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Looking at Menstruation Tracking
Apps with a Focus on User Positions
Regarding Privacy and Data Collection
for Health Research Purposes

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1 The Use of Data from Menstruation Tracking Apps for Health Research

Let me start with a scenario: It is 2022, and in affluent parts of the world, the first Covid-19 vaccination campaigns have been carried out in order to get a grip on the pandemic. In the weeks after, anecdotes about irregular menstrual cycles and shared thoughts about a possible connection to the vaccination lingered in private conversations amongst people with menstrual cycles. In spring of the same year, a study found an elongation of menstrual cycles: Within the study's cohort, menstrual cycles were on average 0.7 days longer after the first dose of the vaccine and 0.9 days longer after the second dose (Edelman et al., 2022). This scenario took place within our reality, in which menstrual cycles and the associated health of people with menstrual cycles are poorly studied and underfunded (cf. Smith 2023). This is part of the gender data gap. The concept describes the absence or underrepresentation of the female norm in data records, whilst the male norm is commonly recorded as neutral and as fitting data for everybody. This concerns all walks of life, including the medical field (Perez 2019).

In the case of the exemplified study, the data of the 3,959 study participants stemmed from a menstruation tracking app (Edelman et al., 2022). The primary purpose of entering data in menstruation tracking apps are personal purposes, such as predicting the start of the next period or fertility windows (cf. Gambier-Ross et al., 2018). The secondary use of such data for medical research suggests that data from menstruation tracking apps can help to narrow the gender research gap and propel medical advancements for people with menstrual cycles. However, this data source opens a number of other critical questions at the same time. Given the sensitivity of the data in combination with the fact that the initial intention of users is often not to donate their health data for research purposes, but for personal use, leads amongst others to the question: *How are user needs and wishes included in decisions regarding the secondary use of their health data from menstruation tracking apps?* Those decisions may concern whether the data is collected by the app providers in the first place, to whom access to the data is given, or under which constraints and security measures.

The question of the position of users regarding the consideration of their needs and wishes – *especially in the context of medical research* – has been the main concern of my CIRCE research fellowship. To address the topic, I have investigated the practices of four different menstruation tracking apps and studied two examples of the explicit inclusion of user needs and wishes – one in the design of a menstruation tracking app and one regarding the process of granting access to health data for research purposes.

This report will walk through my explorations as follows: In Chapter 2, I set the scene with an explanation of what menstruation trackers are and sketch different approaches to data handling (2.1). This is followed by an overview of the public and academic discourse on menstruation tracking apps and their data practices (2.2). A roadmap of my research approach, which evolved from the previously laid out aspects, closes this chapter (2.3). Chapter 3 lays out my multi-methods approach, regarding the case selection (3.1); the privacy policy analysis (3.2); the analysis of the public communication of research activities by the app facilitators (3.3); and the interviews regarding the deep dives on participation (3.4). Chapter 4 delivers the results of the analysis of the data practices (4.1), communication of research activities (4.2), and participatory processes (4.3). The discussion of the users degree of choice in the use of their data (4.4) closes the chapter. The report concludes with linking my project back to CIRCE (Chapter 5).

2 Setting the Scene

2.1 Data Handling and Menstruation Tracking Apps

Menstrual tracking apps allow users to self-track cycle related information by entering it, most often manually

and sometimes via wearables or other gadget, on their smartphone. Such apps typically provide a calendar centric interface that displays the predicted start of the next period, and/or a fertility window is shown (cf. Levy & Romo-Avilés, 2019). Common parameters in the analysed cases were: cycle length, bleeding intensity, body temperature, pain, mood, libido, sexual activity, digestion, skin condition, cervix and cervical mucus. In addition to this non-exhaustive list, some apps offer the opportunity to add custom categories or to take notes. There is not only a large selection of parameters to be entered, but also a wide range of such apps to do so: At the time of writing, 70 different apps are displayed in the Apple App Store when you search for "menstrual monitoring".

Besides health data, other collected data can be personal data such as the name, age, birthday, and contact information of the user. Functions such as tracking behaviour in phone usage or location data are technically feasible too (cf. Alfawzan et al. 2022) and not seldomly used in mobile apps in general.

