rapport (Breidenstein et al. 2013, 60ff.). He invited me to join him at a local T1D meetup where he was presenting on the open-source closed-loop system. After this interview, I decided to ethnographically study the #WeAreNotWaiting movement

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[44] All names mentioned in the text are pseudonyms.

for 17 months in 2018 and 2019.[45] My approach was guided by a simple curiosity to understand “what is going on here” (Goffman 1974, 8). The best way to answer this question is by participating and observing from the inside. Markus would become my gatekeeper; he would later take me to other meetups or community events and connect me to other loopers, helping me immensely in navigating this space. My ethnographic approach to the #WeAreNotWaiting movement brought me to participate in meetups, hackathons, informal community parties, and gatherings, help with proofreading flyers, and even give a presentation together with a looper at a diabetes educator training organized by one of the largest pharmaceutical companies operating in the diabetes space. I met many people with different stories and different relations to the #WeAreNotWaiting movement, but one thing that connected all of them was their shared matters of concern (Latour 2004a)—that of a vision of automating their (self)care practices in order to improve their “chronic living” (Wahlberg et al. 2021). Ingold (2014, 386) puts it fittingly when he describes ethnographic practices as “encounters with people [that] are compounded and folded into what we have come to know as fieldwork.” An ethnographic field site does not exist prior to the engagement of the researcher. Rather ethnographers, the researched individuals, spaces, infrastructures, and non-human artifacts co-construct what becomes the researched field (Gupta and Ferguson 1997, 5). It is not a physical place one can enter and leave but rather an analytical device (Marcus 1999). The construction of the field site involves the process of building relationships (Amit 2000). What makes an ethnographic approach unique is that the researcher studies the social phenomena through observations, co-presence, and long-term participation in the field.

The #WeAreNotWaiting movement is not a physical place or a location-bound community; rather, it is this vision of automation that can travel quickly from one place to another in the world. To analytically grasp this, I undertook a multi-sited ethnography (Marcus 1995) and followed different actors and stories in the movement.[46] This approach “moves out from the single sites and local situations of

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[45] This is also rather difficult for me to define. While I would say that my active fieldwork ended in the end of 2019 and was then completely cut due to the start of the COVID-19 pandemic in 2020, I still observe the practices of the #WeAreNotWaiting movement. For example, in February 2023 I went to the closing conference of the OPEN project in Berlin and learned a lot about the community, which then informed this synopsis. Because the looper community is also engaged in studying themselves and publishing articles, I did not necessarily ever really leave the “field.”

[46] This approach also fits Latour’s suggestion “to follow the actors themselves” (Latour 2005, 12).

conventional ethnographic research design to examine the circulation of cultural meanings, objects and identities in diffuse time-space” (Marcus 1995, 96). In her study of glucometers in Uganda anthropologist Arlena Siobhan Liggins (2020, 17) quite fittingly puts it like this: “ethnography itself emerges to a travelling practice following objects like glucometers, other technologies, ideas and people,” when studying technologies in practice. I too followed people, connections, associations, and different relationships across space (Falzon 2009, 1f.).

I describe the #WeAreNotWaiting movement as a glocal movement (Publication 1): it is a health movement with members all over the globe and with a global reach, but at the same time it has very material and local aspects to it, as it is at its core about (self)care. In order to do justice to this particularity, to consider the entanglement of local and global (the glocal) dimensions of this movement, I became further inspired by the methodological notion of assemblage ethnography introduced by anthropologist Ayo Wahlberg (2022, 2018). This approach acknowledges the significance of local sites (which in my case would be the meetups I regularly attended), but then it allows the ethnographer to follow connections (local and global ones) that emerge out of the single site (Wahlberg 2018, 196). By utilizing an assemblage ethnographic approach, I could also gain “insight into the ways in which certain […] problematizations take form” (Wahlberg 2018, 11), which go beyond the local community. For my inquiry this was vital, as it allowed me to have this local research site (the German looper community, with one specific local meetup group), but then I could follow the traveling stories and narratives, which could not easily be put in “national containers” (Beck 2007). This, for example, led me to interview Dana Lewis, who is situated in the U.S. but is still of great significance in the German community, or I had conducted an ethnographic interview with a looper whom I met in the U.S., which gave me new insights into how the practices of the #WeAreNotWaiting movement were framed differently in the U.S. and the German setting.

The data collection and analysis took place in an iterative process, and for data collection I followed the theoretical sampling strategy of the Grounded Theory Methodology (Charmaz 2006), which means that I was “seeking fresh data sources pertinent to a particular theoretical point” (Clarke et al. 2015, 101). I moved between the “field” and the “desk,” and my analysis informed my further data collection. For example, I realized after a while that there were a lot of legal discussions in the field, but I had not yet engaged much with this part of the research phenomenon. So, I searched for someone with a legal background in the field, who I then interviewed. Another example of this iterative sampling process was when I realized that I had only heard "success stories" of people that managed to set up a closed-loop systems and that were happy with the system. At my "desk" I then read an article by Sally Wyatt (2003) on the importance of thinking of non-users of technologies, so I searched for people who stopped using the system or struggled with the setup. Talking to people that stopped looping or struggled with the setup gave me new dimensions that I had not yet encountered in my fieldwork. This approach led to a diverse body of data material. My main material consists of fieldnotes from participatory observations at one regular meetup group (monthly meeting); different community events, such as hackathons; presentations; as well as online community groups. Furthermore, I conducted twenty-eight problem-centered interviews[47] (Witzel 1985) with loopers, clinicians, caretakers, and other actors.[48] I also included public documents[49] such as different statements from regulatory bodies and newspaper articles in my analysis. A detailed overview of the data corpus can be found in the appendix.

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[47] I decided to conduct problem-centered interviews in an explorative way as suggested by Witzel (1985). A problem-centered interview has a question guideline that is conceptualized dialogically and focused on a specific "problematization" (theme) (Witzel 1985, 36). This allowed me to ask questions focused on things I had already learned in the field, while still being open to the focus of the interviewed. In the interview situation I used the question guideline rather flexibly as a sort of "memory support and orientation guide" ["Gedächtnisstütze und Orientierungsrahmen"] (Witzel 2000, 7). For the interview entry, I chose a fairly general as well as open-ended and story-stimulating question (For the loopers: "Can you tell me a little bit about yourself and how you started looping?"). After the first question that invited narration, I asked more pointed questions. Furthermore, I focused on creating a supportive relationship during the interview (Rosenthal 2011, 210) and always asked if the interview partners had something to add (Rosenthal 2011, 162). Witzel also refers to GTM, specifically to the idea that one always "oscillates" between the empirical and the theoretical, which also fits quite well with my SitA approach.

[48] Many of the people interviewed have double roles, such as being a clinician and a person with T1D.

[49] Some of these documents are also academic journal article such as for example Braune et al. 2022. This again points to the entanglement in the situation of inquiry. My use of these publications as both academic reference and as empirical data material also fits to the 'post-qualitative' critical reflection of the challenges of strict differentiation between data and theory posed by St Pierre and Jackson (2014). This approach also contributes to my commitment to understand the members of the #WeAreNotWaiting movement as "knowledge-making agents in their own right" (Rodríguez-Giralt, Marrero-Guillamón, and Milstein 2018, 6) and to see my research process as a "relationship-building process, as a professional networking process with colleagues (not 'subjects'), as an opportunity for conversation and sharing of knowledge, not simply data gathering" (TallBear 2014, 2), as discussed in publication 3.

