Ethics as Discursive Work: The Role of Ethical Framing in the Promissory Future of Data-driven Healthcare Technologies

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Abstract

The allure of a "data-driven" future healthcare system continues to seduce many. Increasingly, work in Science & Technology Studies and related fields started to interrogate the saliency of this promissory rhetoric by raising ethical questions concerning epistemology, bias, surveillance, security, and opacity. Less visible is how ethical arguments are used as part of discursive work by various practitioners engaged in data-driven initiatives in healthcare. This article argues for more explicit attention to such discursive work

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in shaping the promissory future of data-driven healthcare technologies. Bringing together the hitherto separated themes of promissory futures and an emic approach to ethics as discursive work, we study how actors engaged various data-driven healthcare initiatives discursively conduct such ethics work, implicitly or explicitly assigning tasks and roles for stakeholders. We conceptualize this with the notion of "ethical framing" and identify three widely recurring types: ethics as "balancing act," the technical "fix," and ethics as "collective thought process." We outline the characteristics of these acts of framing and discuss their implications for the envisaged roles and responsibilities of various actors. In the Discussion section, we outline the added value of bringing the distinct bodies of literature on promissory futures and ethical framing together and outline themes for new research.

Introduction

The allure of a "data-driven" future healthcare system continues to seduce many. Driven by technological developments (Mayer-Schönberger and Cukier 2013) and increasing opportunities for algorithmic analysis of large and varied data sets (Raghupathi and Raghupathi 2014), the latest years are marked by a continuous stream of hypes and "buzzwords" about the potential of data-driven healthcare technologies. The underlying promise is remarkably similar: healthcare is expected to improve significantly because *more* data are collected from varied sources and *better* analytical techniques are available to meaningfully process these data. Consequently, healthcare delivery is argued to become better in terms of "prevention" or "personalization" (Raghupathi and Raghupathi 2014; Kruse et al. 2016). While experts in data science and artificial intelligence may shun from the conceptual indeterminacy of the buzzwords in popular discourses—ranging from big data, predictive medicine, and data science to more recent expressions of hope and potential related to artificial intelligence and subfields like machine learning—recent work in STS has analyzed how such buzzwords generate matters of concern, mobilize people by setting attractive goals, and steer the agenda through their "promissory rhetoric" (Bensaude

Vincent 2014; Penkler, Felder, and Felt 2019). Indeed, such promissory rhetoric is highly recognizable in the perceived future of data-driven healthcare technologies (Hoeyer 2019; Stevens, Wehrens, and de Bont 2018).

An increasing strand of work in the fields of STS, critical data studies (CDS), and critical algorithm studies (CAS) has started to interrogate the saliency of this promissory rhetoric by raising more fundamental ethical questions concerning bias, epistemology, surveillance and security, and opacity of data infrastructures (boyd and Crawford 2012; Busch 2017; Bauman and Lyon 2013; Kitchin and Lauriault 2014; Ebeling 2016). Authors highlight the ethical dilemmas of data-driven technologies, providing a rich picture of ethical tensions and concerns (Mittelstadt and Floridi 2016; Salerno et al. 2017; Winter and Davidson 2019; Mittelstadt 2019). An aspect that is less visible in this body of work, however, is how ethical arguments are used as part of discursive work by various practitioners engaged in data-driven initiatives in healthcare. Rather than a set of abstract principles, ethics can also be viewed as an emic resource that actors draw upon to distribute roles and responsibilities, legitimize particular courses of action, and negotiate the tensions and dilemmas involved in translating ambiguous legal principles into responsible courses of action (cf. Cool 2019; Hoeyer, Tupasela, and Rasmussen 2017).

While work on sociotechnical futures in STS has been instrumental in explicating their inherent normativities and performative dimensions (Borup et al. 2006; Brown and Michael 2003; van Lente 2012; Jasanoff and Kim 2009, 2015; Felt 2015), thus destabilizing all-too-sticky narratives of progress and revolution (cf. Jerak-Zuiderent 2015; Stevens, Wehrens, and de Bont 2018), this work has focused less explicitly on the role of ethical framing in shaping promissory futures. This article argues for the analytical saliency of paying attention to the role of ethical framing (Hoeyer 2005; Hoeyer, Tupasela, and Rasmussen 2017). We define the notion of "ethical framing" as the discursive work conducted by actors to characterize the ethical dimensions of data-driven healthcare technologies, thereby assigning tasks and roles for stakeholders and shaping the promissory future of data-driven healthcare technologies. In sum, this paper seeks to bring together the hitherto separated themes of promissory futures and an emic approach to ethics as discursive work in the context of data-driven healthcare technologies.

The article addresses three empirical questions: (1) which ethical frames are enacted by key actors in data-driven healthcare technologies? (2) what consequences follow from these ethical frames in terms of the roles and responsibilities these actors envisage for themselves and others? and (3)

how do these ethical frames shape the promissory future of data-driven healthcare technologies? The article is based on 145 interviews and document analysis conducted within an international research project, in which we compared the regulatory and governance dimensions of health-related "big data"[1] in eight European countries.

In the next section, we further contextualize the theoretical traditions the paper builds on, linking literature on promissory futures, ethics of data-driven technologies, and ethical framing as discursive work. Next, we discuss the methods and introduce the international research program our analysis is based on. In the results, we outline three widely recurring types of ethical framing and show their effects on roles and responsibilities attributed to different actors. In the discussion, we outline the added value of bringing the distinct bodies of literature on promissory futures and ethical framing together and outline themes for new research.

