The Gender of Biomedical Data: Challenges for Personalised and Precision Medicine

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Abstract:
Biomedical data, both in 'traditional', analogue forms as well as in the form of digital, 'big' data, are contingent social products. They reflect the categories and practices that structure our societies. We illustrate this by discussing gender biases in data stemming from clinical trials and electronic health records (EHR) and consider how biomedical data are prone to bias in different phases of data work, from data capture and representation to category building and analysis to using outputs. We argue that developments such as 'Personalised' and 'Precision Medicine' that have been made possible by 'big data' analyses could be seen as a shift away from the male 'standard patient' by trying to comprehensively and objectively represent many different aspects of patients' lives and bodies. At the same time, the very promises of comprehensiveness and objectivity are problematic: The data generated and collected, as well as the infrastructures and analytic tools used to do this, reflect the social realities – including the injustices and inequities – within which they were developed. The knowledge created on the basis of this 'evidence' can thus perpetuate existing biases. While we do not subscribe to a view of the world that considers truly objective, neutral, and – in this sense – 'unbiased' knowledge possible or even desirable, we suggest a number of ways in which gender bias in biomedical data should be made visible, reflected upon, and in certain instances acted upon.

Keywords: personalised medicine; precision medicine; gender; big data; health information; digital health; bias.

Introduction

It is fair to say that medicine has always relied on information about patients. Information about their bodies, lives, expectations, and wishes has been used to guide diagnosis and treatment throughout the history of medicine. For a long time, the information used for this purpose consisted of sensations from touching patients, descriptions of symptoms and life stories of patients, as well as observations by those treating and caring for them. In the Western world, the biomedical model that became prevalent in the nineteenth century meant that information about the body was no longer created in a dialogue between the healer and the patient but was supposed to come from the healer interrogating the patient's body directly. This process largely coincided with the rise of laboratory medicine and the spread of hospitals, whose paradigmatic form of knowledge generation were systematic and quantitatively oriented clinical observation and scientific lab experiments, respectively (Jewson 2009). Both assumed that 'facts' ought to be separated from values, and that medicine should rest upon the former. It was against this background, and in particular with the emergence of the evidence-based medicine movement in the 1990s, that randomised controlled trials and the data and information generated through them became the 'gold standard' (Timmermans & Berg 2010) of evidence in medicine.

In the late twentieth and early twenty-first century, digitisation quickly enabled new forms of information through the generation and collection of previously unattainable data. This included the intro-duction of digital patient records that made it possible to capture ever more detail about people's bodies and lives. Data such as the number of steps measured by fitness trackers, or purchasing records with online retailers, albeit not collected with an initial medical purpose in mind, became usable for medical purposes, blurring the boundary between health and non-health related information (Prainsack 2017; see also Price & Cohen 2019), and possibly paving the way to unprecedented forms of surveillance (Armstrong 1995). Digital tools have also helped to make data collection less intrusive: often the collection of new forms of data does not require contact with the physical body, such as extracting body fluids or other specimens. Instead, these tools operate remotely and unobtrusively in the form of portable or wearable devices, or even in the form of 'disappearables' that can be implanted or swallowed.

Digital technologies and computing power are also used for new ways of storing and analysing data, commonly referred to as 'big data'. The phenomenon of big data denotes a bundle of technological practices and epistemological commitments that claim novelty on

several fronts: In contrast to 'traditional' datasets, big data means 'both a change in scales – speed, capacity, continuous generation – as well as a change in the relationality, flexibility, repurposing, and de-contextualization of data' (Metcalf, Keller, & boyd 2016: 6). The possibility of conducting hypothesis-free analysis of large and diverse datasets promises the detection of previously unnoticed correlations and, thus, new diagnostic or even therapeutic possibilities. Big data approaches come with an epistemology that – either explicitly or tacitly – assumes that truth is best represented in computable data, and that bigger datasets have a privileged role in this process. The pursuit of truth through small and un-datafied observations and statements about the world becomes, quite literally, point-less. At the same time, the data as well as the information generated on their basis are portrayed as neutral and objective and are thereby depoliticised. That is problematic not only because the attribution of objectivity conceals the contingency of certain forms of data, but also because it neglects the role of interpretation and human data work (e.g. Leonelli 2016; Fiske et al. 2019).

