

Enabling digital health companionship is better than empowerment

In June 2019, WHO and the Organisation for Economic Co-operation and Development 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 health care. This meeting followed the April 2018 communication¹ 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” (appendix). Such international calls to action have been effective at spreading the message that digital health will bring patient empowerment to health-care policy makers across the globe. Consequently, empowerment plays a prominent role in many national-level policy documents, including National Health Service England’s Empower the Person strategy (appendix), 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.² 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 aforementioned strategies seek to encourage the adoption of technologies that might make individuals responsible for self-surveilling all aspects of their life through the digital medical gaze (appendix), 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 health care,³ appendix), individuals are encouraged to reflect on how they might be performing against established baselines for health, but not told how these baselines were established² and whether or how far they may apply to them. For example, the individual user does not know 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 (ie, 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.⁴

From this more critical perspective, it can be argued that DHTs do not promote specific actions and behaviours based on objective knowledge (appendix).⁵ 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 health⁶ until they meet the standards of the healthy ideal type.⁵ This potentially dangerously manipulative process reveals what is called empowerment’s correlative vice⁷ (appendix), whereby empowerment can feel like an elaborate mechanism for victim blaming,⁵ 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.²

By highlighting this risk, it becomes clear that promoting digitally enhanced, empowered health care as a techno-utopia is misleading. However, it would also be incorrect to present it as a techno-dystopia. At an aggregate level, those same seemingly anomalous data points identified by empowering DHTs, used to influence individuals, can also be used to enable individuals or groups (ie, 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. Policy makers are faced with the challenge of designing infrastructure that supports ethically good outcomes (infraethics) of a responsible digital health ecosystem⁸ that promotes these, and other, positive outcomes of DHTs, while avoiding the pitfalls.

Exactly how to do this remains an open question. One valuable approach to answering this question 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 relationship (ie, whether the individual [ie, 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, and storing information about their options, wider contexts, and data sharing preferences, DHTs can act as volitional aids;⁹ appendix) which ensure the individual's desire and potential for autonomy and agency is respected and enabled,¹⁰ rather than assuming that they always wish to be empowered.²

This shift from empowering to enabling DHTs as digital companions² can help to 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 and groups (eg, 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 National Health Service as being one of the most painful conditions to live with. Among women, endometriosis is as common as diabetes but takes clinicians 7–10 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 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, reframing alone will not protect against the harms associated with presenting DHTs as a technoutopia. However, we wish to stress that, by encouraging this positioning, policy makers and health-care system designers can provide a more balanced view: one that seeks to capitalise on the benefits of DHTs, while minimising the risks of potential harms.

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