Promissory Futures, Ethics of Data-driven Technologies, and Framing as Discursive Work

New Technologies and Their Promissory Futures

The future has been an important trope in STS research. From various perspectives, authors have analyzed how visions of the future of technology become articulated in imaginaries and narratives (de Wilde 2000; cf. Pollock and Williams 2010).

Two notions are central in STS research on promissory futures. The first notion is "expectations" as developed in the sociology of expectations. This literature focuses on the *informal* production and circulation of expectations in science and technology (Borup et al. 2006). This work emphasizes that expectations harbor values, norms, and provoke role divisions. Expectations can *legitimize* investments, set courses of action, steer the options to be explored by researchers and technology developers, and coordinate activities and role divisions of research and industry networks (van Lente 2012).

The second notion is *sociotechnical imaginaries* (Jasanoff and Kim 2009, 2015). Sociotechnical imaginaries are defined as "collectively held, institutionally stabilized, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology" (Jasanoff and Kim 2015, 4). This work emphasizes the similarity between techno-scientific visions of the future in specific times and places. Originally envisaged as closely tied to nation-states, later work emphasized

that sociotechnical imaginaries can also be articulated by other organized groups and communities (Jasanoff and Kim 2015), can become regionally "translated" in distinctive ways (Levenda et al. 2019), and may acquire particular meanings in specific technopolitical cultures (Felt 2015). In the context of healthcare, several authors have noted that on a European level, broadly similar discourses on the promissory future of data-driven healthcare circulate (Rieder 2018).

Taken together, these bodies of work offer useful analytical anchor points to understand the functions and effects of promissory futures. The sociology of expectations literature emphasizes the performative and political dimensions of the informal expectations that circulate through promissory futures, while the literature on sociotechnical imaginaries emphasizes how expectations become durable and stabilized in narratives that can be circulating on an international level, country-specific, regionally bound or tied to particular groups.

Ethics of Data-driven Technologies

Ethical concerns regarding data-driven technologies have received a relatively large amount of attention in the fields of STS, CDS, and CAS. Several review articles have identified key areas of concern (e.g., algorithmic decision-making) in particular contexts (e.g., biomedicine) (Mittelstadt and Floridi 2016; Mittelstadt et al. 2016; Mittelstadt 2019; Morley et al. 2020). Work on the ethics of data-driven technologies emphasized not only the wide range of ethical dilemmas that should be considered but also focused on further theorization (leading to important discussions on how data-driven technologies can be conceptualized) and problematization (highlighting the misalignments with traditional ethical principles and theories).

For the aim of this paper, we address several insights that problematize traditional ethical notions and theories to address concerns with regard to data-driven technologies (cf. Verbeek 2014). First, many articles argue that ethical aspects should not be viewed as external to data-driven technologies, emphasizing the intertwinement of technologies and ethical dimensions. Traditionally, such work has focused on the "hidden normativities" in data-driven technologies (cf. Ziewitz 2016, for a critique on this popularization of what he calls the "algorithmic drama"). More recently, the focus has been on how this intertwinement co-constitutes new relations between human and nonhuman actors in diverse practices (Ananny 2016; Lee et al. 2019; Lee and Larsen 2019).

Second, many articles focus on the "unprecedented" character of ethical dilemmas, thus questioning the ability of traditional ethical principles and procedures to adequately deal with "new" dilemmas. For instance, Metcalf and Crawford (2016, 2) argue how data-driven technology "fundamentally changes our understanding of research data to be (at least in theory) infinitely connectable, indefinitely repurposable, continuously updatable and easily removed from the context of collection." Such characteristics are fundamentally at odds with the orientation of most institutional review boards and ethics committees, which focus on individual risks (Zook et al. 2017).

Third, recent work also developed critiques on the limited usability of classical ethical theories in the context of data-driven technologies. A core focus of this work has been on explicating misalignments between data-driven technologies and traditional ethical principles that emphasize moral agency and come with a strong set of assumptions about individualism and free will (Zwitter 2014; Prainsack 2018). Such assumptions become especially problematic in the light of data-driven technologies, where the input used for decision-making is opaque, effects are hard to oversee and unequally distributed, and responsibility, trust, and agency become dispersed.

Absent from this literature is an exploration of how ethical arguments become tied to the promissory future of data-driven healthcare technologies while promissory rhetoric also shapes the way ethics is being done and understood. We therefore argue for the analytical productivity of bringing the dimensions of ethical arguments and promissory futures together via the notion of ethical framing. This allows us to focus on how ethical arguments are used by various actors engaged in the development, implementation, and governance of data-driven healthcare technologies (cf. Cool 2019; Hoeyer, Tupasela, and Rasmussen 2017).

Framing as Discursive Work

The notion of "frame" has a long history in STS (Orlikowski and Gash 1994; Bijker 2006) and in interpretive policy studies (IPS). In the latter, the notion originates in both the symbolic interactionist tradition of Goffman (1974) and the public policy analysis developed by Rein and Schön (1993). Goffman used the notion of "frame" to understand how people implicitly "define the situation" in interpersonal encounters as they negotiate the meaning of their interactions. The policy analytic approach of Rein and Schön originally focuses on frame analysis as a methodology for the

analysis of policy controversies. Through frames, policy actors can highlight certain features of a situation, ignore or select out other features, and bind the highlighted features together into a coherent and comprehensible pattern (van Hulst and Yanow 2016). The act of framing then highlights the interactive processes through which frames are constructed through naming, selecting, storytelling, sense-making, and categorizing (van Hulst and Yanow 2016).

