Data Release Review

Health and Social Care
Information Centre
June 2014
Final

pwc

Contents

1. Executive Summary

Background and context

Following concerns expressed by the Health Select Committee on 25 February 2014 in relation to the transparency of data releases undertaken by the Health and Social Care Information Centre's (HSCIC) predecessor organisation, the NHS Information Centre (NHS IC), the HSCIC Board requested that a review of all data releases that were approved by the NHS IC, during the period 1 April 2005 and 31 March 2013 be undertaken. Sir Nick Partridge, a Non-Executive Director on the HSCIC Board, has overseen the review and will report the findings back to the HSCIC Board in May 2014.

PwC LLP was commissioned to review data releases approved by the NHS IC between 1 April 2005 and 31 March 2013. The review examined the arrangements that were in place for the release of data, and provides insight and key observations that will allow the HSCIC to learn from its predecessor's experience and ensure the HSCIC's processes are as robust, open and transparent as possible. Given the commitment to report back to the HSCIC Board, this review has been performed in a rapid and responsive manner over a period of six weeks, from scoping to final report.

The NHS IC was created in 2005 as a special health authority of the Department of Health (DH) that provided facts and figures to help the NHS and social services in England. NHS IC data and information helped local organisations provide better local care, national policy development and delivery and facilitated local and national accountability. Much of the data released by the NHS IC was in aggregated and anonymised form. This supported the publication of more than 100 public health and social care reports, available to view and download, and in more recent years the Open Data Initiative. Such data was used for a broad range of purposes, including ensuring effective understanding and planning of services, helping to predict health trends, and supporting research into the effectiveness of existing and new medicines and treatments.

In addition, from 1 April 2008, the National Back Office (NBO) transferred from the Office for National Statistics (ONS) to the NHS IC. One of the functions of the NBO was to respond to specific trace requests that originated from outside of the NHS/health family, including requests under the Data Protection Act (DPA) 1998 (section 29(3)) and Court Orders. It should be recognised that the subsequent responses to these were not large sets of data but represented 'individual level' records. As a result, this review has considered these trace requests separately from data releases derived from complex data sets released to improve health and social care.

Summary Findings

The standard PwC methodology was adopted for **sample testing** data releases with the prevailing governance arrangements. Samples were selected for each of the functional areas under review. Of the total number of data releases identified (3,059); approximately a 10% sample was tested in total.

Through analysis of the data release listing and sample testing of compliance, the exceptions identified do not indicate significant or systemic failings in terms of the processes, controls and overarching governance arrangements around data releases made by the NHS IC between 1 April 2005 and 31 March 2013.

Analysis and sample testing did identify a number of 'procedural exceptions', which are summarised in the findings section below. However, due to the timescales of the review, it was difficult to ascertain whether these exceptions were a result of limitations in the manner that records have been maintained or procedural non-compliance.

The review observed compliance with governance arrangements for those data requests that required escalation to the relevant Approval Committees. However, inconsistencies across the functional areas relating to the 'end to end' process of handling a data release upon receipt of the request through to the release of the data were observed.

It was also observed that there was no single gateway in the NHS IC for the receipt of data release requests. Such requests were received by each of the relevant functional areas across the organisation.

Functional areas that received a high volume of requests, such as Hospital Episode Statistics (HES) and Medical Research Information Service (MRIS), had clearly defined processes and controls for data release requests, with evidence of review and approval maintained. For other functional areas, typically those that receive lower volumes of requests, there was a lack of evidence to support the processes and controls in operation and limitations in the record keeping relating to data releases. Many of these functional areas were reliant upon the NHS IC Information Governance (IG) team to record details of Data Reuse Agreements/Data Sharing Agreements (DRA/DSAs), which were used by some as the key source of information to identify data releases. However, the IG team operated a reactive process of responding to requests from functional areas indicating the requirement for an agreement. As a result, there was a risk that if a functional area processed a data release request, without informing the IG team, there would be no record maintained. The review observed a general increase in the level and detail of documentation relating to data releases from 2009, which coincides with the timing as to when the handling of HES data requests was brought in house and also the Data Handling Review 2008.

These observations do not indicate significant or systemic cultural failings in terms of the processes, controls and overarching governance arrangements around data releases. Throughout the performance of this review, it has been noted that a sound understanding of the governance arrangements exists, and the importance of robust controls around data releases amongst all of the HSCIC staff that were consulted throughout this review.