3.2 Coding and Mapping: Data Analysis

For my data analysis I followed a combination of the three-step coding procedure of a constructivist Grounded Theory (Charmaz 2006), focusing on gerund coding to analytically grasp the practical and dynamic dimensions of my material as well as the SitA mapping techniques[50] in order to be able to analytically capture the entanglement of people, technologies, and society (Clarke et al. 2015, 101). A SitA mapping approach "[o]ffers a fresh theoretical grasp of the phenomenon" (Clarke et al. 2015, 108) as it makes it possible to include nonhuman as well as discursive elements in the analysis.

In order to do justice to the larger data corpus, I thoroughly reviewed the initial collected material and coded it by themes. Then in a second step the passages that seemed particularly relevant were selected and coded line-by-line to not lose sight of agency and processuality (Charmaz 2011, 367-370). In the process, the texts were broken up, condensed, and restructured in order to be able to derive categories from them. Furthermore, once I conceptualized my first publication, I revisited my analysis and material and re-coded while keeping in mind the specific question and the theoretical concepts, such as tinkering (Mol 2006), patient knowledge (Pols 2013), or recursive public (Kelty 2008) as "sensitizing concepts"[51] (Blumer 1954, 7). In addition to coding, I created a "messy situation map" from the initial coding at the beginning of my fieldwork.[52] Here I tried to visualize all elements that seemed relevant to the #WeAreNotWaiting movement, as well as the relationships between them. Throughout my PhD I revisited this map and added or changed elements; this helped me to sharpen my research interests, especially once I started to write my articles. In contrast to a classical Grounded Theory Methodology (Glaser and Strauss 1967), the goal of the analysis is not to extract a single core category from the material but to focus on the key elements,

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[50] In an SitA approach, the analysis practice consists of constantly and repetitively creating three types of maps 1. relation maps, 2. social world arena maps, and 3. position maps (Clarke 2005, 86). The idea is to be able to visualize who and what exists in the situation, who and what matters in it, and which elements do what (Clarke 2005, 85ff.). In addition, researchers also need to ask about ideas, concepts, discourses, and symbols that may be significant in the situation, as symbolic and discursive elements in maps can be of great significance in the analysis (Clarke 2005, 88).

[51] SitA also offers a theoretical toolbox with useful theoretical concepts for an initial theoretical orientation in the analysis; these are not static and can be extended (Clarke and Star 2008, 119).

[52] In Bubeck and Jansky (2023), I describe in detail how I used the SitA mapping strategies for my analysis, and we introduce heuristic dimensions derived from Puig de la Bellacasa's (2011, 2017) notion of "matters of care" to attend to the materiality of care practices in the analysis.

materialities, discourses, structures, and conditions that characterize the studied situation. The mapping was accompanied by constant memo writing, in which I captured and recorded initial interpretive ideas and theoretical considerations. I also used the ideas in the memos to plan my further strategy for theoretical sampling (Clarke 2005, 102f.). Because I used an explorative approach to the #WeAreNotWaiting movement, at times the movement seemed rather overwhelming for me to analytically capture; with the mapping strategies I was able to break through common ways of data analysis and could look at things from different and new perspectives. The maps worked as analytical tools in dealing with heterogeneity and disorder (Clarke 2012, 74). What was especially helpful from the SitA toolbox was the idea of social world arena maps.[53] Inspired by Anselm Strauss's (1978) notion of social worlds,[54] Clarke suggests that this concept can also be fruitfully utilized in the empirical analysis. At the beginning of my study, I started to map all different elements and their relation in a social world arena map that I revisited throughout my research process. Clarke (2005, 109) suggests to cartographically retrace all collective obligations, relationships, and sites of action (Clarke 2005, 109). The social worlds partially overlap in this process, and individuals/collectives may also participate in more than one social world simultaneously (Clarke 2005, 109). The transformation of the arena and social worlds through negotiations, repositioning, and relationships in the arena can be carved out particularly well with the maps: actors can be included or excluded again and again over time to represent individuals, organizations, social worlds, or actors (Clarke 2005, 127ff.). The #WeAreNotWaiting movement underwent many transformations during my time studying it. By analytically approaching it with the triangulation of GTM coding and SitA mapping, I was able to respond to this dynamic field in my analysis.

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[53] The maps also serve to identify which stories about the overall situation can be told at all in the final presentation of results, so they were limited to being able to tell coherent stories (Clarke 2005, 111). This also means that I could not give equal space to every occurrence in the overall situation in my empirical articles.

[54] Strauss builds on the work of Shibutani (1955) to conceptualize the notion of social worlds.

3.3 From Fieldnotes to Articles: The Centrality of Writing and a Reflection on Temporality

Writing is considered an important part of qualitative research and cannot be looked at as separate from the analysis (Charmaz 2006, 151; Emerson et al. 2011, 19). During my four years of PhD studies, writing gained a centrality in my research process: I scribbled down words, phrases, or terms during my fieldwork in different notebooks, on post-its, loose papers, and my notes app. Later at my desk I wrote down fieldnotes on my computer, either at the office or at home. After interviews I wrote postscripts about the interviews, noting down things that in that moment seemed important to not forget. Fieldnotes are not static; they are difficult to write and can be at times frustrating, as Michael Taussig (2011, 13) puts it: “that drive to get it all down in writing just as it was, that relentless drive that makes you feel sick as the very words you write down seem to erase the reality you are writing about.” The stories, experiences, and encounters that I experienced in these four years, my analysis, and the resulting articles were all created within specific temporalities, and with each I related differently to the #WeAreNotWaiting movement. For example, while in Publication 1 I still refer to the technology in question as “do-it-yourself artificial pancreas system,”[55] as this was the term most people in the field were using, later I would not use this terminology and instead used the words “closed-loop system” or “automated insulin delivery system,” as both of these terms better emphasized the practical aspect of what the loopers were doing: they were closing the loop of their (self)care devices and advocating for automating insulin delivery. There was also a change in attitude concerning the term *hacking*. While in 2018 I attended a hackathon organized by the looper community and the non-profit organization “hacking health,” this term later developed a negative connotation, and it was frowned upon to use it to describe the practices of the loopers.