These two scholarship branches (STS and IPS) highlight the discursive dimensions of framing by placing their analytical focus largely on the shared interpretation of the (technological) object or (policy) issue at stake. Framing however also generates particular tasks and role divisions for various actors, and through framing, roles, and responsibilities become distributed and defined in particular ways. Recent ethnographic work in organization studies has sought to explicate how framing as a discursive activity contributes to role divisions, tasks, and responsibilities of different actors (Oldenhof, Stoopendaal, and Putters 2016; Berghout et al. 2018). Specific to ethics, this point is reinforced by taking into accountWainwright et al.'s (2006) study of ethical boundary work that highlights how scientists conduct ethical boundary work as a process of social demarcation.

To summarize, discursive approaches in IPS and organization studies are instrumental to better understand the specific effects of framing—as a discursive activity—on the interpretation and representation of the technological object or policy issue at stake and on the distribution of specific roles and responsibilities for the various actors involved.

Method

The data on which this paper is based are part of a broader project to investigate the regulatory and governance dimensions of health-related big data in a European context.[2] We have conducted 145 semi-structured expert interviews in eight European countries: Austria, France, Germany, Ireland, the Netherlands, Spain, Sweden, and the United Kingdom. Respondents were identified via desk research and via experts. We selected respondents among the categories: (1) healthcare professionals and management involved in big data-pilots that are part of the project consortium, (2) ethical and legal experts who are knowledgeable about the key discussions in their country, (3) technology developers and data scientists who are involved with the technical dimensions of big data analyses, (4) representatives of patient and professional associations, (5) visible actors in the public debate in order to capture public perspectives on big data, and (6) policy makers

and additional policy experts who can provide input on key governance strategies and challenges.

The goal of the semi-structured interviews was to develop insights into governance approaches, regulatory challenges, ethical dimensions, and societal debates about big data. Upfront a predefined topic list was made, including (1) policy goals and strategies, (2) the main regulations for health-related big data and how such regulations are perceived, (3) ethical questions and debates that are generated by big data, and (4) reflection on how social and cultural aspects are perceived to influence the practices and regulation of big data. The large majority of interviews were conducted face to face, with interviews conducted via video conferences (Zoom, skype, or a similar medium) or phone in exceptional cases. In all cases, permission to record the interview was obtained. All interview transcripts are stored in a secure server (Workspace).

A supplementary document analysis was conducted for each country to become familiar with the different health systems, public discussions, and policy strategies of health-related big data. Interview data were triangulated with policy documents, news articles, scientific papers, presentations, and gray literature provided by the respondents.

In the analysis of the material, we used a method of constant comparison (Strauss and Corbin 1990) to facilitate peer review between team members, increase mutual understanding, and facilitate in-depth comparison. We organized several full-day meetings to present our initial analysis and reflect on similarities and differences between countries.

The theme of ethical framing emerged inductively. We asked all respondents questions about their key ethical concerns to big data in healthcare and we noticed that respondents often used these questions to reflect on a "meta-level" on the role of ethics in the development of data-driven technologies. We were triggered by the way respondents ascribed a particular position to ethics. The remarks about the role of ethics were widespread throughout all the interviews and not limited to particular countries, organizations, or particular groups of experts (such as the ethical experts).

Based on our theoretical familiarity with debates on ethics of data-driven technologies, we conducted an additional abductive analysis (Tavory and Timmermans 2014) on the collected material. During the analysis, we iterated between our empirical material and theoretical work on ethics of big data and the variety of STS literature on sociotechnical futures. In this process, we gradually zoomed in on ways of ethical framing.

We interpreted "ethical" statements broadly in our material, focusing in general terms on what respondents described as things we *ought* to do, or

when they referred to things they considered good, valuable, worthwhile, or laudable. It was not our intention to define ethics upfront. Instead, we took inspiration from Heeney (2017), who does not attempt to distinguish between the "real" ethical position and interviewees' interests but instead states that she is "interested in the discourses interviewees employ and create, and [. . .] use[s] the interview data to consider what they think ought to be considered in relation to what is and is not ethical in terms of practice" (p. 11). We recognize with her that interviewees appear not only as "practicing actors" but also as "thinkers" who relate their desires for their own practices with the wider normative, scientific, and social implications of what they do.

During the analysis, we identified three widely recurring ways of ethical framing. The three ways of ethical framing were by far the most prevalent in our material. As we show in the results, they come in slightly different variants. We excluded framings that were mentioned only a couple of times in interviews.[3] Each of the frames will be illustrated with quotes in the next section of the paper. We recognize that these quotations are not representative of all the European countries from which interviews were drawn, but we want to emphasize that the purpose of the analysis is not to develop a country-comparison. Whereas in other places, we focused on differences and similarities between countries,[4] for the purpose of this paper, we therefore focus on identifying the most common ways of ethical framing that were prevalent in all the interview material and therefore not specific to any country.

