Dear Data Double, Am I Happy?

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INTRODUCTION

Data has become an embedded part of contemporary design processes. Where data gathering previously was a separate, isolated design activity that took place during the research or the validation phase, recent developments in real-time data gathering have turned data into a fluid material [4] to be used throughout the entire design process. Using data as a design material is vastly different from using it as a data science material. The data does not lead the process, instead it is collected and organised to fit the process. Data as a design material often has stories embedded in it, and it is up to us as designers to excavate these stories and to use them to inform design action.

I wish to respond to the workshop call, specifically to the question: "what data can we collect, notably once we expand our horizons beyond data that is considered *useful* and/or *personal*?" [5]. Before considering how to expand beyong useful and personal data, I aim to investigate what useful and personal data in the medical domain encompass for different stakeholders involved. In order to do so, I present four short narratives based on the four narrative archetypes that I have described in more detail in previous work [7]. In prior work on the narratives, I explore different attitudes towards personalised, data-driven healthcare, as part of ongoing research into the collection of contextual and behavioural data for tailoring healthcare [3, 4]. The described system uses the concept of data doubles: "data accumulated through self-tracking creates a new entity that mirrors, resembles, reflects, mediates and interacts with the tracking user" [1, p.5]. Data doubles are close in definition to *digital twins*, but rather than only creating a virtual profile for the user, data doubles also use prediction and simulation to bring the virtual profile to life [1, 2]. All narratives explore a future world where data tracking and data doubles form an inseparable part of a lifestyle-focussed, personalised healthcare system. The narratives build on the Dutch healthcare system, which includes mandatory health insurance for all citizens and permanent residents. The narratives were written using ChatGPT [8] and the images generated with Midjourney [6]. I polished both the narratives and images after they were generated.

FIGHTER

April 4th, 2084. Another night out with friends. It felt different today. We sat at the bar and I couldn't help but notice how obsessed everyone was with their health stats and calorie intake. Every few minutes, they'd check their wrists for a notification dopamine hit, like they were addicted to their data doubles. It was all so sterile, so calculated. It's not how I know my friends at all. Back when we were in school we would always make spontaneous plans. Those are my fondest memories!

There is something unsettling about how much they rely on the data to tell them how to live, as if they have forgotten how to listen to their own bodies. A rumbling stomach should tell you it's time for lunch, but I wonder if they even still feel it rumble.

As it got later, and my mind got a bit foggier, their conversation only seemed to go deeper and deeper into their statistics and how many life-years they had gained with their healthy behaviour. It was like they were speaking a foreign language that I failed to understand. They spoke about their resting heart rate, sleep cycles, steps taken, and hormonal patterns. It was all so clinical, like they were speaking about someone else's body rather than their own.

Meanwhile, I just drank my beer, not caring about my calories or stats. I know that I will die someday, and I don't want to spend my life worrying about my health just because the data tells me to. I'd rather live in the moment and enjoy life as it comes.

