

Care Data: What You Should Know

What is Care.data?

Care data is collecting medical information of all patients without the identifying information. Since 1989, the NHS has been collecting data on hospital stays, known as *hospital episode statistics (HES)*.

This has proved invaluable. For example, HES data played a role in uncovering both the Bristol heart and Mid-Staffordshire scandals. It also provided some of the evidence that led to the introduction of targeted bowel cancer screening in 2006.

Care data wants to expand this database to include what happens to patients when they are under the care of GPs. This information is not collected at the moment. GP data will be more than 10 times the data collected from hospital episodes.

Adding GP record data to hospital data will give fuller picture of the care you have received both in hospital and primary care. This helps to understand the health needs of everyone and the quality of the treatment and care being provided. It also helps researchers by supporting studies that identify patterns in diseases, responses to treatments, and the effectiveness of different services.

What information will be collected?

Your name will not be shared, but the following information will be included, which may allow you to be identified indirectly:

Your NHS number and date of birth.

Your post code.

Your gender and ethnicity.

The medical diagnoses on your record, and any referrals.

Your prescriptions.

Your family history.

Your vaccinations and screening tests (smears, etc).

Your blood test results.

Your body mass index (BMI). (This is body weight indexed to height of person).

Your smoking and alcohol habits.

Where is care data now?

At the moment all hospital data i.e. data of all patients who received care in NHS hospital has been added to care data.

The NHS has some of the best information systems in the world. Since the 1980s, information about every hospital admission has been collected. This information is brought together at the *Health and Social Care Information Centre (HSCIC)*, where it is anonymised.

Plan for the next stage.

NHS wants to collect all the data from GP practices so that one gets full picture. The GP data will be linked with the hospital data already held by the HSCIC.

What you should know

Not all the information from your GP record will be used. Only the agreed amount of information will be used. See '*What information will be collected*' above. The data collected from GP practice will be used to link your records collected from hospitals in a secure environment at the HSCIC. The information collected will include your date of birth, post code and gender.

Care data may provide these data, anonymised, to agencies outside the NHS. Prof Sir Brian Jarman points out that 'under the terms of the Health and Social Care Act 2012, any organisation, including the police, government departments and pharmaceutical companies, will be entitled to apply for access... 'The Departments for Work & Pensions and HM Revenue & Customs have applied for access to personal health data'.

There is concern that information given to outside agencies, with the information they have, though illegal, may be able to identify you. Although outside agencies can apply to obtain the care.data you and your GP will not get access to the data.

Since data is considered anonymised, Data Protection Act and Caldicott principles will not apply to the data collected by care.data. Once your data is collected by HSCIC, opting out at later date will not delete the data already collected by the care.data.

If you do not want your data from your doctor collected, you have to opt out by completing the forms. Otherwise data will be collected automatically.

How HSCIC collects information from GP practices

HSCIC will extract data from GP computer system electronically. This will happen automatically each month so that it will always be up-to-date.

What you should do now.

If you are happy for your information to be used then you do not need to do anything.

If you do not want your medical information shared by HSCIC you have to opt out by filling the form.

You can download the form or collect from the surgery.

You can opt out so that your medical information is not accessed by HSCIC and/or HSCIC not to give your information to anyone outside.

Opting out will not affect the care you receive and you can change your mind at any point and opt back in if you like.

To download the form go to www.nhs.carerecords.nhs.uk/optout

Shouldn't patients opt-in to care.data?

No. The Health and Social Care Act 2012 empowers the HSCIC to require providers to send it personal confidential data when it is directed to do so. The Act also overrides the requirement under the common law duty of confidentiality to seek patient consent. This was because parliament recognised the importance of linking data to deliver high quality health and care services, for the benefit of all. The Secretary of State has, however, allowed patients to object and have this objection respected

Further information

hscic.gov.uk/article/3525/Caredata

emisnug.org.uk/article/patient-information-caredata

www.england.nhs.uk/ourwork/tsd/care-data/

[Prof Sir Brian Jarman's view on care.data](#)

patient.co.uk/health/caredata-sharing-your-information

bbc.co.uk/news/health Feb 2014

[BBC July 2013: Prof Sir Brian Jarman on Mid Staff Scandal](#)