Prevailing Governance Arrangements

The review sought to establish the prevailing governance arrangements in place over data releases approved during the period under review. Through consultation with stakeholders with knowledge of the NHS IC, these arrangements have been established and form the basis of the testing framework for each of the functional areas under review. These arrangements can be summarised as follows:

Approval Committees – required for identifiable and/or sensitive data releases:

- For identifiable data –Patient Information Advisory Group (PIAG) until January 2009, when this became the Ethics and Confidentiality Committee (ECC);
- For sensitive data – Security and Confidentiality Advisory Group (SCAG) until 1 April 2008, when this became the Database Monitoring Sub-Group (DMSG). From September 2010, this became the Data Access Advisory Group (DAAG);
- For Medical Research Information Service (MRIS) study data releases – in addition to the appropriate Approval Committee governance, the research study must have Ethics Committee Approval; and
- For ONS data – legal gateways in place for the release of birth or mortality data.

Data Re-use and Sharing Agreements – required for all identifiable/sensitive, pseudonymised data releases:

- Requests for data received across the functional areas of the NHS IC were subject to local processes in place to review, challenge, and apply for the appropriate DRA/DSA; and
- Policy and process around DRA/DSAs was formalised in 2008. Prior to this date, agreements were used but not consistently recorded and stored centrally.

Please refer to the diagram on the following page which illustrates the Governance Timeline for the period under review.

Governance Timeline

Key:

Governance Group: Identifiable Data. Governance Group: Sensitive Data. Governance Group: ONS Data

Scope and limitations

This review covers data releases approved by the NHS IC from the point it was established (1 April 2005) to the date it ceased to exist (31 March 2013) and subsequently became the HSCIC (1 April 2013). Public releases of data (in anonymised form) are not included in in the scope of the review, although individual releases of such data in response to a single customer enquiry are included. The definition of a 'data release' for the purposes of this review, which has been provided by HSCIC, is as follows:

"A release of data from which there is a potential risk of identifying people. This could be through direct identifiers or by providing enough information for self-identification or identification through combining with other sources. This would include a patient record level extract or a table of data with small numbers that have not been suppressed in line with an agreed standard."

Specifically, the objectives of this review were to:

- Identify and produce a list of those data releases that were made during the lifetime of the NHS IC, including the type of data provided and to which organisations;
- Analyse data releases identified; to provide insight, trends and key observations;
- Assess the arrangements that were in place for each data release to communicate the appropriate use, data handling and data retention controls to the data requestor;
- Identify the prevailing governance and control arrangements, roles and responsibilities in operation within the NHS IC during the period of 1 April 2005 through to 31 March 2013 to review, challenge and approve data releases; and
- Assess compliance with the prevailing governance and control arrangements in place from request through to release for a sample of data releases selected for testing. The sampling methodology for testing was discussed and agreed with the HSCIC prior to detailed working being undertaken – please refer to Appendix 6 for PwC sample testing methodology.

The review has been undertaken using the data and records made available by the HSCIC, to develop the list of data releases in line with stated objectives. PwC have worked closely with HSCIC management and staff to observe and oversee the processes and activities undertaken to produce the list. HSCIC management and staff assisted PwC in the identification of relevant records and data sources. Where this involved third parties or suppliers, HSCIC have contacted them on behalf of PwC. A detailed commentary and analysis in terms of compliance with prevailing governance and control arrangements has also been undertaken.

This review only encompassed those approved data releases not readily available in the public domain and which meet the criteria definition outlined. As a result, the following data releases are out of scope and include, but may not be limited to:

- Parliamentary Questions (PQs);
- Freedom of Information (FOI) requests;
- Media/statistical publications;
- DH and the NHS/social care family specifically for management or validation purposes;
- 'Open Data' that is already publicly available;
- Aggregate data returns; and
- Data released by other predecessor organisations.

Given the number of 'unknowns' associated with this review due to the time period in question and the availability of historical records/evidence, no formal assurance or opinion have been provided over the findings that may be used by the HSCIC to publish their overall conclusions.

This review did not assess or provide assurance around the following:

- Completeness of the data release list from 1 April 2005 through to 31 March 2013. In the method statement section of this document, it describes how PwC have worked with and been assisted by HSCIC management and staff to compile the data release list. PwC did not perform any additional independent investigation

around data releases to confirm that data was released, for example, contacting receiving organisations to confirm receipt of data from the NHS IC;
- Reconciling what data was recorded by the NHS IC as having been released, and what was actually released;
- Whether the data contained in the release, has been used for the intended/stated purpose by the requestor; and
- The 'end to end lifecycle' of DRAs/DSAs, for example, whether the data has been disposed of following release and use in accordance with information governance and data handling policies and procedures.

