

# Care.data — why should we care?

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**Stephanie Pritchett,  
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the debate concerning  
the changes to how  
patient information in  
England could be used by  
NHS bodies and others**

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**A**s stated in a recent blog entry from the Information Commissioner's Office ('ICO'): 'The health sector always provides a wealth of data protection challenges, but without doubt the one currently at the forefront of most peoples' minds is the changes to how patient information in England could be used by NHS bodies and others, with a view to improving care and health services.' These changes have been both controversial and increasingly headline-grabbing over the last few months. What's it all about?

Section 259 of the Health and Social Care Act 2012 ('Health Act') gives NHS England the legal right to extract certain medical data from GP surgeries. NHS England has used its power under the Health Act to direct another public body, the Health and Social Care Information Centre ('HSCIC'), to extract and then maintain the extracted information on their behalf. The extraction was originally due to commence in April 2014.

Data from hospitals are already collected by the HSCIC, and it is proposed that extending this initiative to information held by GPs will enable better research in order to help improve the future quality of care and health services at both national and local levels.

Controversy surrounding the project has arisen for numerous reasons, but perhaps most notably due to the lack of transparent information being provided to individuals about the intended extraction of their medical data and about the intended use of those data by the HSCIC — particularly the intended disclosure of the following extracted information to third parties:

- Green 'Anonymised Data', which are to be made accessible to anyone;
- Amber 'Potentially identifiable data', which we are told may 'only be released to approved organisations, and restricted to specific purposes that will benefit the health and social care system' subject to certain controls; and
- Red 'Identifiable data', which will only be disclosed by the HSCIC where there is a legal basis for doing so, e.g. with patient consent,

where advised by the Confidentiality Advisory Group, or in a public health emergency.

Many campaigners have argued that insufficient information has been provided to UK citizens about both the identities of the actual third parties that may potentially receive the information, and what they may do with it — most controversially the potential use by commercial organisations such as insurance companies.

## Does the DPA apply to the data extraction?

In very basic terms, the Data Protection Act 1998 ('DPA') applies to the scenario as follows.

Data subjects provide sensitive personal data to GPs. GPs, as data controllers, compile that data with records from other health services and record as patient medical history. GPs are required to comply with both the DPA and their own regulatory requirements when processing such medical information.

Under the new Health Act, GP surgeries are required to allow certain sensitive personal data about their patients, to be extracted by the HSCIC on behalf of NHS England.

The GPs must also comply with the DPA when sharing data about their patients. Presumably, this means they will, in particular, be considering some of the following provisions of the DPA:

- section 35, which states that 'personal data are exempt from the 'non-disclosure provisions' where the disclosure is required by or under any enactment; and
- section 27, which defines 'non-disclosure provisions' as (a) the First Data Protection Principle, except to the extent to which it requires compliance with the conditions in Schedules 2 and 3; (b) the Second, Third, Fourth and Fifth Data Protection Principles; and (c) sections 10 and 14(1) to (3) — to the extent that such provisions are inconsistent with the disclosure in question.

To rely on section 35 to allow disclosure of patient data to the HSCIC, GPs will still have to show that they complied with fair processing conditions under Schedules 2 and 3 of the DPA.

In relation to Schedule 2, one or both of the following conditions apply:

- Condition 3 — processing to comply with a legal obligation; or
- Condition 5 — necessary for the exercise of statutory functions; or the exercise of other public functions in the public interest.

In relation to Schedule 3, perhaps they will consider if one or both of the following conditions apply:

- Condition 7 — the processing is necessary for the exercise of any functions conferred on any person by or under an enactment;
- Condition 8 — processing undertaken by a health professional and which is necessary for medical purposes including the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services.

However, one might ask whether the upload to the HSCIC is indeed 'necessary' under these conditions?

NHS England carried out a Privacy Impact Assessment ('PIA') into the Care.data project (copy available at [www.pdpjournals.com/docs/88170](http://www.pdpjournals.com/docs/88170)), which fails to consider many of the DPA issues that one would expect in relation to a project of this scale and

of such public importance. Neither that PIA nor the various guidance notes issued by NHS England to GPs discuss compliance with the Fair Processing Conditions. These documents do, however, discuss that it is NHS England's view that GPs must still comply with the fair processing information requirements under the DPA. This is consistent with the ICO's published articles on the project.

**“Organisations that obtain data from the HSCIC could already be fined up to £500,000 under section 55 of the Data Protection Act 1998 and, reportedly, new laws may now be introduced so that those that have committed even one prior offence involving data disclosed by the HSCIC will be barred from accessing the records indefinitely.”**

Although the responsibility to provide fair processing information technically falls on GPs (as the data controllers who are to disclose the data to the HSCIC), NHS England has been helping GPs with an awareness campaign including the controversial household leaflet drop, described by some as a 'junk mail leaflet' hidden among pizza delivery adverts and the like.

The campaign seems unfortunately to have left the public not very aware at all (of either the project itself or their ability to opt-out of their data being extracted) and has fallen under extreme criticism over the last few months, with campaigners ranging from GPs themselves, patients and representative

groups such as the British Medical Association and the Royal College of GPs all calling for a halt to the planned start of data extraction until at the very least, individuals have been provided with more transparent information about the Care.data project.

These campaigns led to what some press commentators called an embarrassing U-turn by NHS England, when they announced on 18th February

2014, that they would delay initial extraction of data for a six month period.