This shift from medical knowledge creation on the basis of analogue, narrative, and human-mediated information towards digital, quantified, and automated data capture gives priority to specific aspects about our lives and bodies – namely those that can be captured digitally and unobtrusively – while neglecting others. Henrik Vogt and colleagues have called this new way of making patients in the digital age a 'technoscientific holism' (Vogt, Hofman, & Getz 2016) which assumes that, by means of more granular mechanisms and technologies to capture ever more aspects of patients' bodies and lives, it is possible to represent them objectively as 'wholes'. At the same time, however, this 'holism' neglects the organismic aspect of human health and disease (Tretter 2018). We pose that this new way of making patients is an excellent case of the inextricability between bodies, technologies, and techniques, as captured in the concept of 'somatechnics' (Sullivan 2014). In this sense, bodies are constituted in particular ways through the application and use of particular techniques and technologies. Besides the problems inherent in the specific claim to objectivity that technoscientific holism is making, feminist scholars have called into question the very possibility (and desirability) of objective knowledge (e.g. Haraway 1988; Harding 1991; Longino 1990). Objectivity, they argue, disguises the fact that for a long-time scientific knowledge was generated almost exclusively by white males, because the formal and informal institutions of knowledge production were unattainable for all other groups. By obscuring their positionality, privileged white men

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could claim *their* embodied and situated knowledge as being impartial accounts of the world – they conquered 'the gaze from nowhere' (Haraway 1988: 581).

In the field of medicine and healthcare, this privileged male perspective has been the standard view, not only *on* patients but also *of* patients. Not only was the doctor's gaze a male one, but patients were also standardly conceived as male. Historically, gender bias in medicine has been most blatantly displayed in androcentrism, sexism, and misogyny (e.g. Dreifus 1978; Laqueur 1990; Tuana 1993). Such discriminatory practices in medicine and healthcare persist to this day. For example, when accounts from women about their discomfort or pain are taken less seriously than men's (e.g. Hirsh et al. 2014; Schäfer et al. 2016) or when women continue to be underrepresented in medical research (e.g. Duma et al. 2018; Geller et al. 2011; Phillips & Hamberg 2016). Androcentrism in medicine has had detrimental effects on women. Because they deviate from the male 'standard body', people who do not identify as women or men – in particular, intersex, transgender, and queer people – have experienced not only structural discrimination, but also the adverse effects of the prevailing binary gender norm (Eckhert 2016; Fausto-Sterling 2000). Furthermore, both analogue and digital biomedical data are not only structured along the lines of gender but also regarding other dimensions, like race/ethnicity or age (e.g. Denson & Mahipal 2014; Hamel et al. 2016). Just as discrimination in healthcare and health outcomes (e.g. Bastos, Harnois, & Paradies 2018; Krieger et al. 2005; Scheim & Bauer 2019) are likely to intersect, so too are biases in biomedical data.

As we will argue in the following sections of this article, gender biases that have characterised clinical trials and other clinical research for decades continue to live on in the new infrastructures and practices around biomedical big data, even as they have also changed in quality. Despite the fact that gender and sex cannot be taken to reflect an objective reality, these categories are inscribed in our social and political institutions and practices. In this sense, they are realities that our societies need to grapple with, especially when thinking about justice and equality in the digital era.

Gender Bias in Clinical Trials and Big (Health) Data

For a long time, clinical research was a white and male affair. With the notable exception of reproductive medicine, various meta-analyses have shown that the share of women in clinical trials has been typically lower than the proportion of women among the disease population.

Equally, gender-specific analyses have been rare (e.g. Duma et al. 2018; Geller et al. 2011; Phillips & Hamberg 2016). Similarly, health issues predominantly or exclusively affecting gender minorities have been generally not well researched and remain poorly understood (Bondeel et al. 2016). In the case of women, one of the reasons for their under-representation were regulatory frameworks that required the exclusion of all women of childbearing potential from early phases of drug trials in the United States – in particular in the aftermath of the thalidomide scandal in the 1960s (Baird 1999). Following the growing criticism by women's health movements and their allies, regulations started to change in the early 1990s. They now required the equal inclusion of populations, which had been underrepresented in clinical trials (Baird 1999; Epstein 2007).

