



## A data opt-out will reassure patients and improve care

### Fiona Caldicott

Since I was appointed national data guardian nearly three years ago, it has become clear that the health and care system must do more to build public trust in how confidential patient data is used.

In that time we have seen the controversy over the care data plan to link up GP records, a cyberattack which affected numerous services, and earlier this month the information commissioner ruled, with my backing, that an NHS hospital had not used an appropriate legal basis to share 1.6 million patient records with Google's DeepMind. It is obvious to me that security around patient data must be strengthened and the public must be engaged in a conversation about how they want their data used.

Yet while past failures to use patient data safely and respectfully have been well-publicised, it remains the case that the data that the health

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and care system collects has huge potential for good, from researchers making breakthroughs in life-saving medicine to regulators spotting quickly when things go wrong.

My proposals for new data security standards and a new opt-out, accepted by the government yesterday, are designed to address concerns. From March next year, everyone in England will have the opportunity to register an opt-out to their personal confidential health and care data being used to improve services through research and planning.

Yet my support for the creation of a simple data opt-out does not mean that I want people to use it. I have confidence in the system to use my data responsibly to improve services for all. Therefore I will not opt out and I do not want others to opt out.

That might sound contradictory, but it is not: I regard the existence of the opt-out as a key element in the building of public trust. Researchers, administrators and others have an important role in explaining what they want to do with patient data, how they will look after it and the benefits, such as more accurate diagnoses and the design of better treatments.

This has not been explained well so far, but when we discuss it with people many express the altruistic wish to allow their information to be used in this way. If they do, I am confident that an overwhelming majority of people will decide that the risks to themselves are low and the benefits to society are great. To achieve that, the public's trust has to be earned.

**Dame Fiona Caldicott is the national data guardian**