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A Feminist Reframing of Data Practices for Intimate Research Contexts

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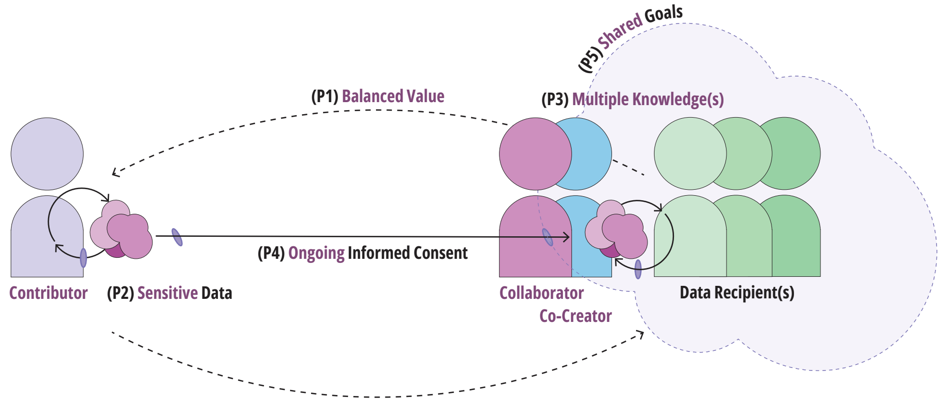

Figure 1: Conceptual framework of Sensitive Data Donation

ABSTRACT

Data donation is an emerging practice for collecting personal data. However, recent data donation approaches are insufficient in intimate research contexts as they perceive data as neutral and objective and do not consider the contexts where data is generated and shaped nor offer choices beyond whether to disclose data. In this paper, we investigate how Data Feminism can inform an alternative form of data donation and propose the Sensitive Data Donation (sDD) method. It recognizes the sensitive nature of data and assumes the importance of situating and contextualizing it through balanced participation from donors, either as contributors, collaborators, or co-creators. To develop the method, we conduct a scoping literature review where we conceptualize data donation theories and practices. These serve as a base to critique recent approaches and propose an alternative: sDD. It comprises five principles integrated into a five-phase approach. We conclude by discussing its limitations and future challenges.

CCS CONCEPTS

• **Human-centered computing** → **HCI design and evaluation methods**; **HCI theory, concepts and models**; • **Security and privacy** → *Social aspects of security and privacy*; • **Social and professional topics** → *Government technology policy*.

KEYWORDS

Data Donation; Data Feminism; Personal Data; Sensitive Data; Participation; Scoping Literature Review.

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1 INTRODUCTION

Data donation is broadly defined as a transaction of personal data to contribute to research [13, 91]. Similar to donating blood or organs, donating data is a voluntary transaction from a person who 'has'[1] data to another person (e.g., researcher) or entity (e.g., healthcare institution) who needs it. Most data donation research has been facilitated by the implementation of the European General Data Protection Regulation (GDPR)[2] in 2018, specifically the rights of access and data portability [27, Art. 13 and 14], which allow people to request and receive their data from data controllers[3] in a machine-readable format and (re)use it.

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[1] The term is in quotation marks as legal scholars have argued about the limits of ownership – as exclusive use– in the context of data [43, 76].

[2] The GDPR applies to the population of the European Union. Yet, the rights to access and data portability are available worldwide, since international companies rarely limit them by geography [18].

[3] A data controller is an entity (e.g., a private company or public authority) that collect personal data.

Data donation offers opportunities to access new insights into people's behavior and experiences and opens the way to investigate critical research questions across various domains. For instance, Razi et al. [81] used data donation to collect private Instagram conversations from teens to identify online risks; including nudity and porn, sexual messages or solicitations, harassment, and violence, among others. Similarly, the human rights organization AlgorithmWatch [3] applied data donation to investigate the functioning of algorithmic systems on TikTok. Healthcare researchers applied data donation to collect private data from wearable devices directed at monitoring the COVID-19 pandemic [83] and advancing research on specific diseases [71]. While communication scholars employed data donation to collect data from YouTube and Google's browser to interrogate algorithmic recommendations during political elections in Germany [2] and Switzerland [14].

However, current forms of data donation are insufficient in research contexts that aim to go beyond the notion of data as neutral and objective, and instead enter a space more situated, contextualized, and rich. To date, empirical approaches to data donation (e.g., [19, 81, 100, 104]) predominantly conduct research *on* people, specifically on their (sensitive) data, instead of *with* people. These approaches rely on data points or datasets disconnected from the specific contexts (i.e., times, places, bodies, devices) where data is generated and shaped and tend to reduce a complex experience to its digital traces [53]. For example, van Driel et al. [100] applied data donation to investigate teens' Instagram use by counting occurrences *on* the received datasets (e.g., messages in a chat) yet found it *"impossible"* to determine when chats started or ended. Furthermore, these approaches rarely invite donors to interact with their sensitive data and draw appropriate boundaries around it [29, 32]. For instance, by not supporting participation from individuals who decide to share their data partly [15] or strongly incentivizing sharing of all data [104].

Previous research in Human-Computer Interaction (HCI) has shown that an important starting point when interacting with data is to recognize its "situatedness" [39], especially in intimate research contexts such as the home (e.g., [23, 50, 69]) and the body (e.g., [32, 51, 59]). This perspective has seldom been considered in data donation research because of the domains, research questions, and contexts where it is applied, each with their needs and priorities, such as sampling a representative group of a population [19, 66], or ensuring the ecological validity of the datasets [81]. We start from this premise to interrogate the data donation status quo through the principles of Data Feminism [26], which build upon concepts such as the "situatedness" of data [39]. These principles, raise questions about the ethos and ethics of current forms of data donation around power and value-gain asymmetries (e.g., Who benefits?), information asymmetries (e.g., Who knows what about data?), and involvement (e.g., What forms of knowledge and participation are prioritized?).

In this paper, we investigate how Data Feminism can inform an alternative approach to data donation that recognizes the sensitive nature of the data and assumes the importance of balanced participation – conducting research *with* people and their sensitive data as opposed to *on* people, or *on* their sensitive data. This alternative approach, which we call Sensitive Data Donation (sDD), involves moving away from engaging with donors as *contributors*, who share or transfer data, to *collaborators*, who participate in interpreting the data, and *co-creators*, who participate in scoping the research [89]. Through three activities, we theoretically ground and propose the sDD method. First, we conduct a scoping literature review through which we construct a conceptual framework of existing forms of data donation in scientific research (Section 4). Second, we develop a critique of recent data donation forms and practices through the lens of Data Feminism (Section 5). Finally, we consolidate the insights derived from the conceptual framework and the critique into the five principles of sDD: **(P1)** Balanced Value, **(P2)** Sensitive Data, **(P3)** Multiple Knowledge(s), **(P4)** Ongoing Consent, and **(P5)** Shared Goals. (Section 6). Further, we integrate these principles into a five-phase approach informed by how data donation has been applied in practice.

