Original Research Article

Why Personal Dreams Matter: How professionals affectively engage with the promises surrounding data-driven healthcare in Europe

Marthe Stevens[1] [iD], **Rik Wehrens**[1] [iD], **Johanna Kostenzer**[1] [iD],
Anne Marie Weggelaar-Jansen[2,3] and **Antoinette de Bont**[1]

Abstract

Recent buzzes around big data, data science and artificial intelligence portray a data-driven future for healthcare. As a response, Europe's key players have stimulated the use of big data technologies to make healthcare more efficient and effective. Critical Data Studies and Science and Technology Studies have developed many concepts to reflect on such overly positive narratives and conduct critical policy evaluations. In this study, we argue that there is *also* much to be learned from studying how professionals in the healthcare field affectively engage with this strong European narrative in concrete big data projects. We followed twelve hospital-based big data pilots in eight European countries and interviewed 145 professionals (including legal, governance and ethical experts, healthcare staff and data scientists) between 2018 and 2020. In this study, we introduce the metaphor of dreams to describe how professionals link the big data promises to their own frustrations, ideas, values and experiences with healthcare. Our research answers the question: how do professionals in concrete data-driven initiatives affectively engage with European Union's data hopes in their 'dreams' – and with what consequences? We describe the dreams of being seen, of timeliness, of connectedness and of being in control. Each of these dreams emphasizes certain aspects of the grand narrative of big data in Europe, makes particular assumptions and has different consequences. We argue that including attention to these dreams in our work could help shine an additional critical light on the big data developments and stimulate the development of responsible data-driven healthcare.

Introduction

There are high hopes for data in the European healthcare field. Public officials seem to embrace big data, machine learning and artificial intelligence and argue for the use of such data-intensive technologies in healthcare practices (e.g. DEH, 2021; EC, 2014; EC, 2018). Their expectations are high and many believe that data-intensive technologies will lead to an awe-inspiring healthcare revolution, gloriously improved healthcare planning and increased quality of care delivery (Stevens, 2021).

These data hopes have proved particularly productive on the European policy level, shaping the strategic positioning of the European Union through a strong narrative that stresses the transformative potential of data (Bareis and Katzenbach, 2021; Daly et al., 2019; Niklas and Dencik, 2020). The European Commission for instance, frequently emphasized how big data can be a cornerstone of a thriving economy and can improve healthcare by increasing its efficiency and effectiveness while also making it more personalized and user-friendly (Rieder, 2018). Questioning such

[1]Department of Health Care Governance, Erasmus School of Health Policy & Management, the Netherlands
[2]Department of Health Services Management & Organisation, Erasmus School of Health Policy & Management, the Netherlands
[3]4TU, Department of Clinical Informatics, Eindhoven University of Technology, Eindhoven, the Netherlands

Corresponding author:
Marthe Stevens, Department of Ethics and Political Philosophy, Radboud University Nijmegen, Erasmusplein 1, 6525 HT, Nijmegen, Gelderland, the Netherlands.
Email: marthe.stevens@ru.nl

modernist discourse (Hoeyer, 2019; Rieder, 2018; Stevens et al., 2018) has been challenging. The current moment in time is presented as exceptional, giving rise to a rhetoric of hurry in which investments are urgently needed for Europe not to become outpaced by other economic entities (Rieder, 2018; cf. De Wilde, 2000).

As many researchers in the sociology of expectations and related fields have shown, such hopes do not stay mere descriptions of a possible future (cf. Jasanoff and Kim, 2009; Van Lente, 1993, 2012) but have strong performative effects: they result in allocating substantial resources to data-intensive technology, new policies and regulations, and all sorts of initiatives (Bareis and Katzenbach, 2021). For example, the European Commission launched a 2.5 billion euro public–private partnership to 'master big data' and put the Union at the 'forefront of the global data race' in 2014 (EC 2014:1) and artificial intelligence projects receive extensive funding within Horizon Europe Programmes (Niklas and Dencik, 2020). In this way, Europe's key players hope to boost the uptake of data-intensive technology, prepare for socio-economic changes and ensure adequate ethical and legal frameworks (Daly et al., 2019).

With these evaluations of European policies, the above-mentioned scholars provide valuable insights into the overtly positive narratives and open up avenues for critical policy evaluations. While such critical analyses are necessary and can be productive, we argue that the extremely widespread storyline about the potential of data-driven technologies cannot be explained by solely viewing it as a purely strategic rhetoric act of 'window-dressing'. Neither do we find it convincing to assume that all types of professionals working in the healthcare field somehow naively fall into the 'trap' of buying into such expectations (and consequentially, that only 'critical' scholars are able to see through this alleged façade of hopes and hypes). Therefore, in this paper, we set out to understand how diverse professionals relate to and work with such optimistic narratives in their daily work in a different way. Utilizing and building on the metaphor of 'dreams', we argue that there is much to be learned from studying how professionals affectively engage with this strong European narrative in concrete big data projects in healthcare organizations.

We were part of a Horizon 2020 project funded by the European Commission that had the ambition to demonstrate the added value of big data for the healthcare sector (BigMedilytics, 2018). Between 2018 and 2020, we followed twelve hospital-based big data pilots in eight European Countries and interviewed 145 professionals involved in developing data-driven healthcare, including legal, governance and ethical experts, and healthcare staff and data scientists. We noticed that these professionals often linked the strong European narrative to their own frustrations, ideas, values and experiences with healthcare.

There we decided to focus on this process of affective engagement that we define as the complex ways in which professionals bodily and cognitively engage with the promissory rhetoric around big data in Europe and connect the ideas to their daily work on big data in healthcare. This leads to the following research question: how do professionals in concrete data-driven initiatives affectively engage with European Union's data hopes in their 'dreams' – and with what consequences?

In what follows, we sketch the theoretical background of the paper. Engaging with literature in the sociology of expectations (e.g. Borup et al., 2006; Konrad et al., 2017; Van Lente, 1993, 2012) and sociotechnical imaginaries (e.g. Jasanoff and Kim, 2015), we build on the underutilized notion of dream as a heuristic tool. The metaphor allows us to shift the focus from the institutionalized, stabilized and publicly performed visions of desirable futures to the personal and individually performed visions of desirable futures. We argue that personal dreams matter and merit more detailed investigations on their own. Next, we introduce our methodology. In the results section, we distinguish four 'data dreams': the dream of *being seen*, the dream of *timeliness,* the dream of *connectedness* and the dream of being *in control*. We show how these dreams present diverse ways of linking the overarching promissory rhetoric to the professionals' personal experiences, ambitions and frustrations with European healthcare. Finally, in the discussion, we reflect on the metaphor of dreams and explain how including attention to professionals' dreams can provide grounds for critical reflection and help the development of responsible data-intensive healthcare.

