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

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## 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

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be uncomfortable and challenging but can be generative. To engage with them can contribute to the accountability of the ethnographer.

### **Keywords**

health movements, ethnographic research, situated knowledge, insider-outsider perspective, digital health, ethics of accountability

### **Introduction**

The (empirical) study of social movements, their formation, reproduction, and their collective expressions of values and identities are central research subjects in sociology. Within this body of literature, there is a persistent and growing interest in patient activism and health movements (Epstein 1995; Geiger 2021; Rabeharisoa, Moreira, and Akrich 2014; Wehling, Viehöver, and Koenen 2015). An ethnographic approach to social movements allows researchers to gain an in-depth understanding of “the meanings of movements that would be difficult if not impossible to learn through other methods alone” (Lichterman 1998, 402). Therefore, it is often the methodology of choice to study the complexities, practices, and nuances of engaging in social movements (e.g., Montenegro 2018; O’Donovan, Moreira and Howlett 2013; Roberts et al. 2016). To engage in ethnographic research is however an approach that requires “time, patience, energy, and the willingness to immerse physically, socially, cognitively, and emotionally in others’ lives” (Smith and Atkinson 2017, 637). Ethnography is as much thinking *about* the researched individuals and their everyday lives as it is to be *with* the researched individuals and their everyday lives (Mellander and Wismeg 2016, 3). Working ethnographically blurs boundaries that might be clearer with other research approaches and can complicate them (Han 2010, 10).

“[U]ncertainty about adequate means of describing social realities” (Marcus and Fisher 1986, 8), the worry of betraying the people that opened up their lives to the researchers, how the interlocutors react to potential critical analysis or dealing with one’s sympathy towards the researched community and emotions in empirical inquiries are part of almost all ethnographies (Newkirk 1996; Sheikh 2022; von Bose 2018, 62f; Wong 1998). When the researched field is constantly negotiating solidarity, “taking sides” or outsider research, when engaging with individuals and groups that might be in precarious situations because of their political engagement and that fight for epistemic legitimacy, these issues and the practice of reflecting on what an accountable “ethnographic attitude” (Haraway 1997, 191) can entail within

the engagement in and with health activist communities is crucial and call for particular attentiveness of the ethnographer.

In the following article, I will turn the attention to my empirical engagement in the global (digital) health movement #WeAreNotWaiting in the context of Type 1 Diabetes (T1D). I want to take my relationships and interactions in this health-political motivated 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. In the empirical case, a group of people with T1D and caregivers (the self-described “looper community”) created a semi-automated insulin-delivery system (often referred to as hybrid closed-loop system) in an open-source manner. To engage in this endeavor is described as looping. I experienced and am experiencing tensions, as this is a field where knowledge production is highly politicized, and where there is a discussion about researchers doing research without having first-hand experiences. I had to find a way to navigate these tensions in a generative way, without abandoning my sociological aim, while at the same time being mindful of the difficult situation the researched community is in.

In the social sciences literature on diabetes, scholars often either disclose that they are affected by diabetes themselves (Hess 2017), care for someone with diabetes (Kingod 2018; Mialet 2022), or they do not disclose this information (Kaziunas et al. 2017; Wiedemann 2019). In this article, I explicitly focus on the fact that I do not share the illness-related experience-background and the explicit personal political aim with the people I study. My empirical research was streaked with encounters where I had to disclose and discuss this otherness of not being affected by T1D myself and not sharing the same personal political goals that are related to these illness-related experiences. Now reflecting with some timely distance on what I actually did and comparing it to textbook descriptions of ethnography, I realize that these moments where I had to explain myself, where I was met with reluctance, curiosity, or experienced tensions were actually the moments that are the most generative for my understanding of the activism and the knowledge practices in the #WeAreNotWaiting movement. In what follows, I will use these experiences and engage with Donna Haraway’s (1988) notion of situated knowledge(s) and Kim TallBear’s (2014) conceptualization of ethics of accountability to argue that the focus on these (at times uncomfortable) negotiations, tensions, experiences of refusal and practices of positioning can help to gain a better understanding of the specific forms of knowledge in the studied situation and the emerging knowledge practices. Rather than arguing for a specific way of engaging in ethnographic inquiries when studying health movements, my

aim is to emphasize the importance of accountability when doing qualitative research in a situation where people are actively fighting for epistemic legitimacy and necessary lifesaving care technologies.