This paper contributes with the following: (1) a conceptual framework of existing forms of data donation that synthesizes concepts and practices from multidisciplinary literature, (2) a set of five principles for Sensitive Data Donation (sDD) informed by a critique of recent approaches through the lens of Data Feminism, and (3) a potential application of the principles into a five-phase approach. Our work can support design and HCI designers and researchers applying data donation and serve as a discussion starter on reframing practices around the collection and use of personal data for (participatory) design research.

2 RELATED WORK

2.1 Personal, Sensitive, and Intimate Data

In relation to people's interactions with connected products and services, personal data[4] have multiple forms, types, and formats [102]; including (1) digital communications (e.g., DMs on Tinder), (2) entertainment consumption (e.g., Netflix logs), (3) finances (e.g., credit card purchases), (4) physical activity (e.g., daily steps), and (5) physiological signals (e.g., heart rate), among many others. All of these data are potentially available through data donation.

These data are often considered "sensitive data", defined in the GDPR as a special category of personal data that includes racial or ethnic origin, political opinions, religious or philosophical beliefs; health-related data; and data concerning a person's sex life or sexual orientation, among others [27, Art. 9]. Beyond regulations, the term "sensitive data" is more broadly applied to data that contains private information that should not be revealed [52] and is mostly unavailable to others [32]. Additionally, HCI scholars have introduced the term "intimate data." What is intimate is often private, to be hidden and kept from others [87]. With the ever-expanding range of digital devices that generate data through everyday interactions including between and/or with our bodies, partners, family, and friends, the data that are generated are potentially intimate [24]. Thus, intimate data refers to data that is entangled with intimate spaces (e.g., the house [69], a couple's bedroom [32]), activities (e.g., sleeping [37], showering [51]), and bodily functions (e.g., menstruating [5], urinating [40]).

Disclosing (sensitive or intimate) personal data is essential for data donation. It is determined by several factors, privacy being the most important [25, 41]. Crabtree and colleagues [22] provided an

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[4] Personal data is defined in the European General Data Protection Regulation (GDPR) as any information related to an identified or identifiable person [27].

overview of the various ways in which privacy is understood in HCI, including *privacy as control*, *privacy as boundary management*, and *privacy as contextual integrity*, among others. Privacy as control relates to the ability to control the flow of personal data through activities such as limiting information disclosure [101] and filtering what gets disclosed [85]. Privacy as boundary management is informed by the work of Irwin Altman [6]; and relates to the selective disclosure of personal information as people move between privacy and publicity according to the context and intention [68]. Based on the boundary metaphore, Sandra Petronio proposes the Communication Privacy Management (CPM) theory; in which the disclosure of private information is based on privacy rules that are negotiated around personal and collective boundaries [73]. Finally, privacy as Contextual Integrity (CI) is a theory proposed by Helen Nissenbaum where privacy is understood in terms of the appropriateness of information flows according to social or cultural norms and grounded in specific contexts [63].

We continue to build on these concepts as we investigate how privacy is conceptualized and applied in current data donation research and how privacy can be supported while promoting the disclosure, and donation, of (sensitive and intimate) data.

2.2 Data Interpretation and Participation

Within HCI and design, a growing research community has been exploring people's engagement with and interpretation of their (sensitive and intimate) data, including sensor data from connected homes (e.g., [51, 96]), digital-trace data from connected appliances inside the home (e.g., [32, 75]), and wearable devices close to the body (e.g., [28, 61]). Interpretation is key as data – on its own – is ambiguous and incomplete. It lacks contextual information (e.g., physical, social, emotional) [72]. For instance, data captured during a period of disruption or non-routine circumstances, such as pregnancy, can be a source of concern if decontextualized [61].

Previous work has employed (interactive) data visualizations to support people in understanding and interpreting their data. Here, participation is a prerequisite for interpretation, as people are seen as experts of their experience, whose knowledge and unique perspective are valuable [21, 86]. Tolmie et al. [96] developed a prototype that supported the legibility of sensor data (e.g., temperature, humidity, motion) collected at home and invited people to interpret and account for the data. These activities involve various orders of reasoning (e.g., place, time, people, practices, and events) and lead to relating data to specific events and reflecting through data. Similarly, Pins et al. [75] developed an interactive tool that supported the exploration of voice assistant data and invited people to interact with it.

These activities also support people in getting close(r) to their data, knowing what information it carries and what it means [24], and identifying the sensitive and intimate information it contains and/or could derive from it [32]. For example, for people using a connected shower in their household, intimacy only emerged as a property of the (shower) data as they interpreted it and saw how it accounted for their showering practices and preferences [51]. In this paper, we approach interpretation as an opportunity to situate and contextualize the entanglements between people and their data as part of the data donation processes and as an invitation for people to get close(r) to their data and define better-informed boundaries around it.

2.3 Critical Perspectives on Data

Several scholars in the fields of Science and Technology Studies (STS), HCI, philosophy, and design propose to challenge common notions and imaginaries around data, such as that they are *clean* or *objective*. Feminist scholar Donna Haraway [39] introduced the concept of *situated knowledges* to illustrate how all forms of knowledge, including data, are produced by specific people in specific circumstances. Expanding on this concept, Yanni Loukissas [53] argued that data are *local*. Thus, deeply attached to and shaped by the places and contexts where they are created and used. Moreover, he challenges the assumption that data are *smooth* and *singular* and underlines that they are plural and heterogeneous. Building upon feminist scholarship, including Haraway's situated knowledge, D'Ignazio and Klein [26] propose Data Feminism as a way to foreground the power differentials embedded in (extractivist) data practices and to interrogate, challenge, and change certain practices in data science that reinforce existing inequalities. They describe seven principles of Data Feminism:

1. **Examine Power:** It relates to the scrutiny of power dynamics by asking *who* questions (e.g., Who benefits and is neglected? Whose priorities are prioritized or overlooked?)
2. **Challenge Power:** It relates to challenging and changing an unjust status quo by taking action (e.g., collecting counter-data, imagining and proposing an alternative).
3. **Elevate Emotion and Embodiment:** It relates to valuing multiple forms of knowledge by challenging the perceived neutrality and objectivity of the data and elevating *"the knowledge that comes from people as living, feeling bodies in the world"* [26].
4. **Rethink Binaries and Hierarchies:** It relates to examining the assumptions behind counting, measuring, and classification in the process of creating knowledge (e.g., What is counted and what is not?).
5. **Embrace Pluralism:** It relates to including a broad range of perspectives and participants to contribute their knowledge to a data project at various stages by cultivating solidarity and a shared understanding. It builds upon Feminist practices in HCI [10, 11].
6. **Consider Context:** It relates to recognizing the context in which the data is generated; by accounting for its *situatedness* [39].
7. **Make Labor Visible:** It relates to recognizing, and valuing the work(-ers) involved in data projects by making them visible.

Our work builds on these considerations, specifically the principles of Data Feminism around power, emotion and embodiment, pluralism, and context, as tools to question and challenge recent forms of data donation.

