

Drawing as a Facilitator of Critical Data Discourse: Reflecting on Problems with Digital Health Data Through Expressive Visualizations of the Unseen Body Landscape

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**DRAWING AS A FACILITATOR OF CRITICAL DATA
DISCOURSE**

**REFLECTING ON PROBLEMS WITH DIGITAL HEALTH DATA
THROUGH EXPRESSIVE VISUALIZATIONS OF THE UNSEEN
BODY LANDSCAPE**

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ABSTRACT

In a 1.5-hour workshop, we used drawing and self-reflection prompts to facilitate a value-driven discussion of personal and institutional data practices. Activities included mark-making in time with one's heartbeat, creating an inventory of one's personal data, and creating a qualitative personal health visualization. This article details the workshop structure and exercises and includes a summary of the discussion, which constructively encompassed both the empowering and the uncomfortable aspects of digital health data collection in a constructive manner. The workshop's design used the format of hands-on, expressive drawing activities to enable participants to achieve depth and breadth in a relatively short discussion about personal health, data autonomy, institutional trust, and consent. Critical discourse about data, especially health data, is a valuable experience for every person whose health data has been or is being collected; and approaches that take personal data as a starting point can support the practice of digital/data sovereignty more broadly.

1 INTRODUCTION

This article describes and reflects on a workshop about the challenges of digital health data. We first review the background on visualizing the body interior, which established common ground; then we describe the drawing exercises and self-reflection prompts used; lastly, we share and reflect on the key themes which emerged from the discussion.

Data that is digitally gathered, such as steps walked or hours slept, provides a quantified summary of behavior that can be difficult for the individual to interpret or to act upon. Data collected by individuals can also be aggregated and (mis)used in unexpected ways. Quantitative data are thought to be the backbone of predicting future health, but they can hamper rather than support everyday citizens' understandings of their health. Predictions based on quantification provide a narrow look at what it means to be healthy or well, and proprietary technologies can have changing, unverifiable, and systematically biased inaccuracies. One motivation for self-tracking through "quantified-self" interventions is to render an unseen body experience visible and to control some aspect of life, but the available tools may not only fail to deliver on many expectations of visibility and control but also introduce new sources of obscurity and powerlessness (Kuksenok & Satsia, 2021), both at a bodily and a societal/institutional level.

The 1.5-hour workshop we hosted combined expressive drawing exercises and discussion prompts to highlight problems with digital health data. We focused on rich data generation, including qualitative data and qualitative representations of quantitative data. Qualitative data, such as visuals or text, resist common summarization practices that quantitative data affords and are thus rich sites for considering the role of algorithmic classification and summary visualizations in reducing and containing data. Qualitative representations of data can also offer insights into individuals' "lived experience," as people tend to express themselves more metaphorically, i.e., "I feel stuffed" or "I slept like a baby" (Lockton et al., 2017). We based our work on prior workshops (Kuksenok, 2022) that featured daily artistic practices of re-thinking what data can be situated within data feminism (D'Ignazio & Klein, 2020) as a framework for reflection on, and critical discourse on, personal and institutional data practices.

2 BACKGROUND

What does it mean to use data to visualize and understand the interior unseen body landscape? To help establish a common starting point, the workshop began with a brief round of participant introductions and a short review of several ideas from existing literature on health data from different fields. The dozen participants in the workshop had different professional experiences, but all had

some personal interest in digital health data. The selected anchoring references, provided as a single-page handout in the workshop and summarized below, situate the expressive exercises (described in Section 3) in relation to the theme of the conference: practicing [digital/data] sovereignty.

Data collected through and about the body can be generative and insightful creative material, “like paint or paper, offering a new way of seeing and engaging with the world” (Lupi & Posavec, 2018). However, data used to render the body more visible—as a “screen body”—may sometimes lead individuals to mistrust their own senses and assume manageability. As the following quote illustrates:

The visual image of the data [contemporary technologies of measuring and observing the body] generate are often privileged as more “objective” than the signs offered by the “real”, fleshy body and the patients’ own accounts of their bodies. ... As part of the project of seeking security and stability, such technologies attempt to penetrate the dark interior of the body and to render it visible, knowable and thereby (it is assumed) manageable. (Lupton, 2016, p. 53, citing others)

Motivations for self-tracking include not only the desire to observe but to gain control: (1) reducing or eliminating uncertainty, (2) truthfully observing a bodily experience, an (3) directing behavior change. However, methods for self-tracking entail losing control, such as when: (2) new sources of uncertainty are encountered, (2) “objective” data brings disconnection from the subjective experience, and (3) behaviors are influenced in unintended ways (Kuksenok & Satstia, 2021). A relative loss of control not only includes the immediate and behavioral but also subtle aspects of data’s role in society.

