

## Enabling digital health companionship is better than empowerment

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In June 2019, the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD) convened a meeting to discuss how best to implement digital health for the purpose of transforming health systems, empowering individuals, and improving the delivery of high-quality healthcare. This followed the April 2018 communication from the European Commission on “enabling the digital transformation of health and care in the Digital Single Market; *empowering* citizens and building a healthier society”. Such international calls to action have been effective at spreading the simple message that ‘digital health will bring patient empowerment’ to healthcare policymakers across the globe. Consequently, empowerment plays a prominent role in many national-level policy documents, including: the NHS England’s *Empower the Person*’ strategy, the eHealth Strategy for Ireland and the National eHealth Strategy of Australia.

The issues with this “empowerment” narrative are varied and covered in more detail elsewhere (1). Here we are primarily concerned with the fact that – because these strategies largely fail to detail *how* digital health tools (DHTs) empower citizens or patients – governments risk using this rhetoric in a potentially deceptive manner. The strategies seek to encourage the adoption of technologies that may make individuals responsible for self-surveilling all aspects of their life through the *digital medical gaze*, instead of focusing on how data derived from DHTs can *enable* better care at the level of systems, population, group, or individuals.

This risk of self-surveilling is ethically worrying because, as part of this process (the lifestylisation of healthcare (2)), individuals are encouraged to reflect on how they may be performing against established baselines for ‘health’ but not told how these baselines were

established (1) and whether or how far they may apply to them. For example, it is not known to the individual user whether their default ‘optimum heart rate’ is actually optimum for a person *like them*, or only for individuals *like those* included in the design trial. In other words, it is not clear whether the specific individual fits the profile associated with the DHT. The advice provided by DHTs promotes conformity rather than autonomy and risks undermining individuals’ integrity of self (3).

From this more critical perspective, one may argue that DHTs do not promote specific actions and behaviours based on objective knowledge (4). Instead, they act as active sociocultural products, promoting some norms, lifestyles and values over others, in a way that disciplines (or frustrates and marginalises) those with supposedly inferior moral beliefs about health (5) until they meet the standards of the healthy ideal type (4). This potentially dangerously manipulative process reveals what (6) call empowerment’s ‘correlative vice’, whereby empowerment can feel like an elaborate mechanism for victim-blaming (4) by creating scenarios in which blame for becoming ‘unhealthy’ or ‘sick’ (which could simply be implied by a seemingly ‘anomalous’ data point) is placed on users for whom it would have been difficult (or perhaps even improper) to achieve the defined standards of health in the first place (1).

By highlighting this risk, it becomes clear that promoting digitally-enhanced, empowered healthcare as a techno-utopia is misleading. However, it would also be incorrect to present it as a techno-dystopia. If looked at an aggregate level, those same seemingly anomalous data points identified and used by ‘empowering’ DHTs to discipline individuals, can also be used to enable individuals or groups (a population, community, or even a family) and deliver significant benefits by improving choice of access, increasing precise care, lowering the costs of care and enabling better preventative care and faster and more accurate diagnosis. The challenge facing policymakers is how to *design* an infrastructure that supports ethically good outcomes (*infraethics*) of a responsible digital health ecosystem (7), that promotes these, and other, positive outcomes of DHTs whilst avoiding the pitfalls highlighted.

Exactly how to do this remains an open question. One valuable approach to answer it is to acknowledge that the benefit of DHTs is in their ability to help individuals and clinicians to navigate the difficult and ever-shifting balance between agency and patiency in doctor-patient relationships, that is, whether the individual (doctor or patient) is active or passive in the decision-making process at any given moment. By acting as external repositories for the desires of the individual in different circumstances, as well as storing information about their options, wider contexts and data sharing preferences, DHTs can act as volitional aids (8), which ensure the

individual's desire and potential for autonomy and agency is respected and enabled (9), rather than assuming that they always wish to be empowered (1).

This shift from empowering to enabling DHTs as *digital companions* (1) can help decrease information asymmetry, as it is more likely that relevant, available information is accessible by both parties, thus enabling the decision to be made by the person who has the right to make it. When used in this manner, DHTs can provide individuals as well as groups (e.g., a family) with a chance to control their desire and potential for autonomy, and clinicians with the chance to present their recommended advice in a way that respects the patients and is interpreted within the context of their specific circumstances.

To illustrate this point, consider endometriosis, which is listed by the NHS as being one of the most painful conditions to live with. Amongst women it is as common as Diabetes but takes human clinicians seven to ten years to diagnose. Research projects like Columbia University's 'Citizen Endo' use DHTs to *enable* patients to record their *own personal symptoms* (rather than those that medical practitioners associate with the disease) to discuss with their clinician. These patients have not been 'empowered' to take greater control of their health by the DHTs, the disease can still only be officially diagnosed and treated surgically. However, such examples do facilitate facilitate more information symmetry (at least for those with the appropriate level of eHealth Literacy), enable the sharing and socialisation of information and the formations of groups (as opposed to a mere clustering in terms of profiling), and thus enhance an individual's autonomy by giving them the opportunity to have a more evenly-balanced conversation with their clinician, one that considers all of their relevant *personalised* information.

Of course, such a reframing alone will not protect against the harms associated with presenting DHTs as a techno-utopia. However, what we wish to stress is that, by encouraging this positioning, policymakers and healthcare system designers can at least provide a more balanced view, one that seeks to capitalise on the benefits of DHTs whilst minimising the risks of potential harms.

## Glossary

Term	Definition
Digital Single Market	A European Commission Initiative designed to ensure citizens can equally access online goods/ services regardless of nationality.
Empower the Person	NHS England's Strategy to provide citizen-facing DHTs,

Lifestylisation of Healthcare	The potential for DHTs to record data on all aspects of a person's life
Digital Medical Gaze	The practice of using the information provided by a DHT to reflect on one's self from the perspective of a medical practitioner
Objective Knowledge	Facts or observations that are believed to be 'true' independently of a person's perceptions, beliefs or emotions
Correlative Vice	A corresponding negative effect
Volitional aids	A device that aids a person in making a choice or a decision

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