Results

We structure the results around the three widely recurring ways of ethical framing. Such frames can be most fruitfully understood as discursive utterances that are mobilized by various actors; sometimes with a specific strategic purpose in mind, but also mobilized more unconsciously (or at least without explicitly being used strategically). At the same time, frames are performative as they structure what ethics should be about, and they may in that sense affect what others see as valid or legitimate concerns if they gain traction. While ethical frames therefore do not operate as sole "causes" of socio-technical change, they are likely to affect the ways in which data-driven healthcare technologies are shaped.

We identify three frames: *ethics as "balancing act," the technical "fix,"* and *ethics as "collective thought process."* We outline the characteristics of these frames and their implications for the envisaged roles and

responsibilities of various actors. In the discussion, we reflect on how they shape the promissory future of data-driven technologies.

Framing Strategy I: Ethics as "Balancing Act"

> I think that in general [. . .] we have to develop a balance. [Big Data] is not something where you can have everything: full privacy, full usage of all data *and* knowledge gain. We have to bring it in balance. First, there is data protection. Here [we] must find the balance between protection for patients' privacy and the possibility to do research with it. [. . .] It is the task of the policy and law makers to find a good balance. So that those that are feeling threatened feel kind of safe, but at the same time the researchers can do what they have to do. [. . .] Also ethically I have to balance it. [. . .] It is nothing else than finding a balance between risk and benefit. (Interview information scientist, Austria)

The first type of framing we encountered is ethics as a *balancing act*. The perceived role for ethics in shaping the promissory future of data-driven healthcare technologies is *to balance*. This framing entails discursive work in which different ethical values or principles are outlined in relation to each other, as exemplified in the above quote. Such relations are then positioned as either being weighed differently in various contexts, as being in tension with each other or as being opposite ends of a spectrum. Ethical use of data-driven healthcare technologies according to this frame then presupposes the *search for an adequate mean between various values* or, in other terms, about *finding an appropriate balance*. As different values become outlined in relation to each other, the "ethical" thing to do becomes envisaged as an attempt to find the right balance: between economic values (such as innovation capacity), public values (such as privacy and data protection), professional values (such as delivering good care), scientific values (such as knowledge development, learning), and legal values (such as data integrity). Respondents implicitly assign the task to all stakeholders involved; the quote expresses this role as both a general assignment ("we have to") and a personal obligation ("also I").

The frame of ethics as a balancing act is also often expressed by policy makers, who recognize the need to mediate between different "goods." The following quote from a Swedish policy maker is exemplary of how this frame is used and explicitly contrasted against perceived differences with policy approaches in other countries:

Some countries have a big fear of integrity [breaches] and they weigh integrity much more than patient safety and that's a problem. In Sweden we always try to balance that. It is in the patient's best interest that we can follow some metrics on your health on the system level. Because otherwise you will die: if you put all efforts to integrity, the next doctor doesn't know anything about you and then you will be mistreated and injured by healthcare. So it's also in best interest of the patient that you have that kind of data in some way. (Interview policy maker, Sweden)

This example shows a policy maker framing ethical use of big data as a balancing act that requires aligning the diverse values of integrity (which is enacted as a way to point to the privacy risks of personal [health] information becoming breached) and patient safety (which is positioned as crucial to avoid injury or mistreatment).

Through this frame, the promissory future of data-driven healthcare technologies is presented as a mixed set of benefits and risks that are not neatly aligned. In some variants of this frame, the balancing act is explicitly presented as a precarious and temporary achievement; like a pendulum, the ethical focus within a country is argued to shift from an emphasis on one value to another. The following quote from a professor in health information in Ireland expresses this variant of the balancing frame as he reflects on what he views as a gradual movement from the emphasis on one ethical value to the current overemphasis on another:

[In Ireland] there is a fear to the point of paralysis of sharing data because of data protection issues. A lot of it is unfounded, but everyone kind of fears data protection and therefore [many organizations] are saying: no, I am not sharing my data. [. . .] *So the pendulum has swung far too far over to the protection of the patient* and I think we are potentially at the point where we are not protecting the patients' care. We are protecting their data, but we may not be protecting their care. So there is a sweet spot in between those two. You know in the past I'd say we could have been more on the other end you know: share everything and no control. I think we probably are going too far at the other way as well. (Interview professor health information, Ireland, emphasis added)

This example shows how a discursive contrast is created between different values, but in this example, they become linked to a (critical) narrative of gradual change over time and overemphasis on the ethical value of *data* protection at the perceived cost of the ethical value of *patient* protection.

The frame of the "balancing act" can also be used as a strategic attempt to reframe the ethical questions that are considered to matter. For instance, various high-level policy makers discursively attempted to reframe the ethical debate toward a recognition that *not* sharing available data is as ethically troublesome as sharing data:

> We can't keep hiding behind the ethics. We say that it is not ethical to use people's data, but maybe it is just the other way around. It is not ethical *not* to use the data. So I think that this is sort of changing and people are very open to donate to healthcare. [. . .] If we say that it's not ethical to use my data in a wider context, it is always very easy to hide behind that, to say: "no, we can't move in this direction with utilizing data in this way." [. . .] It's easy to stay where we are right now, and say that this is the right ethical framework. But I think from a patient perspective it's not ethical *not* to use the data. (Interview policy maker county council, Sweden)

This quote shows a policy maker implicitly utilizing the frame of ethics as a "balancing act" as a way of reframing the current debate on data sharing, which according to her focuses too much on values like privacy and data protection. It can also be understood as an attempt to depict the current position of ethicists as "easy": critically commenting on ethical questions and dilemmas raised by data-driven healthcare technologies is depicted as one-sided and as a way to "hide" from the discussion about whether it is not equally unethical to create barriers for data sharing, as this is argued to lead to patient risks (cf. Langat et al. 2011; Jones et al. 2017). This reframing also comes with frequently used metaphors such as "data donation," highlighting "collective" principles and discursively linking ethics of data sharing to notions of "good citizenship" (i.e., as something that "responsible" citizens do; cf. Puschmann and Burgess 2014). Such collective principles again tie into the framing of ethics as a "balancing act" as they highlight that the emphasis is currently placed too much on individual principles.