For example:

[Although it can be argued] that self-tracking is an alternative data practice that is a form of soft resistance to algorithmic authority and to the harvesting of individuals’ personal data. They argue that self-tracking is... “a profoundly different way of knowing what data is, why it is important, who gets to interpret it, and to what ends. ... However, the issue of gaining access to one’s data remains crucial to questions of data control and use. While a small minority of technically proficient self-trackers are able to devise their own digital technologies for self-tracking and thus exert full control over their personal information, the vast majority must rely on the commercialized products that are available and therefore lose control over where their data are stored and who is able to gain access.” (Lupton, 2016, p. 133; citing Nafus & Sherman, 2014).

Data, especially personal health data, has the capacity for betrayal (ibid.) because it can be used by institutions as mechanisms of surveillance and control. One example of this is when employers require workers to report measures of health and uses these to inform health insurance contribution (O’Neil, 2016). In response to this, contemporary artists have explored the possibility of adapting existing body-observation and body-measurement tools for counter-normative goals (Kuksenok &

Satsia, 2021; Satsia & Kuksenok, 2021). Such subversive body projects may shift the emphasis away from “self-knowledge through numbers” toward “[treating] digital self-tracking devices not as means of self-discovery but as tools for inventing oneself as something new and not yet imagined”; instead of “body projects” that “define progress, success, and satisfaction in terms of the exterior form of the body ... [toward a] counter-normative and more liberating digital body project would perhaps be purposefully goal-unoriented”; and instead of “game design elements” which in practice “do not make self-tracking endeavors truly fun, playful, or pleasurable,” “focus on the quality of one’s interior experience... thereby adopting a counter-normative way of experiencing the body and evaluating how one feels” (Sanders 2017, pp. 21–22). Lastly, we shared the list of data feminism principles (D’Ignazio & Klein, 2020), which stress reflection on context and the examination power dynamics built into data objects, as a starting point for articulating one’s values about personal and institutional data practices.

3 EXERCISES & PROMPTS

Following introductions and context-setting, we went through a series of three exercises that combined drawing and self-reflection. The materials provided were color pens and markers, graph paper, and tracing paper. The handouts with references (as summarized in Section 2) also included one-sentence summaries of the three exercises and the prompts (below, these prompts are *italicized*).

Resonant heartbeats. *Take 1.5 minutes to make tick marks with a pen/pencil on a piece of paper every time your heart beats.* This exercise, adapted from (Lupi & Posavec, 2018), has three key goals within the context of the workshop: (1) It centers on the body, as it can be challenging to find a heartbeat; (2) It supports starting a discussion about data observation—when did you make the tick-mark? Did observing the heartbeat change it? (3) It creates a shared, embodied experience through sound.

Data inventory. List as many existing personal data sources as you can. For each: What would be an obvious finding from this data? What would be a surprising finding? For the whole list: What data sources are complementary? What data sources help validate a surprising finding? When moving on to the next exercise, the participants are encouraged to keep adding to this list if new data sources come to mind. As in prior workshops, some are surprised by how long this list can become.

Data archaeology and re-activation. Decide on a personal topic to retroactively explore for some time interval in the past (the longer the better; months or even years), ideally something that is still relevant today (widely applicable examples include sleep, mood, movement, or food). Start with a memory of key event dates, listing them; then create an accordion with the tracing paper (this was

demonstrated) with as many folds as there are events, drafting the first major timeline. Within this, fill in the middle bits, using, for example, a calendar or other sources of data. Tracing paper can be layered to make revisions and additional notes or participants can use one sheet of paper for one type of data (e.g., sleep) and a second for another (e.g., specific test results). Within the workshop, participants are free to leave placeholders or “coded” notes to self to maintain privacy. Further prompts:

- Were you actively tracking anything during this timeframe? Related or unrelated to the chosen subject? Or passively tracking?
- Are data tracked and stored but inaccessible to you? What or how can that data be retrieved, and would it be useful?
- Does anything emerge as an area of interest—something that maybe you would want to look more closely at?
- How did you deal with missing data or uncertain data? Or data from multiple sources?
- What has been the role of tracking and reflecting on data for you so far? Short versus long-term data tracking? Do any new possibilities arise?