Decisions on what data to collect or not or whom to share it with etc. are commonly made within an organisation and are amongst others influenced by legal and economic circumstances of the organisations. Alternative approaches exist that provide examples of elaborate processes which include users in data-practice-related decisions, but they remain exceptions. Prominent cases are, for example, MIDATA, a data cooperative that holds health data and provides it to researchers. The platform is owned and managed on several levels in a collective manner by the people that provide their patient data on the platform themselves (Vayena & Blasimme, 2017). Another example is a project by the Mozilla Foundation called Common Voice, which builds a language data set for training voice assistants. The data collection is sensitive to biases in regard to gender and hegemonic languages. The data consists of voice donations of individuals and is partly governed by the different language communities whose languages are documented in the project (Züger et al., 2022). These approaches are context sensitive. The underlying motivation of my project is to figure out how participatory approaches can relate to decision making regarding data handling in menstruation tracking apps.

To build the foundation to the case analysis I used a framework by Alfawzan et al. (2022), which proposes four main areas of data practices in women's mobile health apps (which includes menstrual trackers). In order to outline the major areas of data handling, the framework is outlined below:

The *Privacy Policy* is the starting point of the framework. The legal document informs users how the app facilitator processes their data, the approach to consenting to the practice and possible opt-out options. The focus of the questions is particularly on how accessible the information is made. This concerns both available languages and the complexity of the language.

Data Gathering describes what kind of data is collected via the apps. This includes a differentiation between personal data and health-related data. Personal data are e.g. name, email address, birthday and phone number; health-related data regard in the case of menstruation tracking apps the data on e.g. bleeding or temperature that is entered. Another category is tracking data, which can encompass location, usage time, and similar data.

Data Sharing concerns whether and how the collected data is shared. The questions include the following aspects: how data can be deleted; if it is shared with 3rd parties; the possibility of tracking. The questions distinguish between sharing for research, legal or other purposes.

Data Security & Transparency focuses on technological security aspects and how they are explained.

The framework lends itself to point to the variety of decisions in data handling user perspectives can possibly be involved in and to disentangle what kind of data is collected; if/with whom and for what purposes it is shared; and how accessible the information is for users.

2.2 State of the Public and Academic Discourse

An anticipated potential of data from menstruation trackers to help narrow the data gender gap in health research has been discussed in popular media. Amongst them is the New York Times (Gupta & Singer, 2021);

the author of the book *Invisible Women* (Perez, 2019), and the facilitators of menstruation trackers themselves. At the same time, especially following the overturn of *Roe v Wade* (Justia Law, 2022) in 2022, highly critical perspectives on menstruation trackers emerged in the media, reporting mass deletions of menstruation trackers by women in the US (Garamvolgyi, 2022) and the question of how such apps would fit a post *Roe v Wade* reality (Torchinsky, 2022). The main concern are legal threats posed to users by the indications of criminalised abortions in the data collected by menstruation trackers and the access of the data by state authorities.

Questionable data practices are a well known phenomenon in the datafied society; and menstruation trackers are no exception: *Flo*, a popular ovulation and period tracking app with over 10 million users, caught the public eye when it became apparent that the app had shared sensitive health data with third-party firms such as Google and Facebook (FCT, 2021; Garamvolgyi, 2022).

Whilst the public's sensitivity to the unintended access and use of data from menstruation tracking apps had risen in parallel to the described events; the respective data was already inherently sensitive, which is reflected in the academic literature around menstruation tracking apps.

A comparative analysis of 23 women's mobile health apps by Alfawzan et al. (2022) showed a lack in data privacy as well as sharing and security practices. Amongst others, regulations such as the GDPR were not followed appropriately in the cases they looked at (ibid.); a finding which was supported by the analysis of 30 'fertility apps' by Mehrnezhad & Almeida (2021). The authors further discuss privacy risks that emerge with the potential to target users in sensitive and vulnerable situations that can be depicted in the data, such as an abortion, infertility or pregnancy.

Beyond what is stated in the privacy policies, understanding what is said in those documents is necessary to give consent in a meaningful way. Shipp & Blasco (2020) investigate the understandability of privacy information and point out that whilst the 30 analysed apps would perform better than an average app in other fields than that of menstruation trackers, more straightforward language is needed. Once again, their study shows a lack of handling data appropriately, namely the lack of categorising respective health data as especially sensitive (ibid.). The aspect of consent for data collection and data sharing is widely discussed, and explicit consent is a central topic with regard to menstruation trackers (Alaattinoğlu, 2022; Bandana & Doshi, 2022). Gomez Ortega et al. (2022) present a case study on the potential of data donation as a way to actively engage users in the usage of their data. They also suggest that explicit data donations are not the norm case and that the involvement of users in decisions on the usage of their data presents a shortcoming.

