

Registers of approved data releases

Guide to tabs, column descriptions, key terms and abbreviations

Tab descriptions

Since April 2014 the Register has been published in Excel sheet format. Readers can use the tabs at the bottom of the sheet to navigate around the different sorts of information that are in the register. Below is an overview of the information that these different tabs provide.

There have been some format changes since the publication of the first register in response to feedback and in order to make information clearer to readers. Please note therefore that not all tabs are included in each register.

Data Releases tab

This tab gives details of data releases made under data sharing agreements during the period covered by the register.

NBO tab

From July 2014 onwards, the HSCIC began to include National Back Office (NBO) releases in the register. Please see the description of NBO releases in 'key terms and abbreviations' section, below.

Corrections to previous registers

The HSCIC endeavours to ensure that each register is complete at the time of publication. However, in the interests of transparency where omissions or mistakes transpire, these are corrected in the next available register on this tab.

NHS IC approved, carried forward to HSCIC

The July 2014 edition of the register separated out data releases that had been approved by the NHS Information Centre (NHS IC) before the HSCIC came into being on 1 April 2013, but which subsequently had data released by the HSCIC.

Any other predecessor releases

This tab details any releases of data approved by predecessor organisations to the HSCIC.

Column descriptions for the data release tabs

The data release tabs in the registers contain seven columns. From left to right, the definitions of the columns are shown below. Please note that further detail on terms used elsewhere in the register is included in the key terms and abbreviations section of this document (below).

Organisation Name

This column names the organisation that has received data from the HSCIC under a [data sharing agreement](#).

Type of Data Provided

This column covers the data set from which the data was provided (for example [Hospital Episode Statistics](#)) and the way the data was supplied (for example as an [extract](#) or [linked data](#)).

Data Provided to Customer: Identifiable, Pseudonymised, Anonymised and/or Aggregated

Anonymised: this information does not identify any individuals, nor small numbers of patients with rare characteristics or diseases. Since this information is neither personal nor private, the law says that it can be used much freely; for instance anonymous information is published in more than 200 public reports produced by the Health and Social Care Information Centre and viewed and downloaded from our website thousands of times a year. The vast majority of instances where we are sharing anonymised data are therefore not covered by the register.

Aggregated: data that has been supplied in the form of a [tabulation](#). Most if not all identifying details would normally be removed. However, in some cases small numbers of cases, for instance for rare conditions, have not been suppressed, meaning that this data could not be published in the public domain.

Pseudonymised: also referred to as 'de-identified for limited disclosure or access', this is data from which details that would be classed as identifying individuals has been removed, such as NHS number or full postcode and full date of birth. We would never make this type of information publicly available because there is a risk that individuals could be re-identified. There are however particular purposes for which this information is required and it is therefore released under strict controls to approved organisations for approved purposes, and there must be a [data sharing agreement](#) in place.

This [data sharing agreement](#) outlines the purpose to which the recipient can put the data and restricts how they store, share, use and eventually destroy the data. Any recipient found to misuse the information would be in breach of this agreement and could also be contravening the Data Protection Act 1998.

Applications for pseudonymised data on the register have been considered by the individual business area (typically the HSCIC's [Data Linkage and Extract Service](#)), unless the applicant also asked for data that is classed as [sensitive](#). In the latter cases, the application would also have been considered by the [Data Access Advisory Group](#).

Identifiable: also sometimes called 'personal' or 'personal confidential data'. This is data which identifies the patient and is only shared in the following circumstances:

- When the patient has clearly said that we can do it (i.e. when a patient has given their [informed consent](#)).
- Where we have to do it by law (for example, in a public health emergency such as an epidemic).
- Where there is a statutory basis for sharing; where this is the case the statute under which data was shared is made clear in the register, for example under [Regulation 5 of the Health Service \(Control of Patient Information\) Regulations 2002](#) (anecdotally known as 'section 251 support').

Sensitive or Non-Sensitive

The fields classed as sensitive vary from dataset to dataset. Items classed as sensitive within [Hospital Episode Statistics](#) include the code of patients' GPs or their consultant. More information about the items classed as sensitive is available online at www.hscic.gov.uk/dlesaac.

Requests for data that are sensitive, or for identifiable data where individual patient consent is in place, are put to the HSCIC's [Data Access Advisory Group \(DAAG\)](#) for consideration. Further details about DAAG are available online at: www.hscic.gov.uk/daag

Legal Basis for Provision of Data

All data sharing must be made on a legal basis, which is laid out in this column. These bases are listed against each instance of data sharing in the register and described in the glossary below.