Theoretical framework

Promissory rhetorics

Scholars in Science and Technology Studies (STS), Critical Data Studies (CDS), and related fields have developed various concepts to theorize on policy narratives and imaginative work, and to study the complex interplay of discourse, politics and technology. For instance, this extensive body of literature focuses on mythology and future-oriented discourses (e.g. Ames, 2018; De Wilde, 2000; Smits, 2006). These studies describe how novel technologies are regularly surrounded by modern myths full of speculation about the future with such technologies. Instead of viewing such narratives as mere fantasy, these scholars aim to unpack these future narratives, for example, by demonstrating (1) the many ways in which such narratives already steer and shape our current world, (2) how the narratives are situated (culturally and temporally grounded) and represent all sorts of desires, values and underlying power structures.

Scholars have also done related work on expectations within the 'sociology of expectations' (e.g. Borup et al.,

2006; Konrad et al., 2017; Van Lente, 2012). This body of work demonstrated how both formal (which can, for instance, be found in strategy documents of organizations) and more informal (such as ideas that circulate in certain organizations) expectations shape technology and technological fields. It also describes how key actors and institutions expect particular futures and this has important performative effects. These scholars build on concrete empirical cases to show how expectations mobilize actors, legitimate and justify investments, set courses of action and steer the options to be explored by researchers and technology developers (Konrad et al., 2017; Van Lente, 2012).

A concept that has gained particular traction in the field of STS is the concept of sociotechnical imaginaries, introduced in Jasanoff and Kim (2009) and further elaborated in Jasanoff and Kim (2015). It has inspired a growing number of case studies to look for and investigate 'collectively held, institutionally stabilized and publicly performed visions of desirable futures' (Jasanoff, 2015: 4; examples of case studies are Felt, 2015; Levenda et al., 2019; Rieder, 2018). Sociotechnical imaginaries are used to explore how collective imaginaries legitimate specific policies while foreclosing on others. Crucially, sociotechnical imaginaries highlight the embeddedness of future narratives. The concept emphasizes that narratives are co-produced within heterogeneous networks of both human and non-human actors and are often specific to particular geographical areas. This happens, for example, on national and European levels as here actors have the capacity to structure future narratives and combine them with powerful measures such as 'the selection of development priorities, the allocation of funds and the investment in material infrastructures' (Jasanoff and Kim, 2009: 123; Rieder, 2018).

Together, this body of work offers a rich repertoire of concepts that can be used to study the data hopes within the European Union and its many consequences. However, this body of literature often emphasizes that the embedding of particular visions of the future into policies and practices are, per definition, group achievements or the work of particular powerful actors that can 'mobilize the resources for making their visions durable' (Jasanoff, 2015: 25). The reasoning is that countries, institutions and powerful actors operate as the most effective agents of extending particular visions for the future as they already exercise authority and implement the rules of the game (Jasanoff, 2015).

In this paper, we argue that there is *also* much to learn from the professionals that work towards data-driven healthcare and how the data hopes are translated or extended (Jasanoff, 2015: 332) to and take shape in concrete data initiatives. The literature seems to assume that most professionals working on these technologies are mesmerized by the utopian narratives or are mobilized through expectations. We argue that analytically this is unsatisfactory. Professionals are not known to naively follow the promises for the future, nor are they willing to participate in projects that are nonsensical or infeasible. They tend to be highly critical of the adoption of new technologies and other innovations if these cannot be embedded usefully in the daily flow of their work (e.g. Berghout, 2020; Stevens et al., 2020). Indeed, one persistent finding within the sociology of professions literature points towards the substantial agency of professionals in tinkering with, working around, subverting from and outright rejecting of technologies that are perceived to reduce the meaningfulness of clinical work, strengthen managerial hegemony, or impact on professionals' discretionary space to conduct their work (Bar-Lev, 2015; Håland, 2012; Hoeyer and Wadman, 2020; May et al., 2001). Therefore, we want to introduce the metaphor of 'dreams' as an additional heuristic tool in this paper to explore this relationship between the grand narratives *and* the concrete practices in which people work and affectively engage with data-driven healthcare.

The metaphor of dreams

We decided to tease out the analytical potential of this metaphor in more detail after noticing how scholars within STS and CDS use the notion of dreams in their work; haphazardly, often without defining the term. More detailed reflection on the ways the notion is used in STS and CDS literature allowed us to distill three different ways scholars use the notion of dreams. First, we noticed that many scholars use dreams to indicate particular visions of the future (e.g. Koed Madsen, 2018; Wadmann and Hoeyer, 2018; Wilmott, 2016). A clear example can be found in Gillespie (2020) in his paper about social media platforms and content moderation. He states: 'all the major platforms *dream* of software that can identify hate speech, porn, or threats more quickly and more fairly than human reviewers, before the offending content is ever seen' (Gillespie, 2020: 2). Here the notion of dreams is used to describe a particular hope (improved content moderation) from a certain actor (social media platforms) and used to describe actions that the actor takes to achieve their desired future.

Secondly, scholars use the notion of dreams to differentiate portrayals of technological developments from current practices (e.g. Aradau and Blanke, 2015; Chalmers and Edwards, 2017; Seaver, 2017). Venturini et al. (2017) for example, describe 'by our trials and by our errors, we experienced how different the practice [of] digital research [is] from the *dream* of Big Data' (Venturini et al., 2017: 10). In such quotes the notion of dreams is discursively placed in the realm of grand narratives and overarching discourses, and away from actual practices. Sometimes, this use of 'dreams' is extended by mentioning nightmares as a clear counterpart of the dreams to emphasize fears and negative consequences (e.g. Ames, 2018).

Lastly, scholars use dreams to describe something highly personal (e.g. Andrejevic, 2020; Barnes and Wilson, 2014;

Thrift, 2014). Törnberg and Törnberg (2018) reflect on Big Data research and state 'the increasing use of digital services has given social scientists unprecedented access to previously unimaginable data: traces of the lives, *dreams* and feelings of hundreds of millions of people' (Törnberg and Törnberg, 2018:7). In such usage, dreams become part of the personal realm, which often needs some form of protection.

In this paper, we argue for the analytical productivity of taking the notion of dreams, so often used implicitly and interchangeable, more seriously. Therefore, we use the metaphor of dreams as a heuristic tool to study how professionals affectively engage with European Union's data hopes in concrete big data initiatives. We argue that the analytical suitability of this metaphor rests on the way the notion allows us to bring together three key dimensions of the promissory discourse of big data: the hopes of a particular future with data, tensions between grand narratives and practices of big data and the lives and experiences of individual professionals. The metaphor of dreams, we argue, helps thus to understand what particular elements of the grand promises around big data technologies are valued by professionals and with what reason. In addition, it helps to make an explicit connection between the understanding and valuing of the development of big data technologies with the actual realization of the promises in big data pilots.

Methods

Context of this paper

In an effort to 'master Big Data' and to put the European Union at the 'forefront of the global data race', the European Commission decided to stimulate public–private initiatives in its Horizon 2020 program (CORDIS, 2016). In response to this call, we, the authors, partnered with 34 other partners in a consortium in an effort to 'transform healthcare through big data' and were awarded Horizon2020 financing (BigMediltyics, 2020). See Table 1 for an overview of the consortium partners.

