Return of Results in Digital Phenotyping: Ethical Considerations for Real-World Use Cases

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In their thoughtful paper, Shen et al. (2024) discuss optimal solutions to address the challenge of returning individual research results from digital phenotyping in psychiatry. Their conclusion to “recommend that decisions about the return of results be made on a study-by-study basis” is sound and reasonable. The proposed framework offers a useful scaffold for the consideration of applied bioethical principles in making such a study-by-study decision. In addition, they argue that there should be consideration of the clinical and research needs around digital phenotyping that must be implemented before it can be used. In this brief commentary, we elaborate on these two important considerations that Shen et al. identify.

We agree that the potential benefits of digital phenotyping may be legion, but they will not materialize, and might even exacerbate inequities in care, if suitable measures are not implemented. Understanding this requires recognizing the close connection between healthcare ethics and epistemology. As highlighted by philosopher Miranda Fricker, the creation and dissemination of knowledge is considered a significant benefit. Fricker describes epistemic injustice as the range of injustices inflicted on individuals in their role as knowers or contributors of knowledge (Fricker2007). As such, inequalities in legitimate access to such knowledge and participation in knowledge formation constitute an ethical wrong, and in the case of healthcare, can lead to literal harms (Blease et al. 2022) or preclusions from benefits, as we will explain. Epistemic injustice takes two forms: testimonial injustice and hermeneutic injustice. The former arises when individuals are discredited as knowers, and their contributions to knowledge formation activities (including in healthcare) are unjustly deflated; for example, patients may be unduly dismissed or stereotyped.

Indeed, mental health patients often suffer from stigmatization and worry their testimony will not be credited by clinicians. Because digital phenotyping relies on crucial moment-by-moment insights and not just the testimony of patients which risks being negatively stereotyped, digital phenotyping could help serve as a workaround or help to neutralize the kinds of testimonial injustices experienced among patients. With these tools, clinicians, partnering with patients, are required to seriously consider the nuanced, daily, quantified experiences of the people they treat.

Fricker argues that hermeneutic injustice represents the set of structural and social problems that arise because both the speaker and hearer “are laboring under the same inadequate tools.” This form of injustice arises when individuals are precluded from accessing, or can only partially access in a meaningful way, resources that could improve their understanding of their experiences. Kidd and Carel describe the “strategies” by which hermeneutic injustice can be explicitly or implicitly perpetuated (2017). These include a range of structural barriers to participation in practices whereby knowledge is formed, for e.g., physical barriers and subtler exclusions such as employing specific terminologies and conventions that serve to exclude the participation of groups of people - including patients, and subsets of patients - who might otherwise usefully contribute to or partake of knowledge. In the context of digital healthcare, while digital divides are narrowing, the most vulnerable patients - those with disabilities, lower incomes, fewer years of education, older people, and minorities - are still less likely to own digital devices, or have access to broadband access or the digital literacy skills necessary to partake in, and reap the benefits of, digital phenotyping interventions (Sieck et al. 2021). Although advancing digital health
research is a national U.S. priority (White House 2023), without a deeply nuanced, patient-focus on equity, risks of hermeneutic injustice remain. In contrast, appropriately researched, developed, and used, digital phenotyping could strengthen patient understanding of their health.

Unfortunately, the time for frameworks alone to address the epistemic injustice challenges of partnering with patients, in digital healthcare has already passed as there is emerging evidence that digital mental health solutions are already inequitable, spread with access/benefits not reaching the most vulnerable populations in the case of opioid use disorders (Miller-Rosales et al. 2023). More encouragingly, in attempts to redress and help reverse some of the subtle and not-so-subtle exclusions to epistemic justice in healthcare, our team has advanced ready-to-deploy digital literacy curricula and programs to help ensure anyone can obtain a smartphone and gain the requisite skills to use it toward recovery, personal goals, and even digital phenotyping. This program, called Digital Opportunities for Outcomes in Recovery Services (Hoffman et al. 2020) has already been deployed in many community settings ranging from Manchester, UK to Sacramento, California. A related train-the-trainer model has evolved in the digital health navigator who can not only teach digital literacy, support digital health engagement, and even help integrate digital tools into care. The digital health navigator (Perret et al. 2023) can and already does offer digital phenotyping counseling, offering a solution to the concern raised by Shen et al that there is little guidance on digital phenotyping counseling. There is now even an online training that is freely available to all through the SMI Adviser initiative at smiadviser.org/dhn that anyone can complete today.

While having a foundation in digital equity is important, this alone will not permit the return of results in digital phenotyping. Shen et al note that “research teams will need to ensure they have the resources to deliver on the promised return of results.” Fortunately, these resources have been in existence for years, and it is possible to focus on the next stage of assessing the impact of the return of results instead of just ensuring the possibility. Taking the considerations of digital exclusions seriously, our team developed the open-source mindLAMP platform (Currey and Torous 2023), and our patient partners guided us from day one to ensure that any data we capture can be returned and visualized directly on the smartphone itself. To support this return of results we created and shared APIs, code, and resources to produce a suite of visualizations. We actively study the impact of these visualizations and work directly with our patient and clinician partners to make them easier to interpret and more meaningful to use (Scheuer and Torous 2022, Chang et al. 2023). We have created myriad different visualizations to share results back in different studies, for different populations, and different use cases. This hands-on learning and sharing allow direct assessment of the risks as it ensures bias can rapidly be identified and early warning if this monitoring is changing underlying behavior in concerning ways. Illustrating how acquiring knowledge can enhance health advantages, as philosophers of medicine have emphasized, epistemic gains are also tied to beneficence. This is because individuals can gain from their own health data, and for many, it can provide the bonus of heighten-ened empowerment via emotional self-awareness. Thus while Shen et al are correct that research teams must deliver on the promised return of results, research teams can move even further and seek to optimize and adapt the return of results today.

In summary, the return of results in digital phenotyping is not only possible it is already happening. Frameworks like that proposed by Shen et al can help solve questions about when, how, and what data is returned. However, such frameworks will be more valuable when the “strategies of exclusion” emphasized by philosophers of medicine are confronted in practical ways. Paired with a digital mental health equity plan like DOORS or digital health navigators and digital tools like mindLAMP (or any related digital phenotyping apps co-designed with patients) these approaches already support robust data visualization. Our approach has striven to apply theory, bridging philosophy of medicine and ethics, and digital healthcare, to embark on real-world use cases that, in turn, will undergo further empirical and theoretical evaluation. Our team offers our DOORS, Digital Navigator Training, and mindLAMP app as free and accessible tools to ensure any team anywhere in the world can share results today. We argue sharing results is not just an epistemic good, it can lead to patient benefits including empowerment, and might also prevent harm.

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We applaud Shen et al. (2024) for offering a framework to address how to return research results from digital phenotyping within the discipline of psychiatry. However, given the value-laden nature of participant preferences, we believe further bioethical reflection is needed in order for the framework to be successful. The authors’ claim that their framework is rooted in core bioethics principles (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), but both their account and their justification for it could be significantly strengthened were they to clearly describe how this is the case, that is, to offer or reference a specific accounting of the principles as realized in their framework; in this commentary, we focus on the principle of justice. The authors rely on an account of procedural justice,

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