## **The #WeAreNotWaiting Movement as “Field Site”: Setting and Methodological Approaches**

An ethnographic “field site” is not a physical place one can enter and leave but rather an analytical device (Marcus 1995). Ethnographers, the researched individuals, spaces, infrastructures, and non-human artifacts co-construct what becomes the researched field (Gupta and Ferguson 1997, 5). Therefore, it may be more suitable to speak of ethnographic research as a cluster of relationships that have to be established between different human and non-human actors, and practices (Amit 2000). My field of study and the object are neither a specific physical location nor a geographically bound community (Jansky and Langstrup 2023). It is a vision of automation through technical devices and the political fight for epistemic legitimization of these innovative care practices, in a healthcare setting where self-responsibility and the burden associated with it are high. The automated devices at center of this vision are also what weaves together the relationships in my ethnographic inquiry.

T1D develops through an autoimmune destruction of the pancreatic insulin-producing cells (Atkinson, Eisenbarth, and Michels 2014). People living with T1D have to measure their glucose levels multiple times a day. In current digitized therapy in the German healthcare context there are at least two technical devices that are significant to individuals with T1D: a continuous glucose monitoring device (CGM) and an insulin pump. However, these two devices are not communicating with each other; to act as an intermediary between these two devices is part of the “chronic homework” (Mattingly, Grøn, and Meinert 2011) of the affected. Being the communication vehicle between these two devices is an error-prone practice and leaves the affected to be alert agents every day of their lives. For over 60 years, researchers, as well as people with T1D have been envisioning how to automate parts of these care practices (Hovorka 2006, 1). With the emergence of mobile digital health technologies, this idea became more attainable (De Vries and Blackman 2020). Some even started to talk about the vision of a “technical cure” (Heinemann 2017, 226). In a hybrid closed-loop system, a pre-programmed control algorithm would enable a CGM device and an insulin pump to communicate. This algorithm makes minor insulin dosages every few minutes to respond automatically to changing glucose concentrations to keep glucose levels in a predefined target range based on the values that a sensor-based glucose monitoring device has registered (Weaver and Hirsch 2018).

Against the backdrop of high self-responsibility and seemingly slow T1D-technology development processes, a group of people with T1D, their carers, and families started to share their frustration on social media under the hashtag #WeAreNotWaiting. In 2014 Dana Lewis, a person with T1D based in the US, and her now husband Scott Leibrand, together with software engineer Ben West (whom they met via Twitter), took this frustration with the lack of the needed T1D technology as a starting point to develop an open-source version of a closed-loop system, sharing their innovation online on social media under the #WeAreNotWaiting hashtag, and with this also initiating a global movement and community, which referred to themselves as *looper community* (Lewis 2019). Loopers were engaging in this open-source endeavor all over the globe, but mainly in the global North (Braune et al. 2021). Using the established structures of peer-to-peer support, which is important for the management of diabetes, they organized regular meet-up groups in order to help each other. In Germany they were referred to as “*Stammtisch*” (the German word for a friendly recurring get-together pointing to the informal nature), which I would soon regularly join—by invitation of Markus, one of the main individuals of reference for me in the community. The members of the German *looper community* were rather covert with their use of their unusual self-care technologies. Elsewhere I describe the #WeAreNotWaiting movement as a form of “*device activism*” (Jansky and Langstrup 2023). The members do not only advocate for change in their care or work from within the medical and device industry to accelerate this change, as it is described for example by concepts such as “*evidence-based activism*” (Rabeharisoa et al. 2014) or “*treatment activism*” (Epstein 1985), rather they developed the necessary technologies themselves. Devices become both the “*matters of concern*” (Latour 2004) and the means through which the movement comes together as a community and movement.

In February 2019, a few members of this global community engaged in the #WeAreNotWaiting movement, from whom a lot also had academic backgrounds, established the OPEN project. This project, funded by an EU grant and situated at different universities, diabetes organizations, and research centers around Europe, Australia and the US, focuses on both generating evidence for the clinical benefits and exploring the social and psychological aspects of the use of the system (O'Donnell et al. 2019). With this project they strive to mainstream the group's efforts, and the community's health-political goals became more apparent. The members of the #WeAreNotWaiting movement did not wait to be invited to participate in a research project as citizen scientists, they used already existing academic structures to create a knowledge base where evidence is produced, with the possibility of formalizing what loopers know. With the OPEN project, the aspiration for epistemic legitimacy materialized.