The goal of the consortium was to (1) use big data technologies to improve productivity in the healthcare sector, (2) ensure the long-term affordability of healthcare services and (3) stimulate the adoption of big data usage in the sector

Table 1. Overview of the 35 consortium partners.

Type of organization	Number
Research institutes	N = 11
Healthcare providers and insurers	N = 10
Technological companies	N = 7
Universities	N = 6 (including us)
Pharmaceutical companies	N = 1

(BigMedilytics, 2020). Together, we decided to concentrate our efforts in eight European countries (Austria, France, Germany, Ireland, the Netherlands, Spain, Sweden and the United Kingdom) and work on twelve data-driven healthcare initiatives to demonstrate the added value big data technologies.

Our role in the consortium was to gain a better understanding of the formal and informal rules and regulations that surrounded big data in each of the eight countries. We used a broad, sociologically inspired definition of rules and regulations. This meant that we also understood ethical debates and societal discussions as setting important rules for data technologies and that regulations also include informal work practices, organizational procedures, routines and habits (see for more information also Wehrens et al., 2020).

To gain insight into the rules and regulations, we used a combination of qualitative research methods (Mortelmans, 2008). First, we conducted desk research. We analyzed policy documents, news articles, scientific papers and grey literature to become familiar with the different health systems, the public discussions about big data and the diverse perspectives and positions of the countries. This document analysis resulted in draft reports about big data for each country.

Second, we interviewed professionals ($n = 145$) working on data-driven healthcare in the eight European countries between April 2018 and December 2020. We identified respondents via the consortium members and through our desk research. We strived for a balance between different professional categories (healthcare professionals, ethical and legal experts, technology developers and data scientists, patient representatives, policymakers and visible actors in the public debate) in each country.

The semi-structured interviews were based on a predefined topic list, focusing on several core themes yet allowing flexibility and adjustment (Mortelmans, 2008). During the interviews, we asked questions such as: How would you describe the current development of big data in the [name country] healthcare field? What do you consider to be benefits or risks for big data in healthcare – and why? Are in your experience more informal social or cultural norms or customs specific to [name country] relevant to how big data is regulated or received?

Most of the interviews were conducted during country visits as this meant that respondents could show us their organizations, their projects, and we could quickly build rapport. Face-to-face interviews are generally preferable as they allow the interviewer to pick up subtle cues, nonverbal communication, to get a better understanding of a person's context, and to establish a relationship of trust in which the respondent feels comfortable in expressing their thoughts on a topic (Mortelmans, 2008). In case face-to-face interviews were not possible, we held interviews online or by phone. The interviews lasted between

30 and 150 min. At the start of each session, we asked permission to record the interview. In all cases, permission was obtained, and the interviews were recorded and subsequently transcribed ad verbatim.

Our work eventually resulted in infographics that summarize relevant regulations and practices (BigMedilytics, 2018) and video's (BigMedilytics, 2021). More information about our approach can also be found in the methodological appendix we wrote about the project (Wehrens et al., 2020).

The secondary analysis

For this paper, we conducted a secondary analysis of the collected material (Heaton, 2008; Mortelmans, 2008). During our research meetings, we became increasingly interested in how the strong promissory rhetoric regarding big data in the European Union translated to concrete healthcare settings. We noticed how our respondents often recognized or described the grand promises of data, but at the same time shared their own stories with us and explained why they decided to invest time, energy and resources into realizing data-driven healthcare. This is how the focus of this paper emerged as one interesting aspect in the data that needed further analysis.

What followed was an abductive analysis (Timmermans and Tavory, 2012) in which we moved between our empirical material and the theoretical concepts described above. In this process, we gradually zoomed in on the metaphor of dreams to analyze the ways in which professionals affectively engage with the overarching promises in Europe.

We started by revisiting the 145 interviews and annotated passages in which the respondents reflected on the promissory rhetoric of the European Union (e.g. respondents that explained what part of big data was important for them) and explicitly connected those to their hopes for their own organizations and daily work (e.g. how they hoped that their work or organization would change as a result of big data). We paid particular attention to instances where respondents shared personal experiences. These were the moments when a respondent became genuinely enthusiastic, included a touching personal story or changed their tone and began telling why something mattered or what they hoped for or dreamed about for the future of healthcare. Sometimes it was easier for respondents to share their fears and worries instead of their hopes and wishes. We coded these worries as 'nightmares' and understood them as the opposite of the dreams, making other elements of the same dreams visible. Including the fears and concerns in our analysis helped us offer a richer account of the affective engagements of the various professionals we talked to.

Subsequently, we tried to find patterns in the way respondents engaged with the overall promises. We chose to centralize big data's epistemic dimensions in the analysis, thus the promises related to new information and revolutionized knowledge production. We chose this because many promises surrounding data-driven technology are related to promises for new information (e.g. Anderson, 2008; Mayer-Schönberger and Cukier, 2014; Stevens et al., 2018). This meant that we did not look at engagement with promises related to cost-saving or quality improvement, as we assumed that many of these promises are implicitly rooted within a more fundamental epistemological promise. Hopes for more efficiency and cost-reduction of healthcare at least assume that the analytics are correct and produce relevant information. This process eventually led to descriptions of four overarching data-driven dreams concerning healthcare information.

To ensure the quality of the eventual analysis, we critically questioned each other as co-authors. In addition, we presented the results of our overall project to key respondents at the BigMedilytics symposium in December 2020. We organized five workshops (that included all the professional categories we identified previously) to reflect on the past years of the project. In these workshops, we presented our findings on the role of dreams and expectations. The workshops fulfilled a dual role: they acted as a member check and provided us with new and enriched data. We asked permission from respondents for quotations.

Results

During the interviews, the respondents could suddenly switch tone and begin to dream. Discarding managerial-speak with its abstract statements on the importance of data and generic talk about progress, improvement and revolution, respondents at some moments started to explain *why* data-driven technologies were important to them, personally. A key example here is the story of a Spanish lawyer who specializes in data protection regulation:

> For example, my daughter's illness (…) They [medical doctors] told me that the one doctor who has seen the most cases like my daughter's (…) had seen only four in his whole life! If you can't gather information on all the people who have the same disease, you have nothing to work with! It's so important that people know that we must share information because only then can you generate a pool of knowledge that allows you to compare one situation to many other similar situations. Big data lets you do this. (Spanish lawyer)

Full of emotion, the lawyer explained that big data technologies could have helped cure his baby daughter who had a very rare type of cancer. His daughter was lucky and eventually recovered, but the experience was horrific. He hoped that other parents and children did not have to go through the same. He saw innovative big data technologies as the solution and kept emphasizing how improved data

sharing eventually helped to find the right treatment for his daughter.