Within the drawing exercises, the orientation toward one’s health data (supplemented by other, non-health-specific sources) is generally approached from the perspective of possibility and of exploring the potential benefits of long-term self-reflection through data in a way that directly corresponds to participants’ own interests. After a short break, we built on this shared experience of embodied self-reflection within a more abstract, value-oriented discussion.

4 DISCUSSION

In this section, we summarized some of the key themes that arose during the discussion among the dozen participants. Although the exercises initially centered on individual experience, both the follow-up prompts and the context of the conference (“practicing sovereignty”) contributed to themes arising about institutional trust.

How is health data tracked? The discussion distinguished broadly between **passive or active** methods, based on whether any action was needed to record an event. This distinction has ethical, epistemic, and usability implications. At the level of usability and user experience (UX), the discussion brought up the difficulty of active tracking. Food intake tracking, for example, is typically a manual activity, where US-based apps use US-based nutrition and product databases, making it more difficult to use in a non-US context. Self-tracking activities can be more sustained when there is a need; this was the subjective experience of participants who tried self-tracking, and it is generally observed in, for example, research on self-tracking for the management of diabetes, where individuals

need to monitor metabolic state information and well as medical guidance. Most consumer food tracking applications, even when driven by a need, have many opportunities for UX friction, which degrades the accuracy of data: Are users weighing every bit of food they eat to track their food intake, and if a database is used to simplify this process, does it reflect the products in their region? There are accuracy challenges in any tracking application, but the epistemic challenge goes beyond that. Even if accuracy is well-understood, it is never 100%, and implied causal links may not be applicable. Within the realm of medical testing and screening, testing and observation must be justified, especially for tests associated with higher false-positive rates. Meanwhile, consumer tracking applications take the opposite approach, offering quick fixes, although the scale at which meaningful bodily change occurs is typically long. Lastly, on a data-ethical level, the group expressed uncertainty about how much data is being tracked passively on consumer phones; and a concern about the lack of awareness among the general population. Among the conference attendees, there was a high degree of awareness of the potential pitfalls of digital data, but even within the small group, there were different mental models and degrees of awareness of the capacity of health data to be misused.

In considering **autonomy and consent**, the group generally agreed that “everyone should own their own health data” and control it, which would mean any apps involved would not be free. One mechanism for data ownership has been local on-device storage for mobile tracking apps, such as for one menstruation app (Drip) that was mentioned. Following the ban on abortion in many US states, the privacy policies of period-tracking apps have come under scrutiny—the concern is that these apps maintain detailed history of fertility and sexual activity that could be used against the interests of their users. Although on-device storage is a useful mechanism in some cases, it would not necessarily prevent user from being legally compelled to share their data; furthermore, the complexity of each of these apps is such that the consumer must trust both the app and the app ecosystem to operate in good faith. In the discussion of consent, parallels were drawn to the EU’s General Data Protection Regulation (GDPR), with participants noting that consent should be understood in relation to a specific purpose and that autonomy requires the capacity to accept the consequences of providing or not providing health data and knowing the consequences of either sharing or refusal.

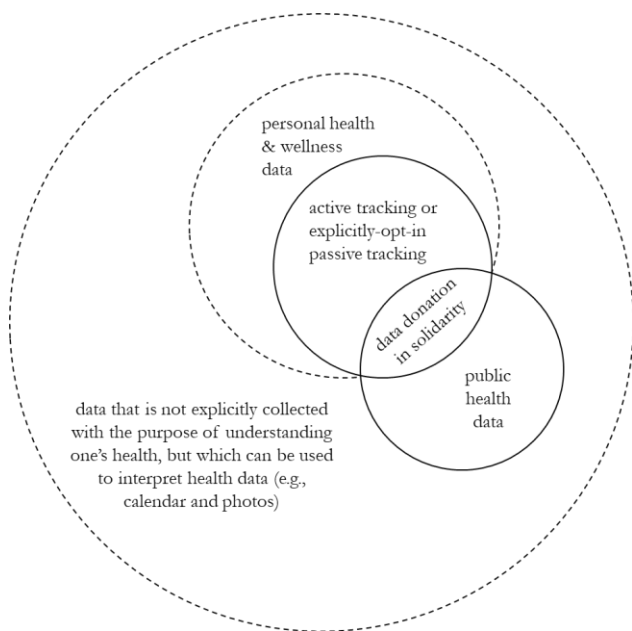


Figure 1. A What is health data? Several overlapping but distinct types of data came up in the discussions.

