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Appropriating Empowerment: Precision Medicine's Proclivity to Epistemic Injustice

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Abstract

Precision medicine (PM) encompasses various emerging, data-intensive healthcare and biomedical research initiatives aimed at tailoring care to individual patient characteristics. While “precision” primarily denotes an epistemological shift in how biomedical research is approached and care delivered, the conviction that PM *empowers* patients in clinical decision-making is central to its vision as it is taken up across policy contexts. In this paper, I critically assess these promises by drawing on recent engagements in *agential epistemic injustice* (Lackey 2020; Medina 2022). I suggest that the social, cultural, and epistemological conditions in which the epistemic practice of precision care unfolds are conducive to epistemic injustice. Despite PM’s explicit aims to address longstanding criticisms regarding the disease-centric nature of contemporary biomedical care practices by including person-centered, non-biomedical features in clinical consideration, exploring its underlying logic suggests its epistemic economy is stacked against patients’ epistemic interests. As such, despite its laudable aim of patient empowerment, the exacerbated risk of epistemic injustice might truncate patients’ (epistemic) agency, further disempowering them in clinical decision-making. To conclude, I suggest that the reliance on “empowerment”- and “person-centered care”-rhetoric dominating PM discourse is a case of *epistemic appropriation* (Davis 2018), further discouraging engagement with social, experiential, and phenomenological dimensions of illness, defanging critics of raising those concerns, and impeding the realization of epistemic justice in healthcare.

1. Introduction

Precision medicine¹ (PM) encompasses various emerging, data-intensive healthcare and biomedical research initiatives aimed at tailoring care to individual patient characteristics. Recent advances in molecular biology, including multi-omics sequencing technologies, developments in data science, and innovations in wearable, sensor, and mobile health technologies have expanded biomedicine’s ability to identify highly refined and individualized disease signatures or personal

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“health maps” (Prainsack 2018). While still in its nascent stages, PM is widely purported to introduce a “fundamental change in the way medicine is practiced and delivered” (Pritchard et al. 2017, 143). For one, PM is expected to break from the “one-size-fits-all”-approach of contemporary evidence-based medicine and its reliance on generalizations from clinical trials and meta-analyses. PM focuses instead on interindividual differences, offering an “individualized” and “holistic” approach to patient health (Flores et al. 2013; Giroux 2020; Topol 2016, 2019; Vandamme et al. 2013; Vogt et al. 2016). The comprehensive integration of physiological, environmental, social, lifestyle and patient-reported data is expected to enhance diagnostic capabilities, therapeutic efficacy, and, crucially, allow for precision prevention: tailoring preventive lifestyle recommendations based on individual risk profiles.

The ambitions of PM extend beyond improving disease identification and risk prediction. At the forefront of precision care’s discourse (Bierman et al. 2023) and central to the political uptake of PM (Blasimme and Vayena 2016) is a decisive role change for the “engaged patient” (Swan 2012). Traditionally conceived as a passive care recipient, the patient is envisioned as an “active partner” who controls their health management (Rothstein 2017; Vegter 2018). A recurring motif is PM’s potential for *patient empowerment* and *democratization* (Chan and Erikainen 2018; Juengst et al. 2012; Prainsack 2018; Roth and Bruni 2021; Sabatello and Appelbaum 2017; Sedda et al. 2019; Vegter 2018).

While laudable, claims of PM as a pathway to patient empowerment warrant closer examination. Critics warn about PM’s (almost exclusive) focus on genomics data (Tabery 2024) as emphasizing individual responsibility for health and disease while diverting attention from social determinants of health and (likely more effective) collective and structural responses in public health (Juengst et al. 2012; Prainsack 2017; Tabery 2023). Others worry that PM may exacerbate inequity if we fail to consider existing socio-economic barriers to healthcare access, bias in data collection and integration, differential public trust in data handling and biomedical research, and enduring consequences of historical injustice (Galasso 2024; Green et al. 2023; Pot et al. 2019). The strain of the exceedingly high costs of comprehensive screening, health monitoring and personalized treatments on healthcare systems also raises justice-related concerns on prioritization and resource allocation (Green et al. 2023; Prainsack 2018).

Beyond these critiques of PM as a public health strategy, the rhetoric of patient empowerment extends into visions for clinical care, where claims of PM facilitating person-centered care and shared decision-making remain largely unexamined.² In this paper, I want to reflect on this more care-oriented understanding of “empowerment” found across policy documents, scientific literature, and popular science. I am particularly interested in suggestions that PM empowers patients in the clinical encounter by facilitating *shared decision-making* and *person-centered care*.³ On this note, access to personal health information and insight into disease risks are suggested to improve the patient’s epistemic standing vis-à-vis healthcare professionals. PM proponents promise more “participatory” (Flores et al. 2013), “democratized,” and “collaborative” care models (Topol 2016), redressing longstanding concerns over medical paternalism.

Critical of these proposals,⁴ I assess PM’s potential for facilitating shared decision-making by evaluating the risk of epistemic injustice in precision care. Drawing on the recent *agential* epistemic injustice literature, I argue that a comprehensive evaluation of PM’s claims of patient empowerment requires scrutiny of the social-epistemic context

within which clinical decision-making will likely occur. I argue that PM, rather than empowering patients, intensifies patients' risk of epistemic injustice. While these risks are latent within PM's epistemic and ontological commitments, its appropriation (Davis 2018; Podosky 2023; Toole 2021) of concepts such as "person-centeredness," "shared decision-making," and "empowerment" potentially further impedes the realization of epistemic justice.

I proceed as follows: in section 2, I set up my critique from epistemic injustice by specifying the relationship between influential visions for PM, empowerment, and shared decision-making. I do so by showing how appeals to "patient participation" and "empowerment" are central to the political legitimization of PM, directing how solutions for challenges of shared decision-making and epistemic injustice in contemporary clinical practice are pursued. In section 3, I overview the epistemic injustice in healthcare literature. Section 4 points to recent proposals for agential epistemic injustice, which emphasize the systemic and structural effects of the social, cultural, and epistemological context on epistemic agency. I suggest that these additional dimensions are necessary to fully understand the breadth and extent of epistemic injustice in the clinical encounter. Section 5 assesses PM's epistemic and ontological commitments and considers its epistemic economy. Finally, section 6 addresses the normative implications of this economy, showing how PM's commitments likely exacerbate the risk and incidence of epistemic injustice. Here, I revisit the issue of empowerment and contend that PM, as it is currently envisioned, is lacking in crucial aspects, ultimately falling short of its goal of empowering patients in clinical decision-making. Instead, its co-opting of "empowerment"-rhetoric in ways orthogonal to the term's emancipatory origins may function to silence patients further and defang critics of contemporary biomedicine.

2. From promise to practice

Although the specific meaning of PM and closely related concepts such as P4- and personalized medicine may differ between contexts (Erikainen and Chan 2019; Galasso et al. 2024; Juengst et al. 2016), these initiatives converge on a shared set of technological tools and, importantly, social meanings shaping future directions for healthcare and research (Baumgartner 2021; Blasimme and Vayena 2016; Lemoine 2017). Compared to earlier approaches like genomic medicine, the explicit alignment with social values of patient empowerment and participation was central to PM's political success (Blasimme and Vayena 2016). The proposal of P4 medicine was particularly influential, as it introduced a distinctly participatory angle to the preventive and predictive potential of new health technologies (Hood 2013). As Blasimme and Vayena (2016) suggest, P4's participatory inclinations crucially solidified PM's political support, as exemplified in President Obama's endorsement of the Precision Medicine Initiative (now All Of Us), which thrust data-intensive healthcare onto the political stage, echoing the promise of "empowering individuals to monitor and take a more active role in their own health" (cited in Blasimme and Vayena 2016). The value of "participation" was equally decisive in EU policy, as evidenced by the Commission's explicit appeal to P4 medicine as enabling and facilitating patient empowerment (Leyens et al. 2014 European Parliament n.d.; European Commission 2023), and explicit references to "patient-centered care" in the Commission's operative definition of "personalized medicine" (Erikainen and Chan 2019).