Scope exclusions:

A number of functional areas have been excluded from the scope of this review. Specifically these are:

- **Secondary Use Service (SUS) – Direct Access** – data was accessed via Smart Cards, which were set up by the Registration Authority, and out of the control of the NHS IC, therefore out of scope;
- **Improving Access to Psychological Therapies (IAPT)** – the DH were the data controllers and the sole requestors of the data, which was used for management information purposes, therefore out of scope;
- **Prescribing and Primary Care Services** – the data shared was not identifiable as it was taken from anonymised patient records held on databases for which the NHS IC were not the data controllers, therefore out of scope;
- **Population Health – Population, Geography and International** – ONS were the data controllers for registration data that was deemed PID but was provided to the DH and NHS/social care family only, therefore out of scope;
- **Casemix** – the National Casemix Office designed and refined classifications that are used by the NHS in England to describe healthcare activity. These classifications underpinned the Payment by Results (PbR) system from costing through to payment, and supported local commissioning and performance management. These did not represent in scope data releases; and
- **Human Resources** – data specifically related to the NHS IC employees, therefore out of scope.

Other limitations

Given the time period under review, and despite full co-operation of the HSCIC, there are some inherent limitations with the manner in which the data release listing has been compiled, specifically:

- For HES data releases made between 1 April 2005 and 2009 when the process for administering all data was outsourced to Northgate, the amount of information that is now held around individual data releases is limited, or is maintained in hard copy format only. As a result, for some elements of information required for the data release listing, it was not possible to extract within the time period available for the review. In these instances, the term "information not available at list compilation stage" has been used;
- For MRIS data releases, it has not been possible to identify individual releases of data given the 'event-driven' nature of MRIS study data. It has been possible to identify the number of agreements in place with organisations to cover approved data releases; and
- For a number of functional areas, there are limited records of data releases maintained. The data release listing has therefore been compiled using the centrally maintained list of DRAs/DSAs by the IG team. There is a risk that this list may not provide a comprehensive list of all data actually released during the time period under review.

Summary Findings – Data Releases – Health and Social Care Data

This summary provides high-level findings of the work undertaken on data releases specific to health and social care related information released by functional areas of the NHS IC in accordance with the terms of reference outlined in Appendix 1. The data release listing provides transparency over which organisations received in-scope data during the period under review. The complete data release listing has been provided separately to this report. Analysis is provided in terms of volume of data released by functional area, the organisations that received the data and then findings related to sample testing of compliance with the prevailing governance and control arrangements (described by the governance timeline).

Data Release Listing – By NHS IC Functional Area

For the period 1 April 2005 to 31 March 2013, a total of **3,059** data releases have been identified from records maintained by the NHS IC. These data releases relate to:

- **HES** – HES data comprised of the admitted patient, outpatient and accident and emergency records for all NHS hospitals in England. There were **1,667** releases of HES data sets;
- **Secondary Use Service (SUS)** – SUS data provided a single repository for patient-based data and information for management and clinical purposes other than direct patient care. There were **509** releases of SUS data sets;
- **MRIS** – MRIS data supported medical research, predominantly for Higher Education Institutions (HEIs), through the provision of 'event-driven' patient specific data. There were **591** approved customers of MRIS data;
- **Mental Health Minimum Data Set (MHMDS)** – the MHMDS contained record-level data about the care adults and older people receive using secondary mental health services that encompasses services provided in outpatient clinics and the community, as well as hospitals. There were **28** releases of MHMDS data sets;
- **Social Care –** record-level adult social care data was collected from local authorities and published at an aggregate level for the local authorities use to plan, deliver and monitor services. There were **26** releases of Social Care data;
- **Clinical Audit** – the clinical audits are nationwide processes designed to understand and enhance care provided to patient. There were **88** releases of clinical audit data;
- **Clinical Indicators** – a number of different indicators were produced for health and social care professionals and information specialists, researchers and citizens. There were **50** releases of clinical indicator data sets;
- **Workforce** – workforce information of GPs and dentists was predominantly used by HMRC who linked individual record-level data to tax records. There were **62** releases of workforce data;
- **Population Health – Surveys** – contractors were commissioned to collect and analyse public health related survey data from consenting participants on behalf of the NHS IC for publication. There were **5** releases of Population Health – Survey data;
- **Population Health – Lifestyles –** the Lifestyles Statistics Section of Population Health dealt with three survey outputs and publishing of other lifestyles national statistical publications. There was **1** release of Population Health – Lifestyle data; and
- **Population Health – Screening and Immunisation** – screening and immunisation data was collected from pathology labs, colposcopy clinics and breast screening units, and sent to the NHS IC by Health Protection Agency (HPA). There were **32** releases of Population Health – Screening and Immunisation data.