At the same time, user studies show a positive reception of the apps by their users (Blair et al., 2021; Levy & Romo-Avilés, 2019) and the user numbers of menstruation trackers reached an estimate of 50 million users in 2020 (Rosato, 2020). Motivations for using menstruation trackers differ broadly and encompass increasing body awareness, pregnancy planning, contraception, and to inform health practitioners when in treatment (Earle et al., 2021; Epstein et al., 2017; Gambier-Ross et al., 2018). Given that using data for research is a secondary use of that data, it is not self explanatory but worth mentioning that supporting research was not among any of the prominent motivations.

It has been laid out that the handling of data that is collected via menstruation trackers is often inadequate, whilst the data is inherently sensitive and carries different risks for users; furthermore, informing users appropriately and designing consent is an issue in connection to the topic. This critical starting point suggests that if the secondary use of data from menstrual trackers for research purposes is to function in a justifiable, low-risk and transparent manner, far higher standards must be applied than are common in the field of menstrual tracking apps. Whilst participatory approaches are no panacea, people to whom the data belongs to need to be taken into account appropriately.

The focus in the literature lies on the primary use of health data, the prediction of menstruation and fertility

windows as well as its accuracy is looked at in the literature (Manhart & Duane, 2022; Moglia et al., 2016; Van De Roemer et al., 2021). Studies focusing on a secondary use of the health data for research purposes are underrepresented in the academic literature.

2.3 Roadmap of My Research Approach

To explore the question of how user needs and wishes can be incorporated into decisions about the secondary use of their health data, I chose a case-based approach.

Within the duration of the fellowship, it turned out to be difficult to join the aspect of data use for research and participatory practices in the same cases. Examples either communicated about their research activities or about participatory practices. However, from publicly available information, it was difficult to say if the cases that communicated about their research also implemented participatory processes. Within the set timeframe, it was difficult to interview representatives, which could have been clarifying in this regard. In order to still look at both aspects, I included cases that communicated about their participatory approach but did not provide data for research practices (which, as shown later, was in one case a result of a participatory process).

Therefore, the four cases I looked at are divided in two groups: two cases which conduct and communicate about research use of data collected by them (later referred to as *data-collector apps*); and two cases which incorporated and communicated about elaborate inclusion of their users (later referred to as *non-collector apps*). It is important to explain the technical setup of the two non-collector apps that do not share data for research: Whilst a vast majority of apps in general collect user data on their end, those two app providers set up their apps in a way that does not grant them access to the data of their users. Whilst users still enter their data to their phone, the data stays locally on the phone of the user and is processed only there. As the technical setup gives no data access to the app providers, they are also not able to know the data of their users (beyond downloading numbers) or share the data with anyone. This privacy-forward approach is an exception. With regard to research activities, this structure of an app prohibits secondary use of the data controlled by the app providers and has several other implications for the organisational processes and strategies.

For the case studies I applied three analytical steps and focused on the following elements:

1. **General standards of the data practices in each case** – to set the scene, I analysed the privacy policy of the apps that state their data practice; e.g. what data they collected, if/with whom they shared which data with; if data is used for research purposes; and how consent to do so is granted (see Chapter 4.1).
2. **Public communication of the conducted research with data from menstruation tracking apps** – both apps that are active in health research communicate publicly about their research activities. As no interviews were conducted before the end of the fellowship, the questions arising from the analysis of this communication remain open at this point (see Chapter 4.2).
3. **Participatory Processes** – to zoom in on processes that include user needs and wishes, I took two deep dives. One looked at participatory processes in the development of a menstruation tracking app (later referred to as *app-case*) and one at an additional platform, which is not specific to menstruation data but grants access to health data for secondary use for research. The latter incorporates a process to include user perspectives in access requests (later referred to as *platform-case*) (see Chapter 4.2).

My methodological approach is explained in greater detail in the next chapter. It remains to mention at this point that this report is part of ongoing research. To bind the current findings together, I discuss the user position within the cases that I look at in Chapter 4.4. With ‘user position’ I refer to the degree of freedom in choice and co-determination that users have in regard to the use of their data.

3 Method

To investigate the laid out aspects, I followed a mixed methods approach and looked at four app-cases: I focused on data practices and research activities connected to menstruation tracking apps, and looked at participatory processes which include user/patient perspectives.

The case selection of menstruation tracking apps for the first part will be laid out in 2.1; the framework used for the analysis of their data practices will be laid out in 2.2; and the analysis of the public communication of the research activity is explained in 2.3. For the second part which focuses on the participatory processes, as a means to include user needs and wishes in connection to menstruation tracking apps and data access, the methodological approach concerning semi-structured expert interviews is laid out in 2.4.