I related differently to the studied phenomenon, and this is reflected in things like using different terms for the same technology. In order to reflect upon this significance of time in my research process, Michael Serres’s topology folding of time can be helpful. In a conversation with Latour, Serres (1995, 45) describes

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[55] There was much debate about the different terms in the community. While artificial pancreas system might mislead to the assumption that the systems are replacing the full functions of a pancreas, the term DIY was often perceived as mis-representing the community as amateurs and lay people.

how he understands the meaning of the term *contemporary*, and he points out that "in order to say 'contemporary', we must already be thinking of a certain time and thinking of it in a certain way." Similar to how Serres describes the contemporary nature of a car with the temporary linearity and connection of its parts being "only contemporary by assemblage," the same can be said for my empirical descriptions of the #WeAreNotWaiting movement. The vision of automation in different times and situations and from different perspectives is negotiated under different names, and with it different claims, classifications, and knowledge are negotiated, too. While I was studying this community their narratives around their engagements changed, new terms were introduced for technologies, practices, and engagement, and at the same time others were rendered less significant. Serres's topology folding of time can be helpful here to understand that the field and my analytical descriptions of it are temporarily folded into each other and with each other, and the articles that make up my dissertation also fall under this idea of folding of time. Within the peer-review processes of the articles, I also wrote many different versions of the same article (For example, for Publication 2 I can find approximately forty slightly different versions saved on my computer spanning from the first draft in 2019 to the final published version of 2023.). With every new version of my articles, I was also referring to a different contemporary version of the studied phenomenon.[56]

3.4 Research Ethics

With qualitative approaches researchers always influence the lives of the interlocutors, and furthermore, the study of a social phenomenon can enable or disable its transformation. This leads to an ethical responsibility of qualitative researchers. Throughout my research process I have reflected the ethics of my engagement with the studied community and my participants. I followed the Ethics Codex of the German Association of Sociology, which includes, among others, the following standards: the maintenance of integrity and objectivity, risk assessment and harm avoidance for participants, anonymization and confidentiality, voluntariness of participation, and informed consent. As this is a qualitative study,

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[56] This observation also fits well with Anselm Strauss's (1978, 123) argument "that we are confronting a universe marked by tremendous fluidity; it won't and can't stand still."

the requirement of objectivity is substituted with reflexive subjectivity, as the subjectivity of the researchers can never be completely excluded and instead needs to be used prolifically in a research process. I focus on the questions of positionality and situated knowledge in the research process in Publication 3, where I argue for a focus on accountability and constant disclosures of otherness in fieldwork. I also obtained an ethics waiver for my study from the ethics committee of the medical faculty of the Ludwig-Maximilians-University. Furthermore, I took guidance from the Research Ethics Guide for Ethnography/Anthropology by the European Union (Iphofen 2020). This guide helped me to navigate decision-making in the fieldwork, how to disclose my research interest, and to always weigh risks. As the studied group is a rather tight-knit community with some of the interlocutors having public roles, I paid great attention to the pseudonymization of my cited material. I, for example, followed the advice of Saunders, Kitzinger, and Kitzinger (2014, 6) to use different pseudonyms for the same person in the cited material, in order to make who my interview partners were opaquer.[57] Furthermore, I summarized my fieldnotes for the publications, focused on eliminating identification markers, and tried to be as precise as possible, while at the same time trying to stay vague enough so that the events I participated in are not immediately retractable.

I also want to acknowledge that “knowledge is intrinsically politically and ethically situated in its purposes and positionalities” (Puig de La Bellacasa 2011, 101) and this includes my own knowledge production. While I go into detail in Publication 3 on how I account for my situatedness, I want to emphasize that throughout my research process I carefully attended to power relations in my own knowledge production and constantly asked myself, as Haraway (1988, 587) suggested: How do I see? Where do I see from? What limits my vision? Furthermore, throughout my analysis process I thought about the role of “implicated actors/actants” (Clarke et al. 2018, 76f.) and how they could be “care-fully” (Law and Lin 2020) considered in the analysis. To think about ethics in the studied situation is more than just checking boxes of ethics guidelines and getting institutional ethics approvals; it is about acknowledging one’s own situatedness and

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[57] This is referred to as “smoke screen strategy” (Kaiser 2009), and it needs to be very carefully considered when to use it in order to not compromise the integrity of the data. I however talked to people who were due to their double role as clinician and loopers, or because of their exposed role in the community in especially difficult and precarious positions and a recognition could be harmful for them, which is why I decided to use this strategy.

that every decision in the field and analysis also has a political dimension to it. While this is crucial for every sociological study, it is especially critical when studying the lives of people engaged in (health) political activism that have a lot at stake.

3.5 Limitations

There are some limitations to my study that I want to address. Firstly, I acknowledge that I do not have lived experiences with living with T1D, which, as I discuss in detail in Publication 3, has implications for my research. Especially in a setting such as healthcare, where the lived experiences and realities of those living with chronic health conditions every day are often disregarded in favor of "those who study it from a distance" (Richards 2008, 1720), this self-reflection is crucial. This dissertation and my analysis are not a "view from above, from nowhere" (Haraway 1988, 589), and I want to acknowledge this. When conducting ethnographic research, researchers do not look at a phenomenon detached from the outside, rather they are positioned participants within the "fields" they study (Shore 1999, 45). This dissertation is one perspective of many "partial visions" (Haraway 1988, 586) on the #WeAreNotWaiting movement. My aim is for it to add a nuanced account of the lived experiences of members of the looper community and their activism for a better life with devices in, on, and with their bodies. My goal is to contribute a sociological perspective on this open-source endeavor. At the time of the start of my PhD, there was little research done on the #WeAreNotWaiting movement, and my explorative approach was most suited to obtaining a better understanding of the phenomenon. There are some aspects that I think might be interesting to look at in the future. I could have engaged more with the clinical perspective. I did interview clinicians, but I focused on the lived experiences of the affected. The same issue occurs with policy makers—I could have included stakeholders in the policy area in my analysis. While I included public documents in my analysis, such as statements of different regulatory bodies and diabetes associations, I only used them to better map the experiences of the loopers navigating these policies. I was also trying to talk to more people that stopped using the system or had problems with the setup, which would have been very interesting for the analysis, but this was hard to accomplish, and, in the end, I only interviewed three people who stopped briefly or stopped completely. As this is one of the first few empirical studies to look at the #WeAreNotWaiting movement, there are still many aspects of this movement that are empirically unexplored. I chose to focus on the lived experiences of loopers and map their knowledge practices and health-political aspirations, while other scholars focused on the socio-psychological aspects (Schipp et al. 2021), clinicians' perspectives (van Os 2023), national health policies (Eitenberger 2023), or autoethnographic approaches (Garfinkel 2021), and thus we all offer "partial visions" (Haraway 1988, 586) on the #WeAreNotWaiting movement.

4. Discussion of results – Patient activism at the intersection of chronic (self)care and open-source innovation

In this dissertation, I studied the practices of people involved in patient activism at the intersection of chronic (self)care and open-source innovation. With an ethnographic approach, I was interested in empirically exploring what it means to (self)care with open-source automated technology. Ethnographic research is not straightforward, and the central research aims are discovered in the field. My initial research interest was to understand the everyday-life experiences of those affected by the entry of digitized, personalized, and customized healthcare technologies into their chronic (self)care. I soon realized that not only was I studying the practices of people involved in a health movement—the #WeAreNotWaiting movement—but by chance I was also studying this community at the pivotal moment in which their efforts increasingly turned from activism to innovation. I observed how people with T1D use devices provided by commercial profit-oriented pharmaceutical companies to create a vision of automation on their own terms, sometimes criticizing these companies and other times aligning and collaborating with them—some with an explicitly voiced health-political aim, others with the aim to create good care for themselves. Along the way the narratives around the looper community started to turn from them being "deviant activists" (Geiger 2021) that "hacked" their medical devices and who were not invited to participate in the ways clinicians, regulatory bodies, and the pharmaceutical industry were, to the #WeAreNotWaiting movement being a showcase for tech-optimist patient innovators (Demonaco et al. 2019; Demonaco and von Hippel 2019). This led me to center my research interest around the everyday activist practices and the question of epistemic legitimacy within this movement. As such, the different publications that ground this dissertation have introduced the everyday practices of activism in digitized and datafied healthcare spheres, highlighting the focus on the intimate entanglement of bodies, devices, and health data that builds the basis for this form of activism. As Marres (2012) emphasizes, devices can promote the political engagement of people interacting with them—loopers use them to participate un/invited in their care. They put the materiality of being an "everyday cyborg" (Haddow et al. 2015) at the center of their engagement. I term this as *device activism* and argue that this form of activism emerges at intersections. It emerges out of care practices—mundane repair and maintenance work of people intimately being entangled with devices in their everyday lives—and it can be described as a continuous moving between caring, advocating, and innovating.

