Reconstructing Intimate Contexts through Data Donation

A Case Study in Menstrual Tracking Technologies

Gomez Ortega, A.; Bourgeois, J.; Kortuem, G.W.

DOI
10.1145/3546155.3546646

Publication date
2022

Document Version
Final published version

Published in
Participative Computing for Sustainable Futures - Proceedings of the 12th Nordic Conference on Human-Computer Interaction, NordiCHI 2022

Reconstructing Intimate Contexts through Data Donation: A Case Study in Menstrual Tracking Technologies

Alejandra Gómez Ortega
Delft University of Technology
Delft, The Netherlands
a.gomezortega@tudelft.nl

Jacky Bourgeois
Delft University of Technology
Delft, The Netherlands
j.bourgeois@tudelft.nl

Gerd Kortuem
Delft University of Technology
Delft, The Netherlands
g.w.kortuem@tudelft.nl

ABSTRACT

Ubiquitous wearable and mobile technologies generate vast amounts of data from sensors and self-logging applications. This data creates opportunities to better understand people's behavior and inform research on intimate topics such as menstruation. However, in design and HCI research, reconstructing the context in which data was collected and understanding the lived experience behind the data often requires the *active* participation of people. In this paper, we augment the concept of data donation beyond *data collection* to explore the possibilities of actively engaging data donors in the (intimate) interpretation of their data. Specifically, we define and implement a menstrual logs *data donation journey*. We received data sets from 35 donors over five weeks, 13 of whom participated in reconstructing the context of their data. We translate our experience into a conceptualization of designerly data donation around the data, data donors, and data receivers, which we discuss along with its implications.

CCS CONCEPTS

• **Human-centered computing → HCI theory, concepts and models**.

KEYWORDS

Data Donation; Personal Data; Intimate Data; Data-Centric Design; Menstrual Tracking; Self-Tracking;

ACM Reference Format:
Alejandra Gómez Ortega, Jacky Bourgeois, and Gerd Kortuem. 2022. Reconstructing Intimate Contexts through Data Donation: A Case Study in Menstrual Tracking Technologies. In *Nordic Human-Computer Interaction Conference (NordiCHI '22), October 8–12, 2022, Aarhus, Denmark*. ACM, New York, NY, USA, 12 pages. https://doi.org/10.1145/3546155.3546646

1 INTRODUCTION

Mobile and Internet of Things technologies have facilitated the continuous generation of data that captures people's behavior. Behavioral data comprises data from sensors (e.g., acceleration, heart rate) and self-reporting apps (e.g., food intake, mood). Design and HCI researchers leverage this data to discover unique insights together with those whose behavior and experiences are captured by the data. This results in methods that combine spatio-temporal insights from data with nuanced and detailed descriptions from people, such as Participatory Data Analysis [12], Data-Enabled Design [7], articulation work [52], and real-time contextual inquiry [30]. In this way, design and HCI researchers gain new perspectives enabling a deeper understanding of the experiences and needs of people even remotely and in-the-wild. Common to the methods described above are (1) the active role of people, experts of their own experiences [47], in reconstructing the context of the data, and (2) the role of probes or prototypes in collecting data (e.g., 'smart meter' [12], 'sensor sleeve' [7], 'platform for capturing data' [52], and 'sensorized Bluetooth speaker' [31]).

However, developing probes and prototypes that collect behavioral data is expensive, effort-intensive [31], and represents a challenge, especially for novice designers and researchers [39]. It underscores the importance of reducing the need for functional and robust prototypes at the early stage of research and facilitate the use of behavioral data throughout the process. Thus, it creates an opportunity to use behavioral data that is available in other ways. We explore this through data donation – an approach to data collection that proposes to reuse data collected by devices that people interact with daily. So far, data donation relies on anonymous data at scale, where donors play no active role in interpreting their data. Hence, adopting data donation in design and HCI research entails a shift, from people who *actively* consent to transfer their data to people who, in addition, *actively* participate in reconstructing its context. Yet, this shift could increase the challenge of recruiting donors. Kwon and colleagues discussed the sensibilities around potentially sharing intimate data (from a connected shower) and concluded that people would willingly share *abstract* and *anonymized* data [38]. Yet, people might be less willing to reveal or discuss the practices and behaviors behind the data that emerge through reconstructing the context.

In this paper, we explore how reconstructing the context of the data can be integrated into data donation. We investigate the following research question: **How can design and HCI researchers actively engage data donors in reconstructing the (intimate) context of their data?** Specifically, we aim to understand: **(1)** What influences donors willingness to reconstruct the (intimate) context of their data? **(2)** What are the characteristics of data obtained and contextualized through data donation? **(3)** What is the role of designers and HCI researchers in enabling data donation and contextualization? To do this, we define and implement a *data donation journey* grounded in the context of menstrual tracking, concretely the app Clue. To demonstrate the feasibility of our approach, we execute the *data donation journey* by reaching out, receiving data, and reconstructing the context of the data. Based on insights

NordiCHI '22, October 8–12, 2022, Aarhus, Denmark

ACM ISBN 978-1-4503-9699-8/22/10.
https://doi.org/10.1145/3546155.3546646

gained through this process, we outline *designerly data donation* around the *data*, *data donors*, and *data receivers*. In addition, we provide recommendations for approaching *designerly data donation*, and we propose three design principles: *transparency*, *autonomy*, and *awareness*. In the remaining of this paper, we introduce the bodies of work that inform our research approach (Section 2). We describe the process of defining and executing the *data donation journey* (Section 3). We report on how we received diverse data sets from 35 donors and reconstructed the context for 13 of them (Section 4). Finally, we reflect on our experience and discuss our findings (Section 5).

2 BACKGROUND

2.1 Reconstructing the Context of the Data

Behavioral data is used in (design) research to understand people's behavior, characteristics, and experiences. Although it is a valuable material for (design) research, potential shortcomings could emerge when it is considered outside of its context or prioritized over the lived experience and knowledge of those behind it [21]. Recently, design and HCI researchers have called attention to the limits of behavioral data alone and highlighted the negative impact of not involving people in the interpretation and sense-making of data, leading to misinterpretation and superficial or incomplete insights [52]. Still, behavioral data provides valuable and situated insights that would not otherwise be available [7, 12]. It provides opportunities to augment data that is Big (and Thin) with Thick insights [8]. For this reason, designers and researchers have been developing methods to harness behavioral data, where reconstructing the context of the data is critical [31, 36, 52, 54]. Although these methods have great potential, in practice, they represent a challenge, especially for novice designers and researchers [31, 39]. Since they often involve building probes and prototypes or adapting existing devices to collect data, these activities are expensive, and effort-intensive [31]. The significant effort represents a high risk and is rarely affordable, especially at the early stages of research where the focus is on exploration, carrying unknowns about the data, the processing, and the potential outcomes [10]. In addition, collecting and reconstructing the context of (personal) behavioral data is subject to regulations and privacy considerations to be considered and addressed, such as the identification of people and the limits of (fully) informed consent [28, 31].

Concluding. Behavioral data is a valuable material for design and HCI research. The active involvement of participants in reconstructing the context of the data is key. Collecting behavioral data involves building probes and prototypes, which is often challenging. We aim to address this challenge by postponing or eliminating the need for prototyping, aiming for data that can be re used through data donation.

2.2 Data Donation

Data donation is the act of a person *actively consenting* to donate, or transfer, their personal data for research [48]. Through data donation, people exercise their autonomy and sovereignty by granting control over their (personal) data and deciding where it goes, who has access to it, and what can be done with it [34]. Recent changes in data sharing and privacy policies, such as the General Data Protection Regulation (GDPR) in Europe, enable data donation. It has been approached primarily in the healthcare domain [27]. Recent applications include the Corona-Data-Donation-App by the Robert Koch Institute in Germany, where donors could share data from fitness trackers and smartwatches to understand better the spread of COVID-19 [20, 46]. And the COVID-RED project from the Julius Center in The Netherlands, collecting data from wearable devices with a similar approach and objectives [35]. Outside of the health domain, recent applications have been made in the fields of data science, and data journalism [1, 42]. For example, in the DataSkop project by AlgorithmWatch, donors could help researchers and journalists investigate YouTube recommendations during Germany's election campaign by donating their recommendation logs [1]. In these fields, data donation is approached at large scales to obtain Big (and Thin) *anonymized* data [8]. While donors *actively consent* to donate their data, they don't further interact with the researchers receiving it, for whom data as a standalone material is enough.

