

Changes to the NHS data-sharing scheme now make it fit for purpose, writes NHS England's information director Tim Kelsey

Last week the Care Bill received Royal Assent and became the Care Act and for the first time we have a clear, statutory basis for sharing information that will enable us to track patient outcomes across health and care services.

To me this feels like a real milestone for patients, clinicians and researchers. The new law means that a person's data can only be shared and analysed when there is a benefit to healthcare, never for other purposes, and that all uses will be scrutinised with full transparency by an independent statutory body. In addition, there will now be a legal basis for people to stop their data being shared if they wish to.

These legal safeguards were introduced as a direct result of concerns about the safeguards around data sharing in the NHS raised in light of the care.data initiative. Care.data is a programme to link data across all care services, starting with hospitals and general practice and make it available to the people who can use it to make services better – clinicians, commissioners, researchers, charities, patients and public – in safe ways that minimise the risk to a person's privacy being compromised in an age of increasingly sophisticated digital threats. For many years, the NHS has analysed data on hospital outcomes and driven improvement in services as a result; health and care services now need to analyse similar data across the whole care pathway.

In February, NHS England announced an extension to the start of data collections until the autumn to ensure concerns expressed by GPs and others were met. The Care Act amendments are an important part of demonstrating how seriously that commitment is taken. Nothing less than an

overhaul of the legal basis for data sharing was necessary, but that on its own is not sufficient. Last month, we confirmed that there will be a phased roll out for the programme, starting with between 100 and 500 practices in the autumn. In this way we can refine and test, with complete transparency, the best ways of supporting GPs to ensure patients are informed of the purposes of this data sharing, its safeguards and how they can opt out.

There are no artificial deadlines for the national roll-out of the programme: the most important priority is that we get it right. And for that reason I am very pleased that the Independent Information Governance Oversight Panel (IIGOP), chaired by Dame Fiona Caldicott, has agreed to advise the programme board and senior responsible owner on the implementation of the programme, and in this context to evaluate the first phase pathfinder stage.

Dame Fiona is known across the NHS for the institution of ‘Caldicott Guardians’, the individuals responsible in every NHS and local authority organisation for making decisions about sharing identifiable information. This requires balancing the public interest of protecting confidential information with the public interest for sharing the information.

Ensuring that information is shared for best care and to promote excellent research is central to the vision encompassed by the care.data programme, as is protecting confidential information and I am grateful that she has agreed to help us.

New advisory panel

In addition, we have established a care.data advisory group under the chairmanship of Ciaran Devane, chief executive of Macmillan Cancer Support and a non-executive director of NHS England, with membership drawn from across health and care, which includes the BMA, the RCGP and **Healthwatch**, as well as voluntary organisations and privacy experts.

I'd like to thank everyone for their help - and especially the GPs, practice managers, citizens and patients who have attended events and workshops across England to surface concerns, debate solutions and help shape the future of data sharing in health and care. There will be many more conversations over the coming weeks and months.

Data-sharing between professionals, patients and public is the prerequisite for a modern, sustainable health and care service. Only last month, Macmillan Cancer Support published a report which revealed that one in four cancer cases is diagnosed in an accident and emergency department - and that those patients were twice as likely to die within a year as those referred to a specialist by their GP. A central conclusion is that better data on the outcomes of these patients and understanding geographic variations in patterns of diagnosis is key to improving life expectancy.

Implemented properly care.data has the power to transform health services - that's why it is so important to get it right.

Tim Kelsey is NHS England's national director for patients and information.