4.1 Summary of the main points of the publications

I now briefly summarize the main points of the dissertation-grounding publications before synthesizing the overarching notions that have emerged from my engagement with and in the #WeAreNotWaiting movement to conclude the synopsis.

The dissertation enters the field of the #WeAreNotWaiting movement in **Publication 1** and introduces the looper community. By retracing the different device-centered narratives of activism in the #WeAreNotWaiting movement, I illustrate the struggles, visions, and negotiations within the global and local forms of this movement. Here I engage in detail with the idea that in order to understand the practices of the loopers, we need to understand them in their local and global (glocal) as well as intimate/private and collective embeddedness. Building on the notion of "material participation" (Marres 2012) and "recursive publics" (Kelty 2008), I present different narratives of how loopers are engaged in the #WeAreNotWaiting movement and introduce the notion of device activism as an analytical tool to foreground how living with *devices* in, on, and with bodies is the global shared concern through which loopers come together and simultaneously the means through which they engage on individual and collective levels. I highlight that this shared concern does not mean that every looper engages with the devices in the same manner. However, the common denominator of all engagement is a recursiveness and materiality, which is tied to a life-sustaining entanglement with personal medical devices. At the center lies a socio-technical vision of free and open-source automated technology for (self)care.

Publication 2 then zooms in on the emerging knowledge practices of the loopers. Here I depart from the literature on patient knowledge (Pols 2013, 2014; Mol 2006), activist ways of knowing as patients (Rabeharisoa et al. 2014; Epstein 1995), as well as empirical studies of self-experimenting in the QS movement

(Jethani 2015; Crawford, Lingel, and Karppi 2015; Sharon 2017; Pantzar and Ruckenstein 2017). Building on this diverse body of literature, I outline three emerging knowledge practices in the looper community: technical, recursive, and methodological and I introduce the notion of *elaborative tinkering*. I argue that in order to understand knowledge practices at the intersection of chronic (self)care, health activism, and patient-led innovation, the analysis needs to be centered around the question of how different ways of knowing are entangled in the studied situations and when they are kept apart. The introduced notion of elaborative tinkering then extends the idea of tinkering (Mol 2006). It offers an approach to understanding that patient knowledge can be individual practices of tinkering with one's care practices and technologies but that it can also be entangled and interrelated with activist and innovative knowledge practices.

In **Publication 3,** I turn my gaze to my own knowledge production and how I navigated doing ethnographic fieldwork in this highly politicized context. Building on Haraway's situated knowledge (1988) and TallBear's idea of the ethics of accountability (2014), I use the moments in my empirical work where I was met with skepticism and where I struggled as a starting point to think about accountability and to argue that in order to be accountable, ethnographers need to generatively engage with their otherness and should include these negotiations in their writing. I introduce the notion of *disclosing otherness* to foreground the significance of engaging with the uncomfortable moments in fieldwork that come from an otherness in the field. I do this by looking at three moments in my empirical work where I had to disclose my "otherness": epistemic disclosure, bodily disclosure, and the disclosure of research objectives. Here I also engage with the ethical questions of studying a group that has a lot at stake and where my research could potentially influence their political fight for epistemic legitimacy.

The notion of looping as an analytical tool beyond the empirical case introduced in the additional **Publication 4** then highlights the bigger questions that are conveyed with the #WeAreNotWaiting movement concerning the role of affected people in algorithmic care. Together with Henriette Langstrup, I revisit our heterogeneous data material from both of our empirical engagements in and with the looper community and synthesize how looping can be understood as a way to share the burden associated with a chronic health condition with an automated system, how looping is a collective and recursive engagement with algorithmic care systems, and how looping includes the ability to opt in and out of algorithmic care systems. We conclude that looping as an analytical tool foregrounds an active, skilled, demanding, ambivalent, and collective engagement between users and automated technologies.

4.2 Overarching themes

In the different publications, I engage with the #WeAreNotWaiting movement in different analytical ways. The themes of *materiality, recursiveness,* and *epistemic legitimacy* are woven through each of them. In a concluding move, I want to bring them together, for each of these themes offers insight into the practices of being engaged in device activism in a different way. These notions reveal how my dissertation contributes to the sociological and STS understanding of healthcare activism in digitized, data-driven, and personalized healthcare settings, as well as chronic (self)caring in this context. In order to distill these themes in the following, I use three slogans that are essential to the #WeAreNotWaiting movement to guide my argument. Slogans have played a crucial role in the global expansion of social movements (van de Velde 2020, 1). These forms of "protest writings" (van de Velde 2020, 3) have become increasingly relevant for social movements within social media and they are—as evidenced by the name-giving slogan—significant to the #WeAreNotWaiting movement.

4.2.1 "Practical cyborgs with T1D": The materiality of device activism

In a presentation about his autoethnographic research on living as a looper, writer and media studies scholar Jonathan Garfinkel describes the entanglement of his body with devices, such as his smartwatch or an insulin pump, as being a "practical cyborg with T1D" (Garfinkel 2021, min 13:39). This self-description as cyborgs is common within the diabetes community, and it is reminiscent of the everyday-cyborg concept (Heddow et al. 2015). Being and becoming cyborgs is not a metaphor for people living with T1D; it is a material everyday practice and not a frictionless endeavor. A growing number of researchers in medical STS and disability studies are currently arguing to shift the analytical focus to these practical cyborgs—the everyday cyborgs that are already living in life-sustaining intimate entanglements with technological devices (Oudshoorn 2020a, 2020b; Heddow et al. 2015; Forlano 2019b. My analysis adds to this literature and highlights the prolificity of attending to this materiality of living with devices, in, on, and with bodies as a core of activism in contemporary digitized, technology-mediated, and personalized healthcare settings. As Haraway (1988, 150) proclaims in relation to Foucault's biopolitics, the politics of the increasing entanglement of humans and technologies is still a "very open field." Adding this acclamation to the study of health movements in datafied healthcare and taking the emphasis on the materiality of the ambivalent entanglement with devices and bodies for chronic (self)care as everyday cyborgs serious as shared matters of concern and *matters of care* can offer a way to understand health movements in contemporary digitized healthcare contexts. With this emphasis on the everyday experiences of being and becoming everyday cyborgs, the findings of this dissertation extend the current sociological and STS understanding of health movements and patient activism.