3 METHODOLOGY

In this paper, we investigate how Data Feminism can inform an alternative approach to data donation that recognizes the sensitive

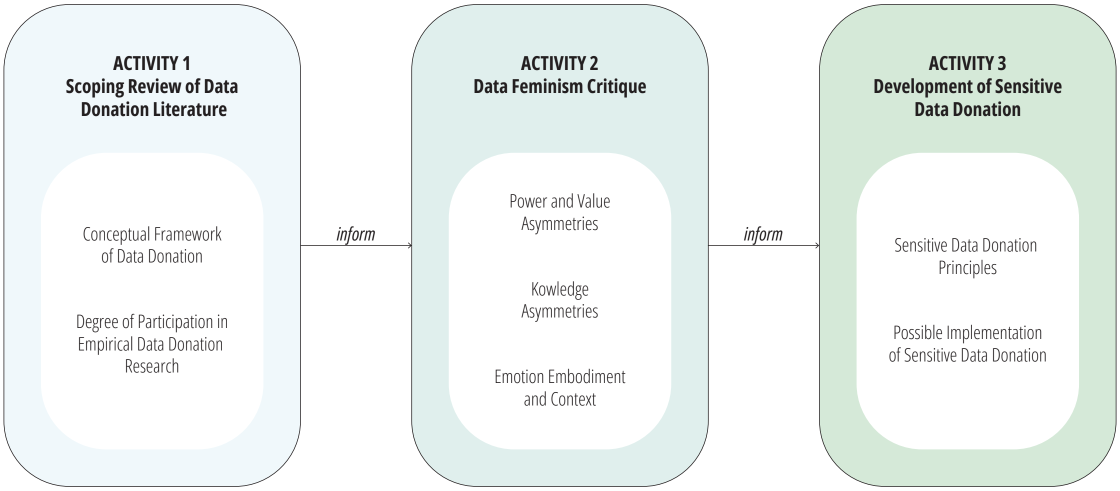

Figure 2: Research activities and their corresponding outputs.

nature of the data and assumes the importance of balanced participation. Our approach comprises three activities (Fig. 2). First, we theoretically ground our data donation approach through a scoping literature review aimed at identifying how data donation is defined, applied, and operationalized in scientific research (Section 4). We synthesize the concepts and practices into a conceptual framework of data donation. Additionally, through the scoping review, we investigate the *degree of participation* of data donors in empirical research applying data donation. Second, we develop a critique of some aspects of the conceptual framework through the lens of Data Feminism (Section 5). For instance, the differentials in the relationship between donors and recipients or between donors and their data. Third, we consolidate the insights derived from the first two activities into five principles of Sensitive Data Donation: **(P1)** Balanced Value, **(P2)** Sensitive Data, **(P3)** Multiple Knowledge(s), **(P4)** Ongoing Consent, and **(P5)** Shared Goals (Section 6). We integrate these principles into a five-phase approach informed by how data donation has been applied in practice and discuss a possible application of the method.

4 CONCEPTUAL FRAMEWORK

In this section, we identify and synthesize into a framework the main actors, concepts, and current practices in the data donation literature across multiple disciplines, including philosophy, psychology, health, social sciences and communication, design, and HCI. We used the conceptual framework analysis proposed by Jabareen [44], describing how conceptual frameworks can be constructed through an iterative qualitative analysis of existing literature, starting from a scoping review of multidisciplinary texts. The resulting framework is visualized in Figure 4 and described in Section 4.3.