The adequate representation of women and gender minorities nonetheless continues to be an issue, and reporting gender-specific outcomes is not yet the rule. Contemporary exclusionary practices by researchers are often explained by a number of practical 'reasons'. Regarding women, one of these reasons is the greater diversity in terms of relevant biophysical parameters in women than in men – including hormone fluctuations related to the menstrual cycle, or later onset of diseases in women (Seeman 2010: 90). These require larger sample sizes, which increase research costs. To test the effectiveness of a new treatment in comparison to already approved treatments, there is also the tendency to mimic previous studies that 'happened to be composed of men' (Söderström 2001: 1524). But more subtle factors also contribute to the ongoing overrepresentation of men in many fields of disease research, and specifically in clinical trials. The requirements of clinical trials – which often mean lengthy periods of time under clinical supervision – can conflict with caring and other responsibilities often held by women (Seeman 2010: 90). Furthermore, women (and more specifically those from a lower socioeconomic status and/or those belonging to ethnic minority groups) show high levels of ethical concern regarding the participation in medical research due to the history of harmful medical experiments, often targeting their reproductive health (Killien et al. 2000).

A famous example of how biased data and knowledge from clinical trials contributes to gendered health disparities is the higher mortality rate among women with coronary heart disease (CHD). For a long time, research on CHD was based predominantly on men. Subsequently, the symptoms shown in men have become the 'typical' symptoms of CHD, while female symptoms are considered 'atypical'. This is not merely a semantic problem: A lack in awareness about typically female symptoms

of CHD often leads to a later diagnosis and higher mortality rates. Furthermore, it was found that the efficacy of common drugs for CHD is lower in women and that they suffer from stronger and more severe side effects (e.g. Maas & Appelman 2010; Papakonstantinou et al. 2013; Sharma & Gulati 2013).

Old Wine in New Bottles? Gender Bias in Big Biomedical Data

Clinical trials present an exemplary case in which gender bias has occurred and still occurs. While clinical trials continue to play a major role in the generation of medical knowledge, the digital revolution has increased opportunities for observational studies and the mining of existing datasets to discern patterns that could inform medical research and practice. Large datasets of various sorts and from various sources are mined to generate valuable information for disease surveillance, predictive modelling and decision-support in healthcare. New types of data include, for example, DNA sequences, MRI scans, electronic health records (EHR), or social media posts (Herland, Khoshgoftaar, & Wald 2014). Twitter messages have been analysed for repetitive thoughts and ruminating behaviour to detect depression (Nambisan et al. 2015), and Instagram posts have been mined to shed light on the fine-grained demographics of illicit drug use (Zhou, Sani, & Luo 2016).

Despite the explicit break with the past that big data epistemologies typically claim, many of the systemic biases around gender that characterised clinical trial data continue to be found in big data-centred practices and technologies as well. Yet, they become harder to detect, because of their entanglements with the everyday social practices through which such data are generated. An example of this is electronic phenotyping. Electronic phenotyping seeks to discover patient characteristics that the patients themselves did not disclose or that they were not even aware of, using advanced statistical analysis of large sets of EHR data. It can be used, for example, to detect (yet undiagnosed) patients with diabetes (Holt et al. 2014) or those with a high risk of suicide (Tran et al. 2014).

At the same time, EHR data have been found to be 'inherently biased by the patient population structure, frequency of healthcare visits, diagnostic criteria, and care pathways' (Prosperi et al. 2018: 10). Because in contrast to clinical trial data, EHR data are generated and collected in heterogeneous and everyday situations and settings; the biases inherent in EHR data are much more entrenched in social structures, more complex, and more difficult to disentangle. This means that the complexities in differences regarding access to healthcare among different

genders are likely to be reflected in EHR data. For example, women's and men's use of healthcare services in the United States differs according to the type of service (Abrahamyan et al. 2018; Vaidya, Partha & Karmakar 2012) and is influenced by structural factors: Women have been found to be disproportionately affected by structural barriers to access such as out-of-pocket payments. They also more likely to face other barriers that lie outside the healthcare system, such as care responsibilities, limited access to transportation or a lack of workplace flexibility (Ranji, Rosenzweig, & Salganicoff 2018). Furthermore, women receive lower quality care, which is associated with their more frequent use of healthcare services (Dehkordy et al. 2016). Similarly, gender minorities have been found to face particular barriers in accessing high quality healthcare, although less so than in the past (Macapagal, Bhatia, & Greene 2016; Snelgrove et al. 2012).