I did not start out my research by identifying this global movement and its health-political and academic aims as a research site. Instead, in an explorative way, I was interested in what it meant to self-care with an unauthorized automated technology and how the entry of digitized, personalized, and customized technologies changes T1D care practices. My fieldwork was conducted between August 2018 and November 2019. I however find this rather difficult to define. I still observe the practices of the #WeAreNotWaiting movement until today, and still participate at community events. For example, in February 2023 I went to the closing conference of the OPEN project in Berlin and learned a lot about the community. Methodologically, I was 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, Friese, and Washburn 2015) to map out the complex human and non-human relations in the studied situation. To consider the entanglement of local and global (the glocal) dimensions of this movement, I was further inspired by the methodological notion of assemblage ethnography introduced by anthropologist Wahlberg (2018, 2022). This approach acknowledges the significance of local sites and allows the ethnographer to follow connections (local and global ones) that emerge out of the single site (Wahlberg 2018, 196). My ethnographic approach also leads to a heterogeneous data corpus. My sample primarily consists of field notes from participatory observation and ethnographic conversations. To gain more in-depth and diverse insights into different aspects of the looper community, I conducted 28 problem-centered interviews (Reiter and Andreas 2012). To better understand public and broader negotiations, I also included media reports, blog posts, and statements from regulatory bodies in my analysis. Data analysis and gathering were mutually informed by one another, following an iterative logic. Data collected early on in this analysis served as a starting point to direct the theoretical sampling strategy (Clarke, Friese, and Washburn 2015, 101f). Which means that I was “seeking fresh data sources pertinent to a particular theoretical point” (Clarke et al. 2015, 101). For example, I realized that I had only heard “success stories” of people that managed to set up a closed loop system and that were happy with the system. At my “desk” I then read an article by 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 set-up. Through my analysis I was constantly reflecting on my positionality and the limitation of my approach to the experiences of the looper community due to my otherness. The notion of disclosing otherness and the three accounts, that I introduce below, were synthesized from a re-coding of my material with the question in mind what it meant for my research that I do not have lived experiences with T1D.

## **“Nothing About Us, Without Us”: Thinking of Positionality Beyond Insider-Outsider Status**

The slogan “nothing about us, without us,” coined by the disability movement in the 1990s (Charlton 2011, 3), points out how often people with disabilities are othered by only being understood as a research subject in biomedical contexts. Affected people, however, have expertise in living with a disability or health condition, a form of knowledge clinicians do not necessarily have, unless they are also living with a health condition (Richards 2008, 1717). The situatedness of the looper community within these broader discussions about epistemic legitimization is significant for the methodological reflection of conducting ethnographic research in this setting. This emphasis on lived and embodied experiences, as well as the reflection on outsider-research, is also what makes health movements particular in relation to some other social movements, such as for example environmental justice movements. While I do believe the arguments in this article can be applied to other social movement research, this focus on embodiment and outsider-research is particular to health movements and needs to be accounted for from researchers doing ethnographic research in health movement contexts.

The reflection on the politics of my ethnographic approaches to the #WeAreNotWaiting movement, which is shaped by struggles around credibility and legitimization, is inspired and grounded in the work of Donna Haraway (1988), who points out that knowledges and methods are irrevocably situated, located, enacted and positioned, as well as Kim TallBear (2014) who emphasizes the importance of accountability in knowledge production. Discussions on positionality, participatory observation, and co-construction in ethnographic research are important to consider and are highly debated within contemporary ethnography methodology discussions (e.g., Yarbrough 2019 or Sheikh 2022). When conducting ethnographic research, researchers do not look at a phenomenon detached from the outside. Instead, they are positioned participants within their research and, therefore, also need to be part of the ethnographic enquiry (Shore 1999, 45).

Haraway’s (1988) notion of “situated knowledge” gives me a lens through which to look at both the knowledge production in the researched situation and my own knowledge production. Haraway stresses that there is no “God trick” in creating knowledge about the world. Researchers cannot “objectively” explore the world disembodied with a “view from above, from nowhere” (Haraway 1988, 589). Every story told about the world also always reflects on the position of the one telling it. Situated knowledge is a powerful concept to grasp how “knowledge is intrinsically politically and ethically situated in its purposes and positionalities” (Puig de La Bellacasa 2010, 101). In



order to reach “a more adequate, richer, better account of a world” (Haraway 1988, 579), researchers need to carefully attend to power relations in knowledge production and reflect upon the different positions one can take in the world and how these are mirrored in the knowledge they create. Following Haraway (1988, 587) to reflect on my empirical engagement with the looper community, I need(ed) to ask myself: How do I see? Where do I see from? What limits my vision? My ethnographic encounters and my interpretation of the data collected need to be understood as one of many “partial visions” (Haraway 1988, 586) of the phenomenon that is the #WeAreNotWaiting movement.

