

Registers of approved data releases

Frequently asked questions

1) Why have the registers been produced?

As part of our commitment to improve the transparency of our decision-making and build public trust in our actions, the Health and Social Care Information Centre (HSCIC) board agreed in January 2014 to publish quarterly registers detailing data released by the HSCIC.

2) Are all HSCIC data releases included in the registers?

The first register was released on April 3 2014 and covered data releases approved by the HSCIC from the point it was established (April 1 2013) to December 31 2013. It also included releases originally approved by a predecessor organisation (the NHS Information Centre) but renewed during the above period.

Subsequent registers cover quarterly periods, with the second register covering the period January 1 2014 to March 31 2014.

Data releases that were approved by the NHS Information Centre (NHS IC) and not renewed by the HSCIC are not included in the registers. They were instead covered in the *Review of Data Releases Made by the NHS IC*, published on June 17 2014. Led by Sir Nick Partridge, the review covered the period 1 April 2005 to 31 March 2013 and is available online at: <http://www.hscic.gov.uk/datareview>.

Public releases of data (in anonymised form) are also not included in the registers, although, in the interests of transparency, individual releases of such data in response to a single customer enquiry are included. Anonymised information does not identify any individuals, nor does it release details where a small number is involved. This is particularly important, for example, when considering counts of patients with rare characteristics or diseases. Information on the HSCIC's anonymisation standard is available online at: <http://www.hscic.gov.uk/article/2741/New-Anonymisation-Standard-for-the-publication-of-health-and-social-care-data-becomes-effective-on-30-April-2013>.

Since anonymised information is neither personal nor private, the law says that it can be used much more freely than data in identifiable form. Anonymised data is published in more than 200 public reports produced by the HSCIC each year. These reports are downloaded and viewed on our website thousands of times a year. An A-Z of the HSCIC's official statistics publications is available online at: <http://www.hscic.gov.uk/statisticsa-z>

The registers also do not cover releases made for direct patient care or releases made by NHS Choices. Releases of Office for National Statistics (ONS) data have been included in the list to aid understanding, since such data is usually released when linked with health data, for example in relation to mortality.

3) How often will the registers be updated?

The registers will be updated on a quarterly basis. We welcome feedback which will be considered for future editions.

4) Where does the data come from that the HSCIC collects?

Whenever a citizen uses health and social care services, those looking after them need to collect information about them and their care for different reasons.

Information about patients and social care users is often moved around electronically to ensure health and care professionals can get to it when they need it. The HSCIC controls many of the systems that allow this to happen.

Important information is also sent securely to us from places where people receive care. This allows activities such as healthcare planning, medical research and clinical audit to be carried out. This is different to using information to support individuals' care directly. The register covers releases of data for these activities; it does not cover releases of data for direct care.

5) What is meant by a data sharing agreement?

There are strict rules about what information the HSCIC can release to other organisations and how those organisations can use and share data.

If there is a possibility of identifying someone, even with their key personal details removed or disguised, there must be a data agreement drawn up to enforce the prevention of such an identification of individuals.

Organisations applying to receive data must outline the purpose to which they wish to use the data and explain how it will benefit the health and social care system. As well as this, each applicant must sign a data sharing agreement which restricts how they store, share, use and eventually destroy the data.

6) How much does the HSCIC charge for the release of data to approved organisations?

The HSCIC does not make a profit from the supply of data, nor do we subsidise any organisation for receiving it. We are required under Treasury rules to recover the costs of providing the data. Charges therefore vary depending on the complexity of the data request and the time taken to prepare and supply the data. The HSCIC does not make any profit from providing the service.

7) What are the rules that have to be followed on data sharing? What approval processes must applicants go through?

The approvals processes for the release of data can be found on the Data Linkage and Extract Service's applications, approvals and charges web page at:
<http://www.hscic.gov.uk/dlesaac>

8) What are National Back Office (NBO) releases, and why are they included on this register but not the last register?

Following feedback, we have included information about non-clinical data releases made by the National Back Office (NBO) in the register. These relate to requests made from organisations such as the police about individuals whom they are trying to trace for law enforcement purposes. The NBO releases information about the geographical area where someone is registered with a GP, along with their name and date of birth. These releases are only made when appropriate legal criteria are met.

The releases are split into two time periods – April 1 2013 to December 31 2013 and 1 January 2014 to 31 March 2014. This brings the NBO information into line with the rest of the register in terms of time frames.

Further information

Further details are available on the HSCIC website:

How we look after health and care information: <http://www.hscic.gov.uk/patientconf>

Why information is needed: <http://www.hscic.gov.uk/article/3385/Why-information-is-needed>

Rules for sharing information: <http://www.hscic.gov.uk/article/3399/Rules-for-sharing-information>