Concluding. Data donation proposes to reuse behavioral data. It has been applied primarily in the context of healthcare and recently in data science and data journalism, where the interaction between donors and receivers is limited to the transaction of anonymized data. We aim to approach data donation in a way where (data) donors *actively* consent to transfer their data and *actively* participate in reconstructing the context of their data. Thus, we explore the possibilities to augment the data (Big and Thin) with Thick and situated insights derived through the (non-anonymous) interaction between (data) donors and (data) receivers.

2.3 Menstrual Tracking Technologies

Menstrual tracking technologies are digital technologies that allow people who menstruate to track and monitor their menstrual cycle. These technologies are often embedded into health platforms (e.g., Apple and Google Health, Fitbit) or widespread apps (e.g., Flo, Clue, Eve). Menstrual tracking technologies regularly collect personal and intimate data from their users (e.g., breast tenderness, sexual activity, sleep pattern) [25, 40]. They have been adopted by a wide range of users, with apps like Flo and Clue having 43 and 8 million active users, respectively [18, 23]. Design and HCI research in this area has explored why and how *women* track their menstrual cycles [22], the privacy implications of menstrual tracking and fertility technologies [25, 33, 40], and the design space for menstrual technologies that mediate self-touch and augment self-knowledge [16, 50]. Several shortcomings of menstrual tracking technologies are well documented in the literature. For instance, their gendered design, since these tend to use stereotypically feminine attributes (e.g., pink, flowers) [22]; or the fact that most technologies are built with normative assumptions that cast aside plural bodies, gender, and sexual minorities, as well as people with irregular cycles or reproductive health disorders [16, 17, 22, 25, 33]. Open questions remain about people's regular interaction with these technologies and how the data collected by these could better support its users.

Concluding. We aim to obtain and reconstruct the context of menstrual logs through data donation to explore how to better support people who track their menstrual cycles. We focus on menstrual

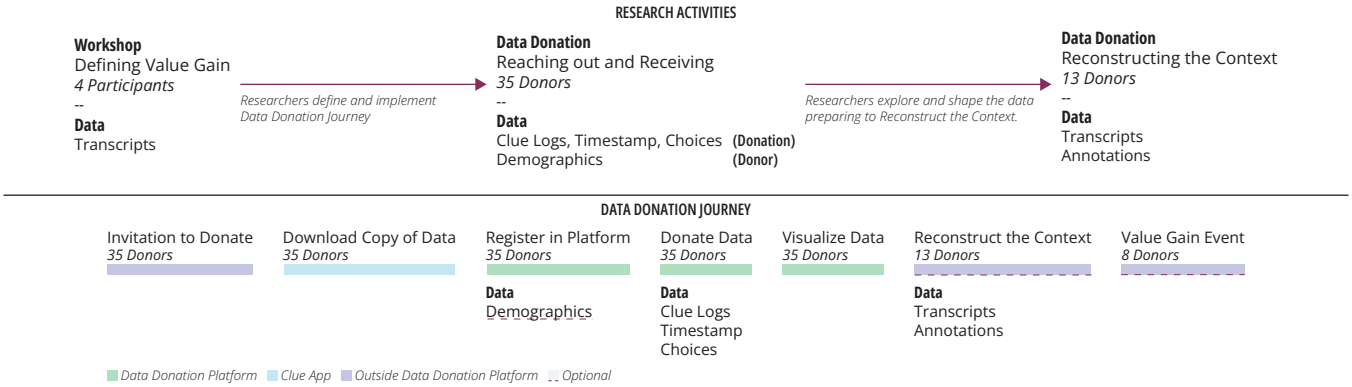


Figure 1: Research activities and resulting data donation journey.

tracking technologies as they collect and store personal and intimate data. Furthermore, since these technologies collect different types of data under the umbrella of menstrual tracking, and their users actively participate in the generation of the data.

3 METHOD

In this paper, we aim to mitigate the challenges of using behavioral data in design and HCI research by leveraging existing data. In this endeavor, we focus on the need to reconstruct the context of the data along with the people whose behavior is captured by it. To achieve this goal, we augment the concept of data donation with the *active* participation from donors. Specifically, we investigate the following research question: **How can design and HCI researchers actively engage data donors in reconstructing the (intimate) context of their data?** To address this research question, we define, implement, and reflect on a *data donation journey* grounded in the context of menstrual tracking – a context with open research and design questions, a need for contextual information, and a clear focus on intimacy. We map this journey along with our research activities in Figure 1. The active participation from donors takes three forms: (1) donors define the terms of their participation, (2) donors actively consent to donate and participate in reconstructing the context of their data, and (3) donors gain value from engaging in data donation.

In this section, we introduce the process of defining the *data donation journey* (Section 3.1). Then, we describe the execution of this journey, involving reaching out and receiving data (Section 3.2) and reconstructing the context of the data (Section 3.3). Through this process, we collect a mix of quantitative and qualitative insights to reflect on the value and limitations of engaging data donors in reconstructing the context of their data. Our institution's Human-Research Ethics Committee and Privacy Team assessed this research along with the data donation platform.

3.1 Defining the Journey

Design Principles: Transparency and Autonomy. The first way that donors actively participate in the *data donation journey* is by defining the terms of their participation. To do so, they must be rightly informed and enabled. Hence, we define two principles that guide the design and implementation of the *data donation journey*:

(1) *Transparency*, relates to the choice of information that is made accessible [51, 53]. Donors should have timely access to intelligible and relevant information on how their data is handled. In this way, they are equipped to make informed decisions from the beginning and over time. We approach it by providing donors with concise and understandable information on how their data will be used and why [11, 41]. We opted for using plain language as well as graphs and diagrams when possible. Additionally, we provide our contact details should donors wish to reach out for additional information.
(2) *Autonomy*, relates to the ability to act [26, 34]. Donors exercise autonomy by inviting others to access and use their data [34, 55]. Donors should have the capacity and the mechanisms to act upon their data by defining their own terms and limitations. We approach it through meaningful choices that allow donors to decide whether to donate, what to donate, and how to participate. In addition, we provide the mechanisms for donors to visualize and manage (e.g., delete) their donations.

These principles are informed by the literature on data donation [6, 37, 55], the ethical challenges posed by the practice of using data [24, 51], and Human-Data Interaction (HDI) [19, 41].

Workshop: Value Gain. To define an engaging *data donation journey*, we explored how to provide value to donors through a generative workshop with four participants, active users of period tracking technologies. The workshop consisted of three activities and lasted 90 minutes. First, we invited participants to reflect individually on their feelings and experiences with menstruation and period tracking technologies. Second, we introduced the concept of data donation and invited participants to envision the timeline of their preferred data donation experience. Finally, we invited the participants to pair up, discuss each other timelines and their preferred ways of gaining value from this experience. The workshop gave us clues on potential value gains relevant to the specific context of menstruation. Beyond the motivation of helping others, broadly contributing to society (e.g., advancing research, raising awareness),

and benefiting from the research outputs, already highlighted in the literature [48], participants expressed the wish for a *community feeling* and *personalized insights and feedback*. We integrate these into the *data donation journey* by organizing a *value gain event* with an expert in reproductive health and sexuality. In doing so, we aimed to create a space for donors to ask questions, learn from the expert and each other, and share experiences. The event took place online in December 2021 and was advertised along with the invitation to donate.

Scope: Clue App. From the plethora of menstrual tracking apps, we decided to focus on the Clue app for practical reasons. Clue users can get a copy of their data by downloading a takeoff file directly from the app. This contrast with other apps from the top five period tracking technologies on the Google and Apple stores in The Netherlands in August, 2021 [4, 29]. Flo's and Eve's users are required to contact the support team to obtain a copy of their data, which complicates the data donation process. In the case of Period Tracker and My Calendar, it is not clear how to obtain a copy of the data from their privacy policy. We are not affiliated with Clue and our research was not conducted in coordination with them. Users of the free version of Clue can log 31 types of data arranged in three groups: (1) single choice categorical data (e.g., *sleep duration:* 0-3 hours, 3-6 hours, 6-9 hours, 9 hours or more, *menstrual bleeding:* light, medium, heavy, spotting), (2) multiple choice categorical data (e.g., *menstrual pain:* cramps, headache, ovulation pain, tender breasts, *sexual activity:* unprotected, protected, high sex drive, withdrawal), (3) manual input (e.g., *weight:* numeric value, *text:* alphanumeric value). Data logged in Clue is stored with a date timestamp with no indication of time (e.g., 2022-09-18T00:00:00).