## Does the DPA apply to the proposed data use?

Once NHS England/the HSCIC has extracted information from the GPs, they in turn will also become joint data controllers for the data they have received, and must therefore ensure compliance with the whole DPA, including the need to tell patients what they are doing with the data, which organisations they will be sharing it with and how they comply with the DPA.

## Amendments to Care Bill

In a bid to appease public fears (and perhaps stop the Care.data project derailing entirely), the Health Secretary announced a few weeks ago that he planned to provide 'rock-solid' assurance to patients that insurance companies will not be able to buy patient medical records and that such medical records will only be released when there is a 'clear health benefit' rather than for 'purely commercial' use by insurers and other companies.

However, the 12th March 2014 Commons Amendments to the Care Bill proposed only that: 'Apart from in limited circumstances where there is a statutory requirement to disclose data, the HSCIC could only share information if disseminating the information would be for the purposes of the provision of health care or adult social care and the promotion of health.'

These proposed amendments do not therefore explicitly prevent private health insurance companies and other commercial organisations from accessing data, but perhaps makes it harder for such organisations to justify their need to access the data.

The amendments also require the HSCIC to consider advice given to it by a committee appointed by the Health Research Authority. While

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this proposal is a welcomed 'check and balance', perhaps consideration by the Secretary of State and Ministers would have been more appropriate than an unelected body. The Care Bill will now be passed back to the House of Lords for consideration of these proposed amendments.

In response to media reports throughout March 2014 about potentially inappropriate and insecure sharing of Hospital Episode Statistics Data (despite previous assurances that there had been no previous incidents), the HSCIC has announced that it will both publish a report on 2nd April 2014 setting out all the data it has released to date (including the legal basis on which data was released and how that data are being used), and that it will audit all data releases made by the NHS Information Centre (the predecessor to the HSCIC), presenting its findings on this to the HSCIC board by the end of April 2014. No doubt this is intended to prove transparency and attempt to restore public confidence. For instance, they may feed back on reports that the NHS Information Centre had in January 2012, sold 13 years' worth of hospital data in relation to 47 million patients to the Institute and Faculty of Actuaries, which help to set pricing for insurance premiums.

## Penalties for non compliance

Organisations that obtain data from the HSCIC could potentially be fined up to £500,000 under the DPA if appropriate sharing controls are put in place by the HSCIC in due course and the third parties are found in breach. Recent media reports suggested that new laws may be introduced so that those that have committed even one prior offence involving data disclosed by the HSCIC may be barred from accessing the records indefinitely and a source close to the Department of Health was reported as saying: 'For some organisations, the risk of no longer being able to access this kind of data may prove a more effective sanction than the current maximum £500,000 fine.'

These amendments are again not present in the 12th March 2014 Commons Amendments and MPs voted against an amendment to make misuse of data provided by the HSCIC a criminal offence liable to unlimited fines and/or up to two years' imprisonment.

## Opting Out?

Although there is no legal opt-out right for patients under the Health Act, there is an ability to make an opt-out request under the terms of the NHS Constitution, and the Secretary of State for Health has offered all patients the ability to do so (what some mooted as being a mere PR exercise). NHS England's Care.data PIA states that, 'whilst it is possible for patients to object to the processing of personal confidential data under section 10 of the DPA, this new 'code' [refers to a technical IT code the GPs use to register the opt-out request] allows patients to exercise, to a large degree, choice more easily: they simply need to ask their GP to enter this code into their GP practice record. Put simply, patients who are concerned about their privacy can now control the flow of confidential data both out of their GP practices and out of the HSCIC'.

The PIA seems contrary to the original NHS England guidance to GPs which stated that: 'Section 10 of the DPA does not apply; the right to object has been implemented as a constitutional rather than legal right'. This statement has notably been removed from the newly re-issued guidance from NHS England to GPs.

In any event, in response to public outcry about an unclear legal right to opt-out, Jeremy Hunt announced that he planned to amend the law to give individuals a clear statutory opt-out right from the HSCIC sharing their personal information where there is 'not a clear health or care benefit for people'. Again, these amendments do not appear present in the 12th March 2014 Commons Amendments.

If individuals fail to opt out, their data are due to be extracted when the project begins towards the end of this year. HSCIC have previously said that although individuals have some later

opt out rights in relation to extracted data, they cannot ask to have the data deleted once those data have been uploaded to the HSCIC.

## Conclusion

Whilst opting out is clearly a personal choice, it should be an educated choice, and that citizens should all be provided with much more detailed information over the coming months about both the proposed legislative changes and the project as a whole, to enable them to make that choice.

I agree with the proponents of this Care.data project that there are many potential benefits for the good of all. However, those benefits should not come at such a high price in terms of privacy. UK citizens would certainly have been paying that price if the project were to go ahead based on the information they have been provided with to date.

What is required is transparent and real 'fair processing information' and properly thought through Privacy Impact Assessments from both GPs and the HSCIC/ NHS England as data controllers to enable citizens to really understand the intended processing of, and disclosures of, information by each of these organisations, in order that they can make a real choice about whether to allow their data to be extracted, or to opt-out until such time as we are more convinced that the project has been fully thought through, and we are happy to opt back in again and transfer our data at that time.

The Chair of the HSCIC, Kingsley Manning, recently wrote to the Guardian to ask for 'an intelligent, grown-up debate' about the issue. Whatever side of the fence you fall, I think it is up to us all to educate ourselves enough to engage in that debate over the coming months. As privacy practitioners, we should be engaged in considering these issues, from both sides.

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