The metaphor of dreams makes visible how most respondents linked the expectations of big data present in policy discourses to particular (and often personal) experiences with illness and health and to longstanding frustrations with the organization of healthcare. These frustrations often had to do with electronic patient records, the lack of data sharing and the difficulty of obtaining information. For instance, the respondents were frustrated that healthcare professionals in some hospitals still used '*paper-based patient records*' (Spanish research manager) and '*fax machines*' (Irish professor in health informatics).

Upon further analysis, we saw many similarities between the dreams of the professionals, even when the respondents regarded their dreams as individual, particular or "only" a personal anecdote. Moreover, we noticed that certain dreams were more prominently used in specific groups of professionals. Further building upon the metaphor of dreams, we could distinguish four different ideal typical ways the professionals engaged with the promissory rhetoric of big data.

In the following, we use the metaphor of dreams to describe four ways professionals affectively engaged with big data promises. We describe to which main group of professionals this particular dream is connected and explain what part of the overarching promissory rhetoric is emphasized and what assumptions are made. Lastly, we analyze the consequences of each of the dreams. To set the tone, each section starts with a characterization of the relevant dreams and related nightmares, based on our theoretically informed interpretation of the various stories we encountered in our interviews.

Dream of being seen

> The dream: you are a patient entering a hospital. The counter staff greets you warmly. They already know that you are coming, remember you from a previous visit and point your way to the consultation room, even without asking! The doctor takes their time with you, listens properly, shares their thoughts and uses the best available evidence that is tailored to your needs. You do not feel like any old patient. You feel that the doctor really sees you. At the end of the consultation, you feel great, supported, and confident about the chosen treatment.

> The nightmare: you are one of a crowd of patients in a hospital waiting room. The hospital feels like a big factory. Everyone is in a hurry and no professional makes eye contact. Once in a while, a doctor peeks out of a consultation room and calls a name … another name … and yet another name. Eventually, they call yours and you follow the doctor into the office. The doctor asks a few general questions and quickly moves on to the usual procedure, based on the usual evidence. You get a standard folder explaining what you should do. You do not feel seen. You feel invisible.

We conceptualize the first way in which professionals affectively engage with the promises of big data as 'the dream of being seen'. In the dream of being seen, respondents stress the importance of healthcare information tailored to the needs of individual patients and adapted to a particular context. The abovementioned example of the Spanish lawyer is an example here. He emphasized throughout the interview that he needed more specific information for his critically ill daughter. Later in the interview, he stated:

> So for me it was you know, one of the most painful parts of this process [the illness of his daughter] was seeing that it was so difficult to get all the information they needed to take care of my daughter (…) and I work every day with processing data – our clients work on big data – but seeing this applied to something that was really relevant for me, in a personal way, it was really hard (…) this really impacted my own life, seeing that they [the medical doctors] could not gather the necessary information about my daughter at the time.

In this quote, the lawyer connects the general big data promises to the illness of his daughter and he wishes for more detailed information about her.

Sometimes the importance of tailoring patient care became more apparent through respondents' fears and worries. They fear that they or their loved ones are not being seen and lose their identity or particularity. This nightmare portrays a healthcare system that does not adapt information to the patient's situation, leading to '*incorrect labeling of people*' (Dutch Chief Medical Information Officer) and other misjudgments that lead to them being misunderstood or misrepresented with all sorts of negative consequences.

All types of respondents made remarks that fitted with this dream when they took on the role of patient or citizen and shared their own experiences with health and illness. This dream was considered important when respondents talked about their health or that of family and friends. Take, for example, a health insurer from France. During his interview, this respondent linked ideas around big data to a prediabetes test that could give him personalized information:

> I'm not sure but I don't think I've ever been tested for prediabetes. I'm in my early fifties, slightly overweight. So, I could be at risk of developing diabetes. Look at me, I don't think I'm obese but truth is, nobody really cares. I'd love to have somebody tell me that I need to take a prediabetes test (…). I'd love to have somebody tell me if it's

right for me to do that. And of course, you'd need a set of data, otherwise, it'd just be an opinion. (…) Maybe (…) checking if I'm at risk shouldn't just look at scientific data but at my behavioral data as well. Most of my spending is by credit card. I don't really buy fast food or stuff like that very often. But if I did, maybe using [behavioral] data would let somebody catch it and get back to me. So, I've been a bit specific, but that's what I'd like to see in the future.

He states that currently, 'nobody really cares' about particular elements of his health. He would love to have a healthcare professional bring together his physical and behavioral data to determine whether he needs specialist treatment. This also illustrates how this dream inhabits a widely shared sense of dissatisfaction with the general level of information used in the healthcare field. The respondents feel that care information is too often about certain groups of patients, averages and usual responses and this restricts its application.

Similar expressions for optimizing individual patient care have been around for decades but have not been broadly realized (e.g. Prainsack, 2018; Tutton, 2012). Just as DNA research promised to individualize treatments based on our genetic material, the hope now is to personalize care by including all sorts of extra health, lifestyle and environmental data (cf. Prainsack, 2018). Respondents understand big data's promises for improved decision-making and better information as more individualized information. The assumption is that it is possible to understand and truly 'see' the individual based on new big data. A computer scientist from Sweden made this connection between the promises and personalized healthcare explicitly, *'I think it's the basis of it all, at least here in Sweden, of lots of expectations: personalized medicine, tailored medicine, optimized healthcare based on individual needs, and so on'*.

Within this dream, many respondents argued for the importance of data sharing. The respondents were not bothered by disclosing personal information because it could help calculate personalized risk scores and develop personalized treatments. In addition, respondents recognized that large scale data were necessary to make more precise comparisons and detailed information about every individual possible. They frequently emphasized how data could help others and using terms such as '*data donation*' (*Swedish policy maker*), thereby discursively linking the ethics of data sharing to notions of 'good citizenship' (i.e. as something that 'good' citizens ought to do).

Dream of timeliness

> The dream: you are a medical doctor sitting in your office and treating a patient. You can log into a health risk warning system to learn about the diseases that the patient in front of you will likely develop in the future. You are happy with this advance because it gives you time to take all sorts of precautions. For example, you can suggest preventive measures, watch out for early symptoms and start treatment in time. It means that you can catch the illness early so that it will have less detrimental effects.
>
> The nightmare: you are again sitting opposite one of your patients. You have no idea what will happen to this patients' health in the future. So many diseases lie in wait, and you do not know if and when a particular condition will hit the patient. You try to watch for the signs and take precautions, but what will happen and what direction to take is a mystery. This makes you insecure and hesitant to do anything.