Data Release Listing – by Receiving Organisation

The data release listing compiled as part of this review has enabled further analysis to identify the split of data releases made by organisation type. This has highlighted the following:

- **879** data releases to Universities for typically the purpose of research and analysis;
- **827** data releases to the Department of Health and the wider NHS for typically the purpose of analytics, benchmarking and research;
- **588** data releases to a range of Private Sector organisations for typically the purpose of analytics, benchmarking and research;
- **358** data releases to Public Corporations (e.g. Audit Commission) for typically the purpose of audit, analytics, benchmarking and research;
- **125** data releases to Research organisations;
- **84** data releases to Registered Charities for typically the purpose of research;
- **50** data releases to Professional Bodies (e.g. The Royal College of Surgeons in England) for typically the purpose of research;
- **41** data releases to Central Government Departments for a variety of purposes typically including research, analysis, census/population studies and benchmarking;
- **48** data releases to Government Agencies for typically a variety of research and analysis purposes;

- **33** data releases to Public Bodies (e.g. Competition Commission) for typically the purpose of research and analysis;
- **24** data releases that were registered to an individual person in the DRA/DSA, instead of an organisation; and
- This left **2** data releases where it was not possible to identify the organisation that received the data based on the information retained by the NHS IC. One release related to HES data post April 2009. Further discussion with Northgate has indicated that this could relate to an internal Northgate request for data; however this could not be confirmed. The other release related to Population Health – Screening, where further investigation and review of a number of additional information sources has indicated that it is likely that this data was released to an individual at a Primary Care Trust in the North West of England for the purposes of medical research.

Summary Findings – Functional Area Analysis and Compliance Testing

Compliance with Approval Committee governance arrangements for identifiable and/or sensitive data

- Sample testing has highlighted 92% (109 of 118 tested) compliance with the prevailing governance arrangements for the release of patient identifiable and/or sensitive data during the period under review. The nine exceptions (seven from 1 April 2005 to 31 March 2009 and two from 1 April 2009 to 31 March 2013) relate specifically to HES data releases;
- For HES data administered by Northgate between 1 April 2005 and 1 April 2009, the manner in which records have been maintained in hard copy format did not enable confirmation within the timescales of the review that the appropriate Approval Committee authorisation was in place for any of the seven sample data releases tested; and
- For HES data releases post 1 April 2009, sample testing highlighted 93% (28 out of 30 tested) compliance. It is not possible to confirm whether the two exceptions were as a result of poor record keeping, loss of traceability as a result of the records transferring from Northgate to NHS IC or non-compliance with governance arrangements.

No record of complaints made against the NHS IC for inappropriately sharing data

- This review examined the process by which complaints could be raised by an individual if they believed their data had been used/released inappropriately by the NHS IC; and
- Fewer than 20 complaints were identified as being recorded by the NHS IC contact centre during its lifetime and subsequent review of available documentation highlighted no specific complaints in respect of inappropriate data releases.

Compliance with Ethics Committee Approvals for MRIS research study related data releases

- Sample testing highlighted 77% (46 of 60 tested) compliance with the requirement for Ethics Committee Approvals for MRIS research related data releases;
- The 14 exceptions noted relate to longer standing studies, all of which were approved and established prior to MRIS becoming part of the NHS IC in 2008 and the requirements for Ethics Committee approval being formalised; and
  Of the 14 studies identified as without Ethics Committee approval by this review, further investigation with the HEIs in question has confirmed that three do have Ethics Committee approvals although this is not recorded centrally, 10 of the studies have closed and one still has no evidence.

Compliance with ONS Legal Gateway requirements

- Although sample testing identified 98% (59 of 60 tested) compliance with the requirements of the ONS Legal Gateway, one study was identified that did not have appropriate approvals. This prompted further investigation across all MRIS data agreements, which identified a further eight research studies that did not have the appropriate ONS Legal Gateway approvals in place for the release of mortality data. These nine studies have been suspended by MRIS pending ONS Gateway approval.

Data Re-use and Data Sharing Agreements

- Analysis and sample testing has indicated that DRAs and DSAs were in place and were predominantly being used for data releases made for the period under review;
- However, the sample testing has identified a number of procedural exceptions relating to existence, completeness and accuracy of DRAs/DSAs in some the functional areas under review; and
- These exceptions include: two out of 60 tested HES agreements had not been signed by both the data requestor and the Caldicott Guardian; two out of 15 tested MHMDS releases were non-compliant with DSAs; eight of the 15 Social Care DSAs sampled remain incomplete; one of the 20 Clinical Audit DSAs could not be located and others tested displayed minor procedural exceptions relating to sign-off protocols; 16 of the Workforce population of 62 did not have evidence of approval or agreement, and two out of 15 tested displayed minor procedural exceptions relating to sign-off protocols; and 15 of the Population Health – Screening and Immunisations population of 32 did not have any record of a DSA.