Purpose

All applicant organisations must outline the purpose to which they wish to put the data and explain how it will benefit the health and social care system. This is recorded in their [data sharing agreement](#) with the HSCIC. The agreement also restricts how they store, share, use and eventually destroy the data. Any recipient found to misuse the information would be in breach of this agreement and could also be contravening the Data Protection Act 1998.

One-off release or ongoing releases

This column details whether the data release is a one-off or is ongoing.

Ongoing relates mainly to MRIS (see definition in key terms and abbreviations section below) where the majority of the releases are for studies which have been going for years and they receive data regularly.

It can also apply to Hospital Episode Statistics (HES) data if the customer gets regular data sent to them, however the majority of HES releases are one-offs.

Row descriptions for the NBO tabs

Rejected: requests to the National Back Office (NBO) for a release of non-clinical data to assist with law enforcement are rejected where the request has not followed correct procedure. For instance, if it has not been countersigned by a police officer of sufficient authority.

Refused: some requests to the NBO for a release of non-clinical data to assist with law enforcement are refused. This is particularly where the suspected offence did not meet criteria for serious crime.

Accepted and approved: these requests were neither refused nor rejected, therefore the NBO attempted to make traces to find data on individuals related to these requests

Approved – Trace: The NBO was able to trace details for the individuals related to these requests.

Approved – No Trace: The NBO was not able to trace any details related to these requests.

Key terms and abbreviations

Aggregated

Data that has been supplied in the form of a tabulation. Most if not all identifying details would normally be removed. However in some cases, small numbers of cases, for instance for rare conditions, have not been suppressed meaning that this data could not be published in the public domain.

Anonymised

This is data that does not identify any individuals, nor small numbers of patients with rare characteristics or diseases. Information on the HSCIC's anonymisation standard is available online at: 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 this information is neither personal nor private, the law says that it can be used much freely; for instance anonymous information is published in more than 200 public reports produced by the HSCIC and viewed and downloaded from our website thousands of times a year. The vast majority of instances where we are sharing anonymised data are therefore not covered by the register.

Bespoke extract

See the section on [data extracts](#).

Bespoke tabulation

See the section on [data extracts](#).

Business Objects

Business Objects was a secure software application which allowed users the ability to interrogate [Hospital Episode Statistics \(HES\)](#) and [Patient Reported Outcome Measures \(PROMs\)](#) databases remotely. Business Objects was provided by Northgate Information Services and was decommissioned on 31 March 2014 as the contract between Northgate and the HSCIC finished. Business Objects has now been replaced by the [HES Data Interrogation System](#) which is hosted and provided by the HSCIC.

Confidentiality Advisory Group (CAG)

The Secretary of State for Health (for non-research purposes) or the Health Research Authority (HRA) (for research purposes) can grant approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 (often referred to as 'section 251 support') to allow confidential information that identifies individuals to be released following independent advice from the Confidentiality Advisory Group (CAG).

CAG considers each application in great detail against the legal framework, and recommends whether approval should or should not be provided together with any conditions. Applicants must demonstrate:

- 1) That the application is in the public interest and for the benefit of the health service;

2) That it is not possible to use information that does not identify individuals; and

3) That it is not possible to ask individuals' permission. There are a variety of reasons why it might not be possible or feasible to ask people; for example, where there are extremely large numbers of patients.

Access to the information is restricted to the specific information necessary for the activity outlined in the application. All approvals must demonstrate compliance with the Data Protection Act 1998.

More information on CAG, including details of its decisions and membership can be found online at: www.hra.nhs.uk/about-the-hra/our-committees/section-251/

Data Access Advisory Group (DAAG)

Requests for data that are [pseudonymised](#) and include [sensitive items](#), or for [identifiable data](#) where [informed patient consent](#) is in place, are put to the [Data Access Advisory Group \(DAAG\)](#) for consideration. Further information about DAAG is available online at: www.hscic.gov.uk/daag.

Where an applicant has requested data that is [pseudonymised](#) but no sensitive items are included, their request is considered by the HSCIC's [Data Linkage and Extract Service](#).

DAAG considers matters including whether:

- Applicants for the data have sufficient safeguards in place to prevent identification, where de-identified data for limited access or disclosure is requested;
- The consent model gives sufficient information and covers the intended use of patients' data (where [informed patient consent](#) has been sought);
- The data security arrangements in place are appropriate;
- The potential benefits of the proposal justify the request.

In addition to obtaining permission from DAAG, an applicant would also have to demonstrate proven security standards and sign a [data sharing agreement](#) which restricts how they store, share, use and eventually destroy the data.