3.1 Case Selection

Four apps were selected as examples, for a first approach to the field. The basic criterion was that the apps offer a function to (mainly manually) track the menstrual cycle. In addition to this, the data practices were relevant for the selection: two apps have been included that collect data (henceforth *data-collector apps*) and use it for medical research and two apps have been included that only process data locally on user devices, which means the last group does not collect data (henceforth *non-collector apps*).

It may seem counter-productive to include cases which do not collect data in this setup – as they cannot share data for research purposes – but as those cases are very rare, it is reasonable to assume that this setup is a conscious decision, possibly with regards to user needs. Those cases therefore offer a valuable perspective on user positions in this context.

The two groups were further subdivided in one app with a focus on an US American context and one with focus on an European context. This arose due to legal differences in relation to data protection through the GDPR and the criminalisation of abortion, and due to the centrality of those regions in the range of available menstruation trackers.

The apps will not be further described due to anonymization purposes and ongoing research. No distinctions between the apps in the two categories will be made.

3.2 Analysis of Data Practices

To analyse the data practices of the app, the interface of the apps and the privacy policies of the apps were looked at with the help of a framework by Alfawzan et al. (2022), which is designed to analyse Women's mobile health apps. The framework consists of 24 questions and is divided into the sections: *Privacy Policy*, *Data Gathering*, *Data Sharing* and *Data Security & Transparency* (to avoid repetitions, please see a description of the categories in 2.1 on page 3). I looked at those aspects to get a better impression of the data practice; as they regard the focus of my research most immediately they are discussed in the insights section.

3.3 Analysis of the Public Communication Regarding Research Activities by the App Facilitators

The data-collector apps collect and share menstruation data for health research purposes, and communicate about their research activities publicly. This source will be used to derive a more refined view on what 1) motivation is stated to share data for research, 2) what the approach to consent is, 3) what is stated regarding granting access requests, 4) what topics are researched 5) what data is used for that and 6) what security measures are taken.

3.4 Interviews with App Facilitator and Platform for Accessing Research Data

To look at participation within a menstruation tracking app and the inclusion of the user perspective in data

access requests for research, I conducted two interviews: the first interview was conducted with a representative of a facilitator of a menstruation tracking app that employed elaborate participatory processes, but does not provide data for research (henceforth *app-case*).

To complement the component of data sharing for research, I conducted a second interview with a representative of a platform that provides access to health data for research in compliance with the GDPR and employs a participatory process regarding data access requests (henceforth *platform-case*).

The interviews were conducted via video call, lasted 45 minutes, were audio recorded, transcribed and evaluated.

The expert interviews were semi-structured and the interview questions were developed according to Helfferich (2019). The questions for the app-case were structured along the blocks *Introductory Questions, Motivation to not collect data, Users & Participation, Providing Data for research and Closing Remarks*. In addition to the interviews, I was provided with two briefs by my interview partner, which described the development of the apps and information on the methodology which was used to realise the participatory processes. The questions for the platform-case were subdivided in *Introductory Questions, Data Provenance, Participation, the Case of data for menstruation tracking and Closing Remarks*. The results and a comparative discussion of the interviews are provided in the insights section (4.).

4 Results and Discussion of Data Practices, Communication of Research

Activities and Participatory Processes

In the following I provide the most relevant aspects from the app and policy analysis; questions following from the public-communication of respective research activities and a comparison of two participatory approaches within the setup of a menstruation tracker and a platform which provides health data to researchers. The section closes with a discussion of the findings.

4.1 Data Practices in the Analysed Cases

To set the scene and build a basic understanding of the data practices of the four apps looked at, the most relevant aspect of the analysis of the apps and their privacy policies, with regards to the accessibility of the *Privacy Policies*, the practices in *Data Gathering* and *Data Sharing*, will be depicted very briefly:

The privacy policy as a document, takes vastly differing formats in the four cases. The documents differ especially in tone. One stands out particularly as it is contextualised in many places, and is clearly aimed at communicating to users too (it does not only refer to other legal text, but also to explanatory articles, which are not legal documents).

The policies of the non-collector apps are shorter, as they have fewer legal obligations due to their practice. In one case, the policy is complemented with elaborate further information on privacy concerns in the app. None of the policies seems to be available in simple language, all are available in English, some are translated to other languages and complemented with summaries in other places in the app. The document is on one hand a legal obligation and on the other hand used as means of communication. This can lead to friction between communicational concerns, style and legal demand.