We conceptualize the second way in which professionals affectively engage with the promises of big data as the 'dream of timeliness'. In the dream of timeliness, respondents talked about real-time analytics that would remove any delay between data collection and analysis, and emphasized the benefits of having information earlier through all sorts of predictions. During the interviews, many respondents explored the opportunities to act on timely information. For instance, an Irish professor in health informatics that worked closely with medical professionals for over fifteen years talked about how overweight people could be nudged into adopting a healthier lifestyle:

> 'We can make interventions earlier; we can try and identify people's risk of conditions quicker. (…) If we know someone is overweight, we can monitor what they are buying. If we see that they are buying really poor food, if we know that they have a very sedentary lifestyle (…) then we could actually intervene and try and encourage them to change their lifestyle a small bit. Try and hopefully prevent them from getting diabetes and thus, a lifetime of difficulty. It relates to education (…), to policies (…). But the potential is there! (…) Why could we not develop wearables and take that data and start to really look at it? Why could we not allow those patients to manage themselves better at home? We have machine learning systems that are keeping an eye on them and flag up when they are potentially going off track and (when) we need to intervene. Then the nurse or the doctor, the general practitioner, can pick up the phone and (…) check-up and make sure you're ok. I think there's lots of potential like that. How far away are we? Five, ten, fifteen years but, definitely, you can see where it's going".

In this quote, the professor connects the general big data promises to timely information and preventive action. He explores how having information earlier can prevent illness, bad decisions and, consequently, reduce harm.

The respondents' fears and worries also expressed the importance of timeliness. They fear that they are taken by surprise by unexpected diseases or are too late to intervene.

For instance, a Dutch professor and advisor in healthcare was involved in a prediction project on a psychiatry ward. He explained that sometimes '*patients get very aggressive during their treatment and that this has a lot of impact on their caregivers. So therefore, they would like to predict when that will happen*'. Such statements bring a nightmare forward in which healthcare is reactive instead of proactive with all sorts of negative consequences.

This dream was especially brought to the fore by healthcare professionals and other professionals closely working with healthcare professionals, often mentioning concrete initiatives in healthcare organizations. For example, two medical doctors explained during their interviews that having timely information could help the treatment of *rheumatic diseases* (medical doctor Sweden) and *lung cancer* (medical doctor Spain) because early diagnosis and early treatment could lead to less severe diseases.

The dream inhabits a widely shared sense of dissatisfaction with the lack of timely information in healthcare. Of course, ideas for prevention have been around for decades as medical professionals have always struggled with epistemic uncertainties they face when providing care and looked for guidance (cf. van Baalen, 2010). Now, these expressions are fuelled by predictions that are part of the promissory rhetoric around big data. Here the underlying assumption seems to be that past knowledge, grounded in enough data, could let us predict the future with near certainty (cf. Busch, 2016). A policymaker from Sweden also emphasized the relationship between the longstanding hopes for certainty in healthcare with newer big data promises during his interview: '*It [big data] is a way of making a healthcare dream come true: not only treating patients when they have fallen ill but preventing them from even getting ill*' (Swedish policymaker).

Within this dream, many respondents seem to emphasize causality and prevention: there is a relation between the future and the present and that we can and will act to prevent. The dream assumes chronological trajectories and that intervention is possible when things are known sooner. The consequence is that although this dream considers both timeliness and the opportunity to act important, they neglect the fact that, as others have argued, the complexity of our social world makes it hard to fix the past and predict the future (Busch, 2016). Sometimes nothing can be done, given a particular prediction. This means that people are given the obligations to act and to know, which leads to all sorts of new responsibilities (Mol, 2006). People can be turned into 'partial patients' or 'patients in waiting' (Harris et al., 2014; Timmermans and Buchbinder, 2010) when no action plan may be available.

Dream of connectedness

The dream: you are a data scientist working in a healthcare organization. You know that many data are being gathered in and outside your organization by healthcare professionals, patients, insurers, and through various administrative processes. It took quite some years, but now everybody is convinced of the importance of connecting all the data and willing to follow the standardized guidelines. This makes it possible to connect qualitative data about patients to quantitative data collected by patients' wearables and other databases in one structured place. All information is finally connected.

The nightmare: you are again working as a data scientist in a healthcare organization, but this time, you know that particular data is out there and you need it. However, you do not know how to reach the data. You find some fragments of datasets in different places, but you cannot connect them. It is impossible to bridge differences. You are at a loss.

We conceptualize the third way in which professionals affectively engage with the promises of big data as the 'dream of connectedness'. In the dream of connectedness, respondents stressed the importance of connecting data and datasets and emphasized the benefits of having all data in one place. During the interviews, the respondents hoped that bringing together diverse data could help uncover all sorts of new insights, information, and truths. A health research expert from the United Kingdom expressed such a desire for connecting data:

From my view (…) – the power [of big data] seems to be locked is in the ability to bring together data. (…) Bringing together large sets of data which may be drawn from many different sources and using that data to [study] a particular issue or problem and (…) bring new knowledge and understanding to it which may result (…) in a different form of knowledge that is going to make a difference for people's lives. (…) it's all about bringing together a large data set and using that to enhance one's knowledge and understanding of something.

In this quote, the research expert understands the promissory rhetoric around big data as a wish for better information, based on different sources. In contrast to the dream of being seen, the respondents put less emphasis on individual and tailored information and expressed more general wishes for improved information and research practices.

Sometimes the dream for connecting data became apparent through the respondents' fears and worries. The respondents often feared scattered and incomplete datasets and shared their frustrations with the lack of digitization of all sorts of healthcare information. For instance, as we mentioned earlier, the respondents were frustrated that healthcare professionals in some hospitals still used '*paper-based patient records*' (Spanish research manager) and '*fax machines*' (Irish professor in health informatics).

This dream was especially brought to the fore by data scientists, IT specialists and researchers. For example, a health researcher from Ireland dreamt about a national system that would enable easy sharing of electronic health records that would make her research easier:

> We don't have electronic health records. At the individual disease stage, some hospitals have electronic databases of patients, kind of patient case-report forming. But they are not part of a national link, [they're not] joined-up. Type in your number and all your health records are in the system. That's the stuff of dreams.

Within this dream, the respondents confront the fragmented, distributed nature of knowledge in the healthcare field, where data are stored in every imaginable format at numerous locations under the control of many different people (Nicolini et al., 2008). Respondents understand the promissory rhetoric around big data literally as a call for large data sets and all sorts of '*big data environments*' (professor in health informatics, Ireland). As a result, respondents considered many aspects of interoperability and standardization important in this dream. They mentioned technical, semantic and organizational functionality, as well as international standardization of regulations and procedures that need bringing together.

These respondents seemed to assume that bringing together different data sources creates greater mass, leading to improved information overall. This is reminiscent of a 'modernist discourse' that assumes that data are 'out there' and only need to be found and brought together to come to new information (Stevens et al., 2018). Such emphasis on data connection brings also the danger of misuse of data. To give the example of a French computer scientist:

> The ideal image [of big data use in the next five years] would be that finally, researchers get access to the massive amount of data to do their research properly and correctly, with a minimal burden. And as I said before and that if they misuse the data, they are punished. But it should not slow down too much the access to data because data is research.