Haraway introduces the notion of situated knowledge as a response to Harding’s (1986) feminist standpoint theory and emphasizes the significance of a “commitment to mobile positioning” (1988, 585). When we think of multidimensional, partial, and situated knowing subjects in any (ethnographic) encounter, this also means that we are “*therefore* able to join with another, to see together without claiming to be another” (Haraway 1988, 586, italics in original). This idea of partial visions allows for possible alliances with as well as critique of the political aims of the #WeAreNotWaiting, without adopting perspectives of the affected people or fundamentally questioning them (Schramm 2013, 223). Rather, it gives me the tools to acknowledge and be accountable for my situatedness and that my perspectives on the looper community are “located in and produced by sets of partial connections” (Law 2004, 69), and my current analysis of the #WeAreNotWaiting is not complete or finished, but rather constructed and situated.

Thinking with this perspective means there is not one single reality assumed, but rather that “realities may be made and remade” (Law 2004, 69). Adopting this approach to my ethnographic reflectivity then means that it may be less about being an insider or outsider but about how to be accountable to the people in my ethnographic assemblage, who opened up their lives to me and shared their lived experiences. Building on situated knowledge, indigenous feminist science and technology studies (STS) scholar TallBear (2014) argued that rather than thinking about giving back or speaking for the studied communities, researchers should consider their accountability to the researched individuals and communities. The relations we build in our research should not be understood as extractivist for data production. Collecting and producing data about individuals always has a political and normative component. While often in these discussions about the ethics of doing empirical research with and about communities, the advice is to give back, TallBear (2014) points out that “[g]iving back,’ [ . . . ] sounds more akin to standing on two sides of a boundary that parties view as pretty much set” (TallBear 2014, 2). Giving back plays into the idea of a binary notion of

knowledge in the biomedical sphere: researcher and research subject, knowledge producers and those who are resources for knowledge production. TallBear (2014, 2) emphasizes that these boundaries need to be softened in order to democratize knowledge production that can serve “not only those who inquire and their institutions but also those who are inquired upon” (TallBear 2014, 2). In this regard I followed TallBear’s advice to think more creatively in terms of the research process and to understand it more 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). For my specific research practices this meant that I was obtaining feedback and guidance from the community on all levels of the research process. I asked for feedback for my interview guideline, I shared my preliminary findings and was discussing them with members of the community. I also looked for opportunities where I could bring attention to their health political aims or consult the members of the community as experts in my academic work beyond my PhD. For me the idea of being accountable also means that I do not stop being involved and interested in the doings of the looper community now that my PhD research is over.

Thinking about positionality (both mine and of the researched individuals) is significant for conducting mindful research about other people’s experiences. To think beyond insider-outsider binaries and focus on how my knowledge about the looper community was and is constructed and what role positionality and relational entanglement plays is significant for being accountable as an ethnographer.

### **Three Accounts of Generative Disclosure of Otherness in My Research Practice**

In each of the following sections, I will reconstruct experiences from my empirical work where thinking about positionality and situated knowledge(s) became especially crucial. I refer to these moments as disclosing otherness. I start each subsection with an ethnographic vignette that stands as an empirical illustration for one of the practices of disclosing otherness that was significant in my research.

#### ***Epistemic Disclosure: I am From a Medical Ethics Institute, But I am Not an Ethicist***

I have now been going regularly for over half a year to the local meet-up group, and while I am following Spradley’s advice always to disclose that I am a

researcher (Spradley 1979, 58f), it sometimes seems difficult for many of the members to understand where I am coming from, what my interests in the community are and why it could be even interesting for someone not involved to participate at the meetings. So, together with Markus, we decided I could give a small presentation at the next meet-up. While the meetings are usually rather casual, having someone to present is not unusual. I met earlier that day with Markus to go over what I am going to present, and Markus has some questions for me. When we arrive at the venue, we sit down outside and discuss the presentation and Markus's questions. His first question is if I can explain what sociology is because it is difficult to understand and also what the difference to psychology is. After all, I am interested in their individual experiences, so it seems like psychology for him. Furthermore, he mentions that I should explain my institutional setting and the research project I am part of at the medical ethics institute. He also thinks it is important to mention that my results will be publicly accessible to the group. I hadn't even thought of mentioning that. Markus also finds it particularly relevant that I should mention that I have spoken with Dana Lewis.