For the data-collector app cases it is important to understand that the apps providing data for research, also collect personal data such as e.g. name, email and birthdate when users setup an account to use the app, besides genuine health data. Such identifiers are removed when health-data is shared (anonymised or pseudonymised).

Whilst neither sell user data, they share non-health data (in a format where personal identifiers are removed, anonymised or pseudonymised and possibly pooled), with research institutions. In one case, consent is given by opt-in when an account is set up, in the other it is stated that users can be asked for their consent for research purposes. Health data is apparently not shared with anyone but research partners and its treatment underlies security protocols/contracts which are described in differing depth in the policies. Personal and behavioural data is shared with 3rd parties to improve the function and features of the app as well as advertisements, users can opt-out from some but not all of the third parties.

It is self-evident that the non-collector apps do not gather or share data; the only exception is contact data, to get back to people reaching out to the support contact.

The privacy policies of the data-collector apps lay out (in differing intensity) that they see the importance in protecting especially the health data for their users. Whilst it is important to evaluate the appropriateness and effectiveness of those measures, this cannot be considered within the scope of this report.

Other risks, which cannot be evaluated in the realm of this report, related to collecting and sharing data become apparent: 1) the scenario of an acquisition of the company and the consequences this would have on data sharing, 2) the role of law enforcement, i.e. the obligation to share data with them and the different legal regimes (e.g. GDPR or the Californian Consumer Privacy Act).

Concerning the case of sharing data for research the following can be summarised: whilst the health data is not shared together with information that can identify people, it is collected together with such data. Users automatically opt-in to the use of their data when consenting to the privacy policy by using the app in one case, but can opt out via an email. In the two cases looked at, health data is not shared for reasons other than research, other than non-health personal data. In neither of the two cases data is sold.

The apps looked at all seem to be cautious of a variety of sensitive aspects and risks, and do not sell data which is not a given. Further in one case of each pool a heightened awareness of a need to communicate can be seen; the other cases provide rather scarce or in tone of voice legal and hard to understand documents. It is possible that they communicate in a different style about their privacy policies in other places in the apps.

4.2 Questions Following the Communication of Research Activities

To explore the research activities of the data-collector app organisations, observations from the public communication of both regarding their research activities are shared in the following, along with questions that arise from those observations.

Both organisations which provide apps that collect, use and share pseudonymised or anonymized health data for research, provide online information on their research activity. One provides an elaborate text with an apparent communication strategy, addressing a variety of questions related to research in a brief and structured way, as well as providing a selection of research prepared for a lay non-academic audience. The other provides a list of research output and a presentation of research regarding the effectiveness of their product.

For both, the stated motivation is to advance health research for people with menstrual cycles. Given the differing organisational histories and evolutions it is of interest to understand, *how the commitment to conduct research themselves as well as to share the data came to be*. Further it is of interest, *if and how user input has been collected to make the decision?*

From the provided lists of research it seems like a number of studies have been conducted by the research teams of both apps themselves, some in collaboration and some only by external research teams. Here it is of interest *how the organisations understand their own role in regards to utilising user data to which they provide access*. Further it is a question *if/how that understanding shifts in the three mentioned constellations (researching themselves, partnering in research or providing data for independent external research)*.

The listed research projects cover a wide variety of topics and use of different data. Further research is conducted by a variety of organisations, amongst them are companies producing consumer products, the *overlap between health research and market research are hazy in many other contexts too, it is a question if and how this aspect influences the decision to share data for research or not.*

Only a share of the cases use menstruation tracking data in an isolated manner, in several cases menstruation tracking data is used in combination with questionnaires, in other cases only questionnaires with patients contacted via the apps are used for research. In cases which include an active part for users, users are aware that they are participating in a study. It is unclear up to now *if users are informed of the concrete use of their data in a study, when their action is not needed, or if users have a chance to find out.*

By giving their consent to the privacy policies, users consent – amongst other uses – to the use of their data for research, which does not necessarily mean that this is the *optimal solution from the perspective of the organisation to deal with consent.* There seems to be a discrepancy in the communication about their research and the consent solution in terms of transparency and user information. Granting the use of their data for research is the first decision moment for users.

It is mentioned repeatedly that the data is not sold. Yet providing data for research is connected to substantial efforts, therefore open questions are, *how this effort on the organisations' side is compensated for, whether researchers are charged for other connected services (e.g. for sending out questionnaires), and if users are compensated.*

It is stated that good scientific conduct including ethics and security and the relevance for people with menstrual cycles and users are crucial for launching collaborations. Getting to know more *about selection protocols and if external advice is part of access decisions is part of the process* is a remaining point of interest.