Gender biases in EHR data do not only apply to quantitative but also to qualitative aspects of representation. Even if all genders were adequately represented numerically, EHR data may still exhibit gender bias relating to unconscious discrimination in medical professionals. Such unconscious bias on the part of healthcare professionals and patients can influence what diagnosis and what treatment patients receive (Blair, Steiner, & Havranek 2011; Matthew 2015). Research indicates that women are often not listened to in medical encounters, their accounts are taken less seriously, and, in contrast to men, their health issues are more frequently dismissed as mere psychological problems. Women are, for example, also less likely to receive pharmaceutical treatment for pain than men, regardless of whether they report higher levels of pain both in severity and length (e.g. Chen et al. 2008; Hirsh et al. 2014; Hamberg et al. 2002; Hoffmann & Tarzian 200; Stålnacke et al. 2015). The recording of such outcomes of medical consultations and treatment in EHR can contribute to biases within EHR datasets in the sense that what these data depict is qualitatively different from what they would depict if they had been collected on men. Furthermore, health professionals receiving more information due to electronic phenotyping, including information that patients did not – for whatever reason – decide to disclose themselves, can also increase a patient's risk of experiencing (unconscious) discrimination by health professionals (Cato, Bockting, & Larson 2018).

The example of EHR shows how optimistic views about big bio-medical data being supposedly unbiased fall short on several fronts. Even if all genders accessed and used technologies proportionally, and, hence, quantitatively delivered the same amount of data, the sheer availability of data about them does not guarantee equal health outcomes. What

matters is not only the proportionally accurate representation of women and gender minorities, but also the quality of their representation, which depends essentially on the quality of healthcare they receive.

The question about qualitative (mis)representation is complicated further by the fact that the generation and collection of analogue as well as digital data relies on technologies and predefined categories that are often already gendered – if only because they use binary gender categories to collect or analyse data. These biases then live on in the results of these data collections and mining exercises.

Gender in Category Building and Analysis

Geoffrey Bowker and Susan Leigh Star (1999), in their seminal analysis of the logics of categories and classifications, emphasised the incompleteness of any attempt to capture our world in a systematic and coherent scheme as categorisation practices necessarily highlight certain elements and silence others. Categories reflect the assumptions of hegemonic groups and cultures in society. In other words, 'the problem of bias in classification can be linked to the nature of classification as a social construct. It reflects the same biases as the culture that creates it' (Olson 1998: 233). At the same time, systems of categorisation do not just represent but also form our world; their very existence brings to life the elements they classify (Hacking 1986).

Dimorphic gender and sex are well known examples of socially constructed categories. This does not mean that these categories have no material substrate, but that the way their materiality is read is shaped by socially shared norms. As Anne Fausto-Sterling (2000) has shown, the binary categories of sex and gender are a 'social decision' and not the representation of inevitable biological realities. Once this decision has been made, scientific knowledge generation gets locked into it to the extent that the research questions that are asked, and the ways in which research findings are analysed and reported, assume the existence of two categories of people. Empirical evidence that does not fit into either of these categories gets qualified as deviant. The result is that scientific knowledge generated about bodies then support the decisions that have structured an inquiry in the first place.

This dimorphic gender conception has been increasingly contested. In the context of EHR, different institutional bodies now suggest including more information about gender identity, to improve healthcare for gender minorities (Deutsch & Buchholz 2014; Grasso et al. 2019). A qualitative study conducted in Oregon in the USA has shown that both patients and providers support this idea, although they disagree about

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what information should be recorded (Dunne et al. 2017). It remains a contested issue (Keyes 2019) whether the attempt to include more data about gender minorities in EHR can substantially challenge what Dean Spade (2015) has called 'administrative violence'.

Within the current trends towards personalised and precision medicine, where the hope is that symptom-based disease taxonomies will be replaced with molecular and other data-rich characterisations of individuals at various stages of health and disease, one could see the end of the use of broad categories such as gender and sex to aide patient stratification. When people are characterised individually with their anatomical, genomic, endocrinological, metabolomic, and other relevant dimensions, we may no longer need generic labels such as gender. The newly founded groups could correspond with clusters along existing gender categories in some respects – such as around pregnancy and childbirth – but not in others, such as in endocrinological terms where 'similar' patients would be grouped together in ways that cut across traditional categories of sex and gender. Personalised and precision medicine could thus also be viewed as a way to overcome existing tensions between the desire for the abolishment of gender bias, on the one hand, and the important critique of the invisibility of women and gender minorities in biomedicine, on the other.