An important implication of framing the role of ethics as balancing act is that values are perceived as comparable. This way of framing thus assumes that values can be "weighed" against each other in a utilitarian cost-benefit type of analysis. As such, this way of framing offers less space for values that are considered to be *incompatible*. The search for the adequate balance mostly implies that more of one type of value leads to less of the other type of value.

This way of framing also has consequences for roles and responsibilities implicitly assigned to ethicists and other actors. As outlined in the discussion of the framing literature, various authors have emphasized how framing comes with task distributions, thereby implicitly or explicitly assigning tasks and roles for various stakeholders. We argue that such implicit assignments can also be viewed in this way of framing. We infer that the role of ethics implicit here is one that is well-demarcated, but simultaneously minor, as ethics becomes primarily about finding and maintaining the right balance between ethical values in particular use contexts of data-driven healthcare technologies. The quotes make clear that balancing is not necessarily tied to ethical experts: policy makers and, indeed, any actor can engage in "ethical reasoning" of this kind. While this act of framing can be perceived as an attempt at democratization, we argue that it also obfuscates aspects that various scholars would describe as important for ethicists in their role as experts. For one, this framing neglects the role of ethical experts as actors whose value lies in their ability to *disrupt* all too optimistic or instrumental narratives (cf. Swierstra 2018). Another aspect of ethics that becomes marginalized in this way of framing is the attention for ethical dilemmas that do not neatly "fit" in the implicit cost-benefit structure of the frame, and for which again many scholars would argue a particular kind of "moral" or "ethical expertise" is warranted (Grunwald 2004; Priaulx, Weinel, and Wrigley 2016). Thus, we infer that this way of framing comes with an implicit set of tasks and role divisions that highlights the role of ethics as "ethical reasoning" any actor can engage in, while neglecting a more "fundamental" role of ethics as "disruptor."

Framing Strategy II: The Technical "Fix"

> I guess one of the difficulties we have at the moment is our ethics committee here. Our institutional review board is still grappling with GDPR regulation [. . .]. So, while they are still grappling with that, there is a little bit of stagnation with the ethics process. And that can be [troublesome], but none of that is insurmountable. [. . .] I guess everyone is figuring it out together you know, which is fine. It's a bit unchartered territory [. . .]. *But once we can demonstrate that we are compliant in anonymizing everything, not making it linkable back to the patient then I don't foresee a problem.* And nor did our data protection officer. (Interview physician, Ireland, emphasis added)

The second type of framing we encountered is the frame of the "*technical fix*." The perceived role for ethics in shaping the promissory future of data-driven healthcare technologies is *to solve*. The above quote from an Irish physician, working on a big data project to reuse hospital data for analytical purposes, is illustrative for this type of framing. This framing entails discursive work in which the ethical problems with data-driven healthcare technologies are recognized, but simultaneously presented as ultimately *solvable* through technical or instrumental means. Thus, while many actors recognize ethical risks of reidentification and lack of informed consent, these ethical risks are not viewed as insurmountable. Rather, given the right instrumental and technical solutions, the idea is that ethical risks can be contained and dealt with adequately via existing institutional structures such as ethical review boards.

Perceived solutions frequently envisaged within this type of framing cluster around three approaches. First, better *technical* solutions. Some respondents focused, for example, on techniques for anonymization or pseudonymization as they were perceived as sufficient safeguards for the ethical use of health data:

> It is not technology that is the main problem, the technology is there. The problem is the lack of clear guidelines. So, there should be no fear for medical practitioners. And even such as like us who are sitting on the other side of the table, computer scientists, those who are triggering new innovations.
>
> Interviewer: Do you then also mean that, for instance, you would have the technical means to ensure compliance to legislation, so, for instance, to ensure anonymization and things like that?
>
> Yes, yes. So, the technology is not behind. The technology is ready, we have the technologies. But there are no clear guidelines how to apply these technologies. And that's the problem. (Computer scientist, Ireland)

This respondent highlights how in his perspective, the technical solutions for ethical problems (such as the risk of reidentification) are already available. The main problem is perceived to be lack of clear procedures.

A second perceived solution within this type of framing therefore centers on better *procedures* that clarify the stakes or seek to navigate around the most problematic ethical aspects.

Some respondents emphasize how well-developed procedures for access to health databases are important to ameliorate ethical concerns about misuse. For example, the development of new authorization procedures for

access to health data in France, legally embedded via the Law for the Modernization of the Health System, are seen as a way to provide clarity about the conditions under which access to health data is acceptable:

> The national system of health data (SNDS) is the biggest database of health data, because it contains the claims of the national insurance for all French people. [. . .] This database has been created in the law in 2016, and since this date, public and private actors can access this data. So this is big progress in terms of access to French health data. [. . .] Now we have a very precise procedure specified in the law, so you are sure that you can have an effective access to the data within a period of six months, which is a real progress in France compared to before. (Interview policy maker, France)

Discursively linking procedures, legislative embedding and ethics, this example points toward the idea that the most important ethical dilemmas can be navigated via procedural "fixes" (such as the "right" process of access). Another example mentioned by respondents was to develop "broad" consent forms for research areas as a procedural "solution" for the ethical problem of repeatedly asking for individual consent.