Prototype: Data Donation Platform. We developed a data donation platform[1] to operationalize the *data donation journey* and collect the donated data and additional information. We are aware that existing platforms, such as Open Humans, allow the sharing of data collected by third parties but these do not yet allow the selection of specific types of data to share, which is critical to implementing the proposed design principles. On the platform, donors can visit the project page where there is information about the project and instructions on how to donate (i.e., downloading/uploading their data from Clue). Donors can register to the platform with an email address and proceed to donate their data. Through the platform, donors are invited to: (1) choose whether to participate in reconstructing the context of the data, (2) choose whether to receive updates from the project, (3) provide their demographic data (i.e., self-reported age and gender), and (4) choose which types of data to donate among the 31 types of data collected by Clue, there is no 'select all' and no options are pre-checked. The availability of this data is subject to the choices made by the donors throughout the process. In addition, donors can explore an interactive visualization of their data, and manage their donations by revoking access to the receivers and deleting their data with the click of a button. Once we receive a donation we collect the following data to reflect on people's engagement and participation: (1) the donation timestamp (i.e., time and date the donation was made), (2) the donor's demographics (i.e., self-reported age and gender), and (3) the choices made by the donor during the process (i.e., whether to participate or receive updates, which (types of) data to donate).

The platform has three open source components that manage (1) the user profiles and authentication, (2) the data storage and sharing, and (3) the donation process. The first two were implemented using TypeScript, and the third was implemented using the Python web framework Django. Data was passed between system components using web APIs.

In the resulting *data donation journey* (Fig. 1), donors receive an invitation to donate. They download a copy of their data from the Clue app and register on the data donation platform, where they can choose to provide demographic information. Then, they select which types of data to donate, donate their data, and can visualize an overview of the data. Finally, they can choose to reconstruct the context of their data and participate in the value gain event.

3.2 Reaching Out and Receiving

To involve participants in the *data donation journey*, we reached out to potential donors and invite them to participate in our research by donating their data. We will use the term *donors* referring to those who took part in the *data donation journey*. We opted for convenience and snowball sampling by using our personal social media, reaching out to existing communities around menstruation, and contacting people and institutions that work around menstruation. In our call to donate, we specified who was conducting the research by stating the name and affiliation of the main researcher, what our goal was, who could participate (i.e., adult active users of the Clue app) and how (i.e., detailed instructions), and the opportunity to take part in the value gain event. Our call was open to donors from all over the world, as Clue is an EU operating company and is GDPR compliant for non-EU citizens, meaning they can also get a copy of their data. We advertised our project for five weeks, from the 15 of October until the 19 of November of 2021. To reflect on our dissemination strategy, we report on the donation timestamps and the choices made by the donors during the journey, specifically which types of data to donate.

3.3 Reconstructing the Context

To reconstruct the context of the donated data, we conducted semi-structured interviews, prompted by the data, with a subset of the donors who agreed to participate in this step. We opted for semi-structured interviews as this is the most common approach in the previous literature [7, 13, 52]. The interviews lasted between 30 and 45 minutes and broadly comprised three activities. First, we invited donors to briefly discuss the highlights of their experience with period tracking technologies. Second, we invited donors to explore, interpret, and reflect upon their data. Third, we invited donors to envision future period tracking technologies that fit their needs. We created interactive data visualizations of the received data to support the interviews. This process helped us develop additional questions in preparation for the interview. We conducted interviews in person (n=2) and via Zoom (n=11). For the in-person setting, we brought data visualizations printed on A3 sheets of paper and interactive data visualizations displayed on a laptop. For the online

[1]Data donation platform: demo in supplementary material, working prototype and data storage and sharing source code.

setting, we used the whiteboard tool Miro. The interviews were conducted in English (n=8) and Spanish (n=5), depending on the preferences of the donors since these are languages with which the authors are familiar. The interviews were audio-recorded and transcribed using MS Office 365 and the transcripts were reflexively thematically analysed using ATLAS.ti [14, 15].

4 RESULTS

4.1 Donors

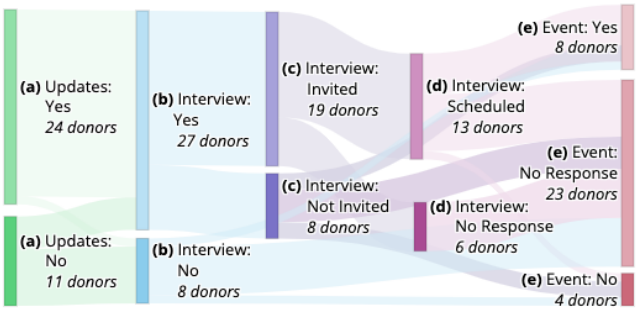


Figure 2: Preferences of the donors (35) throughout the data donation journey. From left to right: (a) receiving updates from the project, (b) participating in interview, (c) receiving an invitation to schedule the interview, (d) scheduling the interview, and (e) attending the value gain event.

In total 35 donors (D1-35), aged 19 to 44 (mean: 30.0, median: 29, 2 did not provide age data), contributed to our project by donating their data (Fig. 2). Out of these, 33 identified as female, one identified as non-binary, and one did not provide gender data. 27 donors indicated that they wanted to participate in the interview. We invited the first 19 to schedule the interview at their convenience, we did not send an invitation to the rest (8) due to limited availability on our side. Ultimately, 13 donors, aged 20 to 36 (mean: 28.8, median: 29) identified as female, scheduled an interview. They were spread across eight countries: Argentina, Brazil, Canada, Colombia, Germany, The Netherlands, Portugal, and The United States. In addition, 8 donors accepted the invitation to participate in the value gain event. Most of the donors (27) did not participate in the value gain event, four responded to our invitation mentioning that they had other commitments.

4.2 Reaching Out and Receiving

Reaching Out: Call to Donate. We distributed our call to donate across different channels, including our personal social media (i.e., LinkedIn and Twitter), online communities (i.e., subreddits r/ Menstruation and r/ MenstruationStation, Get a Clue a Facebook group for users of Clue), and by contacting people and institutions that work on menstruation and related topics. Some of our efforts were unsuccessful, for example, moderators on one subreddit did not approve our request to post the message, while on another, our post was deemed *spam* and removed minutes later. Similarly, some of the people and companies we contacted did not respond or were hesitant to share our message with their community. For instance,

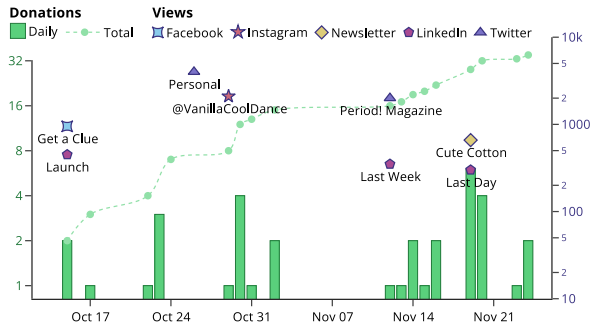


Figure 3: Daily donations over time, derived from the timestamp of the donations, and estimated views of the invitation to donate on different channels.

Clue abstained from sharing it as *"it may be confusing to their users"*. Those who agreed to share our message include social media influencer @VanillaCoolDance, the Period! magazine, and the company of menstrual products Cute Cotton, all three based in the Netherlands. Figure 3 provides an overview of the donations we received over time as well as the estimated views of our invitation throughout the different channels it was advertised. For LinkedIn and Twitter, the estimated views correspond to the number of views reported by each platform, re-posts from our personal contacts are not accounted for. While for Facebook, Instagram, and the Cute Cotton Newsletter they were calculated as a percentage of the number of followers or subscribers. In total, our invitation to donate had an estimated of 8.000 views. Our efforts were more successful (i.e., more people donated their data) when the invitation was shared with existing communities by their members (e.g., @VanillaCoolDance, Cute Cotton), followed by when the call was shared with our personal network. This is consistent with the research of Skatova and colleagues, which highlights that familiarity and trustworthiness with the data receivers can influence the decision to donate [48]. Having established members of existing communities as intermediaries facilitates building trust and familiarity, while using our personal social media means the request was seen and shared by people who are already familiar with us, our research, and our institution. In contrast, our efforts were the least successful (i.e., fewer people donated their data) when we tried to personally share the invitation with existing online communities (e.g., subreddits, Get a Clue). For instance, in the Get a Clue community no one engaged with our post.

