

NEWS

Furore over care.data programme could jeopardise future medical research, doctors and charities warn

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Doctors and charities have warned that if GP patient data are not able to be linked to other datasets and shared with researchers, then important opportunities to improve health will be missed.

In an open letter to the *Times* on 24 February more than 50 of the UK's most senior doctors and health executives have joined forces to outline the research benefits of sharing data.¹ The letter comes just days after a campaigning group supported by more than 70 medical charities warned that the scaremongering about the care.data programme by the anti-data lobby could jeopardise medical research.²

Under the care.data programme England's Health and Social Care Information Centre will bring together health and social care data from primary and secondary care for the first time and make pseudonymised data available to "approved groups of users," including commissioners and researchers for planning and research purposes. Identifiable information would only be released in exceptional circumstances, such as during an epidemic.

Opponents of care.data have argued that data breaches and lack of security threaten patient confidentiality, and that private companies could acquire the patient data and use them for commercial purposes. The government has now delayed uploading of patient data from GP files to care.data for six months so that patients can be provided with more information about the programme, including details of how to opt out.³

In the letter to the *Times* more than 50 of the country's top health professionals argue that opportunities to protect and improve the nation's health could be missed if data cannot be shared. The letter's signatories include the former health minister Ara Darzi, the former NHS chief executive Nigel Crisp, and David Haslam, chairman of the National Institute for Health and Care Excellence, and it provides examples of past health advances made possible by data sharing.

"If data linkage in the UK had not been undertaken in the past we would know less about the causes of disease (eg, pregnant women living near landfill sites have an increased risk of giving birth to babies with congenital anomalies), be unaware of the dangers of some treatments (eg, some drugs for asthma were associated with a 50-fold increased risk of death; metal-on-metal hip implants are best avoided in most patients) and be ignorant

of inequities in access to care (eg, women are less likely to receive intensive care for some conditions). None of these discoveries, and the remedial action taken, would have occurred without our ability to link patients' data from different publicly funded databases," it says.

"Current plans to widen the linkage of hospital and primary care data will lead to further improvements both in the prevention of disease and in the effectiveness and safety of healthcare for the public."

Last week George Freeman, a Conservative MP and a co-founder of the pro-data sharing campaigning group Patients4Data, told the BBC, "There are those who oppose not just the mechanism of data handling but the principle of patient empowerment and greater accountability. We cannot let opponents peddling scaremongering myths stop patients benefiting from this quiet revolution of modern medicine. There are issues to be addressed. But data is a force for good, not a Big Brother-style conspiracy."

Graham Silk, the other co-founder of Patients4Data, who was diagnosed with leukaemia in 2001 and given three years to live, told the *BMJ* his life was saved by the sharing of data. "For me therefore, the arguments against data sharing pale into oblivion compared to the arguments for using our records to help the NHS deliver the plethora of new treatments and drugs."

He added that the concerns that needed to be addressed were not unsurmountable. "The fear of our data being hacked is nothing new. We were told 20 years ago that we'd have all our money stolen by banking and buying online. To begin with people were scared but we now couldn't contemplate our buying experience without using the Internet and giving out account numbers, sort codes and 3 digit security codes. The safeguards are in place."

- 1 Healthcare data. Letters to the Editor. *Times* 24 Feb 2014. www.thetimes.co.uk/tto/opinion/letters/article4013682.ece.
- 2 Trigg N, Brimelow A. Critics of giant NHS database "are scaremongering." *BBC* 21 Feb 2014. www.bbc.co.uk/news/health-26277866.
- 3 Torjesen I. NHS England postpones roll-out of care.data programme by six months. *BMJ* 2014;348:g1689.

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