The implementation of the vision of P4 medicine into EU and US policy demonstrates how promised futures "spill over" into practice. Although the full

realization of P4's participatory vision on PM is still unclear, its material impact is already apparent, particularly in its influence on financial, cultural, and social investments (Galasso et al. 2024; Lee et al. 2019; Nimmesgern et al. 2017). Recent qualitative research on the reception of PM's promises in healthcare professionals and patients similarly shows a generally welcoming and optimistic stance toward PM's potential to empower patients, often drawing on similar rhetoric such as "person-centeredness" and "empowerment" (Antman and Loscalzo 2016; Erikainen and Chan 2019; Fu et al. 2019; Galasso et al. 2024; Gardner 2023; Halverson et al. 2016; Kondylakis et al. 2014; Nardini et al. 2021; Pot et al. 2024; Prosperi et al. 2018; van Os et al. 2017; Voigt et al. 2021).⁵

While these visions are speculative, early indications suggest they shape PM's public perception and political implementation. Given their influence, these promises provide an important, early entry point for ethical engagement. As Marianna Boenink suggests, analyzing promises strikes "a mean between realistic but late and ineffective ethical debate and completely speculative—and in the end also ineffective—early ethical reflection" (Boenink 2010, 21). As such, there is something to be gained from scrutinizing how visions for PM frame patient empowerment and, specifically, whether its proposed solutions for facilitating shared decision-making align with patients' concerns and needs. With this in mind, let us briefly revisit these claims.

PM discourse suggests that access to health information may improve patients' epistemic standing in the clinical encounter and facilitate shared decision-making (Bosnic-Anticevich et al. 2023; Kondylakis et al. 2014; Lupton 2013; Nettleton 2004; Vegter 2018; Xu et al. 2019). Picking up on mHealth's aspirations (Baumgartner 2021) of providing patients with digital interfaces of apps and wearable devices as a means to facilitate shared decision-making (see, e.g., Bosnic-Anticevich et al. 2023; Xu et al. 2019), advocates of PM, too, express beliefs over the accessibility of and insight in health information allowing patients to "challenge expert knowledge" (Fiore-Gartland and Neff 2016). PM is, on these accounts, framed as a decisive move against remnants of medical paternalism residing within contemporary healthcare (Joly et al. 2014; Juengst et al. 2016; Myskja and Steinsbekk 2020). More specifically, access to and insight into health is provided through multi-omics sequencing, digital monitoring devices, and comprehensive risk profiling, allowing patients to assume control of their health and care trajectories. In sum, fueling precision care's future is the belief that access to health data (Bierman et al. 2023; Prosperi et al. 2018), providing patients with tools to communicate and report treatment experiences and outcomes, or including patient preferences in decision-aid models (Birch et al. 2022; Bywall et al. 2022; Kondylakis et al. 2014), will empower patients as "partners" in clinical dialogue (Pritchard et al. 2017; Xu et al. 2019).⁶

From the outset, the effectiveness of PM's primarily data-centric solutions to problems of shared decision-making warrants scrutiny. For one, it is unclear to what extent -omics information and data-intensive decision-making tools will improve patients' epistemic standing. The mounting complexity of health data may inadvertently increase their epistemic dependence on healthcare professionals (Eyal et al. 2019; Juengst et al. 2012). Furthermore, as the epistemic injustice in healthcare literature carefully documents, patient participation in contemporary healthcare settings is hindered by a variety of social dynamics beyond problems of health literacy, including bias, prejudice, and stigmatization (Carel and Kidd 2014; Galasiński et al. 2023; Williams 2020). Patient testimony often fails to garner uptake due to dismissive or biased healthcare workers or operative norms of medical relevance and salience limiting which information is considered in clinical decision-making. So, even if PM leads patients to be

better informed on their individual health status and lifestyle, and patient-reported data are included in comprehensive patient profiles, it remains uncertain whether this translates to an improvement in the patients' epistemic standing in clinical dialogue. If PM were to meaningfully improve a patient's epistemic position in the clinical encounter, it would, at least to some extent, have to contribute to mitigating current risks of epistemic injustice in healthcare.

3. Epistemic injustice in healthcare

In her 2007 book, Miranda Fricker coined "epistemic injustice" to characterize "(...) a wrong done to someone specifically in their capacity as a knower" (Fricker 2007, 1).⁷ Fricker identifies and analyzes specific instances in everyday social practice where particular subjects are hampered in their epistemic role as speakers or contributors to knowledge production. In this, Fricker takes epistemic injustice to involve both epistemic and moral harm, that is, a speaker is prevented from contributing to knowledge production and denied the dignity of being considered a full epistemic subject. While these concern the primary transgressions of epistemic injustice, being denied in one's capacities as an epistemic subject often leads to significant practical or material consequences.

Fricker famously distinguished between testimonial and hermeneutical injustice. Testimonial injustices, on her account, track prejudicial attributions of *credibility deficit* (Fricker 2007). Here, a hearer deflates a speaker's credibility based on a negative, prejudicial assessment of the speaker's social identity. Testimonial injustice, in particular, resonates well with patient experiences. Carel and Kidd (2014) suggest that we can understand widespread dissatisfaction in patient-physician communication (Abdelrahman and Abdelmageed 2017; Montini et al. 2008; Skär and Söderberg 2018) as pointing toward pervasive testimonial injustices in the clinic. Indeed, patients *qua patients* may be subjected to testimonial injustices due to pervasive stereotypical assessments of their epistemic capabilities and contributions to clinical decision-making. As well-documented in life writing, qualitative research, and narrative medicine, patients often encounter medical professionals dismissive of the social, emotional, and experiential dimensions of illness hindering their participation in the clinical encounter (Barnes and Woods 2024; Carel 2019; Charon and Montello 2002; Grim et al. 2019; Halpern 2014; Mostafapour et al. 2024; Naldemirci et al. 2021; Tosas 2021).

Hermeneutical injustice, the second form of epistemic injustice identified by Fricker, is concerned with gaps in our *collective hermeneutical resources*,⁸ precluding (marginalized) subjects from understanding and/or communicating their social experiences due to systematic exclusions from meaning-making practices (Fricker 2007). In healthcare, hermeneutical injustice may manifest when healthcare professionals are unfamiliar with particular (representations of) conditions, such as endometriosis or young-onset dementia, due to prior marginalization of these experiences in biomedical research. This may result in delays in care, diagnosis, and (self-)understanding (Blease et al. 2017; Hudson 2021). Hermeneutical injustice may also occur when patients are unable to understand or communicate their illness experiences due to lacunae in biomedicine's conceptual apparatus. Patients may struggle to find a (clinically) appropriate and clear language or register that accounts for experiences of chronic pain not expressed through validated instruments such as pain scales or questionnaires (Buchman et al. 2017; Nicola et al. 2021). The often emotionally laden, nonlinear, perhaps confused or defensive "expressive styles" with which patients

recount illness experiences may hinder healthcare professionals' appraisals as reliable and credible epistemic actors (Becker 2020; Berkhout and Zaheer 2021; Birk 2013; Blease et al. 2017; Kidd and Carel 2017; Nicola et al. 2021; Rivest et al. 2023; Samulowitz et al. 2018).⁹

Although patient experiences provide crucial information in diagnostic assessment, treatment, and care planning (Svenaeus 2000), systemic prejudices of healthcare professionals may limit the uptake of patient testimony to its factual content. Social, existential, and phenomenological aspects of illness—crucial to patients' illness experiences—are not consistently solicited and rarely play a formal role in clinical reasoning, diagnostic or treatment decisions, biomedical research, and service design (Kidd and Carel 2017).¹⁰ In addition to the moral-epistemic harm of dismissing patient testimonies wholesale or treating patients as mere informants rather than genuine knowers,¹¹ failure to adequately respond to patients' needs may also impact health-related outcomes. Several studies have shown that patient-physician communication impacts clinical and patient-reported outcomes, including treatment satisfaction, health status, quality of life, and therapeutic effectiveness (Sharkiya 2023; Świątoniowska-Lonc et al. 2020; Zhang et al. 2024; Zolnieriek and DiMatteo 2009).