HES data releases

- Between 1 April 2005 and 1 April 2009, all aspects of the HES data release service were run by Northgate. Records for this period are limited and present the risk that total HES data releases may be under reported;
- For pseudonymised HES data released by Northgate prior to 1 April 2009, although 100% (30 out of 30) of the sample tested had some form of data agreement in place, the testing highlighted weaknesses around evidence of approvals, and an inconsistency in the level of detail relating to how data should be handled, secured and controlled by requesting organisations;
- Further review of the Northgate contract was undertaken, specifically clause 2.5.8, which states "The Contractor shall obtain the permission of the Authority to disclose data when access to them is requested by another person. In any disclosure to a third party, the Contractor shall impose a non-disclosure undertaking which prohibits disclosure of the data to any other person by that third party." In the assessment of HES processes for the period 1 April 2005 to 1 April 2009, it has been possible to identify that a non-disclosure undertaking was in place for the items that were tested. Based on the information made available for the purposes of the review, it has not been possible to identify specific evidence, for the sample of 37 tested, of case by case permission or approval from the NHS IC prior to the data being released by Northgate. However, following further discussions with the HSCIC and Northgate, it has been identified that the process used during this period did not require Northgate to seek specific approval from the NHS IC for releases of pseudonymised data; and
- Post 1 April 2009, testing highlighted 100% compliance with DRA/DSA requirements and 93% (28 out of 30) compliance with Approval Committee governance. This is consistent with an observed improvement in the overall quality and level of record keeping and documentation, and better linkage to the evidence of the decision-making.

Limitations in terms of record keeping across functional areas

- Many of the functional areas reviewed had historically maintained limited records of what data had been released. As a result, in these functional areas data release listings for this review have been compiled using the list of DRAs/DSAs maintained centrally by the NHS IC IG Team; and
- As the NHS IC IG Team were 'reactive' in terms of granting agreements, there is a risk that the list of DRAs/DSAs may not be a complete list of all data that has been released by a specific functional area.

Availability of records for the time period under review

- There have been a number of instances where due to the period under review, 1 April 2005 to 31 March 2013, detailed records of data releases have been limited; and

This has been due to a combination of factors including the short timeframe in which the review has been completed, inconsistent and, in places, limited record keeping, and the NHS IC records management policy of not retaining records after five years.

Evidence of data release approval and release process

- Although the review has confirmed that local processes and controls were in operation across the functional areas of the NHS IC during the period under review, a general lack of consistency has been observed; and
- In addition, there is a common theme around the lack of evidence maintained by functional areas to confirm approvals, date of approvals and date of data releases.

Summary Findings – Data Releases – NBO Trace Request Service

This summary provides high-level findings on responses to trace requests specific to the NBO. The NBO provides a trace service under specific legislation to the UK Border Agency (UKBA), Police, Serious Organised Crime Agency (SOCA) and Courts. This review identified:

- **12,954** recorded responses to trace requests were made by the NBO in relation to the person trace service between 1 April 2008 (when the service transferred from the ONS to the NHS IC) and 31 March 2013.

By organisation

- **7,766** responses to trace requests to UKBA for the purpose of the prevention or detection of immigration offences and/or protection of the NHS from potential abuse from immigrants to the UK;
- **3,949** responses to trace requests to the Police and SOCA for the prevention or detection of crime and the apprehension or prosecution of offenders; and
- **1,239** responses to trace requests to Court Orders in relation to person tracing for family or divorce proceedings.