We agree that personalised and precision medicine, in combination with new possibilities for the capture and analysis of new types and volumes of data, does bear the potential to alleviate some of the crudest forms of gender bias. Yet, we also hold that as long as sex and gender remain tenacious in structuring the way that people are conceptualised and categorised outside the field of medicine these concepts will live on within biomedicine as well – at the very least in the form as epidemiological or demographic 'metadata'. With the spread of big data analyses and automated decision-support systems in healthcare settings, new forms of biases and resulting discrimination can emerge if the gender dimension of data goes unnoticed or when the category of gender is omitted from analyses. The effects of these biases will depend on actors' (including healthcare practitioners', patients', and family members') awareness of them, and on how these biases are addressed in policy and practice. Cathy O'Neil (2016) has shown how the application of algorithms for decision-support – if built on biased datasets – can cause harm to people who are searching for jobs, want to go to college, take out a loan, or are sentenced to prison. Biases in such technologies, if they are not detected, might have the most negative effects on those who are already in vulnerable social positions (Eubanks 2018) and can amplify, for example, sexism and racism (Noble 2018).

With the vision of bringing together digital data from multiple sources to get a fuller picture of people's health and disease, the importance of contextual knowledge about this data also increases. An understanding of the contextuality of data – which [given name] Ferryman and [given name] Pitcan (2018: 21) called 'data empathy' – is not only necessary to interpret data in meaningful ways, but also to increase sensibility for potential gender and other biases. Context sensitivity also includes reflections about the reliability and accuracy of results when analyses are based on data that has been collected for a specific purpose and is subsequently analysed for other purposes. This is the case, for example, when data from EHR whose categories have been designed for billing purposes are analysed to aid clinical practice (Ferryman & Pitcan 2018: 21; see also UN Women 2018). Data empathy is currently missing from many contexts of data use, and current funding calls, training curricula, and reward systems at research institutions do not seem to value such care for data (Pinel, Prainsack, & McKevitt under review).

In order to address these concerns, it is important to ask who builds and applies categories, who analyses big datasets and develops technologies, as well as who benefits from the results. We already mentioned that the field of medicine has been a male domain imbued with blatant sexism for a long time, and gender biases continue to live on in the era of digital medicine. Moreover, the field of computer science has been shown to be particularly badly affected with gender stereotyping as well as discrimination (Salter 2017). It is not only a field in which women's representation has decreased over the last decades, but also a field from which women have been systematically excluded once the industry gained economic relevance from the 1970s onwards (Hicks 2017). The male-dominated culture of computer science and the pervasive belief that social issues can be solved by better technologies increases the risk of built-in gender bias going unnoticed, alongside exaggerated expectations and reliance on technologies (Broussard 2018).

Conclusions and Way Forward

We started this article by arguing that what counts as relevant medical information has changed throughout history. From the dialogue between patients and healers, to the direct and standardised interrogation of patients' bodies, and to the usage of digital data generated through technical devices, the history of medical information has been one of increasing standardisation, datafication, and digitisation of the bodies and lives of patients – and people (Armstrong 1995, 2019). Recent developments, such as trends towards personalisation and

precision in medicine that call for increasing attention to individual difference and variation, seem to have reversed some aspects of the trend towards standardisation: As Richard Tutton argues, the shift towards personalised medicine could be seen as the programmatic end of the 'standard patient' (Tutton 2016). However, at the same time as personalised and precision medicine have contributed to a more individual-focused and more 'holistic' (Vogt, Hofmann, & Getz 2016) understanding of patients, they have also – through their focus on digital and other technological data capture – strengthened the view that data are something that can represent patients fully and objectively. The public imagination around big data has also created the idea that bigger data have a privileged access to truth.

At the same time, gender biases persist in the context of biomedical big data, in old and new configurations. In terms of the latter, we argue that digital practices in medicine reconfigure the gendering of societies in at least two ways: By making gender less visible, and by making gender bias harder to detect. About the first, the *invisibility of gender*: In clinical trials, the underrepresentation of women was visible because the gender or sex of participants was recorded; missing women were, literally, missing bodies (Caspar & Moore 2009). The 'data bodies' that digital medicine operates with often have no explicit gender attribution anymore; when digital epidemiology analyses entries in online search engines or the movement of people throughout a city via their phone's geolocation, these data are often used without any information on gender. The non- or underrepresentation of women and gender minorities is thus invisible. Which brings us to the second aspect, the *invisibility of gender bias*: The aforementioned imperative of personalisation insists that individual variation – and, ultimately, individual uniqueness – supersedes and resists group classifications, including gender. This, together with the integration of data from multiple sources and the hypothesis-free mining of datasets, makes biases harder to detect.