4.1 Conceptual Framework Analysis through Scoping Literature Review

We conducted a scoping review of the data donation literature to investigate: **How is data donation defined, operationalized, and applied in scientific research? What is the degree of participation of data donors in research applying data donation?** Our review followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR) [97], structured in four phases (Fig. 3). We searched the Scopus database as it is useful for conducting literature reviews across multiple disciplines [79]. We restricted our search from 2015 to 2023 given that data donation was first proposed around 2015 [1, 88] and further developed with the introduction of the GDPR in 2018. Using Scopus, we searched for journal articles and conference papers mentioning "data donation" in their title, abstract, or keywords. We focused on scientific research, published in venues following peer-review processes, therefore, did not expand the search to include grey literature. We refrained from using synonyms for "donation" such as "sharing", as the term "donation" implies specific motivations and expectations that are different than those of other terms [43], while personal data donation appeals to values such as altruism and solidarity and it is often situated within a research context, personal data sharing sits more broadly. It refers to how personal data is shared with other parties – including people [95] and organizations [84] – online and offline. Nonetheless, we initially sampled literature from terms such as "sharing" but found it too broad and excluded it. The exact Scopus search is as follows:

```
TITLE-ABS-KEY ( "DATA DONATION" ) AND
    PUBYEAR > 2014 AND PUBYEAR <
    2024
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We identified 96 records through Scopus and five more by screening the references (i.e., backward snowballing) of the initial set of papers. The first author screened the initial set of 101 papers, reading the title and abstract. Papers were excluded when they described other forms of donation (e.g., organs or tissue). Next, the first author assessed the eligibility of the remaining set based on the full text. Papers were included when they explicitly stated a theoretical framing or empirical approach contributing to data donation in the abstract, keywords, introduction, contribution statement, or conclusion. They were excluded when (1) they described or discussed data donation after death (i.e., posthumous medical data donation), or (2) they specifically situated data donation in the context of a hospital – where data corresponds to patient data and consent is obtained in clinical care situations and mediated by healthcare professionals [82]. The first author read the remaining papers and analyzed them based on the exclusion criteria. This led to a final corpus of 26, focusing on (1) theoretical frameworks, methods, and (best) practices [13, 15, 38, 43, 45, 47, 62, 64, 65, 76, 94, 103] (2) motivations and willingness to donate data [42, 54, 74, 91, 92], (3) empirical approaches applying data donation [12, 19, 29, 31, 66, 81, 100], and (4) systems and platforms enabling data donation [9, 16].

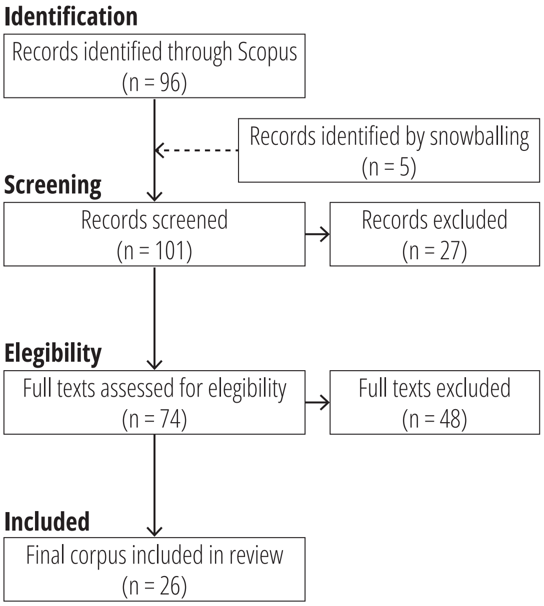

Figure 3: PRISMA-ScR flow of information through the different phases of the systematic literature review

Following the conceptual framework analysis procedure [44], the first author read through each paper, categorized them by discipline, and identified relevant concepts. Next, the first author iteratively grouped similar concepts into a new concept, with a unique name and description. The new concepts were iteratively discussed and synthesized with co-authors. Moreover, the first author examined all papers in our corpus and clustered them based on their main contribution and how they defined, operationalized, or applied data donation. Further, papers applying data donation were classified according to the *degree of participation*. It is defined by Shirk et al. [89] as "the extent to which individuals are involved in the process of scientific research" and it is categorized as: (1) *contributors*, where researchers invite members of the public to contribute data; (2) *collaborators*, where researchers invite members of the public to contribute data, analyze data, and/or disseminate findings; and (3) *co-creators*, where researchers invite members of the public to design the research project and some members are actively involved in other aspects of the research process.

4.2 Defining, Operationalizing, and Applying Data Donation

4.2.1 Defining Data Donation. Data donation emerges from the availability of personal data collected from connected products and services [16, 92]. It is conceived as a voluntary act with an altruistic nature and the purpose of contributing to scientific research [43, 76, 94], especially in the healthcare domain. Further, it is considered a powerful method for data collection [16, 64] and a meaningful alternative to approaches enabling researchers to access data; such as Application Programming Interfaces (APIs) [19, 65] and dedicated tracking technologies [65].

Data donation enables researchers to collect private personal data at the individual level. This is a critical distinction between data donation and other approaches to data collection from which researchers often access public data (e.g. World Health Organization API) [19, 65, 100]. Data is considered private as it is generated and captured in (digital) private spaces (e.g., direct messages on Facebook) in contrast to the public data, captured in (digital) public spaces (e.g., aggregated health indicators). It is considered individual-level as researchers request and access it directly from individuals – who opt-in and consent to their participation [19, 65, 91].

Ethical considerations are critical in data donation and are addressed in several studies. The main consideration is informed consent [15, 43, 45, 48, 64] and how donors can exert their autonomy [38, 43, 45, 48, 76] and preferences (e.g., deciding whether/ what/ and to whom to donate [94]). Further, it concerns ethical aspects related to the relationship between donors and their data and between donors and recipients. The former is shaped by data, which is opaque and potentially sensitive or invasive [43, 45, 62], introducing the challenge of understanding data [45] and other considerations, such as data minimization [16, 64, 65], mitigating harm [13, 76], and uncertainties around future use [43, 62]. The latter requires researchers to be transparent, provide sufficient information [43, 45, 76, 94, 103], and honor donors' contributions [48, 76]. Similarly, studies focused on the motivations and willingness to donate data found that potential donors worry about their privacy, the perceived sensitivity of their data, and its possible misuse [42, 74]. These worries relate to trust in the data recipients and if and how trust is maintained [42, 54, 91, 92].

4.2.2 Operationalizing Data Donation. Several data donation infrastructures have been developed. These mainly constitute digital platforms to which donors can upload a copy of their data. Araujo et al. [9] proposed OSD2F where participants can see the content of their data in tabular form and select the data they (do not) want to donate. Likewise, Boeschoten et al. [15] developed PORT, where data is processed locally and presented to participants in tabular form before they consent to donating them. Studies focused on applying data donation have developed similar platforms. For instance, we [29, 31] designed a platform where participants could locally explore their data through interactive visualizations and select the data they (do not) want to donate before they consent to donate them.

4.2.3 Applying Data Donation. Studies in our corpus applying data donation employ two approaches: (1) digital platforms or repositories where donors upload a copy of their data, previously requested

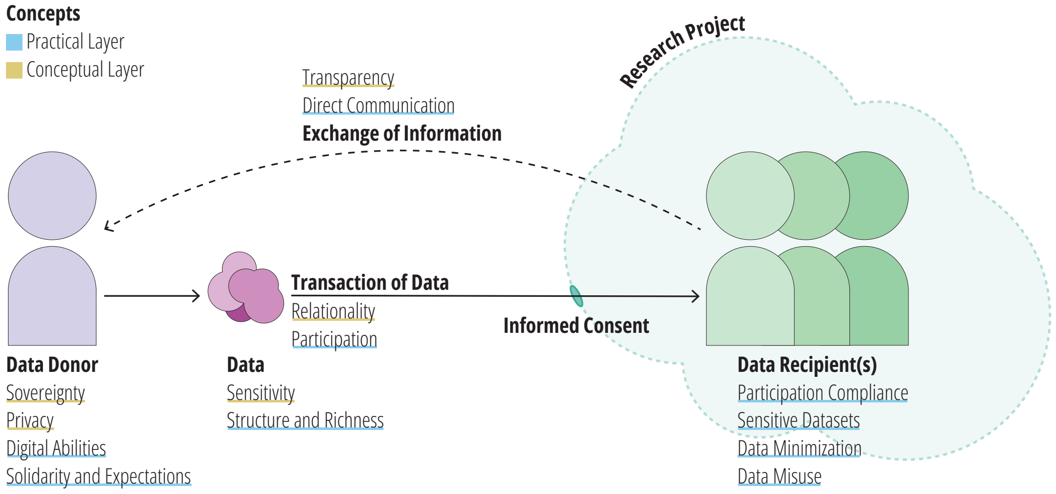

Figure 4: Conceptual framework of data donation

by a data controller [12, 19, 29, 31, 66, 81, 100], and (2) applications where donors consent to scrape data using their account(s) [19, 83]. Breuer et al. [19] applied and compared the two approaches using Facebook data and discussed the legal, privacy, and ethical implications. They concluded that the first offers higher transparency for donors but requires more effort and that both result in the collection of sensitive data. Razi et al. [81] and van Driel et al. [100] applied the first approach to collect Instagram data from teens, they instructed participants to upload their data to a digital platform and a repository respectively. Furthermore, Razi et al. [81] asked donors to annotate their data (i.e., private conversations on Instagram) by flagging them as 'safe' or 'unsafe'. In previous work, we applied the first approach to collect logs from the menstrual tracking app Clue [31] and speech records from Google Assistant [29]. In both studies, we invited a subset of donors to interpret and contextualize their data, represented visually, during semi-structured interviews. Finally, Ohme and Araujo [64] and Baumgartner et al. [12] applied the first approach to collect iOS screen time data, they required donors to upload a screenshot and screen recording respectively and not the data themselves.