Summary Findings – Analysis and Compliance Testing

NBO Trace Requests

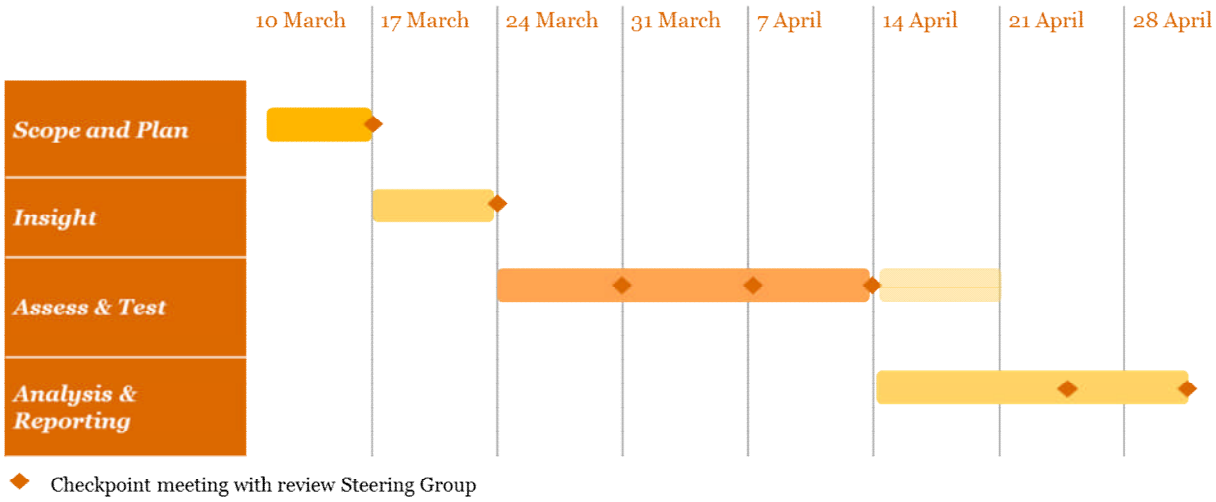
- Records are maintained of all NBO responses to trace requests to confirm whether the request has been accepted, rejected or refused. However, there is no evidence or audit trail maintained to support this process other than the record of the final decision. From compiling responses to trace requests across NBO, it is possible to observe that a proportion of trace requests are either refused or rejected, which indicates that processes and controls were operating;
- Processes and controls governing these trace requests had remained stable since the transfer of the service to the NHS IC in 2008;
- For NBO related trace requests made to the Police, UKBA and SOCA, electronic records have been maintained from 1 August 2010. Prior to this, paper records were maintained and subsequently destroyed in accordance with the NHS IC IG policies for retention and disposal of records in place at that time. Therefore, responses to trace requests between 1 April 2008 and July 2010 have not been included within this review; and
- For NBO related trace requests made as a result of Court Orders, there is no central record maintained of these requests, which were all recorded on a legacy system. The trace response listing was compiled through review of each entry within the legacy system and reconciled to archive files that date back to 1 April 2008.

Closing comment

PwC would like to thank HSCIC management and staff for their co-operation during the course of this review.

2. Method Statement

This review has been undertaken following a four phase approach that is outlined in the diagram below:



The activities and outcomes from each phase are summarised below, and provide the basis of the overall method adopted for the review:

1. Scope and plan

This phase confirmed aims and objectives of the review, established the review governance arrangements and provided a detailed plan for delivery of the review. Please refer to Appendices 1, 2 and 3 respectively for review Terms of Reference (ToR), Review Governance (including Steering Group membership) and Delivery Plan.

2. Insight

Given the time period under review, it was important to rapidly develop an initial understanding of the functional areas of the NHS IC that could have released data between 1 April 2005 and 31 March 2013. The Insight phase of activity was undertaken to:

- Identify what type of data may have been released, to who and what purpose, any third party organisations involved in the release of data, and key contacts within the HSCIC;
- Identify areas of focus, which following suitable investigation, would provide a robust indication of overall review feasibility;
- For each area of focus, hold discussions with relevant HSCIC stakeholders, to develop a view on the feasibility of compiling a list of in scope data releases for the time period of the review. Identify any risks, issues or limitations associated with completion of this task;
- Develop a high level picture of the governance and control arrangements in operation and related to data releases, throughout the life of the NHS IC, supported by review of key documentation available, such as the details provided within the NHS IC records management policies and procedures, and DRA/DSA; and
- Assess the feasibility of effectively testing compliance of in scope data releases with governance and control arrangements. Identify any risks, issues or limitations associated with the review.

A workshop, facilitated by PwC, was held on 14 March 2014. The attendees are listed in Appendix 4 of this document, and were selected by HSCIC management given their knowledge of the NHS IC and understanding of potential data releases over the lifetime of the organisation from 1 April 2005 to 31 March 2013.
Please refer to Appendix 5 for the outcomes of the workshop, which were used to identify the functional areas of the NHS IC that may have released data during the time period under review and therefore clarify the scope of the review.