More information on DAAG, including details of its membership and previous decisions can be found online at: www.hscic.gov.uk/daag

Data extracts

The vast majority of data are supplied in the form of an extract, which could be [pseudonymised](#) or [identifiable](#). Please note that extract recipients do not receive "free access" to a [dataset](#) or databases, rather the HSCIC provides extracts of strictly defined subsets of information from a dataset.

a) Bespoke Extract – An extract contacting only specific fields of data based on the applicant's requirements. For example, an organisation researching the common causes of hip fractures may request [HES](#) inpatient episodes of hip operations linked to external cause episodes of falls.

b) Standard Monthly Extract – A standard set of **pseudonymised** data (unless specified otherwise) with a standard set of fields provided on a monthly basis.

c) Data Linkage and Bespoke Extract – This is where HSCIC data are linked to a dataset from the applicant organisation. For example, **HES** critical care data may be linked to incidents of road accidents to determine areas with high levels of road crashes to inform the provision of health services.

d) Bespoke Tabulation - Summary data in an aggregated format provided as a bespoke product only.

Data linkage

In some instances applicants receive datasets linked by the HSCIC (sometimes called 'bridging files' or 'linked files').

Where the HSCIC has linked data, either to data that we hold or data held by the data recipient, this is termed data linkage. Typically, this will involve using an identifier, such as an NHS number, to link different datasets (for instance mental health data with hospital data). Once linkage has taken place, the identifier will normally be removed and replaced with a pseudonym so that it is "**pseudonymised**" or the data will be **anonymised**.

Data linkage and bespoke extract

See the section on [data extracts](#).

Data Linkage and Extract Service (DLES)

The HSCIC's Data Linkage and Extract Service processes applications for data and gives approvals for data requests classed as non-sensitive and non-identifiable. Details about the service are available online at: www.hscic.gov.uk/dles. Checks included in the DLES approvals process include examining the purpose(s) to which the applicant wishes to put the data (these must be judged to benefit health and social care). In addition, each applicant must sign a **data sharing agreement** which restricts how they store, share, use and eventually destroy the data.

Datasets

The HSCIC provides access to a number of datasets. Further information about national datasets is available online at: www.hscic.gov.uk/datasets.

Data sharing agreement

The **data sharing agreement** outlines the purpose to which the recipient can put the data and restricts how they store, share, use and eventually destroy the data. Any recipient found to misuse the information would be in breach of this agreement and could also be contravening the Data Protection Act 1998.

Direct Care Pathway

The applicant provides direct care to the patients whose data is requested, or they are part of the team providing treatment to the patient.

Ethics and Confidentiality Committee (ECC)

The Ethics and Confidentiality Committee (ECC) is a forerunner to the [Confidentiality Advisory Group \(CAG\)](#). References are provided in the register to some data releases where the ECC recommended approval for a data release.

Health and Social Care Act 2012

The Act of Parliament that set up the HSCIC. This is cited as a legal basis for some instances of sharing [pseudonymised](#) data because the statute set the legal framework for the collection and dissemination of health and social care data.

Hospital Episode Statistics (HES)

Hospital Episodes Statistics contains details of admissions, outpatient appointments, A&E attendances and critical care at NHS hospitals in England. This data is collected during a patient's time in hospital and is submitted to allow hospitals to be paid for the care they deliver. HES data is administrative data and is designed for use for non-clinical purposes. Further information about HES is available online at www.hscic.gov.uk/hes.

Hospital Episode Statistics Data Interrogation System (HDIS)

The HES Data Interrogation System (HDIS) provides users with a secure online access portal to securely access the [Hospital Episode Statistics](#) database and interrogate [pseudonymised](#) data. Organisations approved to access HDIS sign a [data sharing contract](#) with the HSCIC, which includes restrictions on who can access the data, restrictions on linking to other sources and onward sharing. The system is hosted and supported by the HSCIC. Further information about HDIS is available online at: www.hscic.gov.uk/hdis

Identifiable

Also sometimes called 'personal' or 'personal confidential data'. This is data which identifies the patient and is only shared in the following circumstances:

- When the patient has clearly said that we can do it (i.e. when a patient has given their [informed consent](#)).
- Where we have to do it by law (for example, in a public health emergency such as an epidemic).
- Where there is a statutory basis for sharing; where this is the case the statute under which data was shared is made clear in the register, for example under [Regulation 5 of the Health Service \(Control of Patient Information\) Regulations 2002](#) (often referred to as 'section 251 support').