Donors' *degree of participation* [89] is contributory in most studies: they contribute to a project by transferring their data, and might further contribute by augmenting or annotating it. For instance, Breuer et al. [19] integrated a survey on privacy concerns, and digital habits into their Facebook data donation approach, while Razi et al. [81] asked donors to annotate their private conversations on Instagram. Notably, a subset of the donors participated as collaborators in both studies of our previous work [29, 31], as they participated in activities related to interpreting and contextualizing their data. None of the studies in our corpus included donors participating as co-creators.

4.3 Conceptual Framework of Data Donation

The conceptual framework includes the actors involved in data donation (in **bold**), the key concepts (in *italics*), and the relationships among them, mapped visually in Figure 4. It comprises a practical layer, describing concepts related to the implementation and application of data donation, and a conceptual layer, describing theoretical concepts.

Based on the literature review, we describe data donation as the voluntary and *consensual* non-reciprocal *transaction* of personal **data** [13, 76, 91]; made directly from an individual (i.e., **data donor**) to a person or institution, (i.e., **data recipient**). Data donations are *relational* transactions; as they strengthen or change the relationship between donors and recipients [76]. They operate in a specific context around a *research project.* Researchers initiate data donations by defining the data needs of their project [19, 65] and inviting individuals, from the general population or a specific community, to contribute by donating their data. Here, there is *direct* [42] and *transparent* [9, 19, 42, 54, 66, 103] *communication* between researchers and potential donors. Meaning, that researchers openly convey the purposes for which the data is requested, how the data will be collected and handled, and insights gained from the data that may be relevant to donors; which in turn builds trust [55]. Moreover, researchers must ensure that the personal data they request and receive is relevant to answer a specific research question (i.e., *data minimization* [19, 66]), set limits on its (future) use [43, 62, 76], and avoid *misuse* [15, 62, 64].

Donors respond to the invitation by transferring their data; in doing so, they exercise *data sovereignty* (i.e., the power to control their data) [31, 42, 43, 64–66] and actively *participate* in scientific research [13, 31, 43]. Moreover, when contributing to a research project, donors exert *solidarity* [43], recognizing sameness or similarity in the context of a project that is relevant for them [74], and *expect* something in return, not reciprocity, but knowledge, empowerment, recognition, or some type of benefit that derives from the research

[13, 29, 31, 38, 76]. Additionally, they ponder their *privacy* concerns, their relationship with their data, and its perceived *sensitivity.* The individual-level private data that is available through data donation potentially contains sensitive information about donors and their relationship(s) to others [12, 15, 19, 31, 43, 45, 64, 65, 74] and includes *rich* retrospective information that is timestamped and *well-structured* [15, 65, 100]. Thus, *privacy* is an important concept in data donation [9, 45, 103]; so much so that privacy concerns are a predictor of the willingness to donate personal data [42, 74]. The *digital abilities* of data donors are another predictor of the willingness to donate personal data [42], as they are essential for them to successfully navigate the various systems and platforms required to transfer the data to a data recipient [9, 19, 31, 64, 66, 77]. Once data is transferred and consolidated into a dataset, it retains its *sensitivity* and non-publicity; as such it should be treated differently than public and open datasets [15, 64, 81].

5 CRITIQUE: THE DATA DONATION STATUS QUO THROUGH A DATA FEMINISM LENS

In this section, we propose a critique of data donation – as synthesized in the conceptual framework (Section 4.3) – through the principles of Data Feminism. These principles underline the differentials embedded in the relationships between some of the actors and raise important questions about the ethos and ethics of current data donation practices, such as: Who benefits from data donation and who is neglected? Who participates and how, people or their data? What forms of knowledge and data are prioritized? In the following, we explore these questions.

5.1 Power and Value Asymmetries in Data Donation

In most data donation research donors participate as contributors (Section 4.2.3), illustrating the power asymmetries between donors and researchers, who conduct research *on* their data instead of *with* them. Donors, as contributors, are a source of data in a project that is shaped by the researchers; whereas they could be collaborators and co-creators in a shared project that is relevant to them and their community and shaped from within. These asymmetries are reflected in the conceptual framework in Figure 4 through the unidirectional exchange of information between researchers and data donors; through which they communicate the project goals and the participation procedure [9, 19, 42, 54, 66, 103]. Researchers define the project, data needs, and participation criteria, and donors comply or not.

Similarly, there is a value gain asymmetry. Researchers clearly gain value from data donation, they gain access to data and through it advance their research. It is less clear how data donors can gain a similar value [31]. Conceptually, data donations are non-reciprocal transactions [76]. Meaning, they are not a direct exchange (i.e., data is not exchanged for another thing), and donors are not to expect something directly in return. Yet, when donors contribute to a research project, they often perceive it as relevant to them [43, 74], and their contribution implies labor and effort [29, 65, 76]. Thus, they generally expect to benefit in some way (e.g., from the use of the data in the project [54]). In practice, donors predominantly benefit from their participation through financial compensation (e.g., [12, 19, 64, 100]). This can lead to ethical issues such as coercion [70] and limit donors' ability to voluntarily offer consent [99]. More broadly, compensation is not considered a benefit derived from participation but an incentive for participation compliance [36, 99], or the willingness to follow the procedure related to participation, which is low in data donation and similar approaches requiring a transaction of digital trace data [12, 15, 66, 100]. For instance, to encourage TikTok data donation, Zannettou et al. [104] offered donors compensation based on the types of data they choose to donate. It started at 5$ for the video viewing history (mandatory) and increased by 1$ for each additional data (e.g., like history, comments, followers). They claimed that in this way they give *"power"*, or sovereignty, to data donors – the majority of which (95%) chose to donate *"almost all the data"* [104]. We argue that this specific implementation is problematic. Donors get a choice but that choice is shaped by the researchers and not choosing (i.e., donating all data) is strongly incentivized; thus influencing the voluntariness of the transaction and placating potential concerns such as privacy. It further illustrates the power, and value gain asymmetries in data donation. Moreover, it treats data as a commodity, failing to consider that *"data are people"* [105]; meaning data are intertwined with individuals, their behavior, and social relationships [26, 32]. TikTok viewing history could potentially reflect a person's views and interests while her followers and comments could account for her interactions with friends and colleagues; are these worth 7$? Would 7$ represent a similar value to donors as a publication would to researchers?

5.2 Knowledge Asymmetries around Informed Consent in Data Donation

The conceptual framework (Fig. 4) illustrates how informed consent is treated as a single moment and static decision in data donation. It generally takes place when donors agree to participate in the research (e.g., [81, 100]) or when they transfer their data (e.g., [19, 31, 64, 104]). Previous research extensively describes the shortcomings around the static nature of informed consent [20, 46, 93], especially considering the sensitive and obscure nature of personal digital trace data [32, 105]. Data donation research has recognized these limitations and poses meaningfully informed consent as one of its great challenges [29, 42, 45, 64, 65, 74, 76, 94, 100, 103]. They have approached it mainly by offering data donors a choice over whether and which data to donate before they transfer it (Section 4.2.2). For instance, Boeschoten et al. [16] proposed PORT, a software that extracts the relevant data (e.g., visited places) from the files uploaded by the potential donors (e.g., location history from Google Takeout) and displays an overview in the form of a table for them to approve (e.g., Date: January 2020, Number of Places: 24). Similarly, in our previous work, we [29] proposed a digital platform where potential donors can explore a timeline of their data (e.g., speech records from Google Assistant) through an interactive visualization and select exactly which data points they want (not) to disclose.

