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Cite this as: *BMJ* 2021;374:n1694
<http://dx.doi.org/10.1136/bmj.n1694>

Published: 08 July 2021

Data saves lives

But only through creating knowledge that informs practice

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The Department of Health and Social Care in England recently published its new data strategy called, “Data saves lives.”¹ The title copies the #datasaveslives social media campaign,² emphasising that the NHS and social care urgently need a new approach to health and care data. Who can argue with saving lives? Who can dispute that the pandemic has shown the lifesaving value of good data (and, conversely, the lethal consequences of poor data)?

NHSX—the central information technology unit set up by the former health secretary Matt Hancock in 2019—is consulting on this draft strategy with a survey³ that is due to close on 23 July 2021. The survey questions are simplistic, but there are plenty of free text boxes to make more open comments, and we encourage *BMJ* readers to have their say.

The strategy’s key themes are improved data access for the public and care professionals; better data for decision makers, adult social care, and research; better technical infrastructure; and innovation.

We have been here before,^{4–7} so what’s different this time? One crucial step forward is bringing adult social care into the agenda as part of integrated care systems. The strategy accepts that achieving its goals is “a long and complex task.” But the specifics and measurability of its commitments are variable, and many are dependent on the still unpublished digital transformation plan.

The recent change of health secretary is unlikely to alter the priorities of the digital agenda, but whoever is in charge, it is going to cost a lot of taxpayers’ money over many years—more than a few electoral cycles. Ultimately, real transformation will require multiparty consensus on a long term data strategy that outlives any one administration.⁸

The ministerial introduction emphasises the critical role of data and analytics in the pandemic response and claims that the “unprecedented digital transformation throughout health and care” has “transformed people’s relationship with the NHS—for the better.” While there has certainly been an unavoidable shift to virtual consultations (both telephone and video conferencing), it has not been universally welcomed and has not occurred “throughout health and care” but in pockets of both systems. Substantial concerns have been raised, including poor integration of health and social care,⁹ lack of public trust (compounded by cybersecurity concerns),¹⁰ and the “digital divide” that exacerbates the already poorer outcomes of marginalised groups.^{11 12}

The strategy’s ambition to improve people’s access to their own health and care data is laudable. And a promise to simplify information governance and strengthen the duty to share will be welcomed by anyone struggling to provide data to those who legitimately need the information across organisational boundaries. The strategy rightly highlights how the simple yet effective approach of taking the query to the data, not the data to the query,¹³ exemplifies rapid and secure large scale data analytics. It’s still unclear, however, how the new proposals will promote a learning health and care system that continuously uses data to enhance knowledge and improve outcomes for patients.

Learning system

A learning health and care system is a form of continuous quality improvement at any scale, where data from routine processes are used to derive new knowledge, which drives improved practice (fig 1).¹⁴