The emphasis on appropriate legal principles and frameworks constitutes a third aspect of the frame of the technical fix. This can be seen, for instance, in the way discussions about "proper" use of health data congregated around the narrow question whether practices aligned with the new European General Data Protection Regulation (GDPR) or not:

> R1: There have been no clear guidelines from an Irish perspective [about the use of health data] for the research side of things. And what has been published from health legislation is a like book of 500 pages, how is that helpful in a practical day-to-day basis.

> R2: So, there seems to be a general sense of just keep doing what we're doing. We're not doing anything incorrect until we're given direction from government. [. . .] Just make sure you have consent, make sure you document the decisions that you are making and why you're doing that, you know. To be compliant. So, you can have a justification for why you're operating in one way or another. But in the absence of clear and understandable guidelines, everyone's a bit at sea. (Interview physicians, Ireland)

This quote shows how physicians, struggling with the everyday practical translation of new GDPR legislation to determine what would constitute "proper" or "acceptable" use of health data for their research projects, felt

lost "at sea" in the absence of clear direction. At the same time, the quote implies that such clear direction would ultimately be seen to "settle the record" in terms of acceptable use of health data, thus implicitly equating understandable legislative frameworks with ethical use of health data. In this way, discussions about "proper" (i.e., "ethically acceptable") use of health data congregate around the narrow question whether practices align with the new GDPR or not.

As with the framing of ethics as "balancing act," the framing of the "technical fix" also comes with various implications. First and foremost, this way of framing comes with the normalization (and with this the "deflation") of ethical dilemmas. Ethical issues are implicitly perceived as "fixable" with additional procedures, guidelines, instruments, or legislation. As such, this way of framing can result in "ticking-the-box-ethics," even though experts question the saliency of such solutions (cf. Zook et al.'s [2017] final "rule"). Second, the belief in a technical fix in this way of framing backgrounds ethical processes of joint deliberation and compromising. Third, the role of ethics becomes narrowed to "fighting symptoms," as this way of framing emphasizes ethical aspects that are relatively easily "doable," instead of the more complex ethical issues that are often raised in more critical literature on data-driven technologies (boyd and Crawford 2012; Mittelstadt and Floridi 2016; Mittelstadt 2019; Grote and Berens 2020).

As with the previous type of framing, the frame of the technical fix also comes with consequences for the roles and responsibilities assigned to ethicists and other actors. Similar to the framing of ethics as a balancing act, we infer that this type of framing also implies a well-demarcated and relatively minor role for ethics. We argue that in essence, all three variants implicitly render ethical expertise subordinate to other domains or at least render ethical issues and dilemmas "solvable" through other domains: whether by technicians (who can develop the "right" solutions), by policy makers and health managers (who are positioned to develop such "better procedures"), or by lawmakers (who can develop "proper legislative frameworks"). Such implicit task distributions come with risks as well. A potential risk exists in equalizing the development of the "right" procedure as such with the idea of "ethical use" of data. While the development of transparent procedures is undoubtedly valuable in terms of specifying ethical criteria for access and restriction of sensitive health data, we suggest that the procedure as such is unlikely to ameliorate the broader ethical discussions, for example, about forms of opacity; pernicious feedback loops that reinforce effects of inaccurate data, bias, or discrimination; and the ways in

which professionals may become narrowly embedded in "epistemic niches" that constrain or undermine the practical wisdom necessary to make moral decisions (Hayes, van de Poel, and Steen 2020).

Framing Strategy III: Ethics as "Collective Thought Process"

> Ethics is an eminently collective, plural concept. [Therefore], [. . .] the CNIL could not lay claim to any sort of monopoly over ethical discussions on digital technology. On such a vast and cross-cutting subject, on no account should these be held behind closed doors. [. . .] It was in this mindset that the CNIL set a collective approach in motion, for several months overseeing a public debate with the help of partners from various sectorial fields (health, justice . . .). In this respect, *ethics is just as much about the process itself as it is about the outcome*. (Commission Nationale de l'Informatique et des Libertés 2017, 3-4, italics added)

The third type of framing we encountered is the frame of ethics as a *collective thought process*. The perceived role for ethics in shaping the promissory future of data-driven healthcare technologies is *to deliberate*. The above quote from the Commission Nationale de l'Informatique et des Libertés (CNIL), the French national data protection agency, is illustrative for this type of framing. This framing entails discursive work in which ethics becomes viewed as an open-ended process of joint deliberation. In the example above, the CNIL has organized a series of public debates about the development of new digital technologies. It has explicitly positioned ethics as the "crafting [of] a collective and pluralist ethical thought process" (CNIL 2017, 8). Key underlying ideas in this way of framing are notions of deliberation and continued reflection, which are perceived as crucial in engaging with the ethical dimensions of data-driven (health) technologies in a "good" way. Through its emphasis on the processual dimensions of ethics as a form of deliberation, this frame also recognizes the open-ended character of ethics: technological developments are perceived as fundamentally uncertain and thus likely to require continued attention and revision.