Now the first people arrive, and we relocate to the inside of the venue, most of them I know already, but there are always some new people. [. . .] Markus comes up to me and tells me that I can prepare myself to start my presentation in 10 minutes. My presentation goes well, my nervousness is not noticeable, which is mainly because I really know most of the people at the two tables already. At the end of the presentation, Markus whispers "Dana Lewis" to me because I almost forgot that he said I should mention that I have talked to her. Dana Lewis has an almost iconic connotation in the community, as she was one of the initial loopers. Hastily, I mentioned that I talked to her, that she even studied something similar to me, and that she gave me a book tip when we talked. After the presentation, I ask if there are any questions, many hands raise up right away. [. . .] The last question comes from Lisa, to whom I talk to every time I am at the looper meet-up, and it throws me off a bit, she asks if I can position myself: "How are you *personally* feeling about looping?". I then say that I do research from the community's perspective and not the clinician's and that this is important to me. Later, Lisa tells me that she asked me her question because she knows that I have a positive attitude towards the community, but she thought it was important that I mention this again very clearly, so everyone knows.

During my empirical research, I experienced many instances where I had to explain my sociological interest in the community, and my own position. In the described situation above, this practice of disclosing my disciplinary background was particularly apparent when Markus for example, says he has no idea what the difference between sociology and psychology might be. This happened later again, when one of the members of the meet-up group referred me to another researcher who she told I was a psychologist. The

above-described situation reveals much more than just the discussion of my academic background with the interlocutors. It points to this practice of what I refer to as “epistemic disclosure.” I was addressed differently by members of the looper community, and different actors positioned me differently. Sometimes I was a sociology PhD student, and they had to explain the medical and technical aspects of their engagement in great detail. In other instances, I was the medical ethicist (because my PhD project is part of a medical ethics research project) who was here to judge, who they sometimes tried to bring on their side to collaborate and other times needed to be kept away from their activities. Looking at the described situation, I can retrace how I had supporters in the community, like Markus or Lisa, who had an interest in ensuring that my research could be carried out successfully. They gave me hints on how I needed to position myself or what I had to mention in order to be perceived in the right way by the community. Being part of the looper community can be a rather precarious situation to be in; Lisa’s question about my opinion on looping illustrates the importance of positioning oneself.

Coming from a medical ethics institute, I was often put in a position that I was there to judge whether or not the system should be used. This meant that I had to disclose that I was not here to ethically evaluate if the practice of looping would entail risks. At the same time, I learned that it was significant to position myself. This disclosure was opposite to what I thought the medical ethics affiliation would give me. I thought coming to these meetups as a researcher from a medical ethics institute from a prestigious university would make my endeavor more legitimate than coming as a sociology PhD student. However, with this, I was put more into the category of legal scholars, as law and ethics are often considered to be related, as they both are concerned with questions of how people ought to live together in society. Even though I, as a sociologist, was interested in the *is* and not the *ought*. At the time of my active empirical engagement, looping was surrounded by legal uncertainty. Questions such as if it is legal to loop or how to disclose to one’s diabetologist that one is looping and if treatment could be refused were significant issues in the researched situation. People were hesitant to talk to me if they knew I was from a medical ethics institute and decided how much they would let me know about their practices. In many other instances, people from the meet-up group would explore the legal and ethical issues surrounding the practices of looping together with me. This fits Mellander and Wiszmeg’s (2016, 13) argument that “[m]uch like the ethnographer, the participants will use the research situation to further explore the world surrounding them, together as well as apart.” For example, I would inquire with one of my colleagues, a legal scholar, about the legality of a practice that one of the participants at the meet-up was engaged in and then report back to the meet-up group. They would then use this information to analyze the situation.

In summary, I had many instances of resistance and alliances with my research project related to my medical ethics affiliation. These negotiations of my epistemic disclosures of being from a medical ethics institute without being an ethicist became a source of analysis for me to map out the (knowledge) legitimation practices of the looper community. The importance of positioning myself, and also that I had supporters, who helped me to navigate this positioning practice, gave me an understanding of the precarious situation some of the loopers were in. My epistemic disclosure of otherness, and the realization that my connection to medical ethics elicited more skepticism than expected, made it clear that the discussions within the looper community at the time of my research were dominated by a great concern for control of their fragile knowledge and innovative technology. It was through the reaction to my institutional affiliation and the ongoing requirement to position myself as being “pro looping” that I was able to comprehend the extent to which the struggle for recognition of their knowledge exists.

### *Bodily Disclosure: I am Not a “Practical Cyborg With T1D”*

We sit at a table, all of us have a drink in front of us, and Tina tells us that she is now using an implanted glucose sensor. Everyone is visibly excited. Tina reveals her upper arm and says: “You can touch my arm and see if you can feel it under the skin.” After the others touched her arm, I also reach out my finger and gently touch the spot on her skin that indicates the sensor. I can’t really grasp that there is a medical device under the skin. From the other table now Anna and her husband Mark come to us, whom I have known since the beginning of my participation and I had already told several times that I myself do not have diabetes, Anna looks at me and asks me “Are you finally looping now?” I look at her in astonishment and now have to disclose in front of everyone that I not only am not looping, but also do not have diabetes. The others laugh and say, “You knew that Anna,” she looks at me confused and says “Oh, I really forgot.”