4.3.2 "By the Community for the Community": The recursiveness of device activism

The slogan "by the community, for the community" illustrates how the open-source closed-loop system exists only because everyone engaged is also making it possible for others. As described throughout the dissertation, engaging devices is simultaneously a practice of intimate (self)care and a collective response to the political economy of datafication and increasing self-responsibility for one's care. The notion of recursiveness can account for this simultaneousness. I engage the notion of recursiveness,[58] borrowed from programming, to theoretically illustrate how the different observed practices in the community are not only continuously building on each other but also refer back to each other, thus creating recursive relations.

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[58] My argument builds on the conceptualization of recursiveness by Kelty (2008). Other scholars have also engaged the idea of recursion to account for personal chronic illness experiences (see Rogers 2022 as well as Manderson and Warren 2016).

Within the different publications of this dissertation, I offer an in-depth engagement with recursiveness in the context of digitized chronic (self)care and collective responses to the politics of datafication. I suggest that thinking with and through recursion may allow researchers to gain a nuanced understanding of care practices as not only relational but also continuously building on each other and referring back to each other. I have illustrated these recursions by looking at knowledge practices and health-political activities in my specific empirical engagement. I can see, however, how engaging the idea of recursion in other sociological analyses of individuals' experiences within increasingly digitized, technology-mediated, and personalized healthcare settings can help to map and trace the complexities and dynamic and increasing entanglements in digital and data-driven device-centered care. People affected by chronic health conditions are always in recursive cycles with others, clinicians, technical artifacts, and infrastructures in contemporary digitized healthcare. Recursion may offer a theoretical lens for a deeper understanding of these entanglements. Focusing on recursions might also open the possibility of acknowledging how all beings in the world, in one way or another, "depend on each other" (Puig de la Bellacasa 2010, 164).

4.2.3 "It is not about a seat at the table. This IS the table": Epistemic legitimacies of device activism

During the closing conference of the OPEN project, Katarina Braune, one of the project leaders, a person with T1D, looper and diabetologist, ended her presentation with the following Twitter quote: "It is not just about a seat at the table. This IS the table."[59] She illustrated this by depicting a table surrounded by the different hashtags that people with diabetes around the globe use to advocate for their needs and rights: #NothingAboutUsWithoutUs, #Isulin4all, #LanguageMatters, and #WeAreNotWaiting. This quote transmits the influential standing of the community of people with diabetes accomplished in the contemporary healthcare sphere. After all, the Braune et al. (2022) publication cited

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[59] https://twitter.com/Moodwife/status/1628326564587835392/photo/4 (latest access 25.02.2023) (by Tom Robinson, (JDRF [Juvenile Diabetes Research Foundation])

in the introduction of this synopsis is one of the many scientific publications emerging from the looper community and their scientific engagement.

Throughout my research in and with the #WeAreNotWaiting movement, I encountered the question of epistemic legitimacy. In all of the publications I refer to the question of what epistemic legitimacy can entail and how it is negotiated within the looper community. The epistemological significance of people affected by diseases and their health-political engagement with and in biomedical settings and knowledge production is well studied in sociology and medical STS (Epstein 1995, 1996; Rabeharisoa et al. 2014). My dissertation adds new dimensions of these negotiations of epistemic legitimacies in digitized and algorithmic healthcare settings. With my dissertation I can show how digitized patient epistemologies can go beyond the conceptualizations of patient knowledge as practical “know now” (Pols 2013) or tinkering (Mol 2006). The practices that I retraced in the case of the loopers are much more entangled, and they are not necessarily related to the clinical context. With the entry of digitized (self)care technologies and “algorithmic assemblages of care” (Schwennesen 2019) we can increasingly find other forms of knowing beyond the biomedical as crucial in patients’ knowledge practices.

5. Conclusion

To conclude, in this dissertation I ultimately retraced the ambivalence and complexity of living with devices in, on, and with bodies to (self)care for a chronic health condition in contemporary digitalized, technology-mediated, and personalized healthcare settings. I offered a glimpse into the lived experiences of people being engaged in activism and innovation that emerged from their (self)care practices. I made several contributions to the social study of the epistemic and activist practices of people affected by chronic illnesses in digitized, technology-mediated, and personalized healthcare settings. In my sociological engagement with the practices of the loopers, I described the #WeAreNotWaiting movement as a form of patient activism situated between digitized chronic (self)care and patient-led open-source innovation. To account for this specificity, I introduced the notion of *device activism*. The devices in, on, and with bodies, the “intimate components”

(Haraway 1991, 178) that are not entirely within the user's control, are the shared concern in the activism I observed. The practices I empirically retraced are always, in one way or another, aimed at creating solutions for better "chronic living" (Wahlberg et al. 2021) with devices in, on, and with bodies.

In her classic STS study on laboratory practices, Karin Knorr-Cetina (1981, 116) describes how the "innovation metaphor/analogy" is tailored to clearly identifiable successful end products of research. The quote by Braune et al. (2022, 58), which I cited in the introduction to introduce the #WeAreNotWaiting movement, has a similar connotation. Reading the proclamation that open-source automated insulin delivery systems result from "co-creation" by a patient community in one of the most prestigious journals of contemporary biomedicine gives an impression of deliberate collective decisions of the movement that led to this point. However, the move from the legal borderlands and gray zones into the limelight as one of the examples of "user-driven innovations" in healthcare is characterized by an experienced ambivalence and was not as smooth and straightforward as these current discussions in the innovation studies and healthcare literature might suggest. My engagement illustrated that automation in healthcare is not a frictionless endeavor. My study joins a long line of sociological and STS studies on healthcare movements and activism and contributes to the advancement of this field of study. With my dissertation I offer a nuanced account of the different experiences, narratives, visions, hopes, fears, and struggles that all make up this movement. And while I situate my engagement in sociology and STS, the findings might also be of relevance for clinicians and health-science and innovation-studies scholars for an in-depth understanding of these varieties of lived experiences.

The #WeAreNotWaiting movement might currently be the most prominent example of activism in the healthcare context that is based on the intimate entanglement of people with data-driven and data-generating devices. There are, however, increasingly other cases in which the affected are engaging in rethinking and redoing their device-mediated care. The concepts I offer in this dissertation can help other researchers to sociologically grasp these efforts. I, however, want to emphasize that it is crucial to think the #WeAreNotWaiting movement in its situatedness in a global health-data economy and acknowledge that the practices of loopers are clearly aligned with the current socio-technical visions of automated and data-driven healthcare innovation and active "digitally engaged patients"

(Lupton 2013). This might also be the reason why the #WeAreNotWaiting movement moved much faster from the healthcare infrastructural shadows into the innovation limelight than other cases of microactivist affordances, practices of tinkering, and precarious and critical maintenance and repair work in care. This needs to be considered and calls for more empirical engagement with patient-activist practices at the intersections of (self)care and innovation.

