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Public say versus public sway: ‘Lived experience literacy’ in the pursuit of participatory AI

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PJ Annand^{1,#} , Stef Garasto^{2,#} and Lara Groves³

Abstract

Artificial intelligence (AI) technologies are increasingly embedded and promoted across many parts of society. At the same time, concerns persist about their potential to propagate social harms, especially for marginalised and minoritised communities. These concerns include the risk of disconnection between those designing, developing and deploying AI systems and those most affected by it – with the interests of the latter then going underserved or being undermined. Efforts to address these challenges include calls to improve critical AI literacy among the general population, and a drive towards ‘participatory AI’, which seeks to actively involve those most affected by AI technologies in their development. The former is often said to be a necessary precursor to the latter. Nonetheless, while participatory AI’s popularity is growing, its implementation does not always uphold its ideals. Participatory approaches executed poorly risk becoming tokenistic or extractive, undermining their intentions. In this commentary we argue that there is an equally important complement to AI literacy: what we call ‘lived experience literacy’ among AI technologists. Lived experience literacy refers to the capacity to recognise and engage with lived experience as a legitimate form of expertise, and to design participatory processes that value and act on that expertise rather than merely soliciting it. Lived experience literacy, which includes needing a paradigm shift in the value afforded to expertise gained through first-hand experience, can help move participatory AI from rhetoric towards practice, mitigating the risks of ‘participation-washing’, and laying groundwork for more meaningfully participatory forms of AI development.

Keywords

Responsible AI, participatory AI, AI literacy, critical AI literacy, lived experience, critical refusal, coproduction

Artificial intelligence (AI) technologies are now deeply integrated into many parts of society around the world. This has prompted efforts to enhance public understanding of AI. Arguably, however, as the reach of AI systems, and the influence of organisations developing them, expand, there is also a need for another kind of literacy, which we call ‘lived experience literacy’, among AI researchers, developers and executives. We will explain what we mean by that and why we think it is important. We use the term AI to refer to a broad set of automated, data-driven technologies and systems.

Reducing the risk of AI harms

Researchers and activists have long warned of risks and harms accompanying the development and deployment of AI, like data bias (Buolamwini and Gebru, 2018), discriminatory resource allocation (Noble, 2018) and overreaching

surveillance (Kalluri et al., 2025). These are legitimate fears about the risks AI systems could and do pose, especially for marginalised and minoritised communities, across

¹Centre for Care, School of Sociological Studies, The University of Sheffield, Sheffield, United Kingdom of Great Britain and Northern Ireland

²School of Computing and Mathematical Sciences, University of Greenwich, London, United Kingdom of Great Britain and Northern Ireland

³Ada Lovelace Institute, London, United Kingdom of Great Britain and Northern Ireland

[#]These are joint first authors, each entitled to list themselves first in their own records.

Corresponding author:

Stef Garasto, Old Royal Naval College, University of Greenwich, Park Row, London SE10 9LS, United Kingdom of Great Britain and Northern Ireland.

Email: s.garasto@greenwich.ac.uk



intersecting lines of existing inequality. They are accompanied by concerns that the people most affected by AI systems are usually not the ones designing, creating, delivering and, more broadly, steering them, and that their interests may therefore remain, at best, underserved and, at worst, undermined. For example, Samaritans' 'Radar' Project, a Twitter plug-in that attempted to detect suicidality in users' posts, was permanently closed after significant criticism from people with lived experience of mental health services, crisis intervention, and online safety, as well as advocacy groups and researchers (Samaritans, 2015). In their apology, Samaritans acknowledged that they had 'learned that [they] must consult even more widely than [they had] done in the development of Samaritans Radar' and would 'continue to respect and better understand the diversity of existing communities and users'. Other examples exist of AI technologies being produced, before being found unfit for purpose by the communities they are meant to support (e.g. Politico, 2022; Wells, 2023).

These cases underscore the risk of AI-driven interventions that do not align well with the interests of those affected by them. Moreover, they emphasise the importance of sufficiently broad and *substantive* engagement from people whose lived experience makes them particularly well placed to inform them from the outset, prompting deeper interrogation of what competencies are required for this engagement to be meaningful.

Lived experience expertise, participation and AI

Concerns about a disconnect between research, technologies, services and policies and the communities they should supposedly serve are not novel. Domains like mental health, public health, social research and beyond have begun to adopt participatory approaches to research and service design that increasingly recognise and seek out the forms of knowledge and expertise that come with lived experience (knowledge produced through direct, embodied, and situated engagement with social conditions, systems, or harms, particularly when shaped by structural marginalisation). Such approaches have their roots in geopolitical south contexts, and have since become more widespread in the geopolitical north (Lenette, 2022). Here they have taken forms like survivor/community-controlled (Russo, 2012), community-led (Ghanbarpour et al., 2018), service user-led/informed (Sweeney and Morgan, 2009), lived experience-directed/informed (Ashton et al., 2018), co-produced (Needham and Carr, 2009), and beyond. These practices exist on a continuum, often visualised as a ladder or spectrum (e.g. Arnstein, 1969; National Survivor Network, 2023), contrasting tokenistic techniques (simply seeking, for example, to inform or educate) with those facilitating greater power sharing.