Regarding the research activities of the data-collector app organisations, the questions put forward remain open for now, the main points of inquiry are the protocols for granting data access, how users are included in those; if and how they are informed when their data is part of a study and what the position of the organisation in granting access and conducting research is.

4.3 Participatory Practices in the Context of Menstruation Trackers and Data Access Requests

The public communication regarding the research activities of the organisations leave the question open; how users are included in the decision making. Both non-collector apps include participatory elements, the case looked at includes participatory processes throughout the whole developing, implementation and maintenance phase of the app. On the basis of an interview with a representative of the organisation facilitating the app and additional documents, an overview of this process will be given. The decision to collect no data is a result of such participatory processes (henceforth app-case).

To not leave out the aspect of sharing data for research purposes, which was the initial question of my fellowship, an example of a participatory process in this context will be given, also on the basis of an interview. This example regards the inclusion of patient perspectives (amongst others) in granting or denying data access requests to research data, in the context of a platform which provides data for health research (henceforth platform-case).

Both are described in the following, regarding their (1) general setup, (2) the selection of participants, (3) what changed through the implementation of the participatory processes, (4) the motivation for participation, (5) how differences regarding the advice the project's managements are given are handled, (6) additional remarks and (7) their take on menstrual data. In section 4.3.3 the two approaches are compared and discussed.

4.3.1 'The Platform-Case' – Including Patient Perspectives to Consult Decisions on Data Access Requests

The platform organisation is a private company based in Europe and collects health data from different sources, such as medical practices, laboratory or research facilities. The organisation combines data from these different sources, related to a historically more complete anonymised record on an individual, for research purposes. The organisation works in a European country and puts in their communication and operations a specific emphasis on the orientation of their organisation to the GDPR. The organisation developed a process to gather advice regarding access requests from an external board which is aimed at representing different perspectives, one is the patient perspective. This process is the focus of the depiction of the organisation.

The first case regards a platform providing data from health care to researchers. Researchers who wish to conduct research on the basis of data provided by the platform need to file an access request. The request is evaluated by the organisation itself along a protocol which includes a risk-benefit analysis. Additionally, the request is discussed and evaluated by an external board.

(1) The board consists of three people each representing a different perspective, 1. A governance perspective represented by a data protection authority representative 2. A scientific perspective represented by a professor from a university hospital 3. A patient perspective represented by a representative from a self-organised patient representation (NGO) by and for physically, mentally, psychologically disabled and chronically ill people. The task of the board is to evaluate an access request and advise if the request should be considered, and under what conditions, e.g. if adjustments to the proposal should be made.

(2) The members of the board are chosen as representatives of organisations which again shall represent a perspective which is relevant to the endeavour. It was crucial for the organisation to keep the process as well as the board lean.

(3) Through participation, the evaluation of an access request is complemented with three additional views, which are tested against each other in the discussions of the board. Theoretically the board can deny access, which would not have happened up until now, usually adjustments are suggested or demanded in connection to conditionally granting access. The advice is not binding.

(4) The interviewee clearly states that the board helped to build trust in their processes, which is at the same time the core goal of the organisation itself; building trust in their processes would enable them to provide more data for research.

(5) In the same vein it would not be possible to act against the board's advice (even though it is not officially binding in their setup), as it would damage their mission.

(6) An additional remark regarding the issue of consent; the platform uses the data under GDPR but without explicit consent. The interviewee points out that informed consent is a debated topic, that their preferred solution would be to have a national, centralised body where patients can opt-out in a centralised manner from their data being used for different purposes, amongst them research.

4.3.2 'The App-Case' – Participatory Development of a Menstruation Tracking App

The menstruation tracking app is framed as a privacy centric app with a focus on reproductive and sexual health, explicitly including abortion. The app is provided by a collaboration of non-profit organisations, with the lead organisation centred around reproductive health research and based in the USA and South Africa. The app was launched in the late 2010s. The app does not collect data but stores the entered data locally on the smartphone of the user. For keeping track and providing predictions on when the next period starts, the data is processed locally on the phone of the user – the app provider has no access to the data. Beyond not collecting data the app provides further privacy centric features, such as password protection, a function for immediate app data deletion from the phone and a full information section on privacy. The latter contains the privacy policy, including a shortened version in form of FAQs. Additionally to tracking, the app provides elaborate

information on the health topics abortion, contraception, sexuality, miscarriage, pregnancy and sexually transmitted infections. It is explicitly mentioned that abortion is a topic the app addresses as well. For the development and maintenance of the app a variety of participatory processes have been implemented; those are described in the following.