In ethnographic research, it is emphasized that the body and senses of the ethnographer are a significant source for understanding (Alvarez Astacio 2021), and I could not understand in a bodily sense what it meant to loop, to be reliant on technical devices in, on and with one’s body. I do not have any experience in living with this specific chronic health condition; I was not, as Garfinkel (2021, min 13:39) described it, a “practical cyborg with T1D.” I needed to reflect that knowledge production is, as Haraway (1988) puts it, a “view from a body” (Haraway 1988, 589), so my bodily disconnection was something that I, rather than ignoring it, needed to engage with. Following Hitzler’s (1991) advice to employ the idea of being “stupid as method”

("Dummheit als Methode"), I was there being bodily stupid. He suggests that all the knowledge(s) one can have about a situation from everyday life should be intentionally excluded in order to be as "naïve" as possible in a situation (Hitzler 1991, 287). In my case, I did not have to artificially become "stupid" as I, through my bodily disconnection, had no experience in living with this chronic health condition. I was there to learn what it means for the political and knowledge practices to live with this open-source algorithmic care system.

What I learned from my bodily disclosure was, however, not what I expected. For me, it was a constant inner struggle if I could even study looping without having this shared bodily experience. People in the looper community did not see this as the most significant issue, often forgot, or sometimes even positioned me as more knowledgeable than others without T1D because I dedicated my PhD to this topic. People would explicitly not explain things to me, because I was researching the movement. However, in these encounters, I was also always confronted with a limit. No matter what I did, what I read and how much I asked and observed, I was never able to grasp what it means to live with these devices in, on and with my body as a "practical cyborg with T1D" (Garfinkel 2021, min 13:39). This limit can also be described as a "radical difference" (de la Cadena 2015). Reflecting on her ethnographic research retracing the politics of indigenous people in Peru, Marisol de la Cadena (2015) coined this term to grasp irreconcilable differences in ethnographic encounters. While her ethnography has a very different focus, the idea of "differences as relations" (de la Cadena 2015, 62) fits well with my experiences. Like her, I learned to grasp my bodily disconnect, the radical differences between me and the interlocutors, as a "condition between us that made us aware of our mutual misunderstandings" (de la Cadena 2015, 63). While Marcus (1995) points to the fact that often in prolonged fieldwork, researchers can also become insiders, I could never, because of my bodily disconnect, become a bodily insider. This position of never being able to be a bodily insider then creates certain knowledge(s).

To summarize, in these experiences of bodily disconnect, I felt very uncomfortable, but later in the analysis, I understood that if I engaged with this disconnect rather than ignoring it, I could use this to gain a deeper understanding of the emerging knowledge practices and activism of the loopers. Firstly, I learned to focus on the local, intimate and bodily aspects of this open-source online community. While the community and the engagement were related to the online sphere: sharing source code on open-source platforms, working on algorithms, or engaging in online community building and hashtag activism, with this constant bodily reminder, I could grasp theoretically that being engaged in the #WeAreNotWaiting movement and knowing in this context is

overall a material and bodily practice. Secondly, my realization that my bodily disconnect was not as important to the community as it was to me, and their focus shift to me not sharing their explicit health political goals, made me understand that this is a health political activist group and not just a peer-to-peer support group for an unusual self-care technology and practice.

### *Disclosing Research Objectives: I am Personally (and Bodily) Not Invested in the Activism*

While Anna-Lena and I had a nice chat about her studies on the way to the café and I wasn't too worried that the interview would be difficult because we had already met several times before at the meet-up and had always talked nicely, Anna-Lena was like a changed person from the moment I switched on the recording device. She answered very briefly to the questions and was evasive at many instances. After I turned off the recorder, we started to talk, and she immediately apologized for being so brief in our interview. She starts talking again about my research and about my relationship with the community, that I do not loop myself, and how important it is for the community to be in a good light in the public. I explain to her that I can understand that very well, and I can exclude parts of her interview again if she wants to. She said she would consider that, and that we could also redo the whole interview because she was so "bad." I reassured her that our interview is sufficient for me in any case and that I have learned many new things during our interview. Anna-Lena now asks a bit more about my institutional setting, what exactly I work on and what exactly our research group does, and how I relate to the OPEN project. I tell her that my research group is not part of the OPEN project, but that I am frequently in contact with individual researchers from the group. When I tell her that I have also already spoken several times with one of the project leaders of the OPEN project (who has become a prominent figure in the German-speaking community), she visibly loosens up, and then says: "You know, we just have to make sure, if you would loop yourself now, then everything would look completely different, then we could trust you more." I try to explain to her that I am not interested in studying whether looping is better or worse than conventional forms of therapy, and that I think it is great how many people's lives have become easier with looping. Here Anna-Lena intervenes: "You could write these points down in an article, if you would have had such an article where you write positively about looping, then it would certainly no longer be a problem to find more interview partners." She also pointed out I should really consider joining the OPEN project, that would make things easier for me. Because that is the "official" research project of the community.

