

Data-driven innovation: why confidentiality and transparency must underpin the nation's bright vision for the future of health and care

When I hear about the many wonderful ways in which data-driven innovation is rapidly changing health and care, I am reminded of a Futurism exhibition I saw at the Tate Modern many years ago. This early 20th century art movement captured the breathless energy of the modern age, embracing technology, speed and 'the new', in a spirit of liberation from the constraints of the past.

I, too, share that sense of excitement about the potential that data and technology bring. But as we move towards this bright new future, it is important that we don't lose sight of what is important to the people whose data is enabling these advancements, and that opportunities are always balanced against risks and harms.

Successful data initiatives are underpinned by a commitment to transparency and an active understanding of what matters most to people. Professionals and the public want to be informed, involved, and to understand what choices people have. When these conditions are not met, we see situations such as the recent delay and reset of the [General Practice Data for Planning and Research](#) programme.

These fundamentals are so important that in December 2020 Dame Fiona Caldicott enshrined them in a new Caldicott Principle:

Principle 8: Inform patients and service users about how their confidential information is used

A range of steps should be taken to ensure no surprises for patients and service users, so they can have clear expectations about how and why their confidential information is used, and what choices they have about this. These steps will vary depending on the use: as a minimum, this should include providing accessible, relevant and appropriate information – in some cases, greater engagement will be required.

As 'the new principle on the block' it is well timed and adds clarity to the guidance that I have been offering to Government, and others, about their plans for data use.

In [my recent response](#) to the [Government's draft data strategy](#) for health and care, for example, I emphasised the importance of using clear, unambiguous language and being open with people about who might access data about them and why. I also advised that acknowledging potential risks is as important as selling the many benefits. People know that generally there are risks associated with data use, so these need to be addressed for any specific use

and context, alongside saying what is being done to mitigate them.

Principle 8 also informs the advice I gave to the Government about its [Police, Crime, Sentencing and Courts Bill](#), about which I have significant concerns. The Bill imposes a duty on Clinical Commissioning Groups (CCGs) to disclose information to police, and other specified authorities, for the purposes of the duty to collaborate to prevent and reduce serious violence in their local areas. The duty states that they can do so without breaching any obligation of confidence. Whilst tackling serious violence is important, it is essential that the risks and harms that this new duty pose to patient confidentiality, and thereby public trust, are engaged with and addressed.

People need to trust that they can share information in confidence with those responsible for their care without worrying how it will be used, by the police or others. And health professionals need to trust that that confidential information they routinely collect as part of care will not be used in ways that could negatively impact care, or which may be at odds with their professional and ethical duties and obligations to their patients.

If people feel that their information may be used in unexpected ways, for purposes they may not support, this greatly undermines the fundamental relationship of trust. The effect may be to deter patients from seeking treatment, or, when seeking treatment, to only disclose partial or false details, thereby denying clinicians the information they need to deliver safe and effective care. Incomplete and inadequate health and care records are to the detriment of both the safe care of individuals now, and of system wide planning, research, and innovation for the future.

Decisions about data use require not only expert data protection knowledge regarding what's lawful, but practical and professional wisdom and experience to consider what would be ethical and right, balancing potential benefits against the avoidance of future harms. As the momentum for data-driven technology rapidly builds, and as the opportunities for linking data evolve across government and society, it is vital that those seeking to harness the power of data proceed with both optimism and caution: never losing sight of why the duty of confidence is so important within health and care.