3. Assess and test

Following the Insight phase of activity, the scope of the review was confirmed in terms of functional areas of the NHS IC that may have released data during the period. The table below summarises the rationale for the final scope of the review:

Functional Area/Data	In scope?	Comments
Hospital Episode Statistics (HES)	Yes	HES data comprised the admitted patient, outpatient and accident and emergency records for all NHS hospitals in England. The data was stored in a secure data warehouse and was used to calculate the amount to be paid to the Trust for the care provided. Published HES data was suppressed to stop person identification. However, requests for sensitive or identifiable data were made and extracted from HES, in accordance with a defined legal basis, for a variety of purposes including research, benchmarking and analytics for the NHS, government and other organisations.
Secondary Uses Service (SUS)	Yes	SUS data provided a single repository for patient-based data and information for management and clinical purposes other than direct patient care. This data contained patient level information and could be identifiable or pseudonymised as required. SUS data was contained in a secure environment, with restricted access using NHS Registration Authority Smart Card. This healthcare data was used for a range of reporting and analyses to support the NHS in the delivery of healthcare services. An extract service was provided for PbR data obtained from SUS that followed a similar process to HES.
SUS Direct Access	No	Data was accessed via Smart Cards, which were set up by the Registration Authority and out of the control of the NHS IC.
Medical Research Information Service (MRIS)	Yes	MRIS data supported medical research, predominantly for HEIs, through the provision of 'event-driven' patient specific data. Data was released in accordance with the legal basis given that it was identifiable, following a trigger by a specific event. In addition, the data may have been used for clinical audit purposes.
Mental Health and Community – Mental Health Minimum Data Set (MHMDS)	Yes	The MHMDS contained record-level data about the care adults and older people received using secondary mental health services that encompassed services provided in outpatient clinics and the community, as well as hospitals. Regular submissions were made by organisations, for which the data supported a variety of secondary use functions.
Mental Health – Improving Access to Psychological Therapies (IAPT)	No	The DH was the data controller and the sole requestor of the data, which was used for management information purposes.
Social Care	Yes	Record-level adult social care data was collected from local authorities and published at an aggregate level for the use of the local authorities to plan, deliver and monitor services. The unsuppressed data was also used for research purposes.
Clinical Audit	Yes	The clinical audits were nationwide processes designed to

Functional Area/Data	In scope?	Comments
		understand and enhance care provided to patient. The data was reported and disseminated at a pseudonymised or aggregate level, predominantly to healthcare organisations to improve performance to deliver better patient care.
Clinical Indicators	Yes	A number of different indicators were produced for health and social care professionals and information specialists, researchers and citizens. The Summary Hospital-level Mortality Indicator (SHMI) contained identifiable data when linked with ONS data.
Workforce	Yes	Workforce information of GPs and dentists was predominantly used by HMRC who linked individual record-level data to tax records. The Centre for Workforce Intelligence, as a national authority providing advice and information to the health and social care system, and other academic institutions and researchers requested identifiable data and also received it.
Population Health – Surveys	Yes	Contractors were commissioned to collect and analyse public health related survey data from consenting participants on behalf of the NHS IC for publication. Requests for the record-level data may have been made directly to the survey contractor or the NHS IC.
Population Health – Lifestyles	Yes	The Lifestyles Statistics Section of Population Health dealt with three survey outputs and publishing of other lifestyles national statistical publications. Given the nature of the data, it may have been deemed sensitive.
Population Health – Screening	Yes	Screening and immunisation data was collected from pathology labs, colposcopy clinics and breast screening units, and sent to the NHS IC by Health Protection Agency (HPA). The data was aggregated but some small numbers were not suppressed.
Population Health – Population, Geography and International	No	ONS were the data controllers for registration data that was deemed patient-identifiable but was provided to the DH and NHS/social care family only.
Prescribing and Primary Care Services	No	The data shared was not patient-identifiable as it was taken from anonymised patient records held on databases for which the NHS IC was not the data controller.
Casemix	No	The National Casemix Office designed and refined classifications that were used by the NHS in England to describe healthcare activity. These classifications underpinned the PbR system from costing through to payment, and supported local commissioning and performance management.
Human Resources	No	Data specifically related to NHS IC employees.
National Back Office (NBO)	Yes – considered separately	There was a NBO team that responded to specific trace requests that originated from outside of the NHS/health family, including requests under the DPA 1998(section 29(3)) and Court Orders. It should be recognised that the subsequent responses to these trace requests were not large sets of data but represented 'individual level' records. As a result, this review has considered these trace requests separately from data releases derived from complex data sets released to improve health and social care.

The Assess and Test phase focused on working collaboratively with HSCIC staff to:

- Compile a list of in scope data releases for each functional area based on information and records made available by the HSCIC management and staff for the time period under review;
- Sample testing in accordance with the methodology outlined in Appendix 6 was performed to assess compliance, where possible, with prevailing governance arrangements and controls. A 'haphazard' approach to sample testing was adopted[1]. Further insight into the data releases tested within the sample was not used to update the listing.