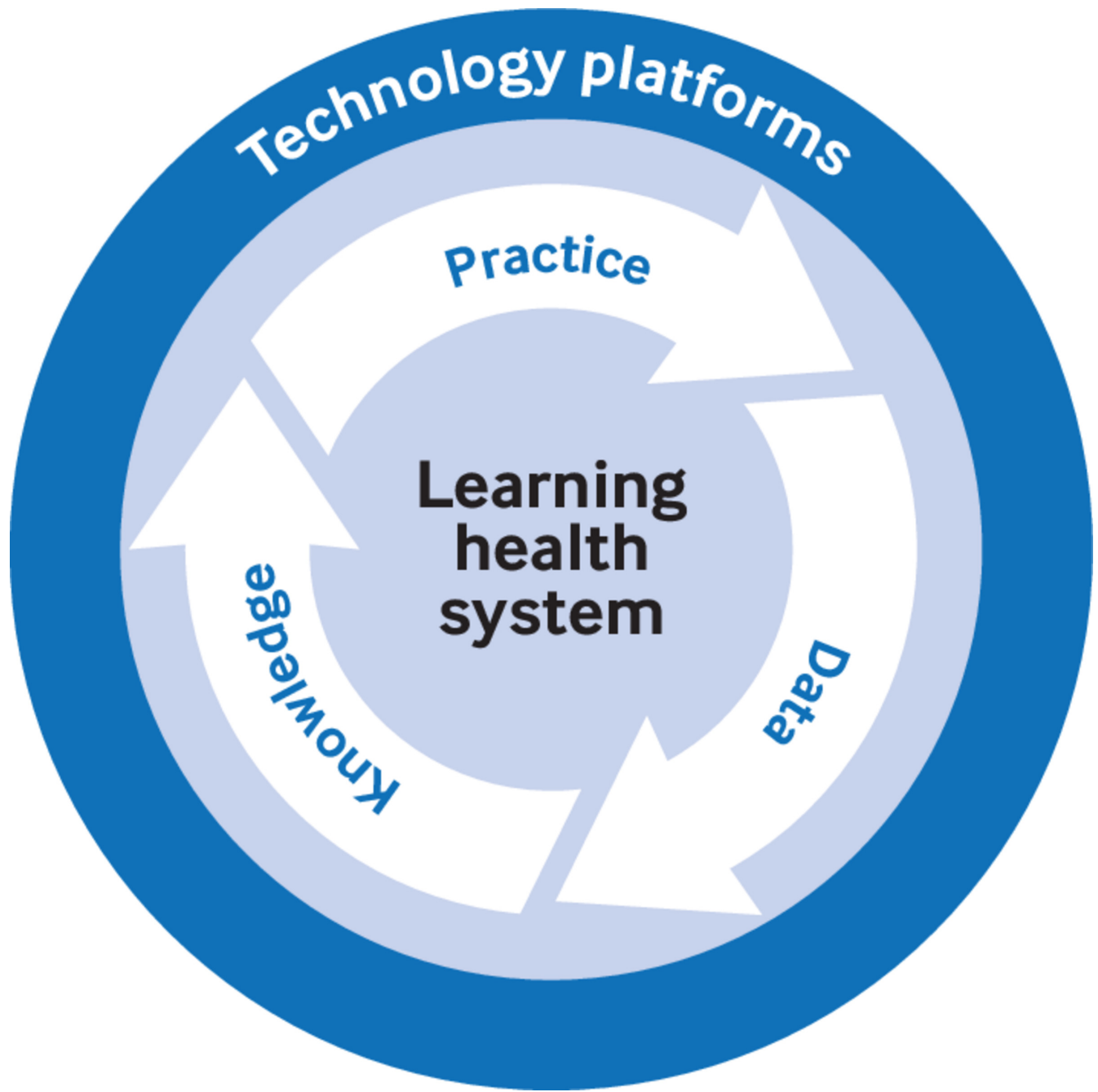


Fig 1 | Learning health and care system (reproduced with permission from Foley et al¹⁴)

Data alone does not save lives. It is knowledge derived from data analysis and applied in practice that saves lives. This is not a pedantic distinction as it shapes funding priorities. The new strategy acknowledges the three phases of the learning cycle but doesn't sufficiently emphasise their separate elements. The knowledge-to-practice phase, for example, includes both knowledge that can be embedded in decision support systems¹⁵ (such as clinical guidelines or machine learnt associations) and the tacit human knowledge so important to changing practice. The practice-to-data phase should include comparative reporting of performance, arguably missing from this strategy.¹⁶

The strategy rightly aims to recruit more analysts and data scientists. However, a learning health and care system is sociotechnical—it

includes people working in interdisciplinary teams, not just technology and data science—so must include a broader range of informatics skills.^{17 18}

Finally, we must remember that the infrastructure for creating, storing, processing, and transmitting health and care data, while sometimes invisible, has environmental and human costs.¹⁹ Just as extracting the raw materials for technology manufacture requires miners to work in unpleasant and sometimes unsafe conditions, the production of healthcare data is often associated with clinician burnout²⁰ and cognitive overload²¹ related to poor system design²² and usability.²³

Patients are also producers and consumers of health and care data, but their current experience is all too often one of blocked access. Rather than dismissing these concerns as someone else's problem, the new strategy and forthcoming transformation plan are a great opportunity to tackle the current deficiencies in data production and culture.

Yes, data are vital. But we need a learning health and care system equally focused on knowledge and practice if we are truly to save more lives.

Competing interests: We have read and understood BMJ policy on declaration of interests and have no interests to declare.

Provenance and peer review: Commissioned; not externally peer reviewed.

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