IG accreditation process for PROMS suppliers, under contract through DH

These organisations have been approved to receive demographic data in order to allow them to send out pre and post-operative PROMS questionnaires to patients. PROMS measures health gain in patients undergoing hip replacement, knee replacement, varicose vein and groin hernia surgery in England, based on responses to questionnaires before and after surgery. The applicant has been through the HSCIC IG accreditation process and has also been approved to receive the data by the Department of Health.

Informed patient consent

Where the individual(s) to whom the data relates have given explicit consent to it being shared. In order to rely on this as a basis for receiving data, an applicant must supply copies of the consent materials used to gain individual consent, including consent forms and any literature such as information provided to patients.

Medical Research Information Services (MRIS)

A service run by the HSCIC which allows researchers access to track patients for long-term studies on mortality and morbidity. MRIS provides [identifiable](#) data so researchers need to gain either [informed patient consent](#) or approval under [Regulation 5 of the Health Service \(Control of Patient Information\) Regulations 2002](#) (often referred to as 'section 251 support').

Mental Health Minimum Data Set (MHMDS)

Information about the Mental Health Minimum Data Set (MHMDS) is available online at: www.hscic.gov.uk/mhmds. MHMDS contains data about the care of adults and older people using secondary mental health services. It is an approved NHS Information Standard that delivers information on people in contact with specialist secondary mental health services that is robust, comprehensive, nationally consistent and comparable.

National Information Governance Board (NIGB)

The National Information Governance Board no longer exists. Among its responsibilities was advising on the use of patient information. It housed the [Ethics and Confidentiality Committee \(ECC\)](#), a forerunner of the [Confidentiality Advisory Group \(CAG\)](#), and the Database Management Sub Group (Mgs), a forerunner of the [Data Access Advisory Group \(DAAG\)](#).

National Back Office (NBO)

The NBO's primary task is to ensure that demographic information on the Personal Demographics Service is accurate so that the NHS can use it for providing care.

The NBO also provides strictly circumscribed non-clinical information to assist with the tracing of individuals for the purposes of law enforcement where certain criteria are met, including where the exemption under section 29(3) of the Data Protection Act applies or where it is compelled to do so by a court order.

The Register lists the numbers of requests received for the purposes of law enforcement from the Police, Serious Organised Crime Agency (SOCA) and later the National Crime Agency which replaced it during 2013, the Home Office and the courts.

Such information is only ever released to the police where the alleged crime is serious, such as rape, murder or an offence against children. Where the request comes from the Home Office the request must relate to serious crime or abuse of the NHS. Where requests come from police or Home Office and the seriousness of the alleged crime does not meet the strict criteria, we refuse the request. Where the request comes from the NCA the criteria for it to be a 'serious crime' is not applied as the purpose of the agency is to investigate serious and organised crime. The HSCIC assesses each of these requests under strict criteria to balance the public interest with the interests of the individual concerned. Where the request comes from a court, the HSCIC must comply with the order.

There is a well-defined protocol for such requests and, if a request is approved, the requesting organisation generally only receive the name and date of birth under which the individual is currently (or has previously been) registered with a GP and the area in which the GP is located – but not the details of the individual GP surgery. The area is now known as the NHAIS Agency.

In rare cases demographic details may be given, such as that an individual has died, but not clinical information. Courts may also request and receive information such as an address and/or details of an individual's GP.

ONS Data Controller Approval

The HSCIC works with the [Office for National Statistics \(ONS\)](#) to provide access to some cancer and mortality data that it holds. For these data items, the decision as to whether access is permitted lies with the ONS.

The General Registers Office (GRO) collects information at the time of birth and death registration. GRO then pass the data to the ONS for statistical and research purposes. ONS carries out statistical processing including coding of the underlying cause of death. This is derived from the sequence of conditions leading directly to the death and is recorded on the death certificate. Deaths are coded in line with the International Statistical Classification of Diseases and Related Health Problems (ICD). ONS produces a range of National Statistics on fertility and mortality and makes the data available to others for statistical and research purposes and when there is a legal gateway.

Individual researchers can apply to ONS for 'Approved Researcher accreditation' which permits ONS to legally supply them with data which are [personal or identifiable](#) information. This permission is granted under s39(4)(i) Statistics and Registration Service Act 2007. This accreditation is per researcher per purpose and must be reviewed and extended or rescinded after one year. The accreditation allows the researcher to access specific datasets through a further process by which the ONS' Microdata Release Panel (MRP) determine the appropriateness of releasing the requested data for the specific project. Further details are available via the ONS website at: www.ons.gov.uk/ons/index.html

Individual researchers can also apply for access to [personal information](#) held by ONS under s42(4) Statistics and Registration Service Act 2007 as amended by s287 Health and Social Care Act 2012 for the purposes of assisting the Secretary of State for Health or the Welsh Ministers in the performance of his or their functions in relation to the Health Service.