Nonetheless, at the moment of informed consent, donors often *"don't know what they don't know"* [45] about their data and are unable to fully understand the implications of sharing it and to define clear boundaries around it [8]. The individual-level data that is transferred through data donation is not only sensitive data [12, 19, 65, 74], but it has opaque and has unknown sensitive elements [32, 45, 65]. Thus, sensitivity is a characteristic of personal data that is not known upfront and needs to be discovered and disentangled from the data through a process of exploration and interpretation [32]. This process is not compatible with data donation approaches that conduct research *on* donors, or their data, instead of *with* them. Integrating such a process into data donation entails embedding informed consent into an ongoing, dynamic, and affirmative process [20, 46, 93].

5.3 Emotion, Embodiment, and Context in Data Donation

The forms of data that constitute a data donation project are primarily digital traces, generated or collected through people's interactions with digital products and services. Recent data donation approaches have focused on social media data from Facebook [19], Instagram [81, 100], TikTok [104], and YouTube [2], and data from wearable devices [83], connected appliances [29], and digital apps [12, 31, 66]. These private individual-level data have several qualities that render them valuable for scientific research, they are structured, spatiotemporal, and rich. Nonetheless, they are decontextualized and unable to adequately reflect people's behavior, feelings, or experiences [96]; although they serve and are often used as a proxy for these.

We mentioned in Section 5.1 how *"data are people"* [105]; referring to how the information encoded in data is deeply related to people and it is difficult to disassociate data from an individual. For instance, a person's interactions with a voice assistant can illustrate her morning routine, interests, and concerns [32]. However, people are *not* data. Their experiences, feelings, and contexts are not entirely captured by their data. It offers a glimpse. It is limited, decontextualized, open for interpretation, and potentially wrong or incomplete [31, 50, 51, 96]. By narrowly focusing on digital trace data, current forms of data donation exclude other forms of knowledge, especially people's embodied and situated knowledge [26, 39], and other forms of participation, such as collaboration and co-creation. Data donation research has begun to address this limitation by integrating ways for people to augment, annotate, and contextualize the data; including surveys [19], manual annotations [81], and semi-structured interviews [29, 31].

6 SENSITIVE DATA DONATION: REFRAMING DATA DONATION

The principles of Data Feminism raise important questions about the ethos and ethics of recent data donation practices. For instance, how current forms of data donation often neglect donors' expectations and efforts, or how these prioritize the researchers' perspectives, biases, and values. While current data donation practices often conduct research *on* people's sensitive data, Data Feminism highlights the importance of conducting research *with* people and their sensitive data – including a broad range of perspectives and participants and recognizing the specific contexts (i.e., times, places, bodies, devices) where data is generated.

In this section, we investigate how Data Feminism can inform an alternative form of data donation that rejects the notion of data as neutral and objective and assumes the importance of balanced participation, context, and pluralism. Specifically, we consolidate the insights derived from the conceptual framework of data Donation (Section 4) and the critique (Section 5) into the five principles of Sensitive Data Donation (sDD) and we integrate these principles into a five-phase approach informed by current data donation practices.

6.1 Principles of Sensitive Data Donation

(P1) **Balanced Value:** This principle calls for recognizing and honoring donors' contributions and efforts by intentionally integrating activities into the data donation process that allows them to derive value. These activities could include acknowledgment of donors by name wherever appropriate [76], dedicated learning activities for donors [31], and new knowledge and empowerment derived through data exploration resulting in data not being *"about donors but theirs"* [29]. It invites the questions: **What contributions will donors make to the research project? What would be a fair benefit to donors?** It derives from the "who" questions posed by Data Feminism around power (i.e., Who benefits and is neglected? Whose priorities are prioritized and overlooked?) Furthermore, it draws from decolonial pathways in research that call for research results to be more relevant and valid to participants than to academics/reviewers [7]. Currently, recipients are in charge of setting up the research and infrastructure, while donors are involved in activities that enable them to transfer their data. There is labor and effort on both sides, and both should derive a similar value from their contribution [32, 48, 76].

(P2) **Sensitive Data:** This principle calls for recognizing the sensitive (and/or intimate) nature of the data as a critical prerequisite for balanced and informed participation. Here, sensitivity is understood as potentially sensitive information that is unknown in the data [31, 32, 45] and as sensitive private information that must be protected and not disclosed [15, 29, 65, 100]. It invites the question: **How can donors know their sensitive data and draw clear boundaries around its disclosure?** It derives from shortcomings of current approaches that fail to consider the practicalities of donating sensitive (and/or intimate) data. Data donation frequently requires people to request and receive a copy of their sensitive data from data controllers (Section 4.2.3). Previous research has demonstrated that this process is *"disempowering"* [4, 18] as most data controllers do not fully comply with access and data portability requests, and when they do, the returned data is *"often difficult to understand, impractical to use, and raised new questions and concerns"* [18]. This reiterates how at the time of donation – and informed consent – donors *"don't know what they don't know"* [45] about their data and the sensitive information it contains and must be encouraged and supported to do so.

(P3) **Multiple Knowledge(s):** This principle calls for involving donors in interpreting and contextualizing their data; prioritizing their embodied and situated knowledge. It builds upon previous research that strives to include donors in these activities [29, 31]. It invites the question: **How can donors**

	Recent Data Donation Approaches	*Sensitive Data Donation*
Data donor(s)	Participate by contributing their digital trace data and contribute additional self-reported data through surveys and annotations.	Participate by contributing their data and can further participate as collaborators, situating and interpreting the data, and co-creators, scoping the research questions and goals.
Sensitive Data	Decontextualized digital trace data annotated or augmented with additional self-reported data.	Situated and contextualized digital trace data enriched with embodied knowledge derived from collaboration.
Transaction	Transactional, often incentivized through financial compensation.	Relational, promoting a similar value gain that harnesses the relevance of the research.
Informed Consent	Static and treated as a single moment.	Dynamic and treated as an ongoing process that promotes an incremental understanding of data and accounts for its sensitive nature.
Research Process	Defined by the data recipients, prescribed and linear. One-directional information flow.	Defined by the data recipients in collaboration with potential donors, open-ended and iterative. Bi-directional information flow.

Table 1: Comparison between recent data donation approaches and the sDD method.

participate in interpreting, contextualizing, and situating their data? It derives from the third principle of Data Feminism, proposing to value multiple forms of knowledge. Especially in intimate research contexts where data is not seen as neutral or objective; but as prompt and support for subjective and situated inquiry. For instance, Tolmie et al. [96] demonstrated how the assumption that people's everyday interactions could be "read off" from sensor data inside their homes is flawed; they argue interpretation and contextualization are key when relying on data to reconstruct an otherwise incomplete human experience.

