

## Simulating (some) individuals in a connected world

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Matthias Braun explores the use of digital twin technology in medicine with a particular emphasis on the question of how such simulations can represent a person.<sup>1</sup> In defining some first conditions for ethically justifiable forms of representation of digital twins, he argues that digital twins do not threaten an embodied person, as long as that person retains control over their simulated representation via dynamic consent, and ideally with the option to choose both form and usage of the simulation.

His thoughtful elaboration provides insight into the challenges inherent in interactions between a person and their digital twin, emphasising the modes of control required to respect personal modes of freedom. This individual-centric approach to the question of representation leaves out the important ethical consideration of ensuring that *all*, not merely some, can be represented. Braun describes dynamic consent as a necessary mode of control, arguing that where a person is unable to give consent, ‘such simulations threaten to become illegitimate representations. They would then shift the kind of interaction from representation to illegitimate forms of prediction or surveillance and thereby could lead to infringements to individual modes of freedom.’ Consequently, the implementation of digital twin technology in healthcare would seem to exclude the most vulnerable members of society from participation in and benefitting from medical innovation, based on their inability to give (dynamic) consent. Although Braun reflects on the challenges of substitution, where a person is acting on behalf of someone without control over how they are represented, he fails to discuss specifically those who, for instance due to age or impairment, may not be able to take control over their digital twins. This seemingly leaves two options: a) limitation of access to digital twin technology to those able to give and manage consent, or b) representation of those unable to consent via someone acting on their behalf. Both options are dissatisfying. First, how can digital twins become an ethically justifiable form of representation if those most in need of appropriate representation are barred from participation? Alternatively, if those unable to give consent require someone else to control and manage their digital twins, how can we avoid the illegitimate space of substitution, aggravated by the combination of proxy representation *and* decision-making?

If this understanding is correct, digital twins do not promote a more equitable and just health system but potentially widen the gap between the most vulnerable people in our society and those with certain (cognitive) resources to engage with it. Current inequalities are of course not the fault of technology; they can however worsen the situation. Technological innovations cannot solve complex social problems, and this kind of ‘technological solutionism’ could have harmful consequences on a large scale.<sup>2</sup> In this context, ethical evaluations should also address the question of what kind of world we want to create, so although Braun is primarily concerned with the impact on individual representation, consideration of potential system impact seems warranted. This also reflects digital twin’s strong connection to the engineering industry where they are used ‘to deal with the increasing complexity of technological systems’, and ‘to provide a relatively holistic understanding not only of a single isolated object but of a complete system or an entire production process.’ It thus seems natural to reflect on medicine (or healthcare) also as a system. If we compare an engine with a heart, we may also compare the complex technological system with the complex social world we live in,

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including the interconnectedness of human beings. Why then limit the discussion of ethically justifiable forms of representation to the representation of an individual person? Can the person even be separated from the system? Current knowledge concerning social determinants of health which demonstrates the strong connection of social and economic factors to individual and collective health,<sup>3</sup> would suggest not. By placing emphasis on the digital twin, responsibility not only for control of the simulation but also for the actions and inactions following the twin's 'knock on the door' is firmly placed with the person – not with the state, the system or society at large, following a neoliberal ideal of individual health promotion.<sup>4</sup> It further insinuates that there is something to be done to improve health, but the news of imminent severe heart disease may not 'offer me any opportunities to ward off the physical manifestations of the disease', but only provide me with non-actionable information. Current medical knowledge may not provide meaningful treatment options, and so-called lifestyle changes are often elitism in disguise, because a person must be able to afford a less stressful job, better food, less exposure to toxins – or to physically distance, as the ongoing pandemic has demonstrated. In these cases, the digital twin will not empower a person, but merely serve as a reminder of the powerlessness of many within the larger system. A holistic understanding, like in the engineering context, would require the digital twin to be positioned in the wider context of our world as it is. A lifeworld that is relational and encompasses system information.

Braun has provided a helpful first step towards the ethical use of digital twins in medicine and has raised important points concerning representation. To advance his position further, and for digital twins to become an ethically justifiable form of representation, two critical aspects must be addressed. First, the potential challenges with this technology need to be considered not merely from an individual perspective. Braun hints at this when he refers to the importance of contextual factors, but this should be explicitly extended to cover the possibility of simulating important health-influencing factors in the society we live in (such as socio-economic, environmental factors). Second, to avoid current exclusionary practices in the medical sphere (e.g., in medical trials and research), an appropriate method for ensuring the inclusion of those lacking capacity to provide dynamic consent must be found. Neither blanket exclusion nor substitution seem justifiable, as one would withhold potentially large benefits from already disadvantaged groups, while the other would potentially open the door to uncontrollable surveillance and exploitation.

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<sup>1</sup> Matthias Braun, 'Represent Me: Please! Towards an Ethics of Digital Twins in Medicine' [2021] *Journal of Medical Ethics* medethics.

<sup>2</sup> E Morozov, *To Save Everything, Click Here: The Folly of Technological Solutionism* (PublicAffairs 2013) 5.

<sup>3</sup> World Health Organization, 'Social Determinants of Health' (n.d.) <<https://www.who.int/teams/maternal-newborn-child-adolescent-health-and-ageing/maternal-health/about/social-determinants-of-health--global>> accessed 20 April 2021.

<sup>4</sup> Nike Ayo, 'Understanding Health Promotion in a Neoliberal Climate and the Making of Health Conscious Citizens' (2012) 22 *Critical Public Health* 99.