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Care Data [1]

There is nothing more important than your health and knowing you can talk to a doctor or nurse in confidence. Now this government has put that at risk. Your doctor will soon have to constantly supply your personal medical data to a central information centre, the "Health and Social Care Information Centre (HSCIC) [2]". And these data can be given to organisations outside the NHS.

All too many people don't know this is happening. This is the most sensitive and intimate information about you and your loved ones.

The government has created dangerous uncertainty about how this information will be used. This has the potential to stop people seeking care. We're worried, for instance, that due to this people with mental health conditions will be less willing to seek the help they need.

The Pirate Party wants to give you the power to choose that the Conservatives and Lib-Dems have denied you.

What you need to know

Care.Data isn't about caring for you

While it's called care.data, it isn't about your individual treatment, and won't help you at your doctors or in hospital. It is supposed to be about sharing information for research, to develop new cures and treatments, and who wouldn't want that? However, doctors and privacy campaigners alike have warned that the government are going about this the wrong way.

This is about what's going on in your body

Ministers have tried to reassure patients that their information won't be revealed. But this information is not properly anonymous. It is recorded in a way that can identify you; your NHS number, date of birth, ethnicity and more. It is matched to codes about your medical history, treatments, prescriptions, habits and diagnoses, right down to whether you've had a "funny turn".

This needlessly puts your personal health information at risk [3]. If this was just about research information, it could be summed up without being tied to you individually.

You should have received information

Every household in the country was supposed to have received a leaflet about the care.data programme, but this did not happen. We have been contacted by many who never received it. A BBC poll [4] found as many as two-thirds of the public had not seen the leaflets come through their letterboxes. Patients and doctors have raised concerns that they had not been given enough time to learn about the project. After all, how can you opt out of something you don't know exists?

Will insurers get get hold of my data

Jeremy Hunt says no. However, this does build up a huge mine of information that that would be seen as prime commercial territory in the "big data" gold rush. What we do know is that medical records of every NHS hospital patient in the country have already been sold [5] for insurance purposes.

Researchers have raised concerns

There have been lots of claims that this programme will save lives and advance medicine, but pharmaceutical researchers have raised concerns that as none of this information can be peer reviewed, it will, in fact, be useless. Ethical medical research requires informed consent - but if you aren't even aware your health information is being shared how can you consent?

What you can do

If in doubt, opt out

Opting out won't affect your medical care. You can always opt back in if you change your mind, but you can not delete any data already uploaded. We're a political party, so we get you may not want to take our word for it. Please do discuss it with your doctor if you have worries.

It's not too late to do something

Following the outcry over the failure to inform the public properly, the care.data scheme has already been delayed for 6 months. It is now due to start at the beginning of September. This means you have time to act, but after that date you won't be able to get uploaded information deleted.

You will also have to consider doing this for anyone you are responsible for - children under 16 and anyone you have power of attorney over.

How to opt out

You will need to contact your GP. It will need an actual signature, so you can't just email. We have prepared a letter that you can download and fill out [6] and post to your GP, or drop it in to the surgery.

You might think you've opted out, but you haven't

You may have opted out of the "Summary Care Record" [7], but that's a different national data base about medicines you have had or aspects of your treatment. Opting out of that doesn't mean you've opted out of care.data. Yes, we know it's confusing.

Make sure that others know about Care.Data

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