The design of the product is from its inception based on user consultation which is a core characteristic of the project, the participatory processes revolve around the entire app.

(1) The 7+ year process consisted chronologically from the following building blocks: partnering with an organisation which had experience in the field of consulting people regarding safely self-managing their abortions; and a landscaping review of existing related apps. The identified gap in the market was an app which centred user needs.

A first round of focus group discussions and in-depth interviews followed. Participants were recruited through partnering organisations, who were in contact with respective groups of people.

This was followed by the design of a prototype, which was informed by the first round of interactions and conducted under the consultation of the community advisory team.

A second round of focus groups and interviews focused on the prototype and its revision. The community advisory team was transferred to a permanent institution in the project. The organisation is currently looking into ways of including broader groups of people in the maintenance phase of the organisation.

(2) The decision on which user groups to include emerged from the location of the organisation and the thematic focus of the app: primarily the selection was led by placing the most vulnerable user groups and their needs in the centre. It was important to represent users living in different areas in the US where different laws regarding abortion applied. A special focus was on hearing young people and people who had experience with seeking an abortion. Besides age and reproductive health experience, racial identity, education and current use of sexual and reproductive health apps were additional decisive factors and structured the focus groups and interview partners. The formats were chosen in correspondence to the sensitivity of the topic e.g. experiences with abortion were rather listened to in interviews than group settings. Participants were reached via partnering organisations.

(3) The set goal is to provide a sexual reproductive health app that informs about the topic of abortion and is user-centric to the core, beyond this fixed essence everything else depends on the input from users and restrictions due to resources.

(4) Particularly the emphasis on data privacy and not collecting data was based on clear and explicit user demand voiced in participatory processes. The circumstance, that no user behaviour data is available to the project managers, other than the download numbers, led to a more immediate relationship between users and the app facilitator as they needed to interact directly instead of spying on the user, as the interviewee put it. This was needed to make the product work e.g. to be informed on malfunctions in the app. This means that the data practice directly influences the necessity to be into direct exchange with one's users.

(5) The interviewee understood the organisation's position as a facilitator and the task as understanding what needs are lying underneath concrete wishes. From this followed that it was sometimes necessary to go back with alternative solutions to the users to discuss if their wishes were not applicable, e.g. due to technical or resource scarcity. Transparency and the willingness to find the best solution for users were considered non-debatables.

(6) The interviewee mentions the existing gap in the research but evaluates the risk which is connected to sharing data from menstruation apps in the US as higher than the utility of the data. Whilst the interviewee explicitly recognises the importance of data for research and the importance of anonymization, they also made the point very clearly, that if there is a genuine concern, it must be possible to gather data in a more thoughtful, presumably more resource intensive, but worthwhile ways to get to know about experiences and health

revolving around menstruation.

4.3.3 Comparison of the Participatory Approaches

Both examples are cases in which no data from a menstruation tracker is used for medical research, nevertheless both are relevant in the context, whilst differing vastly. The different implementation of structurally identical aspects in the inclusion of user/patient perspectives offers valuable insights, especially in comparison.

The platform-case can be understood as a minimalist approach to participation, whilst the app-case is close to a maximalist approach. The former includes perspectives in regards to a distinct decision; the latter puts an entire project design up for debate.

The platform-case includes people as representatives of large conceptual domains (data governance, science, patients), with regards to a distinct decision (granting access). This supports balancing risks against benefits. The app-case on the other hand includes people in their private capacity with regards to identity aspects and in a position which is an integral part of the app, namely as users. This, on the other hand, is a more finely grained perspective on only one interest group and supports a comprehensive adjustment to this group in many facets. One chooses participants by domains, the other by characteristics of people; both aim to include nuanced perspectives.

In that way also the output of the participatory processes differs, which leads to different roles which the organisations fill in in the setups: in the platform-case the relationship is more abstract, professionalised and streamlined, the advice is handed over as a synthesis of a discussion. In the platform-case the synthesis has to be formed by the facilitating organisation itself, whilst the input is much broader and organic, therefore less structured. The extent and design of the participatory processes defines how much flexibility is needed on the side of the facilitating organisation to take the external input into account.