Receiving: Data Donations. Donors could choose which types of data to donate, by manually selecting each one on the data donation platform, there was no 'select all' option. 17 donors selected all types of data upon donation while 18 made a specific selection (Fig. 4). Out of these, 6 donated only their menstrual bleeding, 3 their menstrual bleeding, menstrual fluid and menstrual pain, while the rest made a different range of choices including up to 15 types of data. The datasets we received have unique characteristics that result from data donation. First, different temporal ranges and go back in time for months and even years. From the date where donors first logged their data into the Clue app, different for everyone, to the date

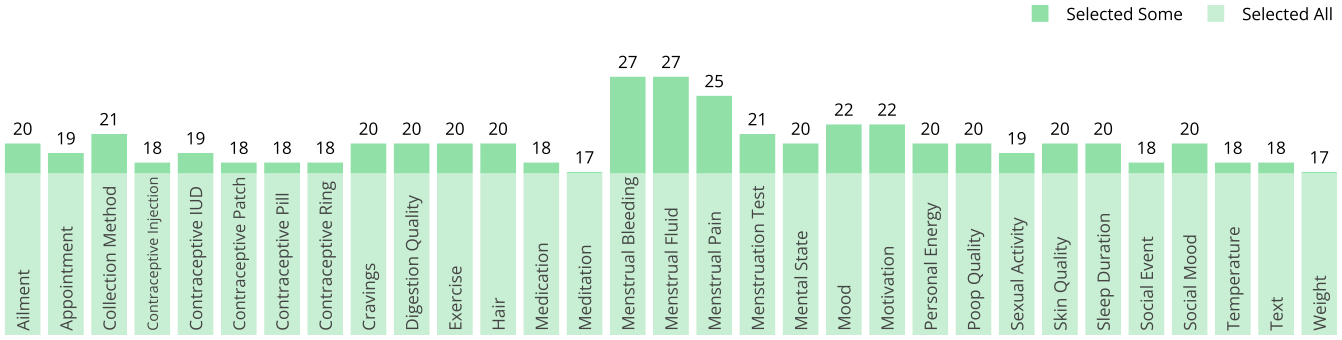


Figure 4: Selections made by the donors at the time of donation for each type of data.

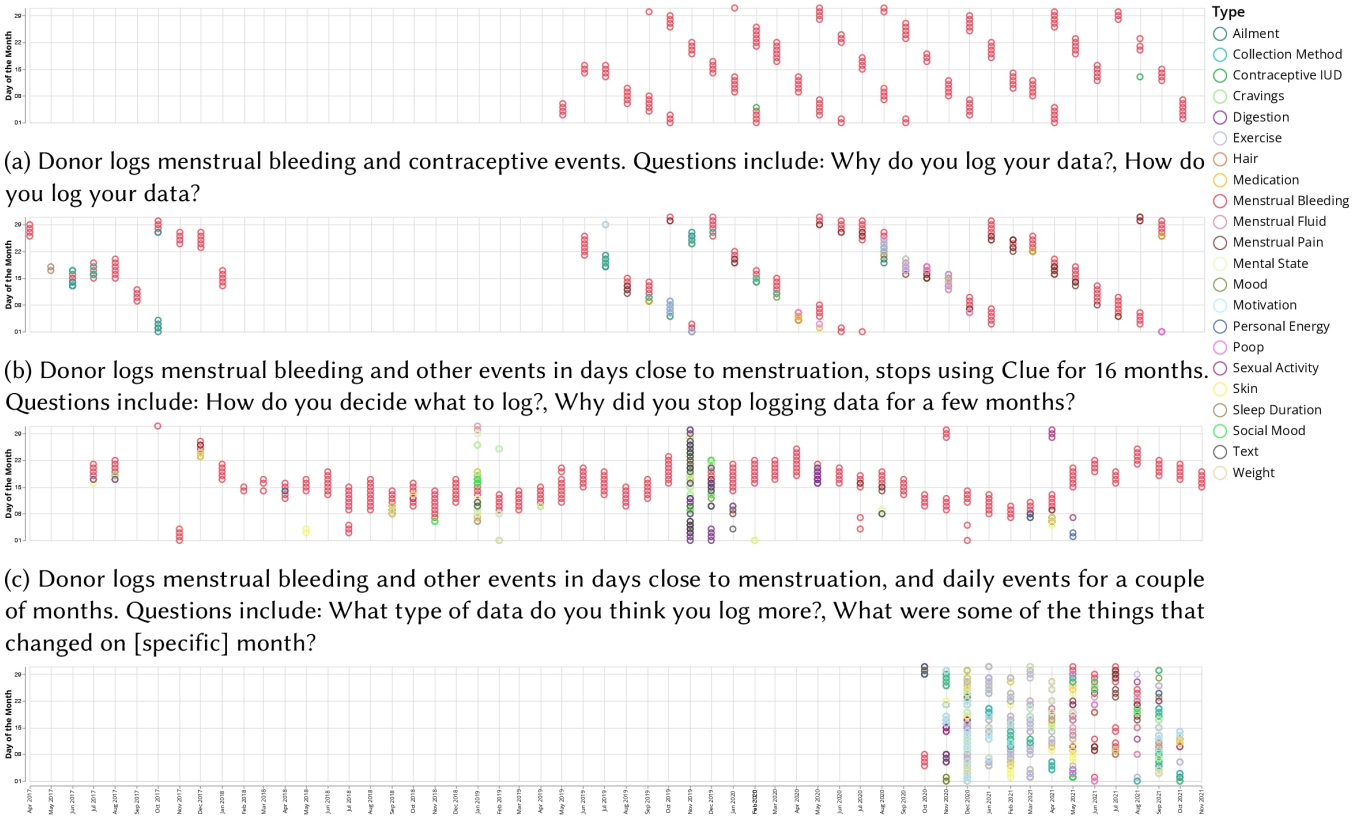
of donation. It leads to the availability of data over an extended period of time without having to conduct a longitudinal study. The earliest starting date dates to mid-2015, while the latest one dates to mid-2021. Second, the data collection is embedded into the donors' routine and is not attached to a research project or a research instrument, thus less prone to observation bias. Third, the datasets contain different types of data because of the selections made by the donors and the unique ways they interact with Clue. In some cases, this meant we didn't have enough information without having to make assumptions or interpretations. For example, one donor donated only the menstrual bleeding and chose not to participate in the interview, leaving us with open questions about the data we did and did not receive. The fact that slightly more than half of the participants made a choice over which data to donate sheds light on the importance of supporting different privacy preferences and adapting to work with the data that is made available. This might be not ideal for designers and researchers, we found it inconvenient in some cases, but it would be an interesting shift towards giving people more control of their data in design and research activities.

4.3 Reconstructing the Context

To support the interviews we used data visualizations. Specifically, we visualize every interaction with the Clue app on a timeline, where the x-axis shows the month and year, and the y-axis shows the day of the month (Fig. 5). If a single interaction is selected, a tooltip shows the type and value of the data point (e.g., *type:* menstrual pain, *value:* tender breasts). We opted for this visualization, as previous research highlights how viewing data as points on a graph arranged by time helps people reason about it [43]. When focusing on specific interactions and patterns, we visualize individual types of data on the timeline by using markers (e.g., *sexual activity:* unprotected, protected, high sex drive, withdrawal) or varying the point size (e.g., *menstrual bleeding:* light, medium, heavy, spotting). In addition, if the donation contains multiple types of data we visualize it on a bar chart to show an overview over time. When visualizing the data we prepare for the corresponding interview, by focusing on specific events or patterns. In addition to introductory questions (e.g., Why did you start using Clue? When do you use Clue?, How did you choose which types of data to track and donate?), we prepare questions informed by the data and specific to each donor. We illustrate this process with four examples in Figure 5.

Donors were positively surprised to see an overview of their data over time which seemed *"more clear"* (D16) and *"say a lot more"* (D15) than the calendar view provided by Clue. During the interviews, we experienced first-hand the value of reconstructing the context of the data, as this allows us to delve into the lived experiences behind it and fill in the gaps. For example, understanding why (and why then) the tracking began, *"I stopped using the the pill in* [date]*, so that's where I really wanted to like track it again"* (D33). Interpreting gaps, *"I've been on and off also trying different methods to actually figure out when my period would come because it's a bit different. But, it's also one of these things I'm doing it for myself so I don't have to be 100%, so it's really useful on and off"*. Explaining changes, *"In* [date] *I was in* [country] *and doing this course with different women and they told me about tracking your cycle so it's more in tune. So then I started tracking* [more aspects]*"* (D29). And managing the intricacies of tracking, *"let's just try to see if my mood has some different changes near [menstruation], but then, I don't know, like on the same day I could be happy, sad, and sensitive"* (D2). In addition, the interviews allowed us to learn about the donation experience from the donor's side. Below, we report on our learnings specific to the donation experience and the contextualized insights on menstrual tracking.