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Part Two – Publications

Overview over publications and my contributions to each publication

Overview over publications and own contribution

Publication	Bibliography	Own Contribution
1	Jansky, B. and Langstrup, H. 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*[a] 18, 498–522 DOI: 10.1057/s41292-022-00278-4	85%
2	Jansky, B. 2023a. Digitized Patients: elaborative tinkering and knowledge practices in the open-source Type 1 Diabetes "looper community" *Science, Technology & Human Values*[b] 49(1), 53-77. https://doi.org/10.1177/01622439231170443.	100%
3	Jansky, B. 2023b. Disclosing otherness: Situated Knowledges and the Politics of Ethnographic Approaches to the #WeAreNotWaiting Movement in Type 1 Diabetes and Beyond. *Journal for Contemporary Ethnography*[c]. Online first. https://doi.org/10.1177/08912416231207648	100%
4	Langstrup, H. and Jansky, B. Looping for (self)care – personal digital health technology and algorithmic systems. In: Giaduollo, Paolo; Miele, Francesco (eds.): Algorithmic care: STS perspectives on automation of care. Palgrave. (Currently in press)	40%

[a] 2-year impact Factor 1.6; 5-year impact factor 2.0; in the top 80% of Journals in the category Social Sciences, Biomedical (Journal Citation Report June 2023).

[b] 2-year impact Factor 3.1; 5-year impact factor 3.5; in the top 30% of Journals in the category Social Issues (Journal Citation Report June 2023).

[c] 2-year impact Factor 1.6; 5-year impact factor 1.7; in the top 70% of Journals in the category Sociology (Journal Citation Report June 2023).

The findings of this dissertation are published/written in three separate peer-reviewed journal articles and one additional peer-reviewed anthology book chapter (see Table 1). Each can be read independently and consists of an introduction, a theoretical underpinning, and an empirical argument.

The first publication (Jansky and Langstrup 2022) was written in collaboration with Henriette Langstrup, with me as first author. This means I was responsible for developing the conceptualization of the article, data collection and analysis was performed by me; I wrote the first draft of the article (introduction, theory section, methods section, results, and discussion). I was responsible for journal communication and later for the final revision before publication.

The second publication (Jansky 2023a) is a single authored article, and all elements are therefore my own. I was responsible for data collection, data analysis, conceptualization of the article, revisions, and journal communication.

The third publication (Jansky 2023b) is also single authored by me, and all elements are my own. I was responsible for data collection, data analysis, conceptualization of the article, revisions, and journal communication.

The fourth publication (Langstrup and Jansky 2023) is an additional publication to the three journal articles. Here Henriette Langstrup took the lead in the conceptualization of the chapter and wrote the first draft. It is an additional publication as it consists of a merging of my collected interview material as well as the open answers of the quantitative OPEN survey (O'Donnell 2019). I contributed to all sections of the chapter, but not as the lead. Henriette Langstrup was in charge of the communication with the book editors and the revision of the final version of the chapter.

In addition to the above-described publications the following peer-reviewed publications were written with the empirical material that grounds this dissertation, without being included in the dissertation:

Jansky, B. and Woll, S. 2019. The Coded Pancreas: Motivations for Implementing and Using a Do-It-Yourself Medical Technology in Type 1 Diabetes Self-Care. Conference Proceedings of the STS Conference Graz 2019, Critical Issues in Science, Technology and Society Studies, Graz, A, 06.-07.05.2019. Hrsg.: G. Getzinger, 205–224, Verlag der Technischen Universität Graz, Graz, A. doi:10.3217/978-3-85125-668-0 [reason for exclusion: Conference proceeding, and written with another PhD Candidate]

Jansky, B.; Hendl, T. and Nocanda, A.Z. 2023. Patient-led innovation and global health justice: Ethical and societal aspects of open-source mHealth in Type 1 Diabetes. Bioethics DOI: 10.1111/bioe.13205 [reason for exclusion: medical ethics article, and written with another PhD Candidate]

Bubeck, M. and **Jansky, B.** 2023. Relational und Dimensional: Heuristische Dimensionen in der Situationsanalyse am Beispiel von Care-Praktiken und deren Materialität. Forum Qualitative Sozialforschung DOI: https://doi.org/10.17169/fqs-24.2.4079 [reason for exclusion: written in German, and with another PhD Candidate]

The following academic presentations are part of this dissertation:

Jansky, B. Patient Knowledge Digitized - Open-source Closed-loop Systems in Type 1 Diabetes Self-care And Practices Of Knowing in On- And Offline Patient Communities [Conhecimento do Paciente Digitalizado - Sistemas de circuito fechado de código aberto em Diabetes Tipo 1 Self-care e Práticas de Conhecimento em Comunidades de Pacientes On- and Offline]. Society for Social Studies of Science (4S)/ESOCITE Meeting, Cholula, Mexico, December 7 - 10, 2022.

Jansky, B. and Hendl, T.: Patient activism in mHealth: by whom and for whom? with a comment by Azakhiwe Nocanda: The invisibility of racialized people in health activism. The Ethics of mHealth as a global phenomenon, Foundation Brocher, Geneva, 27-28. October, 2021.

Jansky, B. and Langstrup, H.: Device Activism and the continuum of material participation in Healthcare. British Sociology Association. Medical Sociology Month, 24. September 2021.

Jansky, B. and Langstrup, H.: Device Activism and the continuum of material participation in Healthcare. Chronic Living Conference, Copenhagen, 4.-6. March 2021.

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Jansky B., Wild V. and Schmietow B.: 2019. "Do-it-Ourselves"-Communities: Wie digitale Diabetestechnologien und soziale Netzwerke das Diabetes Typ 1 Selbstmanagement verändern. Jahrestagung Akademie der Medizinethik, Göttingen, 26.09.-29.09.2019.

Jansky B.: "Device Knowledge – Do-it-yourself Artificial Pancreas Systeme für die Typ 1 Diabetes Therapie und die Produktion von Körperwissen, Zu den neuen sozialen Potenzialen technologisch veränderter Körper", Tagung der Sektion Soziologie des Körpers und des Sports der Deutschen Gesellschaft für Soziologie 2019, Konstanz, 28.–29. November 2019.

Jansky B.: Do-it-Yourself Technologies for Type 1 Diabetes Self-Care and The Transformation of Defined Social Roles, Society of Social Studies of Science (4S) conference, New Orleans, 3.-7. September 2019.

Gehr, B. and **Jansky, B**-: Wer ist hier der Experte? Veränderungen im Arzt-Patienten-Verhältnis durch DIY Technologien. Diabetologisches Zirkeltraining, Schloss Lautrach, 28.06.2019. (Invited by Novo Nordisk and received an honorarium)

Jansky B. and Wild V.: "From Do-it-Yourself to Do-it-Ourselves: Self-care in Type 1 Diabetes therapy as a collective endeavour", The digitally engaged patient Conference, Copenhagen, 11.-12. Juni 2019.

Jansky B.: "Open-source mHealth: development and use of digital do-it-yourself medical and health technologies", 2nd Institute Conference "Wir reflektieren Medizin", Institut für Ethik, Geschichte und Theorie der Medizin, München 21. Mai 2019.

Jansky B., Woll S.: "Code your own pancreas: technology assessment and sociological perspectives on the visions of do-it-yourself artificial pancreas systems in type 1 diabetes therapy", 18th STS Conference Graz 2019 "Critical Issues in Science, Technology and Society Studies", Graz, 6.-7. Mai 2019.