This computer scientist, but also other respondents stressed the need for access to data with minimal burden, automatic connections and retrospective checks and balances. Such reasoning could potentially lead to harmful effects and unjustified data access and use.

Dreams of being in control

> The dream: you are the director of a nursing home and need to decide on the investment in a particular treatment program. You open the information dashboard on your computer. Here, you get a comprehensive overview: you see graphs that you can use to understand the various options that you have quickly. You decide to click on one of the graphs. You know how this particular calculation was made and learn more about the algorithms and data used. This dashboard makes you feel in control. You have all the necessary information at hand to make a good decision.

> The nightmare: you are asked to make a similar investment decision. In your organization, they have implemented an artificial intelligence system that is fully equipped to analyze data and come to conclusions independently. The system is set in motion, but you disagree with its findings. You want to change the decision, but you cannot get a grip on the situation: the system is out of control, you cannot intervene. The system seems to have a life on its own and you do not understand what's happening.

We conceptualize the fourth way in which professionals affectively engage with the promises of big data as the 'dream of being in control'. In the dream of being in control, respondents hope for a data-driven future in which healthcare information is controlled and decision-making can be optimized. The dream of control inhabits a widely shared sense of dissatisfaction with the uncontrollable and out-of-reach character of information in the healthcare field. Respondents hope, for example, for developing medical dashboards and clinical decision support systems that '*doctors can use and draw conclusions from*' (Dutch Patient Representative) or fantasize about other valuable ways to improve decision-making in healthcare.

The respondents' fears and worries also expressed the importance of the being in control. The respondents fear losing control over healthcare decisions because healthcare decision-making is outsourced to self-learning systems and knowledge production is '*black-boxed and so locked up too much*' (Swedish Professor in Public Health) for human intervention. Such statements bring a nightmare forward of uncontrollable self-learning systems that produce information that conflicts with the judgment of professionals.

This dream was particularly emphasized by respondents that were policymakers and decision-makers in healthcare, such as policymakers and hospital managers. A policymaker from Sweden:

> The main opportunity [for big data] is that it can improve the healthcare sector's efficiency and effectiveness both on the provider and patient side. There are huge opportunities, and also on the business side. You can combine diagnostics and treatments data in a new way to support more intelligent decision making (…) and organize care more efficiently.

In this quote, he explains how both healthcare and business decisions in healthcare could benefit from the use of big data because it helps make more intelligent decision-making.

This dream capitalizes on the idea that data-driven technologies might enhance decision-making in all sorts of healthcare processes by offering new kinds of certainty (Grote and Berens, 2019). Similar desires for control of health and illness have always been present in healthcare but now they are fuelled by the emergence of data science as a field (cf. Ribes et al., 2019; Stevens et al., 2020) and repeat age-old scientific promises: that with certain methods and technologies we can bring together a cacophony of insights, opinions, meanings and evidence into one coherent advice for decision-makers in healthcare.

Within this dream, many respondents seem to understand control in two ways. A group of respondents interpreted control in the sense of understanding where information comes from and how it is obtained. These respondents argued for clear and transparent procedures and algorithms, and additional training for professionals in big data technologies. Other respondents understood control primarily as keeping human control in deciding when, how and under what conditions the technologies could be used. Take, for instance, a Dutch professor and healthcare consultant:

> If you use algorithms to come up with a diagnosis, of course, you can say, there is still a doctor behind it. But slowly and surely, this position is no longer tenable. If that algorithm is so much better than a doctor, you can no longer say 'there is a doctor behind it'. So in that case, you have to look for other ways to show that you are in control of the algorithm.

In this quote, the professor understands that it might not always be possible to control 'algorithms' but also not always tenable to uphold existing conditions for the use of the techniques and searches for other ways in which such technologies could be controlled.

Discussion

In this paper, we explored how professionals affectively engage with the strong promises that surround big data technologies in Europe. We argued that, while there is a lot of attention to promissory rhetoric and critical policy evaluations, reflections on how professionals affectively engage with the overarching promises in Europe are often missing in such analyses. We utilized the metaphor of dreams as a theoretical heuristic to study in more detail how professionals affectively engage with European Union's data hopes in twelve concrete big data initiatives in healthcare. The metaphor allows us to distinguish between four common, ideal typical dreams: the dream of

being seen, the dream of timeliness, the dream of connectedness and the dream of being in control. In this discussion, we reflect on the analytical productivity of the metaphor of dreams and consider how bestowing more analytical attention to affective engagement can positively contribute to the development of more responsible big data technologies.

The metaphor of dreams helped us understand how the respondents engaged with the grand promissory rhetoric surrounding data-driven technologies. They linked the grand promises to their own experiences with health and healthcare, which could include general, slow, scattered or uncontrollable information. They also connect the grand promises to desires and needs that are arguably fundamentally human: being seen, feeling connected, feeling secure, and feeling protected against harm.

With this analysis, we seek to make two contributions to the field of CDS. The first contribution is that the metaphor of dreams allows for a form of critical reflection on data-driven technologies and practices that does not take strategic window-dressing or naive trust as primal points of focus. Rather than focusing solely on the performative power of expectations and promissory discourse, this analysis has highlighted its affective dimensions. This allows for a form of generative critique (Verran, 2001) that takes the daily practices and experiences of professionals as a starting point. Such an analysis shows *different* things than critical studies that, for instance, reveal patterns of power (e.g. Micheli et al., 2020; Tanninen, 2020) and focus on how big data technologies (re)produce forms of discrimination and inequality (e.g. boyd and Crawford, 2012; Cruz, 2020; Lee and Bjorklund Larsen, 2019; Tubaro et al., 2020). Instead, the metaphor of dreams allows us to pay close attention to how professionals engage with promises and the priorities they uphold. This shows the different futures that the professionals hope for and opens up avenues to question some of the implicit connections that they make (cf. Latour, 2004; Puig de la Bellacasa, 2017; Verran, 2001).

The second contribution is that the metaphor of personal dreams offers an analytically fruitful entrance for CDS scholars (and other social scientists) to engage with professionals in data initiatives. We noticed how the careful identification of different dreams and the affective engagements within them makes the normativities of data-driven healthcare more specific. While doing our fieldwork and participating in the consortium, we noticed how our focus on dreams enabled professionals to develop a language to evaluate what matters most to them when developing big data technologies in healthcare. This helped to move beyond the general promises to reflect on the particular ways big data was being shaped in healthcare practice.