In machine learning, this has manifested as 'participatory AI', where people affected by AI systems are invited to

actively contribute to design and development processes, presenting considerations that best reflect their needs, values, and preferences (Delgado et al., 2023). Many participatory AI initiatives in technology companies proceed in good faith, spearheaded by a widespread appetite amongst responsible AI practitioners in these firms (e.g. see the inclusive AI playbook by Partnership on AI (2025)). Examples of participatory AI also exist within academic environments, from research projects (Suresh et al., 2022) to community building (Queerina et al., 2023). Groves et al. (2023)'s research highlights that practitioners interested in participatory AI are concerned about tokenism, and keen to understand how to meaningfully incorporate the views of historically marginalised groups.

In practice, however, participation for the purposes of minimising public harms (or even maximising community benefit) may be deprioritised, with modest 'algorithmic performance improvements and process improvements' (Birhane et al., 2022) favoured instead of genuine 'collective exploration'. Participation has at times been over-extended to include *passive*, or otherwise limited, forms of involvement. Issues include participatory AI projects being set up with a focus on discipline-specific technical questions, less familiar to much of the public, increasing the risk of a hollowed-out participatory process. Practitioners trying to adopt participatory AI practices in big tech companies and AI labs also face uphill battles in convincing executives that participation is worthwhile and not an impediment to profit seeking, with a constraining effect (Groves et al., 2023).

Even in less challenging circumstances, all participatory projects present a risk of 'participation-washing' and participation for participation's sake, where there might be a lack of appropriate standards around what is expected from participation and the outcomes of it. Corporate actors may appropriate the banner of participation while using its results for corporate gain not shared with communities, reproducing extractive logics rooted in colonial histories (Birhane et al., 2022; Sloane, 2024).

Two-way literacies as part of the way forward

One proposed response is to improve public AI literacy – a task attracting the attention of various groups, like We and AI, and the Organisation for Economic Co-operation and Development. AI literacy refers to the competencies enabling people to evaluate and use AI technologies critically (Long and Magerko, 2020) – though exact definitions vary (see Ng et al., 2021). A lack of AI literacy amongst the public represents one barrier to direct stakeholder engagement (Delgado et al., 2023), or to participatory work 'around more complex, general purpose AI systems' (Groves et al., 2023: 9).

Another complimentary response, we argue, is a counterpart literacy among *developers, researchers and tech*

executives (hereby termed ‘*AI technologists*’, for brevity) – fostering a two-way, rather than unidirectional, exchange.

We therefore introduce ‘lived experience literacy’, which we position as a *capacity*, comprising skills, dispositions, and epistemic orientations, that enables AI technologists to value, interpret and act on lived experience expertise. It entails recognising the forms of knowledge gained through lived experience as on par with technical and academic knowledge (Díaz and Smith, 2024), coupled with the capacity to act on that recognition. Lived experience literacy involves reflexive awareness of positionality and institutional or commercially driven assumptions (Birhane et al., 2022), a commitment to sharing decision-making power, and a will to engage directly with affected communities. For example, lived experience literacy would facilitate recognition of how using algorithmic proxies (i.e. predictive models trained on people’s preferences; Delgado et al., 2023) as a substitute for public engagement is deeply flawed, since such proxies abstract complex, contested, and relational experiences into static variables, unable to capture community priorities or account for how harms are interpreted over time.

We do not position lived experience literacy as an alternative to participatory traditions, nor as a critique of their epistemological foundations. Indeed, many dispositions we associate with lived experience literacy – epistemic plurality, valuing experiential knowledge, and power redistribution – are central to participatory research’s roots. The challenge, particularly in AI development contexts, is that what is labelled ‘participation’ often takes the form of consultation or extraction, detached from these deeper commitments. Practitioners, for example, may invite input from affected communities but retain control over problem definitions, success metrics, and design, treating experiential knowledge as interesting but not authoritative. Feedback informs technical requirements, but is filtered through existing objectives, or abandoned when conflicting with organisational incentives. Here, participation occurs in form, but not in epistemic substance or decision-making power. In this sense, the issue may be less about the absence of participation *per se* than a mislabelling of practices that fall short of participatory research’s epistemological ambitions. Lived experience literacy names what is required to uphold those ambitions.

Building on this, we differentiate lived experience literacy from participatory AI, which most commonly describes *mechanisms* for engagement (Ada Lovelace Institute, 2021). Instead, we use lived experience literacy to refer to the individual (and potentially also collective) capacity enabling those mechanisms to function with integrity. It is not simply procedural but epistemic, requiring a process of unlearning embedded hierarchies that have historically devalued experiential and community-based knowledge in favour of rationalist, ‘scientific’ or technical expertise (Birhane, 2021; Díaz and Smith, 2024). Without this shift, we contend that participatory AI mechanisms and processes risk tokenism, as the underlying valuation of other knowledges remains unchanged.