Jansky B.: DIY Diabetes. Exploring the appropriation of glucose monitoring devices in a digital global diabetes community. Appropriating technology conference. Copenhagen, 24-25 September 2018.

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

Abstract

The #WeAreNotWaiting movement is a global digital health phenomenon in which people with diabetes, mainly type 1 diabetes (T1D), engage in the development and usage of open-source closed-loop technology for the improvement of their "chronic living" (Wahlberg et al. 2021). The characteristics of a digitally enabled and technologically engaged global activist patient collective feed into existing narratives of user-led and open-source innovation. They also call for more exploration of what it actually means to be locally involved in this kind of technologically mediated and global form of patient engagement. Building on empirical research conducted in the German healthcare context, we explore the different forms of material participation encountered among a group of people with T1D (who describe themselves as loopers), who are engaged in the development and usage of this open-source technology. Introducing the concept of device activism, we retrace three different device-centered narratives that show how a globally shared concern and political participation through technology use varies with local practices. Hereby we stress that the engagement in the #WeAreNotWaiting movement is both shaped by and is shaping the matters of concerns: devices in, on, and with bodies.

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Digitized Patients: elaborative tinkering and knowledge practices in the open-source Type 1 Diabetes "looper community"

Abstract

In this article, I explore knowledge practices in increasingly digitized, data-driven, and personalized health-care 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. 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.

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Disclosing otherness: Situated Knowledges and the Politics of Ethnographic Approaches to the #WeAreNotWaiting Movement in Type 1 Diabetes and Beyond

Abstract

In this article, I reflect on my empirical engagement in the global (digital) health movement #WeAreNotWaiting in the context of Type 1 Diabetes. I want to take my relationships and interactions in this community as a starting point to discuss the multifacetedness of doing ethnographic research in health-political activist communities while not being affected by the health conditions the research participants are affected by and not sharing their explicit personal-political aim. Building on Donna Haraway's conceptualization of situated knowledge and Kim TallBear's notion of ethics of accountability, I empirically retrace three accounts of disclosing otherness in my empirical engagement that were generative for my understanding of the movement. I suggest that the moments where one needs to explain oneself, where one is met with skepticism, or experiences tensions, might be uncomfortable and challenging but can be generative. To engage with them can contribute to the accountability of the ethnographer.

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Looping for (self)care – personal digital health technology and algorithmic systems

Abstract

In this chapter, we analyze the practices and experiences of people with diabetes who develop, use and share open source, non-regulated “recipes” for automating insulin delivery with personal digital health technology. The algorithmic systems are known as Open Source Artificial Pancreas Systems and the algorithm-enabled activity that these people engage in is often referred to as “looping”. Through empirical accounts from the rich and complex practice of using open source algorithms in diabetes self-management we explore how this concept of looping may hold the potential to critically explore and discuss more general issues related to human-algorithms relations in digital health. We suggest three ways in which looping hold general insights about the potentials for more generous human-algorithm relations. First, looping as an active delegation of control given an existing burden of self-care contingent on the acquisition of new skills; second, looping as a collective and recursive engagement with (material) politics of care and data; and third, looping as the ability to opt out – partly or totally – of toxic intimate entanglement with algorithmic systems and of extractivist algorithmic assemblages.

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Appendix

Deutsche Zusammenfassung

Die vorliegende Dissertation liefert einen Beitrag zur Erforschung von Patient*innenaktivismus zwischen chronischer (self)care und patient*innengeleiteter Innovation. Um diese Besonderheit zum Ausdruck zu bringen, habe ich das Konzept des *Device Activism* eingeführt. Empirisch zeichne ich die Ambivalenzen und Komplexitäten des Lebens mit technischen Geräten im, am und mit dem Körper zur (self)care einer chronischen Erkrankung in zeitgenössischer digitalisierter, technologiegestützter und personalisierter Gesundheitsversorgung nach. Dabei biete ich einen Einblick in die gelebten Erfahrungen von Menschen, die sich aus ihren (self)care Praktiken hervorgehend, aktivistisch und innovativ engagieren. Die Praktiken, die ich empirisch nachgezeichnet habe, zielen immer - auf die eine oder andere Weise - darauf ab, Lösungen für ein besseres "chronisches Leben" mit technischen Geräten, in, an und mit Körpern zu schaffen.

Es handelt sich um eine qualitative empirische Studie in der ich ethnographisch in den Jahren 2018 und 2019 mit und in der Gesundheitsbewegung #WeAreNotWaiting im Kontext von Typ 1 Diabetes (T1D) geforscht habe. Diese Gruppe hat, außerhalb der Standardtherapie, Open-Source-Algorithmen zur Automatisierung ihrer Insulinversorgung entwickelt. T1D ist eine chronische Erkrankung, bei der die Bauchspeicheldrüse kein Insulin produziert und das Hormon deshalb von den Betroffenen selbst verabreicht werden muss. Diese Übernahme der Aufgaben des Pankreas durch die Betroffenen wird durch eine Vielzahl technischer Geräte unterstützt, um so eine die individuelle und manuelle Messung des Blutzuckerspiegels sowie die Verabreichung von Insulin möglich zu machen. Trotz der enormen technischen Entwicklungen in der digitalisierten T1D-Versorgung, beruht die Therapie der chronischen Stoffwechselstörung immer noch auf der Erwartung, dass Personen mit T1D einen Großteil der Therapie selbst übernehmen. Die Looper-Community kritisiert den von ihnen als zu langsam wahrgenommen technologischen Fortschritt in ihrer Gesundheitsversorgung und hat deshalb selbstständig Open-Source-Algorithmen zur Automatisierung erarbeitet, um ein sogenanntes *Closed-Loop*-System für die Insulinzufuhr zu entwickeln.

Der Studie liegt ein heterogenes Datenmaterial zugrunde: Feldnotizen aus teilnehmenden Beobachtungen in 2018 und 2019, 28 problemzentrierte Interviews, sowieso öffentliche Dokumente. Die Interviewten wurden nach der theoretischen Sampling-Strategie der Grounded-Theory-Methodologie (GTM) ausgewählt und orientiert an der GTM und der Situationsanalyse ausgewertet. Erkenntnistheoretisch ist die Arbeit in der Medizinsoziologie, sowie in den medizinischen und feministischen Science and Technology Studies (STS) verortet. Zudem greife ich auf Literatur aus den Disability Studies, Mensch-Maschine Interaktion, Anthropologie, Volkswirtschaftswissenschaften und Data Studies zurück.

Die Dissertation ist als eine kumulative Arbeit von fünf Aufsätzen konzipiert und in diesen leiste ich mehrere Beiträge zur soziologischen Analyse der epistemischen und aktivistischen Praktiken von Menschen, die von chronischen Krankheiten in digitalisierten, technologievermittelten und personalisierten Gesundheitssystemen betroffen sind. Vier dieser Aufsätze sind peer-reviewed alleinstehende Veröffentlichungen. Diese Aufsätze sind in sich geschlossen und beinhalten je eine eigene Einleitung, Theorie- und Methodenteil und ein empirisches Argument. Der fünfte Aufsatz ist als ein Rahmentext geschrieben, er führt zum Thema hin, situiert die anderen Aufsätze in größere soziologische theoretische und empirische Diskussionen und diskutiert abschließend die übergeordneten Hauptergebnisse dieser Dissertation.