Motivation to Donate. Donors expressed different drivers that led them to contribute to our project. First, contributing to society by helping advance research, as expressed by D29: *"It feels that you're doing something good for overall society and hope it will make a difference"*. There was a consensus among donors on the importance of contributing to research, *"feeling that I'm contributing to research seems cool to me, it seems important to me"* (D5). Some of the donors had previous experiences with research, either by conducting research themselves (D5, D15, D16, D22) or by participating in data-intensive research studies (D8, D29). As described by D8, *"I haven't done this* [data donation]*, but there is like a big health research in* [country]*. So I'm part of that. Which I think is really interesting because they're just kind of tracking you throughout the years"*. Moreover, donors expressed an eagerness to contribute especially to research about women, menstruation, and FemTech, *"even though there is research on medicine or whatever, I feel that we have a large scope to explore how different all women are and we have*



(a) Donor logs menstrual bleeding and contraceptive events. Questions include: Why do you log your data?, How do you log your data?

(b) Donor logs menstrual bleeding and other events in days close to menstruation, stops using Clue for 16 months. Questions include: How do you decide what to log?, Why did you stop logging data for a few months?

(c) Donor logs menstrual bleeding and other events in days close to menstruation, and daily events for a couple of months. Questions include: What type of data do you think you log more?, What were some of the things that changed on [specific] month?

(d) Donor logs daily events. Questions include: Where in your daily routine do you use Clue? How frequently do you look at your data?

Figure 5: Timeline visualization of four donations, each with a different starting date and different types of data.

always seen each other lagged behind in research" (D15). In fact, a second driver was interest in the research topic and the research outcomes, as expressed by D33: *"I learned over time that this is something that has barely been researched like period. In like the big spectrum. So when I saw this I was immediately, like oh, that sounds interesting, I want to participate in this! And it's quite interesting to see what your research will conclude."* Finally, a third driver for those in our personal network was contributing to *our* research, as expressed by D5: *"it is also cool that I know you, you are my friend and I am helping your research"*.

Data Donation Journey. Donors described the *data donation journey* as a positive experience that led to positive feelings, *"it felt nice to be able to donate data because it's free but it can help so much"* (D29). They found the process of downloading and donating their data fairly easy and appreciated the instructions we provided. *"It was actually quite easy because you all described it quite well on how to do it. So for me to actually upload data it was really easy"* (D33). Although some highlighted that without the instructions *"it was not so easy to export the data, it was not so obvious"* (D5). While one donor described the process as a bit burdensome on our end *"I did have some struggles with the website from your university 'cause I had to click like a few times, but then it was surprisingly easy as well"* (D29). The choice of whether or not to donate was straightforward and resulted from a *why not* mindset. Yet, donors had mixed attitudes with respect to sharing their data and privacy. Some *"are not bothered about sharing data"* (D5) and *"didn't even think of it. Just downloaded* [the data] *and put everything up"* (D22). While others expressed higher privacy concerns and thoroughly informed themselves before making the donation, *"I read everything that you wrote about it. So, what you were researching. And also, there was the option to select which data you wanted to donate, and there's a possibility to withdraw at any moment. So yeah, I felt quite comfortable"* (D33). Similarly, donors had mixed feelings about disclosing and discussing their menstrual cycle. Some consider it to be *"private"* (D7) and *"find it a bit uncomfortable to discuss certain topics"* (D16). While others are actively making an effort to discuss these topics *"openly in daily life"* (D22). Overall, donors trusted our approach: *"I feel like you're doing a really good job the way you're going about* [the data donation process]*"* (D8). Our institution: "[the researchers] *are working in a university I attended, and someone that I knew shared* [the call] *so I had no reason to distrust"* (D13). And the data protection regulations in Europe: *"I feel like in Europe in general, universities are quite good at keeping* [data] *well, they do have privacy rules, right? And regulations"* (D22).

Menstrual Tracking Technologies. Similarly to Epstein and colleagues [22], we identified 6 reasons why people track their menstrual cycle with Clue: (1) get predictions about menstruation, (2) gain a better understanding of the menstruating body throughout the cycle, (3) monitor a specific health condition or pain, (4) get pregnant or avoid getting pregnant, (5) inform conversations with healthcare providers that often begin with *"when was your last period?"*, and (6) prepare, avoid accidents, and plan for various life events. In addition, we identified three ways to interact with Clue to track the menstrual cycle, these are complementary and changing throughout life. First, logging menstruation, which is approached in a *"systematic way"* (D16). Most of the donors who interact with Clue in this way expressed logging their data as soon as they menstruate and retroactively logging *"a few days down the line to fill in any blanks"* (D29). In this case, tracking is primarily a means of receiving accurate predictions and it is seen as a *"monthly task"* (D7). Common among the donors is the notion that logging the data is essential to receiving accurate predictions, as expressed by D7: *"what makes it more accurate is that one begins to enter all the monthly information so that it is much more precise"*. Second, logging menstruation and related events. In this case, tracking enables a better understanding of the menstruating body throughout the cycle and facilitates identifying patterns and managing pain. Here, what is logged, apart from menstrual bleeding, varies greatly between and within donors. *"So I usually put the main things that I never forget, like my period and my skin as well because I was having a lot of acne because I stopped the pill. Then menstrual pain and the energy levels and sexual activity of course, because I don't want to get pregnant"* (D4). Within donors, the types of data that are logged tend to change over time due to various factors, including pregnancy, stress, cycle variations, and a new understanding of the cycle events and symptoms, among others. For instance, for D8 logging changed after identifying a pattern in her cycle: *"I think that's the main reason why I stopped tracking that stuff because I was able to figure out it is my period causing this as it is and not some other random thing"*. While changing what to log or reviewing log settings is possible with Clue, it's not made easy for people. In fact, donors expressed not being aware of some features and using other ways to log data that they could have logged with Clue if they knew it was possible. For instance, D4 uses another app to track her weight *"until about two weeks ago I realized that Clue also had* [an option] *for* [tracking] *the weight"*. Third, logging daily events. In this case, tracking is seen as a way to gain a more *"holistic view"* (D16) of the menstruating body throughout the cycle. Similar to the previous interaction pattern, what is tracked varies greatly between and within donors. In this case, tracking is often prompted by a notification from Clue, *"the app reminds me like, can you track your symptoms?"* (D2). Most of the donors engaging in this pattern of interaction expressed that they rarely looked back at their data, for instance D2 *"I just put it there and then don't really look back. I actually don't know how to do it on Clue. Like I don't know there's a way to see like the past things, right?"*. Furthermore, donors often get discouraged and tend to abandon this pattern of interaction over time *"I started tracking* [daily], *but I never actually did it more. Yeah, I guess I was bored of it"* (D29).

5 DISCUSSION

The core objective of this paper is to augment the concept of data donation by harnessing the opportunity of actively engaging data donors in the (intimate) interpretation of their data. Specifically, we aim to understand: **(1)** what influences donors willingness to reconstruct the (intimate) context of their data? **(2)** what are the characteristics of data obtained and contextualized through data donation? **(3)** what is the role of designers and HCI researchers in enabling data donation and contextualization? Over five weeks, we received diverse datasets from 35 donors and reconstructed the context of 13 of them, demonstrating the feasibility of our approach. This number is more than sufficient for data-centric design research projects that are normally conducted with a smaller sample of participants (e.g., 5 to 10) [7, 12, 30]. To the best of our knowledge, our work is the first to integrate contextualization activities into a data donation approach. We anticipated it to be a hurdle as it entails donors being available and willing to discuss topics that might be considered personal and awkward. Hence, we were positively surprised when the majority of donors (27) expressed their willingness to participate in this step, exceeding our planned interview capacity. The attitude of the donors, reflected in their choices, is promising for future data donation projects. Moreover, the flexibility of the material we used for the interviews allowed us to conduct them in-person and remotely. The flexible setup and the possibility to conduct remote research were suitable for the context of the COVID-19 pandemic. Yet, opting for interviews meant that the process was time-consuming, and during the last few weeks of the project it was difficult for us to schedule a meeting with everyone who was willing to do so. Future data donation projects, could benefit from approaches that allow contextualization activities to be carried out remotely and asynchronously.

In this section, we address the research questions by abstracting our experience from the research activities and translating it into a conceptualization of *designerly data donation* around the *data*, *donors*, and *receivers* (Section 5.1). Furthermore, we provide design recommendations for approaching *designerly data donation* (Section 5.2), and propose three design principles: *transparency*, *autonomy*, and *awareness* (Section 5.3).

5.1 Conceptualization: Towards Designerly Data Donation

From the insights derived from this study, we outline *designerly data donation* as a collaborative process that produces *intimate data*, where a donor *intentionally* transfers her personal data to, and might reconstruct the context of her data with, a data receiver, who will use it in a design or research project and is *accountable* for it. Designerly data donation offers designers and researchers the opportunity to *actively* collaborate with donors.