We argue that including attention to dreams in our work can help shine an additional critical light on the big data developments. The approach we took in this paper moves away from many critical (policy) analyses but also from,

for example, normative academic ethics focusing on abstract principles (e.g. 'fair', 'transparent' and 'trust-worthy' data analytics) that attempt to solve all sorts of ethical (and, in parallel, legal) issues surrounding data-driven technologies upfront (Stevens, 2021; Wehrens et al., 2021). Instead, we argue for the importance of empirical research to study how data-driven technologies become part of healthcare practices. Not from an 'externalist', but rather from an 'internalist' perspective, in which we, as researchers, accompany the development of data-driven healthcare (cf. Verbeek, 2014). This means following and critically thinking along with all kinds of data-driven experiments currently underway in the healthcare sector. Here, professionals learn to work with data (Wallenburg and Bal, 2019), balance multiple, conflicting regulatory frameworks (cf. van de Bovenkamp et al., 2014, 2020), negotiate about epistemic norms and values (Stevens et al., 2020) and affectively engage with European Union's data hopes. Insights from such studies can be used to question the implicit connections that are made, evaluate (policy) choices, steer away from any negative consequences and can help to create more responsible data-driven innovation in healthcare (Stevens, 2021).

To conclude, we argue that it is vital to study data-driven practices and shed light on the affective engagements through which data-driven technologies and initiatives are formed. We chose to do so via the metaphor of dreams that gives insights into the affective dimensions of data-driven promises in a way that is fuelled by empirical research. Such a study does not provide ready-made alternatives or solutions or improvements for data practices. However, listening to dreams and fears allows for due attention to the affectivities and normativities of the professionals and can help to improve the practices of data-driven healthcare.

Acknowledgements

Authors' note

Marthe Stevens is now affiliated with the Department of Ethics and Political Philosophy, Radboud University, Nijmegen, the Netherlands. She is also connected to Radboud University's Interdisciplinary research Hub on Digitalization and Society (iHub); Johanna Kostenzer is now affiliated with the European Foundation for the Care of Newborn Infants (EFCNI), München, Germany; and Antoinette de Bont is now affiliated with Tilburg School of Social & Behavioral Sciences, Tilburg University, the Netherlands.

Declaration of conflicting interests

Funding

ORCID iDs

Marthe Stevens https://orcid.org/0000-0003-0135-0523
Rik Wehrens https://orcid.org/0000-0002-6141-9863
Johanna Kostenzer https://orcid.org/0000-0001-7878-8510

References

Ames MG (2018) Deconstructing the algorithmic sublime. *Big Data & Society* 5(1): – 4.

Anderson C (2008) The end of theory: The data deluge makes the scientific method obsolete. In: Wired. Available at: www.wired.com/2008/06/pb-theory/ (accessed 5 September 2017).

Andrejevic M (2020) Shareable and un-sharable. *Big Data & Society* 7(1): – 4.

Aradau C and Blanke T (2015) The (big) data-security assemblage: Knowledge and critique. *Big Data & Society* 2(2): 1–12.

Bar-Lev S (2015) The politics of healthcare informatics: Knowledge management using an electronic medical record system. *Sociology of Health & Illness* 37(3): 404–421.

Bareis J and Katzenbach C (2021) Talking AI into being: The narratives and imaginaries of national AI strategies and their performative politics. *Science, Technology, & Human Values*: 1–27. https://doi.org/10.1177/01622439211030007.

Barnes TJ and Wilson MW (2014) Big Data, social physics, and spatial analysis: The early years. *Big Data & Society* 1(1): 1–14.

Berghout M (2020) *Medical Leadership: Transforming Professional Practice and Identity*. Rotterdam: Erasmus University Rotterdam.

BigMedilytics (2018) Infographics. https://www.eur.nl/eshpm/media/2019-01-workpackage53infographicsfinalversions (accessed 28 October 2020).

Bigmedilytics (2020) Improving healthcare in Europe through big data. https://www.bigmedilytics.eu (accessed 30 October 2020).

Bigmedilytics (2021) News. https://www.bigmedilytics.eu/news-events/ (accessed 15 September 2021).

Borup M, Brown N, Konrad K, et al. (2006) The sociology of expectations in science and technology. *Technology Analysis & Strategic Management* 18(3-4): 285–298.

boyd d and Crawford K (2012) Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon. *Information, Communication & Society* 15(5): 662–679.

Busch L (2016) Looking in the wrong (La)place? The promise and perils of becoming big data. *Science, Technology and Human Values* 42(4): 657–678.

Chalmers MK and Edwards PN (2017) Producing "one vast index": Google Boox Search as an algorithmic system. *Big Data & Society* 4(2): 1–16.

CORDIS (2016) Big Data PPP: Large Scale Pilot actions in sectors best benefitting from data-driven innovation. https://cordis.europa.eu/programme/id/H2020_ICT-15-2016-2017 (accessed 15 September 2021).

Cruz TM (2020) Perils of data-driven equity: Safety-net care and big data's elusive grasp on health inequality. *Big Data & Society* 7(1): 1–14.

Daly A, Hagendorff T, Li H, et al. (2019) Artificial intelligence, governance and ethics: Global perspectives. *The Chinese University of Hong Kong Faculty of Law Research Paper* 15: 1–42.

De Wilde R (2000) *De voorspellers: een kritiek op de toekomstindustrie*. Amsterdam: De Balie.

Digital Health Europe (2021) Report on the 2021 Digital Health Europe Summit. Available at: https://digitalhealtheurope.eu/wp-content/uploads/DHE_Summit_Report_Final.pdf (accessed 1 December 2021).

EC (2014) European Commission and data industry launch €2,5 billion partnership to master big data. Available at: https://ec.europa.eu/commission/presscorner/detail/en/IP_14_1129 (accessed 30 October 2020).

EC (2018) Communication from the commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2018:233:FIN (accessed 1 December 2021).

Felt U (2015) Keeping technologies out: Sociotechnical imaginaries and the formation of Austria's technopolitical identity. In: Jasanoff S and Kim SH (eds) *Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power*. Chicago: The University of Chicago Press, pp.103–125.

Gillespie T (2020) Content moderation, AI, and the question of scale. *Big Data & Society* 7(2): 1–5.

Grote T and Berens P (2020) On the ethics of algorithmic decision-making in healthcare. *Journal of Medical Ethics* 46(3): 205–211.

Håland E (2012) Introducing the electronic patient record (EPR) in a hospital setting: Boundary work and shifting constructions of professional identities: EPR boundary work and constructions of identity. *Sociology of Health & Illness* 34(5): 761–775.

Harris A, Kelly SE and Wyatt S (2014) Autobiologies on YouTube: Narratives of direct-to-consumer genetic testing. *New Genetics and Society* 33(1): 60–78.

Heaton J (2008) Secondary analysis of qualitative data: An overview. *Historical Social Research* 33(3): 33–45.

Hoeyer K (2019) Data as promise: Reconfiguring Danish public health through personalized medicine. *Social Studies of Science* 49(4): 531–555.

Hoeyer K and Wadmann S (2020) 'Meaningless work': How the datafication of health reconfigures knowledge about work and erodes professional judgement. *Economy and Society* 49(3): 433–454.

Jasnaoff S (2015) Future Imperfect: Science, Technology, and the Imaginations of Modernity. In: Jasanoff S and Kim SH (eds) *Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power*, pp.1–33.

Jasanoff S and Kim SH (2009) Containing the atom: Sociotechnical imaginaries and nuclear power in the United States and South Korea. *Minerva* 47(2): 119–146.