While epistemic injustice accrues to patients in general, the prevalence and associated harms may compound in patients with intersecting marginalized identities (hereafter, marginalized patients).¹² Gendered, racial, linguistic, and pathophobic biases often intersect, amplifying the risk of testimonial injustice in healthcare. While patients suffering from chronic pain in general encounter difficulties in being taken seriously (Goldberg 2017), women's pain has been particularly scrutinized on the grounds of being "merely" psychosomatic or as an overemotional, "hysterical" reaction (Hoffmann and Tarzian 2001; Manne 2021; Samulowitz et al. 2018).¹³ Black patients are at particular risk of being dismissed or undertreated due to racial stereotypes or assumptions of drug-seeking behavior in healthcare professionals; this has been shown to affect analgesic treatment decisions (Avenanti et al. 2010; Del Pozo and Rich 2021; Hamed et al. 2022; Hoffman et al. 2016). Trans patients are similarly vulnerable to testimonial injustices due to administrative staff or healthcare professionals favoring preconceived (binary) notions of gender over patients' self-identification, leading to persistent misgendering (Bullock 2023).

The risk of hermeneutical injustice increases for marginalized patients as well. For one, missed or "contested" diagnoses such as endometriosis or CFS/ME can be conceived as cases of conceptual impoverishment which can be traced to prior hermeneutical marginalization—in the case of endometriosis a persistent lack of interest in non-male bodies in biomedical research (Blease et al. 2017; Byrne 2020; Hudson 2021). Similar concerns have been expressed about the (lack of) prioritization of research and treatment for sickle cell disease in the Black community (Del Pozo and Rich 2021). In trans healthcare, the necessity of psychological assessment prior to medical transition, as is standard in most healthcare systems, can similarly be conceived as the privileging of cissexist assumptions over self-determination or more nuanced conceptions of gender identity developed in trans communities. While far from exhaustive, this overview suggests that the risks and harms of epistemic injustice in healthcare compound for members of marginalized communities. These concerns are particularly urgent in PM, as I will explain in section 6.

Problems of epistemic injustice are pervasive in contemporary clinical contexts. This, at least in part, motivates the emphasis in scholarship and policy on shared decision-making and person-centered care. It is clear that any instance of unfair dismissal of

patients' concerns in the clinical encounter is incompatible with most accounts of shared decision-making and person-centered care (Galasiński et al. 2023; Grim et al. 2019; Williams 2020). As defective credibility attributions truncate patients' means of expressing concerns it would be in their interest to convey to healthcare professionals, and, as such, fail to contribute to the epistemic practice of care, we fail to live up to shared decision-making's ideal of a dialogue between peers. Conversely, assessments of the risk of epistemic injustice offer an important tool for identifying and understanding patients' persistent concerns over healthcare professionals' conduct and communication. However, while existing frameworks and discussions effectively highlight epistemic harms as they arise in clinical dialogue, their indebtedness to Fricker's original account may inadvertently restrict our analysis of structural causes of the epistemic harms suffered by patients. In the next section, I discuss recent proposals for agential epistemic injustice as offering a more comprehensive understanding of the complexities of patients' predicaments.

4. Agential epistemic injustice

Several authors have recently expressed concerns regarding the individualistic and episodic focus of Fricker's initial analysis and much of the literature that follows it. More specifically, her critics worry that Fricker's attention to epistemically harmful *instances* within testimonial exchanges (Anderson 2012; Medina 2011; Pohlhaus 2020) and identifiable *perpetrators* (Doan 2017; Kwong 2015) may limit our engagement with broader structural conditions constraining marginalized knowers' contributions in a variety of epistemic practices (Anderson 2012; Hookway 2010).¹⁴ As Doan (2017) suggests, this emphasis may be an artifact of the virtue epistemological framing of much of the epistemic injustice literature. Much subsequent work in epistemic injustice follows Fricker's initial characterization of (testimonial) epistemic injustice as involving instances of vicious judgment on the hearer's part. The correctives, similarly grounded in the *individual* epistemic virtues of testimonial and hermeneutical justice, again pick out individuals as responsible for remediating injustice, focusing primarily on virtuous or vicious hearers (Anderson 2012).¹⁵ This focus in the literature on "one-off" instances (Pohlhaus 2020) and individual "culprits" (Doan 2017; Kwong 2015) may obscure epistemic injustice's institutional, structural, and epistemological causes.

To address these concerns, authors increasingly explore *agential epistemic injustice* (Davis 2018; Dotson 2014; Lackey 2020; Medina 2022; Pohlhaus 2020). Agential epistemic injustice involves the unfair constraining or subversion of marginalized individuals' or communities' epistemic agency (Medina 2022), that is, of their capacity to produce, convey, challenge, or revise shared epistemic resources in a given social context (Catala 2020; Dotson 2014). Underlying this notion is a "participant perspective" on epistemic injustice (Hookway 2010; Medina 2022), highlighting various ways epistemic agents may be hindered in contributing to epistemic activities beyond testimonial exchanges. In many cases of epistemic injustice, marginalized knowers are not merely mistreated with regard to their assertions or testimony; rather, (systemic) constraints preclude them from fairly participating in epistemic activities in the first place. As I will explain further, agential accounts analyze how individual prejudice *and* structural dynamics intersect compromising knowers' ability to exercise epistemic agency. These accounts also broaden the scope of harms considered in an analysis of epistemic injustice to include *any* unjustifiable stymying of a subject's epistemic agency resulting from deficient or excessive credibility attributions, lacunae in dominant epistemic resources,

or the harmful inclusion or exclusion of epistemic agents in meaning-making practices (Davis 2018; Lackey 2020; Medina 2022; Pohlhaus 2020). In the following paragraphs, I delve further into two ways in which agential epistemic injustice shifts the focus of epistemic injustice. I also highlight what these accounts bring to the epistemic injustice in healthcare literature.

First, agential accounts stress the role of the social, cultural, political, and epistemological in manifestations of epistemic injustice. José Medina (2011), for example, highlights how credibility ascriptions are deeply implicated in socio-historical patterns of recognition. The social imaginary, a dominantly shared repository of prevalent imagery, rhetoric, and social scripts operative in a given (intra-)cultural context or community (Churcher 2022; Medina 2011), affords intelligibility to specific types of knowledge and ways of knowing by making visible particular features of the epistemic landscape and drawing attention to specific epistemic actors often at the expense of others. This perspective underscores how epistemic injustices are not only rooted in one-off instances of prejudicial credibility ascriptions in testimonial exchanges but emerge and are reinforced through broader socio-cultural patterns. Kristie Dotson (2014) contends that epistemological systems—our community-dependent ways of *constructing and evaluating* knowledge—are also involved in epistemic injustice. Our epistemic resources—that is, the socially sanctioned collection of dominant concepts, evidentiary standards, methods, and methodologies through which knowledge is produced, recognized, and evaluated in an epistemic community—may similarly reinforce unfair distributions of credibility and intelligibility or even render specific actors wholly *incapable* of epistemic contribution (Dotson 2014; Toole 2021; Woomer 2018).¹⁶ Epistemic resources shared within marginalized communities may, for example, fail to meet the evidentiary standards of dominant epistemic communities. These may be seen as “merely anecdotal” or fail to meet existing epistemic requirements in other ways and are discarded as unreliable. Anne-Marie Gagné-Julien (2022) offers an example from psychology and suggests epistemic resources arising from Mad Studies and patient advocacy have been systematically dismissed by the psychiatric community due to a persistent reliance on a biomedical model for mental health. The perpetuation of epistemic harms may be thus implicated in *how* knowledge is conceived and produced within a specific epistemic community by limiting engagement or preventing concerns from non-dominantly situated knowers from surfacing (Pohlhaus 2020).