Data: Shaped by the process and fostering intimacy. Data is at the core of data donation and has unique properties that enable and result from the process. First and foremost, data is *personal*, it relates to a person, is partially created by a person, her behavior, her characteristics, and her interactions [44], and is donated and contextualized by a person. Second, data is *dynamic*, spatiotemporal, and changing through people's actions and choices. Donated data

could be from the past, present, and future and could be enriched by reconstructing its context. Third, data is *multiple*, defined by Prainsack as being able to be in more places that one at the same time, and being able to be copied and used by several people at the same time, independent of what the others are doing [44, 45]. Multiplicity enables data donation and allows donors to simultaneously contribute to one or more projects.

Furthermore, we argue that through designerly data donation data is *intimate*. The term 'intimate data' has been used in IxD and HCI to refer to data collected from intimate activities (e.g., sleeping, showering, urinating), or activities whose data might be perceived as *unusual* or *awkward* [3, 38]. Recent work highlights different perspectives and approaches. Kwon and colleagues explore the collection and sense-making of intimate data in the context of showering, where they combine sensor data (e.g., gyroscope, temperature, water flow) with contextual interviews where participants reflected on the data collection [38]. They argue that sensor data is not intimate per se, but it gets intimate connotations by the articulation of shower practices. In the area of bodily care and women's health, often subject to taboos and associated with notions of filth and shame [2], intimacy is deeply rooted into the nature of the experiences and interactions, that are then captured and transformed into data [3, 5, 32, 40]. For instance, Helms reflects on how her own urinating data transforms a bodily experience into something that is sensed or measured [32], and Almeida and colleagues, set out to support and empower body literacy through digital technologies that promote looking at the vagina and harness the *awkwardness* [3]. In the case of menstrual logs, intimacy derives both from the data, depicting a bodily experience, and from reconstructing its context. In this way, designerly data donation produces intimate data, where intimacy is a product of the data itself, depicting a person's behavior and characteristics, and its further contextualization. Moreover, as data gains intimacy while being shaped by a person's behavior and further contextualization, it fosters intimacy between donors and receivers.

Data Donors: Intentionally giving. Data donors are people who knowingly and willingly contribute to a project by donating and actively reconstructing the context of their personal data. In this way, donors *intentionally* contribute to research or design projects in specific contexts. Intentionality is important since it brings to light specific characteristics of the donors, such as their high regard for research in topics they consider relevant [48], and their willingness to participate in research activities [9]. Nonetheless, a variety of factors influence donors' willingness to donate including the type of data being donated, the data donation effort, the way information is presented, the context of the project, familiarity and trustworthiness of data receivers, as well as privacy concerns, as highlighted by previous research [48, 49]. For this reason, even when donors are highly motivated it is fundamental to enable them to define their own privacy preferences [6, 37, 55]. We suggest supporting privacy preferences on an individual and granular level as it might lower the donation threshold for donors with higher privacy concerns who might be hesitant. Besides, donors' privacy preferences could become design research insights themselves.

On the other hand, intentionality means that donors donate their data with underlying expectations over the research process and benefits, and with the hope that an outcome will be achieved. This is reflected in the choices donors made throughout the *data donation journey*, where the majority (24) agreed to receive updates from the project (Fig. 2). Focusing on outcomes is not realistic, especially in design contexts where some projects are open-ended and exploratory. Still, donors' expectations over the process and benefits should be honored within reason. In designerly data donation, where reconstructing the context is part of the process and involves donors' engagement over time, honoring donors' expectations is central in building and maintaining a trusted long-term collaboration resulting in richer and more intimate datasets.

Data Receivers: Driving collaboration through accountability. Data receivers are designers and researchers working on a topic or project that involves personal data who seek the active collaboration of people. Designerly data donation requires them to take on various roles and tasks. For example, considering the needs and wants of donors and defining ways for them to benefit [6, 34, 37, 44], interacting with regulatory bodies (e.g., Human Research Ethics Committees, Institutional Review Boards) to define a process that minimizes risks to donors, and receiving, shaping, and contextualizing the data, where they engage donors in activities of interpretation and sense-making. The last two are already part of design and HCI research activities [11, 28, 31, 54].

Data receivers initiate data donation by inviting potential donors but it is up to donors to carry through [34]. In this way, designerly data donation, and consequently the quality of the data, is reliant on the donors' willingness to donate and reconstruct the context of their personal data. We previously described how donors carry underlying expectations over the data donation process and the outcomes, for the receivers these expectations translate into *accountability*. We suggest data receivers be accountable to donors and regulatory bodies as designerly data donation unfolds. In this case, accountability includes delivering on the expected ways to gain value, informing donors about the process, progress, and limitations, notifying donors in case of data and security breaches, updating donors about the ways they are expected to contribute, and including donors in the final outputs. Thus, data receivers build and maintain a bond with the donors that fosters a feeling of ownership over the process and promotes collaboration.

5.2 Recommendations: Approaching Designerly Data Donation

As part of our research, we conducted several activities that strengthened our understanding of how to approach data donation in design and HCI research. Based on our experience we develop five recommendations for data receivers, designers and researchers.

(1) Donors enable designerly data donation and in doing so facilitate design and research. There are no intermediaries or third parties, donors directly and willingly contribute to a design or research project, as a result, donors should directly gain value and their contributions should be valued. Data receivers should find ways to offer direct and time-bound value to donors. For instance, providing insights obtained from the data or benefits derived from research outputs.

(2) Data receivers should support donors throughout the data donation process. For example, by providing clear instructions on how to donate and making the process as simple as possible. Yet, this process is limited by the data portability alternatives offered by data controllers. Moreover, data receivers should encourage donors to (re)define their privacy preferences even if this might result in less data available.
(3) Data receivers should carefully consider where and how to invite potential data donors. Having members of existing communities as intermediaries facilitate spreading a call to donate, but might hamper diversity and lead to bias.
(4) Data obtained through designerly data donation was collected and generated in-the-wild, where people behave freely, naturally, and even wildly (e.g., in unique and unexpected ways). Data receivers should be prepared to work with datasets that are dynamic, diverse, and reflect this wildness (e.g., unique, incomplete).
(5) Shaping and reconstructing the context of the data obtained through designerly data donation requires data receivers to be flexible and adaptable to multiple contexts (e.g., remote research, in-person research) and (privacy) preferences. In addition to finding suitable ways to visualize the data and communicate with donors through it.

5.3 Design Principles: Developing Designerly Data Donation

The data donation platform was a central element in defining the journey and shaping our approach, and a first effort to translate the principles of *transparency*, and *autonomy* into practice. Based on our experience, we discuss our shortcomings in putting these principles into practice, propose future considerations, and suggest a third principle: *awareness*.

(1) *Transparency*, we aimed to provide donors with access to understandable information on how their personal data is handled by providing clear details up-front. Although not the case of our project, the objectives and ways of handling data can change throughout design research projects that are open and exploratory, meaning transparency should be maintained along the way. Donors should be informed in a timely manner across the process, through reminders and updates that can be adapted to donors' privacy preferences.
(2) *Autonomy*, we facilitated autonomy by allowing donors to decide whether to donate, what to donate, and how to participate. However, during the one-on-one session, we learned that some donors were uncomfortable sharing specific events *"I was a little concerned with* [a data point], *I don't feel as comfortable sharing that and letting others know"* (D16). Donors could choose which types of data to donate, but within each type, they could not choose whether to donate or exclude certain data. Donor autonomy should be supported in an even more granular way. For instance, by facilitating the filtering of specific data points. In addition, we provided the mechanisms for donors to donate their data, revoke access to the researchers and delete their data from the platform. As of April 2022, no donor has revoked access to the researchers or deleted their data from the platform. Similarly, in traditional design research participants seldom withdraw. As design researchers, and data receivers, we shall become more proactive towards helping people exercise their autonomy and reassess the terms of their participation. Beyond providing the mechanisms, supporting the process, and establishing checkpoints.
(3) *Awareness*, across the *data donation journey*, we failed to provide donors with a way to explore their data before making a donation. Due to the multiple ways in which data can be collected and generated (e.g., manual self-reporting, automated logging or sensing), people may have an active or passive role in the process and may be more or less aware of what the data contains. Besides, most data controllers give users a JSON takeout file with their data, and these files are not easily explored by people without a technical background. There is an opportunity to better support donors understand what is on these files, resulting in a better-informed decision. Donors should have the capacity and the mechanisms to explore the content of their data before making a donation. For instance, by visualizing and exploring the data before donors make a decision to donate.