The most important disclosure, and the most difficult one for me, was to disclose to the people that I engaged with, epistemically, I wanted something



other than what they wanted. While I have a deep sympathy with the community and their political goals, I am not (and cannot be) invested in the same personal-political and activist ways with my research as the members of the community. I—as stated above—do not have to live with T1D, my health does not rely on the accessibility of therapeutic and lifesaving technologies, and I cannot personally know the burden associated with this chronic health condition. This also leaves me in a different position in relation to the #WeAreNotWaiting movement, as researchers with T1D. While I positioned myself throughout my research and engagement with the looper community in sympathy to their health political aim, I did not start my research with a personal health political goal, and this is significant to reflect upon and needs to be accounted for. The postscript of my interview with Anna-Lena illustrates quite well how my interlocutors often had skepticism towards me because of my other, not necessarily activist, research objectives. Yet, at the same time, the majority of people I encountered during my empirical engagement saw it as important that people did research on the community. Anna-Lena expressed skepticism about my research, while at the same time, she is giving me tips on how I can overcome the skepticism in the community. Similar to how Markus and Lisa helped me navigate my presentation at the looper meet-up and to position me.

As I described above, I do not share the lived experiences of “having” a body with diabetes, and I do not have the shared political goal of fighting for epistemic legitimacy of the unauthorized self-care technology. This became (and still becomes) a topic of disclosure, especially after the OPEN project was formed. While being in contact with researchers involved in the project, and one OPEN researcher co-supervising my PhD, I was not part of the consortium. Gan (2018) points out that relating and relations always “involves becoming attuned to the temporalities of how things hold” (Gan 2018, 106, see also Gan & Tsing 2018). While I started out studying the practices of a community of people with T1D that re-engineered their medical devices in order to better live with a chronic health condition, in a rather unorganized way, in globally spread online and offline communities, I later also engaged with an academic research group working on building an evidence base with and for the community, with a strong health political aim.

I was very open in sharing preliminary findings from my interviews and my ideas for papers. My research and I have been discussed and reflected on by the community, and in a way, it is also part of the legitimization process of the community. I refer to publications from the community and the OPEN project for my work. The community also tried to think of ways to use my research for their purposes. For example, the local meet-up group was interested in my interviews with clinicians, and in another instance, I



helped one of the members of the local meet-up group with my interview material to work on the interface of their online community platform. Here I could make my training as a qualitative sociologist useful, as we were using what my interview participants told me about the accessibility of the online sources as guidance to understand what people wanted from an online community platform and how to make it accessible easier. This means I have become part of the legitimation process through my research. While I was and am sympathetic to the health political goals of the looper community, my conducted research was not aimed at changing health politics. I did not, for example, know what my results would be and if they would be beneficial for fighting for epistemic legitimacy. This means that epistemically, I wanted to know something other than most of my research participants. I do not say it is opposite to their goals, but it is not the same, and this needed constant self-reflection and engagement with people in the community from me.

To summarize, I realized by thinking of my different research goals from the looper community that, first of all I engaged with people who know that they are negotiating knowledge legitimacy and have been themselves studying the very issue at stake. This constant disclosure of my research objectives and the negotiation with the researched people about what I should study and how I should go on about my research helped me later to understand and grasp that the shared concern of the looper community is both developing and using a technology that can automate parts of the self-care as well as change health politics and challenge commercial manufacturers' data monopolies and to challenge the dominant self-care regimens in T1D. This experience helped me to grasp how the technology at the center of the movement was not developed with an individualistic idea in mind, but rather how everyone who is using the system is part of codifying the knowledge that they create and legitimizing the practice of looping in the established healthcare structures. People have a strong sense of unity and solidarity towards the community: this goes from sharing data they generate while looping or testing and evaluating new system features, to establishing an academic research project. This aim of establishing looping as a legitimized form of self-care and building a scientific knowledge base also leads to reluctance and hesitancy to share experiences with researchers who are not necessarily part of the looper community as people could not be sure how I would be using what they shared with me. The looper community was, however, not defined by, what I had thought for a long time, the bodily connection of "having" diabetes, but rather it was more about institutional affiliations, networks and political aims.