May 1st, 2084. Joined the protests today. As I chanted "DOWN WITH BIG DATA," I couldn't help but feel a sense of purpose. We have to protect ourselves and future generations from becoming completely reliant on data. We have to fight against the dangers of data tracking and the data doubles and put our sanity first!
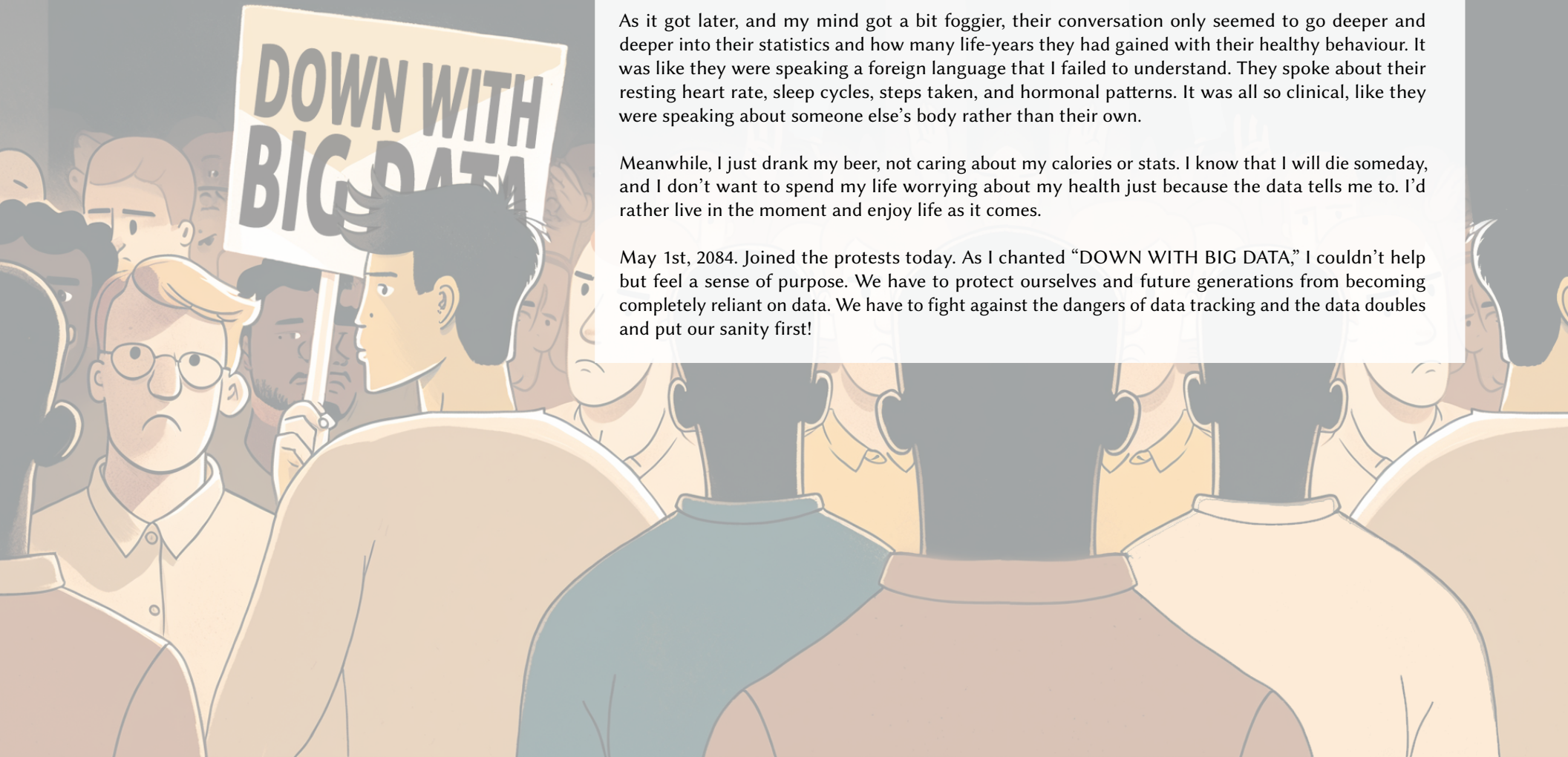
SETTLED

Step into my workshop and you'll be transported into a world of innovation and creativity that you might not expect from a doctor's workspace. Filled with interactive surfaces and drawers filled with data trackers ready to hand out to patients. But what really sets my work apart is the way I approach data. To me, data is not just information, it's a medium that I use to craft personalized solutions for my patients. When I use data in my work, I pick it up off the shelf like a carpenter picks up a piece of wood to build a piece of furniture. Just like the wood comes in different types and colours that hold different properties, I pick the data that feels right for the situation. I let my intuition guide me, like an artist.

It might surprise you to learn that I spend more time behind a computer than I do talking to patients. I look over my patients' daily activities, and by combining their real-time information with their unique profiles, I know exactly how to help them. Based on my presets, the systems deals with the easier cases, while I spend my time figuring out the complex and unusual ones. Through years of practice, I've honed my skills to know exactly where to look for clues and how to create the most effective health interventions. For example, last week I could not figure out why one of my patients suddenly stopped going for walks, when he normally has no trouble getting his steps in. His other health data looked normal, but I thought it was a bit strange. I called him up the next day and turns out that his dog passed away that week. He was devastated and said he could not motivate himself to go out anymore. I quickly searched my database and could match him up with one of my other patients who lives close by. Now they go for walks together almost every day, imagine that!

OUTSIDER

I did not feel great when I woke up this morning. I can't really say what it is, but it feels like something is off. I'm not as fast as I used to be on my daily morning walk, but I can just about make it to my favourite bench in the park and back home without wearing myself out. My husband and I loved this park, and we spent many hours on this bench together. Now, I come here by myself and think of all the memories we made. The past few days it has been more difficult to reach the bench.

I worry that I might get sick. I don't have as much energy as I used to have. I called the doctor yesterday but she said to take a paracetamol and to come back if it gets worse. She was always nice to me, but she is so busy now. She never has the time to talk so I don't want to bother her too much. And I don't think it's getting worse. Not yet, at least...

The doctor said I could get one of those health watches that all the young ones have now, but I don't think they are for me. The neighbour's kid showed his to me once but it looked very complicated, with graphs and charts and stuff. I've never been much of a reader anyway and they aren't cheap either. The kids have also been telling me to get one but I don't think it's worth it. I will just see what I can make of it with the nice lady from the pharmacy. She's always very helpful and it's nice to have a little chat with her on my way to the park.