We are aware that the design principles entail a trade-off (e.g., more information could be overwhelming, reminders could be annoying, and exploring/filtering datasets could be burdensome) which is why they ought to be adapted to the (privacy) preferences of each donor and the characteristics of the design process.

6 LIMITATIONS AND FUTURE CHALLENGES

Our research provides preliminary evidence on the feasibility of actively reconstructing the context of the data with donors. Yet, there are limitations to this approach. First, our research is grounded and limited by the specific context of menstrual tracking. Future research should explore design research projects with different data needs, contexts and organizations. Second, there might be limitations in who is able and willing to donate their data. A group of donors might likely be different from one recruited through different means or responding to different incentives (e.g., money, rewards). Similarly, our study was limited by the people who could donate their data, the framing and channels we used to disseminate our call to donate, and the types of data we requested. Future research should investigate how these factors influence the willingness to donate and the overall quality of the data. Third, designerly data donation relies on data controllers making data available to donors, which can take up to 30 days and may be limited by local regulations. Future data donation research should align with data controllers and regulators to find more effective ways for people to donate their data. Furthermore, donors are expected to have a certain level of technical literacy, so they can obtain a copy of their data. Due to the nature of our study, we missed the opportunity to identify what led people *not* to donate their data and who these people are. Future research should account for non-donors and their potential impact on the data donation process and the resulting data (e.g., selection bias). Moreover, future research could account for scenarios where data is collected or generated by shared artifacts (e.g., smart assistants in a common room) and could be donated by one or more people (e.g., family members, roommates).

7 CONCLUSION

In this paper, we explored how to approach data donation in a way where people play an *active* role in reconstructing the context of the donated data, in addition to *actively* consenting to transfer their data. To do this, we defined and implemented a *data donation journey* grounded in the context of menstrual tracking, concretely the app Clue. We executed our data donation approach by reaching out, receiving data and reconstructing the context of the data. Through this process, we received, over the course of 5 weeks, 35 donations of diverse datasets, 13 of which were contextualized with the donors, demonstrating the feasibility of our data donation approach. To the best of our knowledge, our work is the first to integrate contextualization activities into a data donation process. We reported and reflected on our experience, and we translated it into a conceptualization of *designerly data donation* around the *data*, *data donors*, and *data receivers*. Additionally, we provided design recommendations for approaching designerly data donation, and proposed three design principles: *transparency*, *autonomy*, and *awareness*.

ACKNOWLEDGMENTS

We appreciate the people who donated their data and shared their experiences with us, as well as those who shared our call for their immense contribution to this research. We thank the reviewers for their thoughtful and valuable feedback and Carlo van der Valk for his tremendous support.

REFERENCES

[1] Algorithm Watch. 2021. DataSkop: Investigating YouTube's algorithm during Germany's election campaign. https://algorithmwatch.org/en/dataskop-investigating-youtubes-algorithm-during-germanys-election-campaign/

[2] Teresa Almeida, Rob Comber, and Madeline Balaam. 2016. HCI and intimate care as an agenda for change in women's health. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), San Jose, CA, USA, 2599–2611. https://doi.org/10.1145/2858036.2858187

[3] Teresa Almeida, Rob Comber, Gavin Wood, Dean Saraf, and Madeline Balaam. 2016. On looking at the vagina through Labella. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), San Jose, CA, USA, 1810–1821. https://doi.org/10.1145/2858036.2858119

[4] Apple App Store. 2021. Search Result for 'Period Tracker' on Apple App Store. https://www.apple.com/nl/search/Period-Tracker?src=globalnav

[5] Madeline Balaam, Rob Comber, Ed Jenkins, Selina Sutton, and Andrew Garbett. 2015. Feedfinder: A location-mapping mobile application for breastfeeding women. *Conference on Human Factors in Computing Systems - Proceedings* 2015-April (2015), 1709–1718. https://doi.org/10.1145/2702123.2702328

[6] Matthew Bietz, Kevin Patrick, and Cinnamon Bloss. 2019. Data Donation as a Model for Citizen Science Health Research. *Citizen Science: Theory and Practice* 4, 1 (2019), 1–11. https://doi.org/10.5334/cstp.178

[7] Sander Bogers, Joep Frens, Janne Van Kollenburg, Eva Deckers, and Caroline Hummels. 2016. Connected baby bottle: A design case study towards a framework for data-enabled design. In *DIS 2016 - Proceedings of the 2016 ACM Conference on Designing Interactive Systems: Fuse*. Association for Computing Machinery, Inc, New York, NY, USA, 301–311. https://doi.org/10.1145/2901790.2901855

[8] Tobias Bornakke and Brian L. Due. 2018. Big–Thick Blending: A method for mixing analytical insights from big and thick data sources. *Big Data and Society* 5, 1 (2018), 1–16. https://doi.org/10.1177/2053951718765026

[9] Jacky Bourgeois, Stefan Foell, Gerd Kortuem, Blaine A. Price, Janet Van Der Linden, Eiman Y. Elbanhawy, and Christopher Rimmer. 2015. Harvesting green miles from my roof: An investigation into self-sufficient mobility with electric vehicles. In *UbiComp 2015 - Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*. Association for Computing Machinery (ACM), Osaka, Japan, 1065–1076. https://doi.org/10.1145/2750858.2807546

[10] Jacky Bourgeois and Gerd Kortuem. 2019. Towards responsible design with internet of things data. *Proceedings of the International Conference on Engineering Design, ICED* 2019-Augus, AUGUST (2019), 3421–3430. https://doi.org/10.1017/dsi.2019.349

[11] Jacky Bourgeois, Gerd Kortuem, and Fahim Kawsar. 2018. Trusted and GDPR-compliant research with the internet of things. In *ACM International Conference Proceeding Series*. Association for Computing Machinery, New York, NY, USA, 1–8. https://doi.org/10.1145/3277593.3277604

[12] Jacky Bourgeois, Janet Van Der Linden, Gerd Kortuem, Blaine A. Price, and Christopher Rimmer. 2014. Conversations with my washing machine: An in-the-wild study of demand shifting with self-generated energy. In *UbiComp 2014 - Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing*. Association for Computing Machinery, New York, NY, USA, 459–470. https://doi.org/10.1145/2632048.2632106

[13] J. Bourgeois, J. Van Der Linden, G. Kortuem, B. A. Price, and C. Rimmer. 2014. Using participatory data analysis to understand social constraints and opportunities of electricity demand-shifting. In *ICT for Sustainability 2014, ICT4S 2014*. Atlantis Press, Stockholm, Sweden, 392–401. https://doi.org/10.2991/ict4s-14.2014.49

[14] Virginia Braun and Victoria Clarke. 2006. Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101. http://www.tandfonline.com/action/journalInformation?journalCode=uqrp20%5Cnhttp://www.tandfonline.com/action/journalInformation?journalCode=uqrp20

[15] Virginia Braun and Victoria Clarke. 2013. *Successful Qualitative Research. A Practical Guide for Beginners*. SAGE Publications Ltd, London. 400 pages.

[16] Nadia Campo Woytuk, Marie Louise Juul Søndergaard, Marianela Ciolfi Felice, and Madeline Balaam. 2020. Touching and Being in Touch with the Menstruating Body. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), Honolulu, HI, USA, 1–14. https://doi.org/10.1145/3313831.3376471

[17] Shaan Chopra, Rachael Zehrung, and Tamil A. Shanmugam. 2021. Living with uncertainty and stigma: Self-experimentation and support-seeking around polycystic ovary syndrome. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), Yokohama, Japan. https://doi.org/10.1145/3411764.3445706

[18] Clue by Biowink. 2021. Clue: The app to track your period, and so much more. https://helloclue.com/period-tracker-app

[19] Andy Crabtree and Richard Mortier. 2015. Human Data Interaction: Historical Lessons from Social Studies and CSCW. In *ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work*, Nina Boulus-Rodje, Gunnar Ellignsen, Tone Bratteteig, Margunn Aanestad, and Pernille Bjorn (Eds.). Springer International Publishing, Oslo, Norway, 19–23. https://doi.org/10.1007/978-3-319-20499-4

[20] Daniel Diethei and Jasmin Niess. 2021. Sharing heartbeats: Motivations of citizen scientists in times of crises. *Conference on Human Factors in Computing Systems - Proceedings* 2020, April (2021), 15. https://doi.org/10.1145/3411764.3445665

[21] Catherine D'Ignazio and Lauren F. Klein. 2020. *Data Feminism.* MIT Press. 328 pages. https://doi.org/10.7551/mitpress/11805.001.0001

[22] Daniel A. Epstein, Nicole B. Lee, Jennifer H. Kang, Elena Agapie, Jessica Schroeder, Laura R. Pina, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2017. Examining menstrual tracking to inform the design of personal informatics tools. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2017-May. Association for Computing Machinery, Denver, Colorado, USA, 6876–6888. https://doi.org/10.1145/3025453.3025635

[23] Flo Health. 2021. About Flo. https://flo.health/about-flohttps://flo.health/about-flo

[24] Luciano Floridi. 2014. Open Data, Data Protection, and Group Privacy. *Philosophy and Technology* 27, 1 (2014), 1–3. https://doi.org/10.1007/s13347-014-0157-8

[25] Sarah Fox, Noura Howell, Richmond Wong, and Franchesca Spektor. 2019. Vivewell: Speculating near-future menstrual tracking through current data practices. In *DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference*. Association for Computing Machinery (ACM), San Diego, CA, USA, 541–552. https://doi.org/10.1145/3322276.3323695

[26] Batya Friedman and Peter H Kahn. 2002. Human Values, Ethics, and Design. In *The Human-Computer Interaction Handbook: Fundamentals, Evolving Technologies and Emerging Applications*. L. Erlbaum Associates Inc., 1177–1201.