(P4) **Ongoing Consent:** This principle calls for embedding informed consent as an ongoing incremental process that accounts for donors' preferences regarding participation and disclosure of sensitive information over time. It invites the question: **How can donors be empowered to increasingly know their sensitive data and identify whether and what information to disclose?** It derives from the obscure nature of digital-trace data [32, 43, 45] and the need to promote data sovereignty and meaningful choice in data donation [15, 43, 64]. Explicit informed consent is an ethical and legal requirement for research involving human participants and a prerequisite for processing sensitive data under the GDPR [27, Art. 9]. It requires that donors understand how and why their data will be used and the advantages, disadvantages, and potential risks, associated with it [67], which is challenging due to the nature of the data and the potential sensitive information it contains or could reveal [29, 45]. Thus, it must be approached as an ongoing process and not as a single instance [29, 46].

(P5) **Shared Goals:** This principle calls for supporting different degrees of participation in data donation (i.e., contributors, collaborators, and co-creators [89]) and inviting interested potential donors to relate to and shape the research project and goals from the start. It invites the question: **How could donors play a more active role in data donation research projects?** It draws from participatory traditions on HCI and Design research calling for people's power and agency throughout the (design research) process [21, 49, 56]. It underlines the limited participation of donors in data donation research (Section 4.2.3) and how it bounds the questions and contexts that are investigated and prioritized. These are often relevant to individual donors and their communities. Thus, their perspectives could be valuable to the research(ers) and should be included throughout the process.

In Figure 1, we synthesize the five principles into a conceptual framework of Sensitive Data Donation. In Table 1, we summarize the five principles and contrast them with recent approaches to data donation.

6.2 Sensitive Data Donation Approach

We integrate the five principles into a five-phase approach[5], represented visually in Figure 5. These phases stem from how previous research has approached and applied data donation (e.g., [15, 30, 31, 81, 100]) and how the five principles can be implemented in practice. Each phase includes a procedural principle related to ethical data practices.

1. **Identify, prepare, and communicate:** Researchers and potential donors co-create and scope the research questions and goals and co-define the value-gain strategy, data needs, and how these can be flexible enough to suit individual preferences. This requires researchers to explicitly consider how potential donors can derive value from their participation and change how they conceive the data needs of a given project: from not receiving donations from individuals who decide to partly share their data [15] to defining practices that support data sovereignty and preparing to use partial and messy datasets. Additionally, researchers invite potential donors to participate in the research. Here, we incorporate

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[5] We empirically apply this approach, with a focus on participation, in Gómez Ortega et al. [33]

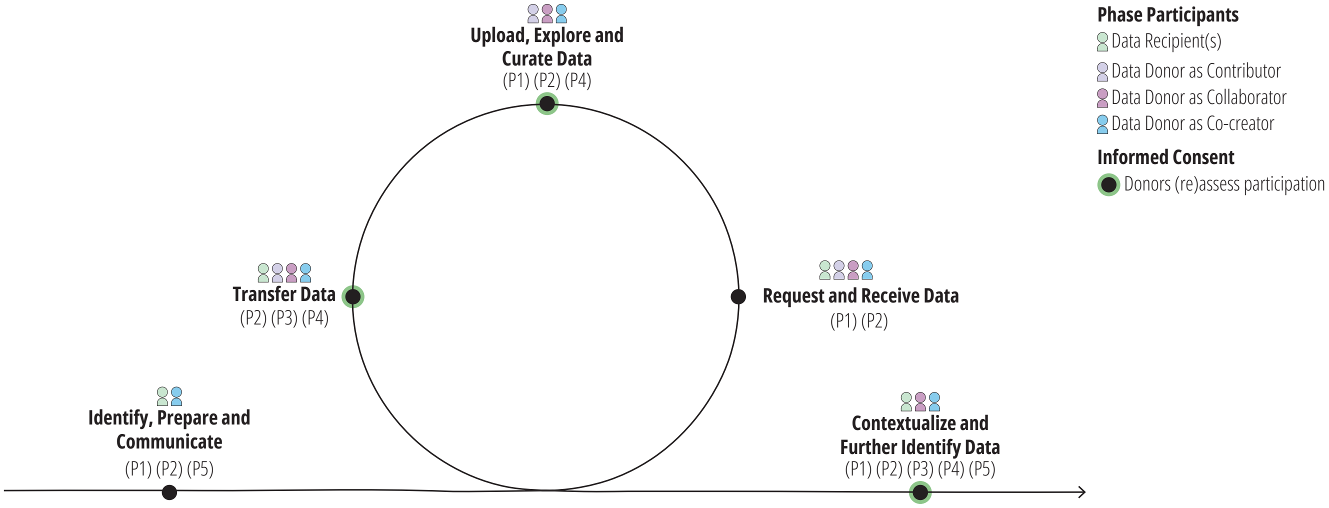

Figure 5: Five phases of Sensitive Data Donation illustrating how they relate to the principles (P1-5) and donors' involvement across different degrees of participation.

the procedural principle of **inclusion** by allowing potential donors to shape the research process and incorporate their perspectives [57, 78].

(2) **Request and receive data:** Potential donors respond to researchers' invitation by following the steps to request and obtain a copy of their data from data controllers, with assistance from researchers if necessary. This requires researchers to become familiar with the practicalities of the process and be available to guide and support as well as to clarify questions about the research process and goals. Here, we incorporate the procedural principle of **transparency** by clearly communicating why and how data will be used, and the benefits and risks associated with participation [57, 78, 98, 100].

(3) **Upload, explore, and curate data:** Researchers support potential donors to autonomously explore and draw boundaries around their data and the information they wish to disclose *before* they disclose it. This requires researchers to facilitate potential donors' interaction with their data even before they become research participants by making the (opaque) data visible, inspectable, and easy to understand and manipulate. In doing so, they encourage and support donors to engage with the content and characteristics of their data and reflect on what is sensitive about them. Here, we incorporate the procedural principle of **privacy** as boundary management [73] and contextual integrity [63] by explicitly inviting individuals to define where sensitive information resides and limiting its disclosure.

(4) **Transfer data:** Donors transfer (a part of) their data to researchers – after having explored and defined clear boundaries around it – and consent to their participation in the research; they can (re)evaluate their consent from this point onward. Additionally, they decide on their preferred degree of participation (i.e., contributors, collaborators, and co-creators [89]). This requires researchers to delay the first moment of informed consent and the actual data donation until donors have explored the data. Here, we incorporate the procedural principle of **autonomy** by explicitly enabling individuals to determine whether and what data they wish to donate and how they wish to participate [31, 43, 57].

(5) **Contextualize and further identify data:** Donors participating as collaborators and co-creators are invited to interpret and contextualize their data with the researchers, (re)evaluate their participation (i.e., confirm or revoke consent), and further scope the research questions and directions. This requires researchers to prepare and represent the data as a tool to elicit and invite multiple forms of knowledge and to communicate the progress and directions of the research. Here, we incorporate the procedural principle of **accountability**: researchers ought to inform donors about the process, progress, and limitations of the research, and deliver on the expected ways to provide value [31, 58, 60, 78].

7 DISCUSSION

In this paper, we develop and propose Sensitive Data Donation (sDD), a data donation method that rejects the notion of data as neutral and objective and assumes the importance of balanced participation with data; which requires engaging with its sensitivity from the start. It can be applied by designers and HCI researchers aiming to (1) understand and interrogate the use and implications of data artifacts, where delving into data and its situatedness can illustrate patterns of (mis)use and potential alternatives; (2) better design data artifacts and the interactions between people and their data, where contextualizing and problematizing existing data can motivate alternatives; and (3) investigate a design research question through data; where carefully managed data can be a window into sensitive and intimate domains.

In this section, we discuss the implications of the sDD method, provide recommendations on how to apply it in practice, and reflect on its limitations and future challenges.

7.1 Reflecting on Sensitive Data Donation

Sensitive Data Donation (sDD) builds upon principles and practices described in the data donation literature. These include Jones' [45] incongruities around data awareness, underlining how donors *"don't know what they don't know"*, approaches inviting donors to interpret and contextualize data [29, 31], implementations of data donation platforms and systems [9, 16, 81], and legal and ethical considerations [19, 43, 64]. Contrasting with recent approaches, it stems from and advocates for a different way of thinking about data. When applying sDD the goal is not to achieve ecological validity [81, 100] or generalizability [15, 94] but to foreground the content and characteristics of data and how it relates to individuals' knowledge and experiences in a given (intimate) context.