## Concluding Reflection

There is a significant closeness involved in ethnography. With this closeness comes a continuous articulation, conceptualization and re-figuration of the relations in the ethnographic network (Mellander and Wismeg 2016, 3). In ethnographic research, the goals, anticipations, hopes and perceptions of both the researcher and the researched may increasingly be entangled. An “ethnographic attitude” (Haraway 1997, 191) then is to be accountable and mindful, it “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). In a space that is as politicized as the #WeAreNotWaiting movement and where people are in precarious situations because of their engagement, reflecting upon one’s accountability becomes crucial.

Explicitly writing about uncomfortable moments and doubt can serve as productive on two levels. Firstly, retracing these situations of disclosing otherness is generative for a deeper understanding of the knowledge practices and the activism of the studied health movement. In my specific case, I also became part of the network around this vision and health-political fight for automation of self-care practices in T1D. My sociological engagement with the community, giving academic presentations about looping and writing academic articles also all contributed to legitimizing the practice. At the same time, I refer to and build on their scientific engagement in my research. Only by shifting the focus to these practices, I could later understand that the knowledges of loopers and the looper community is generated in those exchanges with people that study the community and the technology and not preceding it. This means that the points where it is unclear, where one’s own understanding of one’s position and where legitimacies have been at stake can also be the moments where significant knowledge about the studied community is created. Secondly, with writing this article, and focusing on these practices of disclosure of otherness, the negotiations of what the members of the community deemed as important for my research, the skepticism, and the boundaries that were set with me by the community, I want to be held accountable for my research. This begins by constantly reflecting and recognizing that I am writing and engaging with a group of people living with a chronic health condition (which I cannot bodily grasp), struggling for necessary life-saving care technologies but also defending epistemic legitimacy for their practices. Following TallBear’s (2014, 2) suggestion throughout my research, I articulated overlapping intellectual, ethical and institutional ideas while at the same time being critically engaged and producing (sociological) knowledge about the engagement in the looper community. What is significant and

essential to reflect on is that no research is done at a distance. It is always “based on the lives and knowledge priorities of subjects [and this] helps open up one’s mind to working in non-standard ways” (TallBear 2014, 6). I (even though I had little overlap with lived experiences) chose “to study a community in whose projects I could be invested” (TallBear 2014, 5), I had however not the same bodily and personal political aim to my research. Part of my accountability as ethnographer is that I continue to be invested in the doings of the #WeAreNotWaiting movement. Not with a “giving back” mindset but with a humble attitude of wanting to further learn from the experiences of this community and collaborate. Studying communities where one is not bodily or actively invested should be accompanied by a constant reflection on one’s accountability rather than just using the notion of insider versus outsider to set boundaries of what one thinks they are entitled to study and what they are not. Law (2021, 3; and Law and Lin 2020) just recently reminded us by conceptualizing the notion of “care-ful” research that in conducting (empirical) social sciences, researchers should be aiming for “care-ful research [that] is sensitive to changing exigencies, concerns, tensions and forms of othering. It is, yes, uncomfortable. But it is slow, it is iterative, it is modest, and it tries to find ways of holding things together for a moment” (Law 2021, 3).

I end this article by emphasizing that when studying communities and movements where the researchers are not sharing the illness-related background with the communities, it is crucial to think of how this otherness can be generative and to not hide the negotiations, tensions and participant’s reluctance, refusal or skepticism in their writing about their (research) experiences. These are difficult discussions, but they are worthwhile, as ethnographic approaches to health movements can help to understand “often taken-for-granted meanings of activism” (Litcherman 1998, 402). Within these discussions, we should understand ethnography as “a way of remaining mindful and accountable” (Haraway 1997, 191). After all, as ethnographers, we engage with the lives, hopes, and visions of the people we study, which is why we should be accountable for our research, especially when we are not necessarily part of the researched group. In this article, I cannot give a concrete answer to how and if one should study health movements they are not a part of. Rather I reflected upon the uncomfortable moments in my empirical engagement in order to inspire others to do the same. While I situate my study in the context of health movements, and especially answer to their specific characteristics, the insights of this article may also be helpful for other social movement researchers reflecting on their “otherness.” How focusing on disclosures of otherness as forms of being accountable can unfold in different research settings calls for more methodological engagement within the qualitative research community.

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