These accounts resonate well with recent proposals highlighting systemic and structural features of healthcare’s social organization and medical epistemology as constitutive of epistemic injustice. Kidd and Carel (2018, 2019) suggest that some of biomedicine’s ontological and epistemic commitments are conducive to the epistemic harms suffered by patients. In particular, an overemphasis on *naturalistic conceptions of disease*¹⁷—taking biological dysfunction as a necessary, or even primary condition to disease—is said to function as configuring a particular epistemic economy within care practices. As the authors point out:

naturalistic conceptions of health can *entrench discriminative economies of credibility and intelligibility*, ones that define relevance, salience, and similar norms to a delimited range of knowledge, experiences, and methods. Credibility becomes confined to, because defined in terms of, the methods and deliverances of biomedical science (Kidd and Carel 2018, 228, emphasis added)

Framing and understanding medicine as (exclusively or even primarily) a form of applied biology, as it became prominent throughout the nineteenth and twentieth centuries (Jewson 1976), also had distinct effects on biomedical researchers and healthcare professionals as an epistemic community and healthcare as an epistemic practice. As technologies, such as X-ray imaging, monitoring devices, and clinical assays, increasingly became the epistemic tools of choice to investigate disease (Jewson 1976), medicine enacted particular economies of intelligibility and credibility, shaping the agency of the various actors involved. Crucially, rather than being an issue of vicious (individual) actors and echoing Dotson's assessment of epistemological systems, Kidd and Carel point out that the seeds of epistemically unjust care practices may be epistemological "all the way down" (Kidd and Carel 2018, 227).¹⁸

A second contribution of agential epistemic injustice involves a shift *qua target* of analysis. Less concerned with so-called "good knowers" (Pohlhaus 2020), these accounts take the epistemic status of those harmed by injustice as the locus of analysis and restoration: that is, how are (epistemically) marginalized groups harmed in their (exercise of) epistemic agency. This requires considering a broader scope of epistemic harms beyond those resulting from prejudicial credibility deficits and hermeneutical gaps. Medina (2011), for example, suggests that *excessive* attributions of credibility also hamper other agents' epistemic contributions from gaining traction. *Contributory injustice* (Dotson 2012; Gagné-Julien 2022), or the unwarranted *exclusion* of extant epistemic resources originating from marginalized groups as invalid or irrelevant, represents another way in which the relevant agential capacities of particular knowers can be upset. In such cases, harm arises not from the unintelligibility of a knower's own experiences due to hermeneutical gaps; instead, the lack of *uptake* of existing resources by dominant knowers may result in harm. Additionally, the harmful or improper *inclusion* of epistemic contributions might also curtail epistemic agency if these resources are appropriated in ways orthogonal to marginalized knowers' epistemic goals (Davis 2018; Medina 2011; Pohlhaus 2020).

These forms of epistemic harm are also evident in healthcare. Lauren Freeman's (2015) analysis of the epistemic role of ultrasounds and Fetal Heart Rate monitors in pregnancy care, for example, shows how an increasingly technologically mediated clinical gaze informs credibility distribution, devaluing pregnant peoples' testimonies as imprecise and unreliable relative to technological assessment.¹⁹ In this sense, medical technologies are operationalized in ways that encroach on patients' epistemic privilege concerning their embodied and experiential knowledge by attributing *excessive* credibility to technoscientific approaches to medical knowledge-making. Similarly, Alistair Wardrope (2015) suggests that an exclusive reliance on or privileging of biomedical epistemic resources in medical meaning-making hinders patients and physicians from understanding and communicating non-biomedical dimensions of disease (see also Reynolds 2020). Rather than those resources stipulating the existential, social, and phenomenological dimensions of illness being strictly unavailable—they have been developed in disability studies, phenomenology, and life writing—a "failure of circulation" (Berenstein 2016) in physician and patient communities results in the associated harms. As such, the unjustified and persistent exclusion of illness experience in medical practice and research—constituted and reinforced by features of the social, cultural, and epistemological structures of the biomedical community—may truncate patients' epistemic agency.

To conclude, agential accounts of epistemic injustice emphasize that social, political, cultural, and, crucially, epistemological commitments contribute to establishing an

epistemic economy, that is, structures managing credibility and intelligibility distribution, as well as the production and sanctioning of epistemic resources within an epistemic community (Catala 2022). For healthcare, the upshot is that gauging patients' epistemic standing vis-à-vis healthcare professionals requires a comprehensive evaluation of the epistemological system of biomedicine as a whole. It requires assessing how dominant conceptions of disease and medical knowledge-making affect extant economies of credibility and intelligibility and prefigure patients' capacities to contribute to the clinical encounter. Moreover, it suggests that ameliorating epistemic injustice by improving care providers' (epistemic) attitudes or character severely underestimates the complexities at hand. The epistemic harms observed in medical practice run more profound as they pertain to systemic and structural features of medical knowledge-making.

Where does this leave us with regard to PM? First, it is worth noting that PM's proposal for epistemological reform of current medical practice and its commitment to participatory, person-centered care seemingly echoes the more humanistic ideals proposed by critics of the biomedical model. Moreover, as we will see in the next section, its attempt to personalize healthcare is at least partially motivated by the recognition and inclusion of non-biomedical and subjectively-sourced data on illness experience. At face value, PM offers good prospects for future care practices—notably for shared decision-making. However, if the above analysis is correct and social, cultural, and epistemological commitments constitute the social epistemic context in which clinical decision-making occurs, we should assess PM's epistemological shifts in light of the epistemic economies they inform. This is my task for the next section, where I highlight PM's epistemic commitments.

5. Mapping precision medicine's epistemic landscape

As suggested earlier, it is difficult to pinpoint a single, shared program for PM. The often polysemic literature does, however, admit to particular technologies driving the transition toward data-intensive healthcare (Lemoine 2017). Molecular biology and the informational sciences (including Big Data and machine learning approaches for the mining and integrating of population, omics-sequencing, and wearable data), in particular, are at the forefront of PM's epistemic landscape—realizing a definite *informational turn* in healthcare and biomedical research (Nettleton 2004; Vegter 2018). These technologies and the informational focus they introduce to healthcare and biomedical research substantially impact how disease, medical knowledge production, and the distribution of epistemic authority therein are conceived (Vegter 2018). In this section, I address three epistemically relevant dynamics co-constituting PM's medical social epistemology, namely (i) “molecularization” (Baumgartner 2021; Guchet 2022; Strand 2022), (ii) quantification, and (iii) mechanical objectivity (Morrison and Kelly 2021). In section 6, I suggest that these aspects of PM's “logic” constitute a distinct epistemic economy and introduce a distinct risk and proclivity for epistemic injustice.

5.1 Molecularization

The first central dynamic in PM's epistemology pertains to the “molecularization” of health and disease. With the advent of PM, molecular biology reaffirms its position as the dominant conceptual resource for understanding, diagnosing, and assessing disease (Guchet 2022). As stated, advances in multi-omics analysis allow for identifying molecular signatures or personal health maps (Prainsack 2017) in individual patients.

On a macro-level, molecularization is expected to establish stratified, finer-grained diagnostic categories informed by pathophysiological insights (Green et al. 2019; National Research Council 2011). In general, PM frames, recognizes, and acknowledges the body, health, disease, and environment primarily in molecular terms (Zwart 2016). This becomes clear when we consider (i) how disease is understood and (ii) how the environment is integrated into comprehensive health profiles.

PM's aim to molecularize all aspects of disease is evident in proponents' claims to "demystify disease" or to "eliminate vagueness and ambiguity" (Flores et al. 2013, cited in Vogt et al., 2016, 314). Demystification here is understood as providing an objective, scientific basis for disease (and health) to counter individual and social bias in diagnostic and treatment assessments. Despite these paradigm-shift level claims and its explicit commitment towards a holistic view of the patient in their environment, PM's heavy reliance on molecular biology and adherence to a multi-level "cascade model" account of biological dysfunction (Boenink 2017; Vegter 2018) reveals a continued commitment to an intensely naturalistic understanding of disease (Vogt et al. 2016).

Particularly revealing in this respect—and indicative of the force of molecularization—is the influence of molecular biology and mechanistic reasoning in considering the role of health-environment interactions. Exposomics, a novel field central to including environmental influence in disease and risk assessment, aims to determine and quantify various exogenous disease-environment interactions (including lifestyle, environmental exposure, and social factors). Importantly, it primarily engages with the environment through "assessing the relevant biomarkers" (National Research Council 2011). Again, a similar reduction to a molecularized (internalist) view on health and disease is deemed central to assessing the impact of the environment on health. Several authors have, however, pointed out that approaching health-environment interactions solely (or even primarily) through molecularized correlates crucially stifles the interventions deemed appropriate for mitigating its effects, for example, by excluding socio-historical or political considerations (Boenink 2017; Ferryman and Pitcan 2018; Guchet 2022; Tabery 2024). In sum, while PM proposes a "new holism," its conception of "the whole"—the unique individual in their environment—is ultimately *technoscientific* (Vogt et al. 2016), rendering human biology and disease wholly in mechanistic and molecular terms, potentially at the expense of social and political determinants of health and disease.