[27] Alejandra Gomez Ortega, Jacky Bourgeois, and Gerd Kortuem. 2021. Towards Designerly Data Donation. In *UbiComp/ISWC 2021 - Adjunct Proceedings of the 2021 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2021 ACM International Symposium on Wearable Computers*. Association for Computing Machinery (ACM), Virtual, 496–501. https://doi.org/10.1145/3460418.3479362

[28] Elizabeth Goodman. 2014. Design and ethics in the era of big data. *Interactions* 21, 3 (2014), 22–24. https://doi.org/10.1145/2598902

[29] Google Play. 2021. Search Result for 'Period Tracker' on Google Play. https://play.google.com/store/apps/collection/cluster?clp=ggEQCg5QZXJpb2QgVHJhY2tlcg%3D%3D:S:ANO1ljK-sJY&gsr=ChOCARAKDlBlcmlvZCBUcmFja2Vy:S:ANO1ljJYGCU

[30] Katerina Gorkovenko, Daniel J Burnett, James Thorp, Daniel Richards, and Dave Murray-Rust. 2019. Supporting Real-Time Contextual Inquiry Through Sensor Data Supporting Real-Time Contextual Inquiry Through Sensor Data. In *Ethnographic Praxis in Industry Conference Proceedings*. Edinburgh, UK, 1–29.

[31] Katerina Gorkovenko, Daniel J Burnett, James K Thorp, Daniel Richards, and Dave Murray-Rust. 2020. Exploring the Future of Data-Driven Product Design. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery, New York, NY, USA, 1–14. https://doi.org/10.1145/3313831.3376560

[32] Karey Helms. 2019. Do you have to pee? A design space for intimate and somatic data. In *DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference*. Association for Computing Machinery (ACM), San Diego, CA, USA, 1209–1222. https://doi.org/10.1145/3322276.3322290

[33] Sarah Homewood. 2018. Designing for the changing body: A feminist exploration of self-tracking technologies. *Conference on Human Factors in Computing Systems - Proceedings* 2018-April (2018), 1–4. https://doi.org/10.1145/3170427.3173031

[34] Patrik Hummel, Matthias Braun, and Peter Dabrock. 2019. *Data Donations as Exercises of Sovereignty*. Vol. 137. Springer International Publishing, Cham. 23–54 pages. https://doi.org/10.1007/978-3-030-04363-6{_}3

[35] Julius Center. 2021. About COVID-RED. https://www.covid-red.eu/en/

[36] Gerd Kortuem, Jacky Bourgeois, Janet Van Der Linden, and Blaine Price. 2014. Participatory data analysis: A new method for investigating human energy practices. *CEUR Workshop Proceedings* 1203 (2014), 32–34.

[37] Jenny Krutzinna, Mariarosaria Taddeo, and Luciano Floridi. 2019. An Ethical Code for Posthumous Medical Data Donation. *Philosophical Studies Series* 137 (2019), 181–195. https://doi.org/10.1007/978-3-030-04363-6{_}12

[38] Hyosun Kwon, Joel Fischer, Martin Flintham, and James Colley. 2018. The Connected Shower: Studying Intimate Data in Everyday Life. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 2, 4 (2018), 1–22. https://doi.org/10.1145/3287054

[39] Jiahao Lu, Alejandra Gomez Ortega, Milene Gonçalves, and Jacky Bourgeois. 2021. the Impact of Data on the Role of Designers and Their Process. *Proceedings of the Design Society* 1, August (2021), 3021–3030. https://doi.org/10.1017/pds.2021.563

[40] Maryam Mehrnezhad and Teresa Almeida. 2021. Caring for intimate data in fertility technologies. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), Yokohama, Japan, 11. https://doi.org/10.1145/3411764.3445132

[41] Richard Mortier, Hamed Haddadi, Tristan Henderson, Derek McAuley, and Jon Crowcroft. 2014. Human-Data Interaction: The Human Face of the Data-Driven Society. *SSRN Electronic Journal* 10 (2014), 1–11. https://doi.org/10.2139/ssrn.2508051

[42] Jakob Ohme, Theo Araujo, Claes H. de Vreese, and Jessica Taylor Piotrowski. 2021. Mobile data donations: Assessing self-report accuracy and sample biases with the iOS Screen Time function. *Mobile Media and Communication* 9, 2 (2021), 293–313. https://doi.org/10.1177/2050157920959106

[43] Dominik Pins, Timo Jakobi, Alexander Boden, Fatemeh Alizadeh, and Volker Wulf. 2021. Alexa, We Need to Talk: A Data Literacy Approach on Voice Assistants. In *DIS 2021 - Proceedings of the 2021 ACM Designing Interactive Systems Conference: Nowhere and Everywhere*. ACM, New York, NY, USA, 495–507. https://doi.org/10.1145/3461778.3462001

[44] Barbara Prainsack. 2019. Data Donation: How to Resist the iLeviathan. *Philosophical Studies Series* 137 (2019), 9–22. https://doi.org/10.1007/978-3-030-04363-6{_}2

[45] Barbara Prainsack. 2019. Logged out: Ownership, exclusion and public value in the digital data and information commons. *Big Data and Society* 6, 1 (2019), 1–15. https://doi.org/10.1177/2053951719829773

[46] Robert Koch Institut. 2020. Corona-Datenspende. https://corona-datenspende.de/science/en/

[47] E Sanders and PJ Stappers. 2008. Co-creation and the new landscapes of design. *CoDesign* 4, 1 (2008), 5–18. https://doi.org/10.1080/15710880701875068

[48] Anya Skatova and James Goulding. 2019. Psychology of personal data donation. *PLoS ONE* 14, 11 (2019), 1–20. https://doi.org/10.1371/journal.pone.0224240

[49] Anya Skatova, Esther Ng, and James Goulding. 2014. Data Donation: Sharing Personal Data for Public Good?. In *Digital Economy All Hands Meeting*. 1–3. https://doi.org/10.13140/2.1.2567.8405

[50] Marie Louise Juul Sondergaard, Marianela Ciolf Felice, and Madeline Balaam. 2021. Designing menstrual technologies with adolescents. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery (ACM), Yokohama, Japan, 14. https://doi.org/10.1145/3411764.3445471

[51] Mariarosaria Taddeo and Luciano Floridi. 2016. What is Data Ethics ? Subject Areas : Author for correspondence :. *Philosophical transactions. Series A* 374(2083):, Dec 28 (2016), 1–5.

[52] Peter Tolmie, Andy Crabtree, Tom Rodden, James A Colley, and Ewa A Luger. 2016. "This has to be the cats" - Personal Data Legibility in Networked Sensing Systems. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16 (CSCW '16)*. ACM, New York, NY, USA, 490–501. https://doi.org/10.1145/2818048.2819992

[53] Matteo Turilli and Luciano Floridi. 2009. The ethics of information transparency. *Ethics and Information Technology* 11, 2 (2009), 105–112. https://doi.org/10.1007/s10676-009-9187-9

[54] Janne van Kollenburg and Sander Bogers. 2019. *Data-enabled design : a situated design approach that uses data as creative material when designing for intelligent ecosystems*. Technical Report 2019. Eindhoven University of Technology, Eindhoven, The Netherlands. https://research.tue.nl/en/publications/data-enabled-design-a-situated-design-approach-that-uses-data-as-

[55] John Wilbanks and Stephen H. Friend. 2016. First, design for data sharing. *Nature Biotechnology* 34, 4 (2016), 377–379. https://doi.org/10.1038/nbt.3516