Patient Information Advisory Group (PIAG)

The Patient Information Advisory Group (PIAG) was a forerunner to the [Ethics and Confidentiality Committee \(ECC\)](#) which was in turn was a forerunner to the [Confidentiality Advisory Group \(CAG\)](#).

Patient Reported Outcome Measures (PROMs)

PROMs measures health gain in patients undergoing hip replacement, knee replacement, varicose vein and groin hernia surgery in England, based on responses to questionnaires before and after surgery. You can find out more about PROMs online at: www.hscic.gov.uk/proms

Payment by Results (PbR)

Payment by Results (PbR) is a system of paying NHS healthcare providers a standard national price or tariff for each patient seen or treated, taking into account the complexity of the patient's healthcare needs. More information can be found online at:

www.hscic.gov.uk/pbr

Personal Demographics Service (PDS)

The Personal Demographics Service (PDS) is the national electronic database of NHS patient demographic details such as name, address, date of birth, NHS Number and registered GP. You can find more information online at:

<http://systems.hscic.gov.uk/demographics/pds>

Pseudonymised

Also referred to as “de-identified for limited disclosure or access”, this is data from which details that would be classed as identifying individuals, such as NHS number, full postcode and full date of birth, have been removed.

We would never make this type of information publicly available because there is a risk that individuals could be re-identified. There are however particular purposes for which this information is required and it is therefore released under strict controls to approved organisations for approved purposes, and there must be a [data sharing agreement](#) in place.

This [data sharing agreement](#) outlines the purpose to which the recipient can put the data and restricts how they store, share, use and eventually destroy the data. Any recipient found to misuse the information would be in breach of this agreement and could also be contravening the Data Protection Act 1998.

Applications for [pseudonymised](#) data on the register have been considered by the individual business area (typically the HSCIC's [Data Linkage and Extract Service](#)), unless the applicant also asked for data that is classed as [sensitive](#). In the latter cases, the application would also have been considered by the HSCIC's [Data Access Advisory Group](#).

Public Health England (PHE)

Information about Public Health England is available online at:

www.gov.uk/government/organisations/public-health-england

Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002

This is a legal basis for the provision of data where it is needed for public health. Data can be released here to diagnose communicable diseases and other risks to public health; control and prevent the spread of such diseases and risks; and monitor and manage public health.

Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002

See section on the [Confidentiality Advisory Group \(CAG\)](#).

Risk Stratification

Risk stratification is a means of determining which people in a population are at high risk of experiencing outcomes - such as unplanned hospital admissions - that are simultaneously:

- undesirable for patients
- costly to the health service, and
- potential markers of low-quality care and then targeting additional preventative care interventions to high risk patients.

Secondary Uses Service (SUS)

The Secondary Uses Service (SUS) contains information about the treatment of NHS patients in secondary care settings (hospitals) in England. The data is submitted by the hospitals and contains information about the patient treated, the treatment provided and the clinicians responsible for providing the treatment. Information about the treatments provided is coded using internationally recognised coding systems. The information in SUS is held in patient [identifiable](#) and [pseudonymised](#) form. Where the nature of the treatment is considered very sensitive, the patient details are [anonymised](#).

Where a treatment is covered by a [PbR](#) tariff the data in SUS is used as the basis for the PbR calculation. The data in SUS also forms the basis for the [HES](#) and [HDIS](#) services.

Aside from providing data for these services the primary purpose of SUS is to act as a clearing system allowing hospital trusts to tell commissioners what work has been undertaken. This in turn enables the commissioners and hospital trusts to agree what payments are due.

The HSCIC has a legal duty to hold and manage the SUS database. Other organisations may be given access to some or all of the patient [identifiable](#) data in SUS with the approval of the [CAG](#). Organisations may also apply to receive [pseudonymised](#) data from SUS.

Section 251

See section on the [Confidentiality Advisory Group \(CAG\)](#).

Sensitive data

The fields classed as sensitive vary from dataset to dataset. Items classed as sensitive within [Hospital Episode Statistics](#) include the code of patients' GPs or their consultant. More information on the items classed as sensitive is available online at: www.hscic.gov.uk/dlesaac.

Requests for data that are sensitive, or for identifiable data where individual [patient consent](#) is in place, are put to the [Data Access Advisory Group \(DAAG\)](#) for consideration.

Standard Monthly Extract

See the section on [data extracts](#).

Tabulations

See the section on [data extracts](#).