The method starts with a research question or goal that is scoped in collaboration with potential donors. Here, the initial research(ers) goals are present; yet they expand to incorporate people's interests, preferences, and experiences. This invites reconsidering how the data needs of a project are conceived: from fixed to flexible criteria encouraging choices. Similarly, it invites to understand successful participation in terms of power, agency, and the relevance of the research instead of participation compliance, or the willingness to follow the procedure related to participation (e.g., [12, 15, 66]). Echoing decolonial pathways in design and HCI, sDD invites designers and researchers to *"Reconsider the How and Changing the For Whom"* [7] throughout data-mediated processes and partnerships.

The method promotes different degrees of participation (i.e., contributors, collaborators, and co-creators [89]), which might result in diverse datasets, as these are created from boundaries and exploration and account differently for contextual factors around data. Consequently, the resulting data might not always be "complete" nor situated and contextualized. This might also be inconvenient, and opposite to the tidy and clean datasets expected in most data science projects [26, 80]. Similar to D'Ignazio and Klein [26] who argue that the process of cleaning and tidying data *"can be a destructive rather than constructive act"*, we argue that sDD requires embracing the messiness and heterogeneity of data and determining what data is useful and when.

Further, the research process defined by sDD is intended to be useful beyond the resulting datasets or outcomes of the data analysis; by inviting individuals to engage with and explore their sensitive data. This underlines the importance of deliberately supporting people in rendering their opaque data visible as a prerequisite for transferring it, and throughout the research process. This process might lead (potential) donors to re-consider their preferences and decisions. Thus, we echo previous research (e.g., [20, 46, 93]) advocating for continuous and dynamic consent processes in data donation and similar practices that entail transactions of personal data, where participants are supported in understanding their data and its implications and continuously invited to (re)assess their participation. We acknowledge that this process might lead to slowing down, and feelings of discomfort or creepiness [90], opposite to what is enabled through other data collection methods that are prioritized by researchers (e.g., crowdsourcing, web scrapping). Additionally, this process could be perceived as burdensome, yet, with the sDD method, we don't necessarily aim to reduce effort but to increase attention and understanding. We position it as a slow method both for researchers and participants. For researchers, the data is not available in minutes or days but through a lengthy iterative process. For participants, the incentive is not to complete a task as quickly as possible to get a (financial) reward instead they are invited to slow down, pay attention, and engage with their data. We join Gould [35] in questioning: Do we need speed? Further, referring back to the principles of Data Feminism [26], we question: Whose priorities are prioritized when prioritizing speed?

7.2 Practical Recommendations: Applying Sensitive Data Donation

We provide the following practical recommendations for designers and researchers aiming to apply the principles of Sensitive Data Donation:

- **Balanced Value:** What non-transactional forms of value can we offer donors? This question can be daunting – as we are used to the convenience of monetary incentives, yet it can be answered in collaboration with (potential) donors. If possible, we recommend (co-)defining value-gain strategies that align with the research activities and that harness our abilities as designers or researchers. For instance, these could take the form of a personal data representation or the knowledge derived from interacting with project stakeholders.
- **Sensitive Data:** How can we support donors in the exploration and interpretation of their data? We recommend drawing from the methods and practices described in the literature on data interpretation and human-data interaction (e.g., [50, 75, 96]). For instance, developing interactive tools where potential donors can explore their data before deciding whether and what to donate.
- **Multiple Knowledge(s):** What knowledge(s) other than data could we incorporate into the research process? Through which activities? We recommend building upon designerly methods where personal data is used as a probe to elicit reflection and interpretation during workshops, semi-structured interviews, and narratives (e.g., [17, 24, 34]). These have been successfully incorporated into data donation practices [29, 31].
- **Ongoing Consent:** How can we proactively invite donors to re-assess their participation? Research processes involving human participants already include the possibility for them to withdraw from the research; however, most of them do not. We recommend proactively reminding donors of this option throughout the research activities, and maintaining a bi-lateral communication where they can receive updates about the project and how their data is being used.
- **Shared Goals:** When should we involve (potential) donors in the research process? We recommend doing so as early as possible and allowing their involvement to shape the research questions and other considerations. Additionally, we recommend familiarizing donors with the timelines of research processes and the different activities they entail – such as interacting with Human Research Ethics Committees.

7.3 Limitations and Future Challenges of Sensitive Data Donation

We discuss the limitations and future challenges of each phase of the sDD method.

- **Identify, Prepare and Communicate:** Scoping the research questions, objectives, and data needs with potential donors requires their active involvement. Yet, not all individuals can or wish to participate in this process; which might limit the perspectives included in the early stages of the research – for example, by only including those of highly motivated participants. How can we best involve diverse perspectives and participants? Future research should explore how research projects can include and accommodate diverse voices and experiences early and throughout the process.
- **Request and Receive Data:** Several factors limit people's willingness and ability to donate personal data. For instance, owning a specific device, having used the device for a given time, having sufficient digital abilities to request and transfer the data, and having sufficient trust in the research, among others. Thus, a group of donors might likely differ from one recruited through different means (e.g., crowdsourcing) or responding to different incentives (e.g., money); which might bias the research process and outcomes. How can we recognize these biases? Future research should propose tools for researchers and participants in collaborative projects to reflect on their positionality and biases.
- **Upload, Explore, and Curate Data:** Recent approaches to data donation represent data in tabular form [9, 16] and through interactive data visualizations [29, 31]. What are best practices when supporting autonomous data exploration? Future research should evaluate how to best (re)present data to donors.
- **Transfer Data:** We propose to delay the initial moment of informed consent until after donors are invited to explore their data. However, inviting them to explore and inspect their data does not mean they will. Does this limit their initial ability to assess and consent to their participation at the time of the transaction? Future research should explore how to implement and disseminate dynamic consent modes.
- **Contextualise, and Further Identify Data:** What happens after data donation? There are critical open challenges around these activities. For instance: What happens to donated data after the end of a project? How can donors guarantee that (all copies) of their data are deleted? Future research should propose considerations on how to conclude sensitive data donation projects and handle the private sensitive data that results from them.

8 CONCLUSION

In this paper, we developed and proposed an alternative form of data donation – the Sensitive Data Donation method. Through a scoping literature review, we explored the actors, concepts, and practices involved in current forms of data donation and we synthesized these into a conceptual framework. We used the conceptual framework as a starting point to challenge and critique recent approaches to data donation through the principles of Data Feminism. We consolidated the insights derived from the scoping review and the critique into five principles of Sensitive Data Donation: Balanced Value, Sensitive Data, Multiple Knowledge(s), Ongoing Consent, and Shared Goals. Through these principles, we advocate for a different way of thinking about and approaching data in participatory design research projects.

CREDIT STATEMENT

Alejandra Gómez Ortega: Conceptualization, Methodology, Formal Analysis, Data Curation, Writing - Original Draft, Writing - Review & Editing, Visualization, Project Administration. **Jacky Bourgeois:** Resources. **Gerd Kortuem:** Formal Analysis, Writing - Review & Editing.

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