5.2 Quantification

Closely related to "molecularization" is PM's commitment to a "computerization" of medicine (Lemoine 2017). The informational sciences feature centrally in providing the means to cross-reference (individual) molecular signatures with data from population biobanks, as well as non-traditional data sources, including social media feeds, wearables, and consumption patterns, to provide additional insight into health, disease, and prevention. While reliance on Big Data analytics and machine learning is necessary to store, manipulate, and assess an individual's molecular makeup, the "logic of quantification" (Morrison and Kelly 2021) to which these technologies adhere functions to vastly expand what are considered "clinically relevant" data. However, the authoritative force of quantification extends beyond molecular biology and is perhaps most clearly expressed in the intention to include behavioral and subjective patient data in comprehensive health models. Indeed, PM aims to *personalize* care by including

traditionally non-biomedical features, including behavioral and social characteristics, through various *digital biomarkers*.

Digital biomarkers refer to supposedly objective and reliable digital traces, tracking behavioral, social, and experiential characteristics of patients generated actively or passively through digital devices, such as smartphones, wearables, or sensors (Baumgartner 2021). While these tools allow for gathering large comprehensive datasets of non-biomedical, even subjectively sourced data, they offer the additional benefit of representing these features of the patient *in situ*, i.e., in real-time and outside of the clinical context. While the intent to include non-biomedical data in health assessments may, at face value, represent a clear departure from a strictly biomedical view, it is essential to consider precisely *how* these data are included. The inclusion of so-called patient-experience measures to assess healthcare and treatment experiences provides an exemplary case of the authoritative force of quantification.

Patient-reported Outcome and Experience Measures (PROMs and PREMs, respectively), standardized survey-based patient-facing tools to assess real-time therapeutic effectiveness, satisfaction, and patient experiences, are increasingly included in PM approaches as “cornerstones of more individualized therapies” (Distler et al. 2021). PROMIS—featured in the US National Research Council proposal “Toward Precision Medicine” (National Research Council 2011)—aims to establish scientifically validated means to include (real-time, *in situ*) “subjective” data in treatment and care decisions by providing patients with standardized (quantifiable) surveys.

Recognizing subjective experiences as essential aspects of treatment and care (seemingly) marks a significant departure from a strictly biomedical view of health and disease. It is essential, however, to consider the modalities through which such inclusions translate experience to clinically relevant parameters. While surveys, questionnaires, and wearables are conceived as digital mirrors, reflections of—or at the very least reliable proxies for—the patient’s experience, Vegter and colleagues (2021) remind us that the “funhouse mirrors” of data-intensive practices skew reality in important respects, that is, in ways conducive to quantification. I highlight two ways in which quantification shapes the inclusion of patient experiences. First, the authority of quantification introduces systemic bias to which aspects of (or proxies for) experience are included, favoring easily quantifiable ones. The AURORA study, for example, used accelerometry data, keystroke patterns, phone call duration, words/symbol usage, and GPS data to assess post-traumatic stress (Baumgartner 2021). Second, the need for computation of health stimulates the reduction of complex experiences to quantifiable scales. In PROMIS patient experiences are reduced to standardized quantified scales and scores—necessary for modeling patient outcomes in comprehensive health data models. In doing so, patient experiences, while included in health modeling, are narrowed along pre-programmed constraints (e.g., reduction of experience to a particular scale or limited set of possibilities) imposed by technologies, questionnaires, and surveys. In section 6, I suggest how the “epistemic narrowing of experience” (Berkhout and Zaheer 2021) may inform hermeneutical injustice.

In sum, in expanding the scope of medical relevance, PM aspires to capture all (health-relevant) aspects of life in a range of quantified and objective datasets. By characterizing and quantifying every step on the molecular cascade and including user-generated data, PM conceives of life—albeit in wholly biological, digital, and ultimately quantifiable means—as understandable, predictable, and ultimately controllable (Strand and Chu 2022).

5.3 Mechanical objectivity

The final element constitutive of PM's logic is the presumed epistemic authority of a technologically mediated medical gaze or a preference for *mechanical objectivity* (Daston and Galison 2007; Morrison and Kelly 2021). Historians of science Lorraine Daston and Peter Galison (2007) conceive of mechanical objectivity as an epistemic community's increasing reliance on technology to minimize subjective interference in scientific knowledge production. Under the rubric of mechanical objectivity, technological mediation in knowledge production is deemed to afford the critical distance necessary to attain objectivity. The nineteenth and twentieth centuries, in particular, saw technological advancements increasingly rendering imaging, monitoring, and diagnostic assays as the means par excellence to claim medical knowledge (Jewson 1976).

PM's insistence on technological mediation in medical knowledge-making can be said to represent another step towards the effectuation of the regulative ideal of mechanical objectivity in healthcare. First, PM's reliance on Big Data epistemologies reflects assumptions of mechanical objectivity. By employing a range of algorithms, including decision-support systems, data mining, or even fully featured digital twins, both patient and physician are supported in knowledge production and decision-making by supposedly objective, competent, and reliable systems. Moreover, the reliance on wearables and (digital) surveys to capture real-time, subjective, and lifestyle data represents another methodological scrubbing of subjective influence through technological mediation. This turn toward quantifying subjective experience measures in so-called digital biomarkers marks an additional reference to an "objective," technologically-assisted representation, or "deeper truth" behind patient reports (Baumgartner 2021).

In this context, Catherine D'Ignazio and Lauren F. Klein (2020) draw parallels to earlier discussions in feminist philosophy of science on the "view from nowhere" as conditional for objectivity to suggest that the specter of positivism haunts current discussions on AI and data-intensive science. Instead, they suggest that "algorithmic objectivity" and so-called "raw data" are situated, that is, bound up with the social, cultural, and material contexts from which they emerge. Their comments echo a more significant movement in feminist philosophy and STS, highlighting the various ways through which algorithms encode, reflect, and reinforce social bias and injustice (see, e.g., Biddle 2020; Johnson 2021; Kassam and Marino 2022; Lin and Chen 2022; Pot et al. 2019). These concerns are particularly pressing in the context of healthcare, where as Lin and Chen (2022) suggest AI systems and social bias coalesce, potentially exacerbating existing social inequalities and hardcoding injustice in data-intensive healthcare. As feminist engagements with algorithmic objectivity show, there are good reasons to be critical of claims for (mechanical) objectivity commonly upheld within PM discourse. Despite these concerns, however, as I will show in section 6, algorithms and similar technologies are still widely regarded as epistemically authoritative in various social contexts, including healthcare, potentially threatening patients' epistemic agency in shared decision-making.

To summarize, mapping the dynamics of molecularization, quantification, and mechanical objectivity as they shape PM's logic helps to paint a preliminary picture of the epistemic landscape envisioned in contemporary visions for precision care. Notably, my analysis shows that, rather than the paradigmatic shift its proponents claim, a more apt description suggests PM to be an *intensification* of standing norms in contemporary biomedicine (Boniolo and Nathan 2020; Jewson 1976; Morrison and Kelly 2021; Vegter

2018). PM aims to establish medicine as a “harder science” by operationalizing the methods and presuppositions of biomedicine to expand and include features of health illusive to today’s clinical gaze (Strand and Chu 2022; Vogt et al. 2016). In the next section, I assess the normative implications of PM’s epistemic commitments and examine how, in establishing a particular epistemic economy governed by its logic, PM might promote epistemically unjust treatment of patients and, as such, increase the risk and incidence of epistemic injustice in precision care practice.

6. Precision Medicine, epistemic injustice and appropriation

Building upon my analysis of agential epistemic injustice in healthcare, this final section explores how PM’s operative logic may inform the socio-epistemic conditions under which clinical decision-making will occur. Contrary to its claims for person-centered care and facilitating shared decision-making, I suggest that PM’s epistemic commitments potentially intensify existing epistemic injustice risks. Moreover, I conclude by arguing that its reliance on “empowerment” and “person-centered care” language may function to exacerbate these risks even more. I suggest that PM’s co-opting of language traditionally associated with humanistic alternatives to a biomedical model involves a case of *epistemic appropriation* (Davis 2018). As such, the “empowerment”-rhetoric on which it capitalizes can work to obscure PM’s proclivity to epistemic injustice and deflate criticisms of the unwarranted exclusion of features of lived illness in precision care.