Untenstehend die übersetzen Zusammenfassungen der einzelnen Artikel:

Publikation 1: *Device Activism und materielle Teilhabe an und in der Gesundheitsversorgung: Formen des Engagements in der #WeAreNotWaiting-Bewegung für open-source Closed-Loop-Systeme in Typ-1-Diabetes*

Die #WeAreNotWaiting-Bewegung ist ein globales und digitales Gesundheitsphänomen, bei dem sich Menschen mit Diabetes, vor allem Typ-1-Diabetes (T1D), für die Entwicklung und Nutzung von Open-Source-Technologien in Form von Closed-Loop-Lösungen einsetzen, um ihr "chronisches Leben" zu verbessern (Wahlberg et al. 2021). Die Merkmale eines digital befähigten und technologisch engagierten globalen aktivistischen Patient*innenkollektivs fügen sich in bestehende Erzählungen über nutzendengeleitete Open-Source-Innovationen ein. Sie verlangen aber auch nach einer genaueren Untersuchung dessen, was es eigentlich bedeutet, lokal in diese Art von technologisch vermittelter und globaler Form des Patient*innenengagements eingebunden zu sein. Aufbauend auf empirischer Forschung im deutschen Gesundheitskontext untersuchen wir die verschiedenen Formen der materiellen Beteiligung einer Gruppe von Menschen mit T1D (die sich selbst als "Looper" bezeichnen), die an der Entwicklung und Nutzung dieser Open-Source-Technologie beteiligt sind. Wir führen das Konzept des Device Activism ein und zeichnen drei verschiedene device-zentrierte Narrative nach, die zeigen, wie ein global geteiltes Anliegen und die politische Beteiligung durch den Einsatz von Technologie mit lokalen Praktiken variiert. Dabei betonen wir, dass das Engagement in der #WeAreNotWaiting-Bewegung sowohl von den Anliegen geprägt ist als auch diese prägt: Geräte in, an und mit Körpern.

Publikation 2: *Digitalisierte Patient*innen: Elaborative Tinkering und Wissenspraktiken in der Open-Source Typ 1 Diabetes "Looper Community*"

In diesem Artikel beschäftige ich mich mit Wissenspraktiken in zunehmend digitalisierten, datengesteuerten und personalisierten Gesundheitssystemen, indem ich mich empirisch auf die "Looper Community" im Bereich Diabetes Typ 1 konzentriere. Diese Community entwickelt und nutzt Open-Source-Systeme zur automatischen Insulinverabreichung und kritisiert dabei häufig die langsamen Innovationszyklen und Datenmonopole der kommerziellen Gerätehersteller. Ausgehend von der Literatur über Patient*innenwissen argumentiere ich, dass die Analyse dieser Wissenspraktiken an der Schnittstelle von digitalisierter und personalisierter Gesundheitsversorgung, Open-Source-Innovation und Patient*innenaktivismus eine Erweiterung der theoretischen Vorstellungen von Patient*innenwissen erfordert. Empirisch skizziere ich drei Wissenspraktiken: technische, einschließlich Wartungs- und Reparaturarbeiten; rekursive, einschließlich des Aufbaus und der Aufrechterhaltung zusätzlicher Versorgungs- und Unterstützungsstrukturen; und methodologische, einschließlich wissenschaftlicher Formen des Selbstexperimentierens. Ich schlage "elaborative tinkering" als ein Konzept vor, um die Nuancen hervorzuheben, wann und wie die verschiedenen Formen der Wissenspraktiken von Patient*innen ineinandergreifen und wann sie voneinander getrennt werden. Dieser Ansatz bietet neue Begriffe für das Verständnis dessen, was Patient*innenwissen in Bereichen der (chronischen) (self)care, der Innovation und des Aktivismus bedeutet.

Publikation 3: *Anderssein offenlegen: Situiertes Wissen und die Politik ethnografischer Ansätze in der #WeAreNotWaiting-Bewegung bei Typ-1-Diabetes und darüber hinaus*

In diesem Artikel reflektiere ich meine empirische Feldforschung in der globalen (digitalen) Gesundheitsbewegung #WeAreNotWaiting im Kontext von Typ-1-Diabetes (T1D). Ich möchte meine Beziehungen und Interaktionen in dieser Community als Ausgangspunkt nehmen, um die Vielschichtigkeit ethnographischer Forschung in gesundheitspolitischen, aktivistischen Communities zu diskutieren, ohne Teil des Aktivismus zu sein und ohne von den gesundheitlichen Bedingungen betroffen zu sein, von denen die Forschungsteilnehmer*innen betroffen sind. Aufbauend auf Donna Haraways Konzeptualisierung des situierten Wissens und Kim TallBears Begriff der Ethik der Verantwortung zeichne ich empirisch drei Erzählungen über die Offenlegung des Andersseins in meiner Feldforschung nach, die für mein Verständnis der Bewegung förderlich waren. Ich schlage vor, dass die Momente, in denen man sich erklären muss, in denen man auf Skepsis stößt oder Spannungen im "Feld" erfährt, unangenehm und herausfordernd sein können, aber auch generativ wirken können. Sich auf sie einzulassen, kann zur Verantwortlichkeit der Ethnograph*in beitragen.

Zusätzliche Publikation 4: *Looping für (self)care - persönliche digitale Gesundheitstechnologie und algorithmische Systeme*.

In diesem Kapitel analysieren wir die Praktiken und Erfahrungen von Menschen mit Diabetes, die nicht regulierte Open Source "Rezepte" zur Automatisierung der Insulinverabreichung mit persönlicher digitaler Gesundheitstechnologie entwickeln, verwenden und weitergeben. Die algorithmischen Systeme sind als Open Source Artificial Pancreas Systems bekannt, und die algorithmusgestützte Aktivität, die diese Menschen ausüben, wird oft als "looping" bezeichnet. Anhand von empirischen Berichten der vielfältigen und komplexen Praktiken des Einsatzes von Open-Source-Algorithmen im Diabetes-Selbstmanagement ergründen wir, inwiefern dieses Konzept des Loopings das Potenzial hat, allgemeinere Fragen im Zusammenhang mit den Beziehungen zwischen Mensch und Algorithmus in der digitalen Gesundheit kritisch zu untersuchen und zu diskutieren. Wir schlagen drei Aspekte vor, in denen Looping allgemeine Erkenntnisse über die Möglichkeiten einer generativen Mensch-Algorithmus-Beziehung liefert. Erstens: Looping als aktive Delegation von Kontrolle angesichts einer bestehenden Last der (self)care, die vom Erwerb neuer Fähigkeiten abhängt; zweitens: Looping als kollektive und rekursive Auseinandersetzung mit der (materiellen) Politik von Care und Daten; und drittens: Looping als die Möglichkeit, aus der toxischen, intimen Verflechtung mit algorithmischen Systemen und aus extraktivistischen, algorithmischen Assemblagen - teilweise oder ganz - auszusteigen.

Sample overview

Auf Anfrage verfügbar