Different variants of this type of framing can be distinguished. At the minimum, it contains an argument about the need to inform the public about the use of their data because they have a "right to know," even if public deliberation on data privacy is not considered to be part of a country's culture. A Spanish ethicist reflects on this "right to know" in a cultural context he considers to be relatively unopen:

The [. . .] problem is that there is no culture on data privacy [in Spain]. In the past this was not relevant because you [could] assume or you [had] trust in those who were in touch with your data in the clinic. [. . .] Now you know that everybody shares data or wants to share data. [. . .] Citizens deserve to know, because the citizens are those who are going to give you this raw material to be exploited in the proper way [. . .]. (Interview ethicist, Spain)

This quote represents a way of framing that links ethical use of data ("to be exploited *in the proper way*") with citizens' right to know, thus highlighting the collective aspects of ethics (although only at the level of "providing" information).

Aligned with this way of framing is a critique on a narrow expert focus. A policy approach often seen is to "outsource" ethical discussions to expert advisory organizations and committees. In Austria, for example, discussions about new data-driven healthcare technologies are mostly organized in terms of expert deliberation. A patient representative working at an advocacy organization enacts the frame of ethics as a collective thought process to question this narrow focus on experts:

So the debate [on data-driven healthcare technologies] takes place in a very small group, so it does not take place in the general population [. . .]. But then it is immediately . . . when it is no longer an urgent topic, it breaks down relatively quickly. So, the general population doesn't really take part in the debate. These are debates that actually run among the experts. (Interview patient representative, Austria)

In this way of ethical framing, the tendency to limit ethical debates to experts is explicitly problematized. This line of reasoning can also be seen in the argumentation of the CNIL, as the institute outlines how such limitations may lead not only to public mistrust and suspicion, but also because expert perspectives are insufficient given the complexities and uncertainties in the evolution of digital technologies (CNIL 2017, 4).

Again, this way of framing comes with a set of implications. The implications of this frame are primarily that it asks for a democratization of ethics, with the aim to include not only "ethical experts" but to open up the realm of ethics to many stakeholders, including lay persons affected by new technological developments. We postulate that an implicit rationale is often underlying this way of framing. This is the rationale that new technologies will affect many citizens and that this entitles them to become involved in ethical deliberations. As such, ethics and "citizenship" become

discursively entwined in this way of framing. Another implication of this way of framing is that it explicitly allows for—and even seeks to organize—forms of multiplicity and diversity.

As with the previous ways of framing, the frame of ethics as a collective thought process comes with consequences for the roles and responsibilities assigned to ethicists and other actors. We argue that the most notable consequence is that it comes with a broadening of responsibility to a much more varied set of actors. As ethics becomes a public concern that is not limited to a set of expert actors nor something that can be fixed procedurally or technically, anyone can—and one might even say "should"—become involved in ethical reasoning. In this sense, we infer that the frame explicitly distances itself from a perspective on ethics as belonging to a specialist domain. Simultaneously, the way this frame is enacted can also affirm organizations in taking up a key position. The example of the CNIL shows how this agency positions itself as the "custodian" of key ethical principles and as the organization most suited to organize this process of inclusive deliberation. As the CNIL decides on the core ethical principles, their role becomes one of facilitating debate and crafting key messages to policy makers (which involves a lot of translation efforts; not only summarizing the debate but also selecting the most important outcomes and tailoring these to policy recommendations). Next to setting the "rules of the game" and translating outcomes, one could argue that this role of "custodian" also involves responsibilities of ensuring "voice and choice" (who is included and under what terms?) and creating favorable conditions to prevent subtle exclusion strategies (cf. Oldenhof and Wehrens 2018).

Discussion

By bringing together STS literature on promissory futures, ethics literature on data-driven technologies, and policy literature on framing as discursive work, we identified three widely recurring types of ethical framing: ethics as a *balancing act*, the *technical fix*, and ethics as *collective thought process*. These types of framing come with different perceived roles for ethics in the promissory future of data-driven healthcare technologies: "to balance," "to solve," and "to deliberate." In the discussion, we answer the final question we introduced in the paper: how do these ethical frames shape the promissory future of data-driven healthcare technologies? From there, we extrapolate our findings to be able to reflect on the broader analytical and policy implications of our work.

Our analysis showed that the ethical frames are mostly supportive of data-driven technologies. In the frame of ethics as balancing act and the frame of the technical fix, ethical aspects of data-driven technologies are considered important but also relatively well-demarcated (i.e., they are perceived to not be about fundamental issues). Only the frame of ethics as collective thought process seems to recognize on a more fundamental level the uncertainties and contingencies of technology development, thus providing discursive space for more fundamental concerns and questions. Our study suggests that, in addition to earlier observations that broadly similar discourses on the promissory future of data-driven healthcare circulate in different countries (Rieder 2018), we can similarly recognize distinctive types of ethical framing that are prevalent irrespective of country-specific or regionally bound traditions and data practices (cf. Tupasela, Snell, and Tarkkala 2020; Felt 2015). In other words, the increased convergence of ethical arguments seems constitutive in further shaping the promissory future of data-driven technologies as they generate particular (instrumental, *manageable*) concerns and steer the agenda in particular ways (technical, procedural, and legal "fixes," cost-benefit types of decision-making). While the normative dimensions of promissory futures are widely recognized (Borup et al. 2006; van Lente 2012; Jasanoff and Kim 2009, 2015; de Wilde 2000), our paper thus contributes to this work by disentangling the role of ethical framing in supporting such futures.[5]