Just as AI literacy is important for meaningful community involvement in AI, so is lived experience literacy for AI technologists. *Both* of these can help efforts to build AI systems that benefit people and society. By arguing for lived experience *literacy* specifically, we intend to emphasise the need to grow this capacity with adequate support, beyond, for example, brief mentions of the importance of stakeholder engagement within AI ethics toolkits (Wong et al., 2023). We also wish to echo literacy’s emancipatory potential (Long and Magerko, 2020) for those building this capacity but also, in this case, beyond. Finally, like learning a language, literacy is not a fixed endpoint but an ongoing process of dialogue, listening, and reflection.

Such a shift is especially necessary given the narrow epistemological lens that currently dominates the field. Malik and Malik (2021) describe how AI’s ‘technical formalisation’ encourages dismissal of the social sciences as ‘vague’. Lived experience literacy challenges this insularity, inviting AI technologists to engage with other ways of knowing and recognise experiential expertise as essential to understanding AI’s social world.

What we might achieve ... and how

Lived experience literacy, we contend, has something to offer the struggle to move from consultation to participation, towards co-produced approaches where community stakeholders have *sway* as well as *say*. Himmelreich (2023) cautions against treating participation as an intrinsic good, noting that it can replicate existing governance processes and divert attention from structural reform. Participation can also be extractive if poorly designed (Co-production Collective, 2022). Our argument responds to this concern by positioning lived experience literacy not as participation itself but as a capacity that gives participation ethical and epistemic depth.

Indeed, such capacity is important for enabling identification of when not to engage, or when to redistribute power and resources and take a step back. In this sense, lived experience literacy supports the need to make space for the possibility of reform, and see refusal as potentially generative, rather than simply a form of disengagement (Lysen and Wyatt, 2024). Particularly where timelines, product imperatives, and investor pressures dominate, taking lived experience seriously entails accepting that affected communities may say ‘no’ or ‘not like this’; consistently including refusal within ‘what is on offer’ during participation (Delgado et al., 2023); and understanding such acts not as obstruction or irrationality but as forms of indispensable knowledge that can reshape research agendas and design processes.

If lived experience literacy is to become more than an abstract aspiration, it must be deliberately cultivated. Malik and Malik (2021) note that social research training routinely introduces diverse research paradigms – positivist, interpretivist, critical, and beyond – yet science, technology,

engineering and mathematics education rarely does. Embedding such training for engineers and computer scientists could help expand the epistemological horizons currently shaping AI practice (Raji et al., 2021). We advocate greater exposure to epistemological pluralism as one way of cultivating lived experience literacy. Malik and Malik (2021) also argue for integrating performative pedagogies, such as Boal's (1979) Theatre of the Oppressed, to foster critical reflection – tools for what they call 'critical technical awakenings'. Similarly, such awakenings likely align with lived experience literacy endeavours, extending reflexive awareness into a sustained capacity to engage with lived experience as legitimate expertise.

At the organisational level, cultivating lived experience literacy may entail making relational work visible and rewarded, recognising it as a necessary foundation of technical work. At the level of funders and institutional incentives, it could involve incentivising practices like changing direction, slowing development, or not deploying a system, rather than privileging delivery and scale alone. We hope future empirical research will further explore lived experience literacy-building mechanisms in practice within individuals and institutions.

To conclude, without genuine esteem for lived experience expertise and the capacity to enact it, participation in AI risks being empty at best and complicit in exacerbated harms, at worst. Our argument is thus that AI literacy initiatives would ideally always be coupled with lived experience literacy efforts. Achieving participatory AI that tops the metaphorical participatory ladder requires the public and community stakeholders to not only have a say but also sway. This entails challenging existing organisational incentives and knowledge hierarchies.

Whether this is possible within current socio-economic structures remains uncertain in the absence of 'a political-economic outlook addressing how such power is distributed and reproduced' (Maas and Inglés, 2024: 937), since capitalist imperatives like competition, data extraction and technological solutionism often foreclose genuine power-sharing. Yet, even within such constraints, cultivating lived experience literacy can, in our view, foster incremental reform, creating pockets of better practice. Ultimately, whenever AI literacy interventions are proposed for communities, our wish is that they are complemented with lived experience literacy endeavours for technologists. While not promising to transform the structural conditions of AI production, this dual commitment may nonetheless open pathways towards truly meaningful participatory AI.

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ORCID iDs

PJ Annand  <https://orcid.org/0000-0002-9322-5078>
 Stef Garasto  <https://orcid.org/0000-0001-5742-8073>
 Lara Groves  <https://orcid.org/0009-0001-9687-3353>

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Ethical approval was not needed for this work.

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Author contributions

PA and SG contributed to the initial design and conceptualisation; PA, SG and LG contributed to shaping and refining the arguments; PA wrote the initial draft; PA, SG and LG critically revised, edited and expanded the manuscript. All authors gave final approval and agree to be accountable for all aspects of the work.

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