What is the purpose of collecting personal health data? Aside from general wellness-related goals or the context of managing one's health within a medical treatment plan, the group also recognized public goals. Personal and public health datasets can overlap when personal data can be donated to a trusted institution (despite some possible risk even when anonymity is maintained) as an act of **solidarity**. This is typically organized by institutions requiring active, opt-in consent. For example, female citizens in Belgium aged 50–69 can participate in a breast cancer screening examination, which can be aggregated at the population level. Such screenings are based on informed consent, which is explained on the screening websites, and derive their trustworthiness from being government initiatives intended to create a social good. Nevertheless, this aggregate data still has the potential to adversely affect particular populations if it informs policy connected to health insurance (depending, of course, on the context and content of such policy). The risks associated with any aggregation of personal data into public datasets, by either public or private institutions, depend on the specific vendors and technologies used. Both personal and aggregated/public health data are within a broader sphere that includes health data that users do not explicitly consent to (such as passive step tracking by a mobile device that a user has forgotten about), or non-health-specific data that could potentially be used together with the health data. This broader realm of data is not typically easily usable through tracking software, but it is subject to similar data-ethical issues of ownership and storage. Aggregate data, such as the data in public health datasets, contributes to another challenge that the discussion touched on: that medical professionals may not have the time to look deeply into the data available, or when they do, they may pay more attention to the aggregate than to the subjective experience.

This discussion had wide-ranging themes, which we have summarized above. Although the facilitators asked follow-up and clarification questions, the discussion prompts were either general and grounded in personal data reflection (such as those in Section 3) or open-ended and related to the anchoring references (such as those in section 2). The breadth and depth of this discussion reflects the variety of perspectives that the participants offered. The facilitator took care to keep the discussion constructive, by building connections between recurring themes—*When is a particular data practice worth the risk? What is the risk?*—instead of initiating a polarizing debate by asking questions on whether a particular data practice is good or bad. Participants had different professional and personal relationships to digital health and tracking applications, and even in the shared context of a conference on data sovereignty, these different backgrounds led to different perceptions and interpretations of the practical state of data tracking in relation to the shared ethical sense that autonomy and consent are essential. For example: although there was some consensus that even not entirely risk-free activities (active self-tracking for specific reasons; donations to a public health dataset) could be worth undertaking within the context of trust and credibility (trusting a credible app; trusting a credible institution), no mechanisms for establishing or recognizing this trust were suggested. All topics in this discussion are the subjects of active research, but they are also deeply relevant to everyday citizens, whose data (health and beyond) is collected, aggregated, and used extensively. Thus, we believe it was valuable to facilitate a workshop where these subjects could be explored actively (through drawing and discussion), rather than passively (through reading popular articles, which can be polarizing).

5 CONCLUSION

The goal of our workshop was to enable participants to (1) try out new ways of encountering tracked and health data for reflection, (2) practice applying critical and reflective data practices to health data and beyond, and (3) experience community data reflection in action and reflect on their values with respect to data. As documented in this article, these goals were addressed through drawing and discussion over the course of 1.5 hours. Although the conference context provided some shared background about digital technologies generally, the participants' backgrounds with respect to health data varied widely. The topics in the discussion are subjects of active research but are not typically the subject of casual public discourse. Even when they are brought up, it can be difficult to reflect both the empowering and the uncomfortable aspects of digital health data collection in a constructive manner. This example of this workshop illustrated how the format of hands-on, expressive drawing activities can lend depth and breadth even in a relatively short discussion among strangers. We held this workshop because we believe that critical discourse about data, especially health data, is a

valuable experience for every person whose health data has been or is being collected; and that starting with personal data can support crucial discourse on other aspects of how data is produced and handled, to practicing digital/data sovereignty more broadly.

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