Jasanoff S and Kim SH (Eds) (2015) *Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power*. Chicago: University of Chicago Press.

Koed Madsen A (2018) Data in the smart city: How incongruent frames challenge the transition from ideal to practice. *Big Data & Society* 5(2): –3.

Konrad K, van Lente H, Groves C, et al. (2017) Performing and governing the future in science and technology. In: Felt U, Fouché R, Miller CA and Smith-Doerr L (eds) *The Handbook of Science and Technology Studies Fourth Edition*. Cambridge/Londen: The MIT Press, pp. 465–494.

Latour B (2004) Why has critique run out of steam? From matters of fact to matters of concern. *Critiqual Inquiry* 30(2): 225–248.

Lee F and Björklund Larsen L (2019) How should we theorize algorithms? Five ideal types in analyzing algorithmic normativities. *Big Data & Society* 6(2): –6.

Levenda AM, Richter J, Miller T, et al. (2019) Regional sociotechnical imaginaries and the governance of energy innovations. *Futures* 109(1): 181–191.

May C, Gask L, Atkinson T, et al. (2001) Resisting and promoting new technologies in clinical practice: The case of telepsychiatry. *Social Science & Medicine* 52(12): 1889–1901.

Mayer-Schönberger V and Cukier K (2014) *Big Data: A Revolution That Will Transform How We Live Work, and Think*. Boston: Mariner Books.

Micheli M, Ponti M, Craglia M, et al. (2020) Emerging models of data governance in the age of datafication. *Big Data & Society* 7(2): 1–15.

Mol A (2006) Proving or improving: On health care research as a form of self-reflection. *Qualitative Health Research* 16(3): 405–414.

Mortelmans D (2008) *Handboek kwalitatieve onderzoeksmethoden*. Den Haag: Acco.

Nicolini D, Powell J, Conville P, et al. (2008) Managing knowledge in the healthcare sector. A review. *International Journal of Management Reviews* 10(3): 245–263.

Niklas J and Dencik L (2020) Working paper: European Artificial Intelligence Policy: Mapping the institutional landscape. *Data Justice Lab*. https://datajusticeproject.net/wp-content/uploads/sites/30/2020/07/WP_AI-Policy-in-Europe.pdf.

Prainsack B (2018) The "we" in the "me" solidarity and health care in the era of personalized medicine. *Science, Technology, & Human Values* 43(1): 21–44.

Puig de la Bellacasa M (2017) *Matters of Care*. Minneapolis: University of Minnesota Press.

Ribes D, Hoffman A, Slota SC and Bowker GC (2019) The logic of domains. *Social Studies of Science* 49(3): 281–309.

Rieder G (2018) Tracing big data imaginaries through public policy: The case of the European Commission. In: Rudinow Sætmam A, Schneider I and Green N (eds) *The Politics and Policies of Big Data: Big Data, Big Brother*. London/New York: Routledge, pp.89–101.

Seaver N (2017) Algorithms as culture: Some tactics for the ethnography of algorithmic systems. *Big Data & Society* 4(2): –2.

Smits M (2006) Taming monsters: The cultural domestication of new technology. *Technology in Society* 28(4): 489–504.

Stevens M (2021) Dreaming with Data: Assembling responsible knowledge practices in data-driven healthcare. Erasmus University Rotterdam.

Stevens M, Wehrens R and de Bont A (2018) Conceptualizations of Big Data and their epistemological claims in healthcare: A discourse analysis. *Big Data & Society* 5(2): 1–21.

Stevens M, Wehrens R and de Bont A (2020) Epistemic virtues and data-driven dreams: On sameness and difference between data-driven and medical practices. *Social Science & Medicine* 258: –8.

Tanninen M (2020) Contested technology: Social scientific perspectives of behavior-based insurance. *Big Data & Society* 7(2): 1–14.

Thrift N (2014) The 'senient city' and what it may portend. *Big Data & Society* 1(1): 1–21.

Timmermans S and Buchbinder M (2010) Patients-in-waiting: Living between sickness and health in the genomics era. *Journal of Health and Social Behavior* 51(4): 408–423.

Timmermans S and Tavory I (2012) Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory* 30(3): 167–186.

Törnberg P and Thörnberg A (2018) The limits of computation: A philosophical critique on contemporary Big Data research. *Big Data & Society* 5(2): 1–12.

Tubaro P, Casilli AA and Coville M (2020) The trainer, the verifier, the imitator: Three ways in which human platform workers support artificial intelligence. *Big Data & Society* 7(1): 1–12.

Tutton R (2012) Personalizing medicine: Futures present and past *Social Science & Medicine* 75(10): 1721–1728.

Van Baalen S (2010) Knowing in Medical Practice: Expertise, Imaging Technologies and Interdisciplinarity. Universiteit Twente.

Van de Bovenkamp H, De Mul M, Quartz J, et al. (2014) Institutional layering in governing healthcare quality. *Public Administration* 92(1): 208–223.

Van de Bovenkamp H, Stoopendaal A, Van Bochove M, et al. (2020) Tackling the problem of regulatory pressure in Dutch elderly care: The need for recoupling to establish functional rules. *Health Policy* 124(3): 275–281.

Van Lente H (1993) Promising Technology: The Dynamics of Expectations in Technological Developments. Universiteit Twente.

Van Lente H (2012) Navigating foresight in a sea of expectations: Lessons from the sociology of expectations. *Technology Analysis & Strategic Management* 24(8): 769–782.

Venturini T, Jacomy M, Meunier A, et al. (2017) An unexpected journey: A few lessons from sciences Po médialab's experience. *Big Data & Society* 4(2): 1–11.

Verbeek PPCC (2014) *Op de vleugels van Icarus: Hoe techniek en moraal met elkaar meebewegen*. Rotterdam: Lemniscaat.

Verran H (2001) *Science and an African Logic*. Chicago: University of Chicago Press.

Wadmann S and Hoeyer K (2018) Dangers of the digital fit: Rethinking seamlessness and social sustainability in data-intensive healthcare. *Big Data & Society* 5(1): 1–13.

Wallenburg I and Bal R (2019) The gaming healthcare practitioner: How practices of datafication and gamification reconfigure care. *Health Informatics Journal* 25(3): 549–557.

Wehrens R, Sihag V, Sülz S, et al. (2020) Understanding the uptake of big data in health care: Protocol for a multinational mixed-methods study. *JMIR Research Protocols* 9(10): e16779.

Wehrens R, Stevens M, Kostenzer J, et al. (2021) Ethics as discursive work: The role of ethical framing in the promissory future of data-driven healthcare technologies. *Science, Technology, & Human Values* : 1–29. https://doi.org/10.1177/01622439211053661.

Wilmott C (2016) Small moments in Spatial Big Data: Calculability, authority and interoperability in everyday mobile mapping. *Big Data & Society* 3(2): 1–16.