Our analysis shows that ethics is more than a set of abstract principles; it is also a discursive resource that various actors implicitly or explicitly use in their daily work to legitimize (or question) developments and decide about what is acceptable or not. Health professionals and data scientists working with data-driven technologies continuously construct ethical arguments. Ethics has predominantly focused on issues of agenda-setting (making visible ethical dilemmas), theorization (leading to new conceptualizations of data-driven technologies), and problematization (highlighting the misalignments with traditional ethical concepts and principles; Zwitter 2014; Metcalf and Crawford 2016; Mittelstadt and Floridi 2016; Zook et al. 2017; Lee and Larsen 2019; Mittelstadt 2019). We plea for a parallel research program that studies how ethical arguments are constructed and negotiated in situ. Through ethnographic research, such studies can reveal how ethical decisions are made within the mundane work practices of health practitioners, data scientists, and other stakeholders (such as patient groups) in data-driven initiatives (Heeney 2017). There is much to be learnt about how ethical arguments are negotiated between different groups in medical practice; how ethical considerations are made and justified; and how data

scientists, technologists, and medical practitioners jointly work on establishing norms and shared "epistemic virtues" in concrete initiatives (cf. Stevens, Wehrens, and de Bont 2020). On a broader policy level, our analysis raises new research questions regarding what kinds of actor coalitions emerge and how framing efforts affect the perceived legitimacy of data-driven healthcare technologies (cf. Geels and Verhees 2011).

Within fields of STS, CDS, and CAS, much analytical attention has been placed on exposing the harmful effects and negative consequences of new data-driven technologies, for instance, regarding how they (re)produce forms of discrimination and inequality (e.g., boyd and Crawford 2012; Lee and Larsen 2019). It is perhaps tempting to also interpret our analysis in this critical light; for instance, by interpreting acts of framing as insidious or deceitful attempts at circumventing "deeper" ethical reflection. We, however, propose a future research agenda in which the ethical perspective shifts toward an ethnographic approach that studies responsibility-in-the-making, highlighting how various actors "care for" ethical data practices (Stevens 2021). This approach can also build on previous research that focused on how numbers are "made," "cared for," "played with," and how they travel between sites (Wallenburg and Bal 2019) and "internalist" ethical approaches that focus on technology "accompaniment" rather than external critique (Verbeek 2014; Smits 2006).

To conclude, we believe that our study also harbors important implications for policy. Most importantly, our study makes apparent the omnipresence of ethical arguments. Policy makers, healthcare managers, and practitioners should therefore avoid the "outsourcing" of ethics to specific committees but instead facilitate ways to organize multidisciplinary modes of reflection. For instance, through the organization of "data dialogues," the legal, technical, and ethical dimensions of concrete Artificial Intelligence applications and their use in (medical) practice can be explored collectively (Stevens 2021). Such dialogues can help to enhance mutual understanding and make underlying arguments and ways of reasoning explicit.

Second, recognizing the normativities already present in healthcare practices can serve as a useful reminder for policy makers to move away from the idea that all ethical (and, in parallel, legal) issues surrounding data-driven technologies can be solved upfront. Although undoubtedly valuable, embedding such technologies responsibly in healthcare asks for *more* than technical solutions, formal rules and regulations, and the establishment of ethical principles. Various ethnographic studies into the governance of healthcare have showed how the layering of multiple, conflicting rules and principles could obfuscate healthcare work and increase regulatory

pressure, which in turn reduces space to provide good care (van de Boven-kamp et al. 2014, 2020; Wallenburg, Weggelaar, and Bal 2019). Organizing for responsible data practices may therefore require, next to the identification and deliberation of ethical arguments and decisions, a focus on resilience in addition to rules (cf. Healy and Mesman 2014).

In conclusion, we can envisage that *good data practices* are produced and maintained not only by ethical principles and legislation, but especially become shaped in these everyday practices and routines, through articulations of ethical frames, but also through the mundane decisions and valuations that are made by medical professionals, data scientists, healthcare managers, and patients.

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Notes

1. We utilized a broad interpretation of big data, which moves beyond specific technologies for data aggregation and analysis. This broad interpretation is in line with the sociotechnical approach developed in boyd and Crawford (2012). We summarized it here under the term "data-driven healthcare technologies."
2. See https://www.bigmedilytics.eu/ for more information about the consortium of which this project was a part.
3. Examples include the framing of ethics as "not being up for the task" and the framing of ethical problems as being solvable through legislation. The latter we decided to subsume under the framing of the "technical fix" as it shares many characteristics.
4. See https://www.bigmedilytics.eu/infographics-on-regulations-for-big-data-technologies-in-the-healthcare-sector-in-european-countries/ for details.
5. This of course also raises questions regarding what happens with concerns that do not fit within these dominant frames. These could contain important messages that become silenced through the wide recurrence of these three types of ethical framing—and one might even argue that this paper's focus on dominant frames could lead to further "backgrounding" of less visible frames. The purpose of the paper however is to "follow the actors" in terms of their discursive work, focusing on the most widely occurring frames and their consequences. Future studies could of course follow a more "emancipatory" agenda in terms of explicitly foregrounding subordinate or silenced narratives.

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