We do not believe that gender bias is something that can be abolished or overcome entirely. Instead we believe that biases are something that should be reflected upon critically in all instances where they are known or likely to occur and reduced where they are problematic. Unacknowledged and implicit biases are problematic in the sense that they deprive people, who use the data or their results, of the opportunity to consider how the bias may have affected the outcome. Rather than assuming that the replacement of humans (who are known to hold explicit and implicit biases) with machines (who are often seen as, if not unbiased, then at least dispassionate and disinterested) can solve these problems, actors within and outside of the healthcare field

Table 1. Six sets of questions to increase the visibility of gender bias in biomedical data. (Source: adapted from Prainsack 2014)

Topic	Set of questions
I. Coordination	• Who has what kind of influence in the development and coordination of health data projects and can decide on the purposes, procedural aspects, and questions pertaining to intellectual property? • What are the role and interests of the state, of public and private bodies, and particularly technological and pharmaceutical companies involved in health data projects? • What are the gender structures in these organisations and groups, and how do they work towards gender equality, if at all?
II. Participation	• What are the explicit and implicit mechanisms – including the availability or unavailability of institutional, technological, financial, and educational resources – that influence participation in health data projects? • What are the enabling and constraining factors that affect the quantitative representation of women and gender minorities in health data projects? What are their motivations to participate, and what forms does their participation take? • How are core issues of health data projects perceived by different groups of participants? For example, do women and gender minorities have other motivations for participation than central coordinating actors, and are their interests accounted for?
III. Community	• Are women and gender minorities invited to participate *qua* their genders, or is gender not a visible and explicit category in this health data project?
IV. Evaluation	• Who has the power to decide what good outcomes of health data projects are? • How are the criteria of evaluation decided upon, and what happens to the results of an evaluation? • Who defines how gender biases are defined and how datasets and technologies are dealt with, once gender biases have been detected? • What is done to reduce biases?

Table 1. Continued

Topic	Set of questions
V. Openness	• How are access to data and openness of data regulated? • Who has access to the data and who has what kind of rights and competences relating to the curation of data? • Can participants – in our case, in particular women and gender minorities – access their data in uncomplicated ways, if they so desire, and decide themselves what they want to happen with their data? • By whom, and how are attempts to 'de-bias' datasets undertaken? • What other mechanism of data quality control are in place?
VI. Entrepreneurship	• How are the financial needs of data projects met, and how are for-profit and other interests aligned or where do they conflict? • What commercial stakes are involved in data projects? • Has health data originally been generated for other purposes? And was there awareness and reflection about possible gender biases in the first instance? • Have commercial stakes outside of the healthcare system been inscribed in the data sets or infrastructures (e.g. in how and what data were collected, how people were compensated or not compensated etc.)?

should explore how bias is displayed at various phases of biomedical data work, and what its likely effects are.

Questions we will have to pose to counteract detrimental effects on women and gender minorities in particular include how they are quantitatively and qualitatively represented as well as how existing structures replicate and possibly amplify gender biases. The extrapolation of health-relevant information from data that were not generated for this purpose – such as data from social media or fitness trackers – needs to be scrutinised especially closely, considering as to how this process affects the distribution of power and resources within and across populations. We propose a set of critical questions pertaining to developments of datafication for productively reflecting on gender bias in old and new practices and technologies. We believe that the questions outlined in Table 1 (adapted from Prainsack 2014) can help to

make gender biases in biomedical big data practices and their potential effects on the distribution of power and agency visible, and thus provide the starting point to counteract them.

More broadly, and building on these open-ended sets of questions, we want to highlight that gender-sensitive practices require discussions that go beyond both quantitative and qualitative representation. In practice, this means that those who design strategies for data collection and data use in medicine and healthcare should always ask what underlies these designs – including assumptions about gender being binary, about some groups of people being different from others and so on, and about what effects these assumptions have on the conclusions that may be drawn on the basis of the data.

Acknowledgements

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