To recap, agential accounts of epistemic injustice emphasize the role of systemic effects (social, cultural, historical, and epistemological) in establishing epistemic economies. Additionally, they draw attention to the impact these intelligibility and credibility distributions may have on the various epistemic agents within a specific social context. I contend that the intensification of PM’s risk (and incidence) of epistemic injustice lies in its promotion and, potentially, the requirement for lived experience to be accounted for quantitatively to feature in ever more complex systems of diagnostic decision-making. I will first explore these risks in more detail as they pertain to hermeneutical and testimonial injustice.

6.1 Hermeneutical injustice

Recall that hermeneutical injustice arises from (persistent) hermeneutical gaps in dominant resources surfacing due to the systematic exclusion of particular groups and/or the privileging of particular perspectives in meaning-making. Applied to contemporary healthcare practice, hermeneutical injustice results from the privileging of the epistemic resources of biomedical science (both in research and the clinical encounter) over experiential aspects of illness, limiting both patients’ understanding of illness and stifling attempts to address these experiential aspects of living-with-illness for their proper consideration in care contexts.

In relation to PM, quantification and molecularization are central dynamics shaping how disease is conceptualized and which factors are included in clinical assessment and health modeling. As such, these dynamics are central in supplying the epistemic resources defining and delimiting intelligibility and salience in the clinical encounter. Indeed, PM establishes a “tacit data hierarchy” (Ashcroft et al. 2017; Baumgartner 2021; Prainsack 2017; Vogt et al. 2016). Features that lend themselves well to quantification are given central significance as they are readily available for data handling and

modeling. In contrast, unstructured narrative and qualitative evidence are deemed of secondary importance because of supposed subjectivity and pragmatic constraints concerning their computation. Molecularization, quantification, and according epistemic resources are, as such, critical features in the epistemic landscape of PM, both through technological limitations as well as pervasive assumptions on the comprehensiveness of a molecular, datafied, behaviorist vision of life (Baumgartner 2021; Tabery 2024; Weiner et al. 2017). Despite attending to non-biomedical features, PM seemingly further divests from thick, phenomenologically informed accounts of illness experience (Prainsack 2018).

Moreover, risks of epistemic injustice embedded in precision care may *intensify* precisely due to the expansion of “medical relevance” beyond traditional biomedical data. Indeed, including lifestyle data or patient-reported experience measures in diagnostic and treatment considerations is crucial to PM’s claims for *personalizing* healthcare. However, to the extent that these measures take the form of standardized surveys or superficial engagements on qualitative or quantitative scales, patient experience is included only in “epistemically narrowing” ways (Berkhout and Zaheer 2021). Conceptualizing patient experiences as ultimately quantifiable discourages engagement with in-depth, thick descriptions of the lived experience of illness. Moreover, standardization of these experience measures necessarily limits the kinds of experiences considered for inclusion by limiting the ways patients can respond (e.g., through having to map experience to numerical scales or a limited set of answers), limiting the aspects of experience patients can express due to survey design, and failing to acknowledge the diversity of patient experiences across (and within) social and cultural contexts. Ironically, even though the intent of personalization involves a clear recognition of the necessity of engaging with patient experiences, reducing “subjective” experiences to quantified and standardized measures severely truncate patients’ capabilities to express social, phenomenological, or experiential concerns over diagnosis, treatment, and care.²⁰ In sum, I propose that the risk for hermeneutical injustice intensifies to the extent that epistemic resources relating to lived experience of illness are potentially further rendered unintelligible, devalued, or only relevant to the extent they fit the epistemic resources of the practice at hand.²¹

6.2 Testimonial injustice

As well-documented, contemporary medical practice upholds significant risks for testimonial injustice due to biases in healthcare workers and, more generally, to biomedicine’s proclivity to disvalue patient testimony on experiential, social, and axiological aspects of illness in favor of technologically mediated assessments of disease (Freeman 2015). As stated in section 3, while these risks and associated harms accrue in patients qua patients, marginalized patients are at particular risk of testimonial injustice due to extant social biases and limited insight into the experiences of marginalized patients.

There are several reasons to assume the credibility economy within PM continues to favor technologically mediated perspectives on disease. First, *mechanical objectivity* was identified as a primary inspiration for PM, as it strives to reduce bias from individual patient reporting and physicians alike. Moreover, the rhetoric of mechanical objectivity in the context of PM—conceiving of algorithms as legitimate, trustworthy, neutral, and epistemically proficient sociotechnical (epistemic) actors (Carlson 2019; Crompton 2020; Gillespie 2014)—further affords societal recognition and epistemic authority to

the supposedly value-free and neutral ways in which algorithms contribute to knowledge production—so-called *markers of epistemic trustworthiness* (Pozzi 2023). Despite the myriad issues of bias noted in section 5, the credibility of algorithmic decision-making tools and related technologies with regard to their epistemic capabilities barely seems to wane. As Crompton argues, their procedural legitimization is amplified and further entrenched by the increasing use of algorithms in instituted practices (Crompton 2020; Keyes et al. 2021). Moreover, the widespread attribution of epistemic authority to algorithmic actors is increasingly finding empirical support in human-computer interaction studies reporting physicians and the general public favoring algorithmic decisions over those made by human actors (Gaube et al. 2021; Logg et al. 2019).

A credibility economy skewed toward technologically mediated knowledge and sociotechnical actors is further reflected in the envisioned epistemic roles of the physician and patient in precision care. In a critical assessment of the All Of Us Research Program, Mira Vegter suggests the healthcare professional in precision practice is portrayed as a *data consultant*, helping patients to navigate this comprehensive data-intensive view of their individual health and suggest biomarker-based behavioral changes in the form of treatment or lifestyle changes (Vegter 2018). The patient, in turn, is conceived as a *digital consumer* who actively collects and shares data or engages in -omics screening and self-monitoring (Vegter 2018). Note, then, that in these characterizations both the patient's and physician's epistemic roles in PM are epistemically subordinated to technological, algorithmic knowledge-making practices.

In sum, the potential devaluation of patient credibility by awarding excessive epistemic worth to sociotechnical epistemic actors and further limiting engagement with non-quantifiable aspects of illness can thus be suggested to increase the risk (and incidence) of testimonial injustice. Algorithms, and by extension other technological means are systematically “perceived as *being better knowers of ourselves* than we are, thus weakening our entitlement to be credible about ourselves” (Origgi and Ciranna 2017, 303). So, while credibility is not necessarily a zero-sum game (Medina 2011), the *odds* in PM's epistemic economy are seemingly stacked against the individual patient. The relevant moral-epistemic harm then consists of thwarting patients' epistemic agency, which may further amount to practical harm as it limits patients in contributing essential (non-quantifiable) aspects of illness experiences to their care.

Again, while the epistemic odds are likely stacked against patients qua patients, marginalized patients are at disproportional risk for testimonial injustice due to the confluence of social and algorithmic biases in precision care. As discussed earlier, both algorithmic bias and epistemic injustice track social marginalization, leading to heightened risks for marginalized patients in data-intensive healthcare. Examples abound of medical devices and technologies, including pulse oxygen meters and spirometers (Liao and Carbonell 2024), kidney function algorithms (Braun et al. 2021), genome-wide association studies (Haga 2010), health risk assessment for triage (Obermeyer et al. 2019), and pain assessment tools in radiology (Pierson et al. 2021) performing significantly worse on marginalized patients. These problems will likely exacerbate, given the historical and structural biases in existing health datasets encoded within clinical algorithms and the authority given to a technological gaze.

The inflexibility of data-intensive healthcare applications and the portability of health data (such as electronic health records) similarly pose particular risks for marginalized patients. For one, data-intensive technologies are often insufficiently flexible in managing social identity categories. So-called “menu-driven identities” produce and reproduce gender binaries and racial hierarchies that often persist along patients' care

trajectories (Benjamin 2021). Moreover, data-intensive healthcare is also liable to “data inheritance,” where prior data entries, for example, diagnostic codes in electronic health records or social identity categories, can, despite them being no longer relevant or accurate, travel across healthcare contexts affecting how algorithms perform and patients are perceived by future healthcare professionals (Green and Svendsen 2021). This may, again, be particularly problematic for marginalized patients, given that social biases affect how healthcare professionals currently register (and whether) patient data in the first place (Pot et al. 2019). Opposition to these encoded identities or irrelevant diagnoses may function to deflate further the patient’s credibility (Bullock 2023).