In both cases, the participatory process has the capacity to cause friction and substantially influence the data practice of the organisations. In the app-case this notably led to a research organisation building an app, which did not collect data, which was mentioned as a remarkable circumstance by the interviewee. In the platform-case the decisions by the board can mean that no data will be shared.

4.4 Discussion of User Positions

The two examples show how different the scope of processes which include user or patient perspectives can be. Whilst the app-case directly concerns a menstruation tracker, the platform-case deals with a related topic in a different context.

In both cases the inclusion of user wishes can lead to a reduction of either data collection or data access. Whilst the inclusion of users in the platform-case may lead to not sharing data, the strengthening of the user position also strengthened the organisation even if it is genuinely built towards sharing data. Stronger user positions can introduce uncertainty on a small scale and can strengthen an endeavour on a wider level.

Via the analysis of the data practices and communication of the research activities of the menstruation trackers which provide data for research, conclusions about the position of users within the setup can be drawn. The user position in the setup is not strong: the apps at this point in time (presumably) only work technically when user data is gathered, a decision against data gathering would be a decision against using those apps. Additionally a large variety of different data is collected together. This includes data which is not necessarily needed for research purposes. The use of data for research is managed in one case via opt-in, which is not necessarily conscious and therefore hardly a decision for sharing data. It is not clear if users are informed / how

they are asked for consent about the concrete use of their data. It is further not clear if user perspectives are included in granting access to the data for research.

In the setup of handling/collecting data and sharing data for research purposes the position which is taken by organisations facilitating the apps can be interpreted as that of a spokesperson or custodian over user data; without explicitly mandated by users to do so. Such a mandate can be given, but even if that is the case, advice from external parties to include a user's perspective may be beneficial.

In any way the decision scope of users should be increased in several steps: on an individual level regarding the question if they want their data to be collected and used, for which purposes; and on a collective level with regards to granting data access.

The menstruation trackers I looked at belong to the ones signalling in many places their eagerness to be responsible; and are dedicated to a scientific conduct in their organisational endeavours. Not least due the sensitivity of the field they are operating in they are and need to be held to high standards.

Beyond the given insights, it needs to be investigated, what the quality and contribution of the conducted research on the basis of apps actually is and how valuable the data such apps can provide actually is for health research. To close the chapter it is to state that the collection of data via personal apps and the narrowing of the data gender gap are not inseparable and certainly not causally connected to each other. The data gender gap in health research continues to exist among other aspects due to too little funding and interest in diseases which disproportionately affect women and people with a menstrual cycle (Smith, 2023). This will not be solved by cheap solutions such as the secondary use of data from apps and not by the labour of women tracking their bodily symptoms.

5 Linking back to CIRCE

In the beginning of my fellowship I expected my contribution to the CIRCE aim, namely “explore and test new ways and creative solutions for dealing with the challenges of our time”, would be to provide insights on ways to strengthen the user positions in sharing health data for research, particularly data from menstruation trackers. The most innovative aspect, that emerged as a point of attention in the research process, were apps that do not collect data, whilst still processing them. Such apps are rare. Amongst others, because they are economically hard to sustain. The two examples looked at during my fellowship are run with the help of volunteer work, funds and via other philanthropic paths. Both apps are free to use. Both put user privacy first. Whilst paying for the use of non-data collecting apps can possibly be a way to sustain them economically, such movements run the risk of making privacy and therefore security a luxury good. We are already seeing a version of that, when insurance policies become more affordable when data is shared with insurers. Such developments mean that people who are already disproportionately less safe, are the ones who cannot afford a privacy forward version of a service and are consequently exposed to additional risks. The pros and cons of fund based models, pay versions or freemium options have to be looked at and tested in that context – but rather with a sustainability mindset than with a growth vision. It is important to note that a setup where the app moderators do not have access to user data does not have to exclude e.g. health data donations, but rather requires other procedures.

Both apps which did not collect data, were either developed in a user community or out of organisations with intense user contact. While one organisation keeps the app technically running through volunteers, the other organisation continuously raises funds to maintain and develop the project through people in their professional roles, not as volunteers. Sufficient effort from communities to realise such projects, seems to be present. But tech projects are expensive as well as participatory processes. In terms of technology, lean solutions, which e.g. do not collect and manage data, promise to be cheaper in maintenance and legal setup. Nevertheless, the

maintenance of technological infrastructures themselves is especially expensive. This is, at the same time, the moment when innovations are likely not considered innovations anymore. This lowers the chances to attract funding. If we are interested in the long term success of sustainable technologies that are serving the interest of users, funding as well as organisational and business models need to adapt.

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