POWERFUL

As I stand before the group in the meeting room, I can feel their eager anticipation as I present the new PocDoc system that we have developed for use in hospitals. "Our PocPrograms module automatically selects and configures the programs to make them most suitable to the patient. In this way, they already receive relevant care before they ever come into contact with the hospital. The stress on the health care system is relieved to make more time for complex cases. The chat functionality also lets patients talk to an AI that has been trained as their personal health data double." Suddenly, one of the hotshots in the room interrupts me with a question. "What's the biggest risk for care quality?" they ask. I feel my cheeks flush with embarrassment as I pause to think.

I was shocked when I learned that one of the patients in our trial had, late at night, typed into the chat: *Am I happy?* The chatbot had responded that it could not answer that question, per protocol for sensitive questions. However, the patient continued to ask follow-up questions: *How can I be happier about my body? How do I find meaning in my life? Will it ever get better?* The chatbot had continued repeating the same sentence after each question: *I'm sorry, I can't help you with that, please contact your doctor.*

The patient never reached out to their doctor, and I still feel guilty about our failure to design for these sensitive situations. I wish I could do something about it, but I'm so swamped and I really need this customer to reach my targets. And surely, this was an outlier in the group. We have made big, positive impact with many of the other patients... Right?
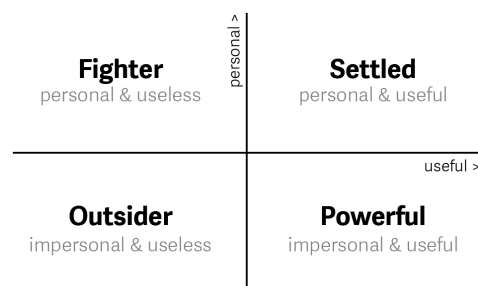
Fighter
personal & useless

Settled
personal & useful

personal >

useful >

Outsider
impersonal & useless

Powerful
impersonal & useful

Figure 1: Matrix of the usefulness and level of personalisation of the data described in each of the narratives

REFLECTIONS

The narratives that I have presented here have very different scopes and formats. I wanted to use the different perspectives to explore what *personal* and *useful* data could mean in the healthcare domain. I have employed different interpretations of both terms, and they come across in different ways in the four narratives. Figure 1 shows how the data uses represented in the narratives map onto axes of usefulness and personalisation.

Fighter. The Fighter narrative explores data interactions that are highly personalised from the perspective of the care consumer. The friends of our narrator get tailored feedback on the health data they share with their healthcare providers. The envisioned system gives them actionable feedback that can be directly implemented in daily life, hence the continuous glancing at their devices. At the same time, our narrator makes us wonder whether the feedback is actually that useful, because it is actively disrupting their everyday life and arguably, their mental health.

Settled. The Settled narrative is the only one out of the four narratives that shows us an interaction with the data system that has personal as well as useful qualities. The caregiver has an efficient workflow and is able to understand the patient's personal situation through the data collected about them, such as their affectionate response to the passing of the patient's pet. This narrative highlights the data system as a tool to support the caregiver in their job rather than replace them. It also demonstrates the importance of a human interpreter of the data in order to meaningfully personalise. However, this narrative is not just positive as it perpetuates data solutionism, and one could easily imagine a different scenario where the solutions the caregiver presents are not effective.

Outsider. The Outsider perspective is meant to demonstrate how personalised, data-driven care might not be accessible to everyone, and indicates the importance of considering groups that for a myriad of reasons might not have access to the data solutions that we provide. In this case, the data solution is neither personal nor useful, as our narrator is both financially and practically hindered from using it. This perspective demonstrates the need for data double interfaces that are easy to afford and use for a diverse audience, and highlights the risks of a society that depends on this novel technology.

Powerful. In the Powerful perspective, in the memory that the narrator recollects we see the opposite of the fighter perspective. The chatbot facilitates easy access to healthcare advice, but fails to understand the patient's personal situation. In this case, the patient was not looking for useful advice, but rather for a personal response to cheer them up and calm them down. This demonstrates the importance of the system being holistic and flexible in switching between different modes depending on the current situation.

CONCLUSION

In this short paper, I have explored several everyday consequences of the implementation of the concept of data doubles in the healthcare domain. The narratives give a perspective on the different stakeholders that would be impacted by the introduction of this technology. Furthermore, they explore the usefulness and the personalised nature of these data doubles. Based on these narratives and the analysis, data doubles in healthcare are useful when they can (1) give users actionable insight into their health without disruption, (2) make the caregiver's workflow more efficient, and (3) be affordable and easy to use by a diverse audience. Simultaneously, in order for the system to be personalised, it needs to (1) fit into user's personal routines, (2) empower caregivers to interpret personal data, and (3) provide holistic and flexible care to be able to tailor not just to the person but also to the moment.

ACKNOWLEDGEMENTS

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