The predicament of marginalized patients in data-intensive PM thus seems particularly troubling. Considering that social biases infiltrate clinical algorithms and technologies, often seen as epistemically authoritative, and considering that marginalized groups already face heightened vulnerability to biased healthcare professionals, these patients may be especially susceptible to (the harms of) testimonial injustice within precision care. The confluence of social and algorithmic bias may, in turn, hinder their ability to address and mitigate potential errors in algorithmic predictions—more likely in marginalized patients—leading to potential medical harm.

Central to this assessment of PM’s epistemic economy is the issue of whether patients are empowered to engage in shared decision-making. While proponents of PM suggest that patient experiences and values are readily incorporated into a holistic, comprehensive view of health and disease, on closer examination, its epistemic commitments reveal that their inclusion is premised on a logic severely constraining which patient values and experiences are deemed salient and, therefore, how they are up for consideration. Rather than empowering patients, it is likely that, given its prospective epistemic economy, PM may further disempower patients. To conclude, I contend that this disempowerment is not solely confined to the operationalization of PM in the clinical encounter but is also perpetuated and further entrenched by the rhetoric surrounding the project as a whole.

6.3 Epistemic appropriation

Beyond PM’s epistemic commitments, that rhetoric of empowerment” and “person-centered care” accompanying contemporary policy visions may inform more specific, pernicious forms of agential epistemic injustice through what Brianna Toole (2021) calls *self-masking*. As PM is seemingly driven by a person-centered reform of current healthcare practices, we are justified to expect it to amend communicative issues in contemporary healthcare. My analysis, however, reveals the limited extent to which this reform is attainable given current proposals. The rhetoric centering on “person-centeredness” and “empowerment” may mask PM’s proclivity to epistemic injustice. One strategy for self-masking, particularly relevant here, is *epistemic appropriation* (Davis 2018; Toole 2021).

Epistemic appropriation, as developed by Emmalon Davis (2018), involves a form of agential epistemic injustice in which epistemic resources (conceived broadly as meanings, (counter)stories, and testimonies) originating in marginalized communities gain uptake in dominant circles yet in this process are (i) *detached* from their social origins, and (ii) *misdirected* toward particular goals which misalign with the epistemic interests of the relevant community. Whereas Davis primarily has cases in mind where the meaning of those resources is preserved in the process of detachment, Podosky (2023) suggests that epistemic appropriation may also involve *obscuring* the epistemic

resources' original understanding. An epistemic resource initially developed to convey some (socially relevant, emancipatory) meaning may in its detachment lose its original sense and be replaced by one that better serves dominant interests.

This resource-obscuring form of epistemic appropriation best captures PM's rhetorical strategy. Much of the appeal of concepts such as "empowerment," "shared decision-making," and "person-centered care" is precisely that they seem responsive to longstanding criticisms of existing (biomedical) healthcare practices as overly reductionist and generalist. Appeals to patient empowerment evoke a liberatory spirit, signifying a distinct break from a paternalist medical practice (Bogaert 2020). "Person-centered care" was similarly developed within scholarship and patient advocacy groups explicitly critical of the biomedical model. Although these terms vary both in content and emphasis, they generally share a vision of the centrality of the patient as a *person* and an appeal to *holism* in healthcare practice (Ferry-Danini 2018; Miles and Asbridge 2017; Vogt et al. 2014). As I have tried to show above, much of these meanings is lost in PM. The concepts of person-centeredness, empowerment, shared decision-making, or even the purported holism in PM have been developed primarily *within* a biomedical epistemic framework. The detachment of this conceptual repertoire originating in countermovements and patient activism and its misalignment to motivate patients and policymakers to engage with PM makes this a clear case of epistemic appropriation.

PM's epistemic appropriation of "empowerment"—and associated language—may have important implications for its potential for person-centered care and for its critics addressing the importance of a more humanistically oriented care system. First, it serves to reaffirm the scientific foundations of medicine and expand the scope of medical practice and research, seemingly incorporating concerns central to patients and advocacy groups. This rhetorical strategy will likely enhance scientific medicine's credibility and consolidate its exclusive role within healthcare practice (Davis 2018). Moreover, this approach can also result in material consequences at a structural level. Research funding may further favor investments in biomedical research and quantitative methodologies, potentially overlooking issues better addressed through qualitative means—which, as suggested earlier, is currently happening in the funding of PM projects. Secondly, the presentation of PM as a humanistic endeavor may serve to defang patients and patient associations from voicing criticisms against the epistemically unjust dynamics identified in the previous section (Medina 2022). In sum, the epistemic appropriation of person-centered language can obscure and further undermine patients' epistemic agency by co-opting the concepts necessary to address oppressive structures and denying them their critical potential.

7. Conclusion

This paper critically examined PM's claims of patient empowerment by analyzing how its epistemic commitments may shape the socio-epistemic conditions in which shared decision-making occurs. Contrary to its professed aim of empowering patients, my analysis suggests that PM is instead likely to disempower patients vis-à-vis their epistemic standing in clinical dialogue. In general, PM risks further neglecting the crucial phenomenological dimensions of illness by an overreliance on molecularization, quantification, and the epistemic authority of technologically mediated knowledge claims. This likely increases the risk of epistemic injustice, particularly for marginalized patients, given the impact of structural injustice and algorithmic bias on the performance of data-intensive healthcare in (historically) marginalized groups.

Although PM seemingly aligns with ideals of humanistic medicine by promoting patient empowerment, person-centered care, holism, and shared decision-making, my analysis indicates that it may do so in ways that conflict with the epistemic interests of patients and the countermovements from which these concepts initially emerged. Through this process of epistemic appropriation, PM, rather than improving the patients' epistemic standing, may exacerbate and further entrench epistemic injustice in healthcare. Hence, by deploying the theoretical resources from the agential epistemic injustice literature, I suggest that the purported claims of empowerment as professed in PM's promises are considerably undermined. This underscores the need to explore and devise alternative approaches to the commendable objective of epistemically empowering patients. As my analysis aimed to show, this will be a difficult task, turning on the very epistemological core of biomedical practice.

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Notes

1 The terminology in this field is contested. Precision medicine is sometimes referred to as personalized, stratified, or P4 (personalized, participatory, preventive, and predictive) medicine. While often used interchangeably these terms may convey slightly different meanings depending on the (political or scientific) context in which they are used. I discuss this further in section 2 and suggest that we can, despite this polysemy, identify shared values in policy, academic, and industry proposals for PM.

2 Eyal et al. (2019) do address this and are doubtful that PM will lead to a redistribution of epistemic authority to patients and their families given the increasing complexity of health data. The present paper expands on these suggestions and explores potential mechanisms—namely epistemic injustice—through which this loss of authority and control may occur, furthering bolstering these worries.

3 Concepts like person-centered care, patient-centered care, and shared decision-making are themselves deeply contested. Some authors, for example, insist on the difference between person- and patient-centered care. As Morgan and Yoder (2012) show in their review, the use of these terms depends largely on contextual features, and their meaning converges on the *individualization* of care for the person *as a whole*. I will primarily refer to person-centered care. Any references to “patient-centered care”—e.g., in direct quotes—are to be taken as interchangeable with “person-centered care.” Following Thomas et al. (2020) and Galasiński et al. (2023), I take shared decision-making to be the core participatory component of person-centered care, where patients' testimony beyond preferences—particularly on social, experiential, axiological dimensions of illness—is considered an *integral* part of the epistemic practice of clinical decision-making. Epistemic justice, on this account, is a necessary condition for shared decision-making.

4 As several authors have highlighted there are good reasons to be critical of the program of PM and the lofty goals of individualization, personalization, and democratization its advocates often invoke. In philosophy of science and medicine several authors have raised questions with regard to PM's claims for “precision” and “individualization” (see, e.g., Giroux 2020; Vogt 2022). For a review on the increase of medical uncertainty in PM, see Lohse 2023. For an excellent collection of essays tackling these and related concerns arising from the rhetoric of a more personal and precise paradigm in healthcare and biomedical research see Barilan et al. 2022. I take my analysis to be informed by and broadly compatible with these concerns, yet focused on how PM's advocates envision precision care, rather than the implications of PM for healthcare systems as a whole.

5 That is, of course, not to say that this optimism is universally shared. The research cited shows that patients and healthcare professionals, too, raise concerns over the potential harms of PM to individual patients and the healthcare system as a whole.

6 These claims on partnerships are immediately suspicious given the asymmetric relationship between patient and healthcare professional. On a more charitable reading, we can take the advocates of PM to suggest that patients empowered through health information are better positioned to engage in treatment and care decisions. I will argue throughout this article that even this limited improvement on patients' epistemic standing is unlikely.

7 As several authors have suggested, the ideas expressed by Fricker have a more substantial history in Black feminist thought (Collins 2017; Medina 2021).

8 The notion of 'collective hermeneutical resources' is contentious within the epistemic injustice literature. I return to these discussions further in this section.

9 Following Bueter (2023), I grant that, in some cases, dismissals based on expressive style—particularly when speech lacks coherence—may involve epistemic bad luck rather than hermeneutical injustice. However, I urge caution here, as framing such dismissals as bad luck may, as Dotson (2012) suggests, obscure underlying epistemic injustice. For instance, as Spencer (2023) suggests, non-verbal expressions—such as in late-stage dementia—are often unfairly dismissed. This may constitute epistemic injustice rather than bad luck given our general capacity to interpret non-verbal communication. As such, we should maintain a high threshold for what counts as epistemic bad luck and be aware of the ways in which our understanding is shaped by patterns of epistemic exclusion.

10 Several strategies have been formulated within and outside the epistemic injustice in healthcare literature to effectuate more epistemically just healthcare practices. Freeman (2015), for example, argues for the recognition of patients' epistemic privilege and proposes a model of epistemic peership where the "representation" of medical technologies is actively scrutinized against the "sensation" of patients' experiences. Similar partnership models have been proposed emphasizing the value of the contributions of (often highly skilled, knowledgeable) patients (see Côté 2024 for a review). Despite these epistemic resources and strategies existing within patient (and allied) communities—exemplified by patient reports, life writing, patient advocacy, and academic work on illness experiences—they remain systematically excluded from clinical consideration and research design in epistemically meaningful ways (Reynolds 2020).

11 The moral-epistemic harm discussed here thus admits to degrees ranging from the complete dismissal of patient testimony to a selective uptake to the extent that the information offered is considered to be clinically relevant. As the empirical literature cited earlier suggests, it is likely that the extent to which patients are considered as interlocutors in the clinical encounter is contingent on other axes of oppression or marginalization.

12 I follow Freeman and Stewart's (2019) suggestion that patients qua patients occupy a marginalized position in the clinical encounter relative to healthcare professionals, due to the vulnerabilities associated with illness, the epistemic and institutional authority physicians hold, and the aforementioned presuppositions with regard to patients' epistemic capacities. As such, patients occupying a relatively dominant social identity outside of the clinic can still be subjected to epistemic injustice qua *patients* in healthcare. In this respect, harms and risks of epistemic injustice can also compound when patients belong to marginalized groups outside the clinic. For clarity, however, I will refer to "marginalized patients" as those marginalized along multiple axes of social oppression.

13 As Manne (2021) notes, the credibility deficit women encounter concerning their own pain stands in stark contrast to their authority when testifying on the health of their children, further rendering support to a contextually sensitive, agential approach to epistemic injustice introduced in section 4.

14 In a 2016 paper Fricker responds that her original analysis is amenable to more structural interpretations and can accommodate broader systemic concerns, even if these were not her initial focus. I do not intend to assess the merits of Fricker's response here, nor to settle the debate between agential and non-agential accounts of epistemic injustice. My concern rests primarily with the narrow uptake of Fricker's work in the epistemic injustice in healthcare literature sharing her original individualist focus and limiting our understanding of epistemic injustice in the clinic. Resources from agential epistemic injustice, I want to suggest, at the very least, complement this perspective by allowing for a more comprehensive assessment of patients' epistemic predicament.

15 Fricker (2016) emphasizes that hermeneutical injustice, as a structural phenomenon, does not involve individual perpetrators of the broader injustice. However, she further explains that the failure to exercise the virtue of hermeneutical justice can result in interpersonal wrongdoing. In agreement with her critics, Fricker acknowledges the need to address both the structures that inspire or perpetuate the injustice *and* individual vices.

16 I take an epistemological system to be situated and operative within a specific epistemic community. Following Nelson (1993), an epistemic community is a group identifiable by shared interests, beliefs, standards, accepted procedures, questions, and a set of dominant epistemic practices. Epistemic practices refer to the various activities involved in gathering, implementing, and evaluating evidence governed by procedures and rules within the relevant community. The biomedical community can then be considered an epistemic community in that it relies on specific procedures, beliefs, standards, and interests to come to medical knowledge. The clinical encounter can be considered as a set of (patient-facing) epistemic practices directed by the standards, interests, and aims of the biomedical community. Differential diagnosis, anamnesis, following diagnostic or treatment protocols, ordering diagnostic tests are several other examples of epistemic practices informed by the standards and principles of the biomedical community. Importantly, Nelson does not suppose epistemic communities to be static nor monolithic but rather, “multiple, historically contingent, and dynamic” (1993, 125). Moreover, individual knowers can inhabit several (sub) communities. As I will show for biomedicine, the epistemic framework adopted by a community is informed by the specific political, social, and cultural context in which it is operative. I thank an anonymous reviewer for prompting me to clarify the relationship between epistemic frameworks, communities, and practices.

17 Naturalists take biological dysfunction as a necessary and conceptually prior criterium for disease. In doing so, they proclaim to align themselves with biomedicine’s understanding of disease (but see Schermer and Binney 2024 for an overview on conceptual pluralism in biomedicine). Normativists (or constructivists), in contrast, suggest that disease involves a value judgment on the (social) desirability of a condition. The contemporary debate between these positions centers not on whether disease is purely objective or constructed, but on whether its classification is primarily a matter of social or scientific judgment. Note, however, that both positions operate on a third-person perspective compared to the emphasis on the first-personal, illness experience in phenomenological accounts of illness (Carel 2019). Kidd and Carel’s (and my own) concern lies not with a naturalistic concept of disease per se, but rather with the overemphasis on biological dysfunction in clinical practice at the expense of social or phenomenological dimensions of health.

18 The connection between the onto-epistemic commitments of medicine and social arrangements of clinical care, while relatively novel in the epistemic injustice literature, has been duly explored within the sociology of medicine. Nicholas Jewson (1976), famously, offered a similar connection between systematic features of an epistemological system and the agency of the actors involved. Surveying a significant shift in medical epistemology in the late nineteenth century, Jewson suggests that the advent of *hospital* (and later *laboratory*) medicine enacted a redistribution of epistemic authority in medical decision-making. As disease increasingly became a matter of physiology rather than illness experience, the division of epistemic labor and the epistemic roles of individual actors involved altered significantly, with physicians and lab technicians increasingly gaining authority in medical knowledge-making.

19 While Freeman’s focus is on the role of technology on testimony in pregnancy and labor specifically, she explicitly leaves room for more general interpretations of her account.

20 A further downstream consequence of PMs personalization may be “epistemic fragmentation” (Milano and Prunkl 2025), i.e., harms resulting from difficulties in sharing experiences and revising epistemic resources due to the increasing individualization of illness. This harm seems particularly relevant given PM’s aim to revise existing disease taxonomies according to individual molecular characteristics and the (historical) importance of shared experiences in illness and healthcare for patient organizing and structural reform.

21 Symons and Alvarado (2022) suggest that data science technologies, including algorithms, may contribute to hermeneutical injustice due to their opacity. The fact that such systems are often proprietary or epistemically complex limits the ability of those affected by algorithmic decisions to seek recourse. The extent to which these risks of hermeneutical injustice will materialize for data-intensive healthcare depends on regulatory decisions regarding transparency requirements for the implementation of algorithmic decision-making systems in highly sensitive social contexts like healthcare.

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