4. Analysis and reporting

The final phase of the review focused on analysing the data release listing and providing commentary and findings. The following sections of this document provide:

- Summary level analysis and findings – based on the full data release listing; and
- Detailed findings – based on the data release listing and testing for each functional area of the NHS IC under review.

[1] International Standard on Auditing 530 Audit Sampling – Appendix 4.

3. Summary Level Findings and Analysis

This section of the document provides summary findings and analysis in relation to:

a) Summary Findings – Data Releases – Health and Social Care Data
- The data release listing for the period 1 April 2005 to 31 March 2013 specific to data releases of health and social care related information – analysed by NHS IC Functional Area, receiving organisations, with any exceptions identified;
- The prevailing governance arrangements in place during this time period; and
- Summary findings from functional area analysis and compliance sample testing.

b) Summary Findings – Data Releases – NBO Trace Request Service
- The trace request listing for the period 1 April 2008 (when the service transferred from the ONS to the NHS IC) and 31 March 2013 – analysed by receiving organisations; and
- Summary findings from functional area analysis and compliance sample testing.

a) Summary Findings – Data Releases – Healthcare Data

Data Release Listing – By NHS IC Functional Area

For the period 1 April 2005 to 31 March 2013, a total of **3,059** data releases have been identified from records maintained by the NHS IC. The table below provides a breakdown of the number of data releases per functional area or data type:

Functional Area/Data Type	Data Releases
Hospital Episode Statistics	1,667
Secondary Use Service	509
Medical Research Information Service	591
Mental Health Minimum Data Set	28
Social Care	26
Clinical Audit	88
Clinical Indicators	50
Workforce	62
Population Health – Surveys	5
Population Health – Lifestyles	1
Population Health – Screening	32
Total	**3,059**

Data Release Listing – Receiving Organisations

Further analysis on the data releases made by the NHS IC during the period under review has enabled a breakdown of releases by the type of organisation receiving the data. The table below provides a summary of data releases by organisation type:

Organisation Type	Definition	Typical Purpose	Data releases
University	Institutions of higher education awarding degrees	Research studies	879
Department of Health and wider NHS	Department of Health and Arm's Length Bodies (ALB), and NHS organisations where data is not used for management or validation purposes	Various – e.g. Research/analytics/ benchmarking	827
Private Sector	Private sector organisation, excluding charities	Various – e.g. Research/analytics/ benchmarking	588
Public Corporation	Statutory corporation (e.g. Audit Commission)	Various – e.g. Research/analytics/ benchmarking	358
Research Body	Organisation whose purpose is specifically research, but is not a charity or university (e.g. Economic and Social Research Council)	Research	125
Charity	Registered charity	Research	84
Professional Body	Organisation relating to one particular profession (e.g. The Royal College of Surgeons in England)	Research	50
Central Government Department	UK Central Government Department	Varied, most commonly for Census purposes	41
Government Agency	UK Government Agency	Research	48
Public Body	Public Body which has a role in national government, but not regarded as a government agency or department (e.g. Competition Commission)	Research and analysis	33
Individual	Where DRA/DSA is registered to an individual person	Extension or amendments of existing agreements	24
Not defined	Where either the organisation name or type has been unable to be determined with the provided reference number. NIC, DRA/DSA or Northgate reference available.	Unknown	2

The analysis by organisation type and purposes highlights a number of findings:

- **879** data releases were made to universities, primarily for the purposes of health related research and study. The institutions that received the highest volume of data are as follows:

Top 10 Universities	Data Releases
Imperial College London	118
University of Oxford	60
University of York	51

Top 10 Universities	Data Releases
London School of Hygiene & Tropical Medicine	35
UCL	35
The University of Manchester	34
The University of Birmingham	30
Clinical Trial Service Unit (CTSU)	24
University of Bristol	21
Institute of Cancer Research	21

- **588** data releases were made to a variety of private sector organisations during the time period under review. This data is used for a variety of purposes, focused around analytics and research. The private sector organisations that received the highest volume of data are as follows:

Top 20 Private Sector Organisations	Description	Data Releases
CHKS Limited	Healthcare Data	45
NHIS Ltd	Healthcare Consultancy	22
Civil Eyes Research Ltd	Clinical Benchmarking	19
Beacon Consulting	Pharmaceutical Consultancy	18
McKinsey and Company	Management Consultancy	17
AstraZeneca	Pharmaceutical	16
Translucency Ltd	Healthcare Reimbursement	14
Dr Foster Intelligence Ltd	Healthcare Data	13
Binleys	Healthcare Data & Mailing Lists	12
York Health Economics Consortium Ltd	Research	12
GlaxoSmithKline	Pharmaceutical	11
Finnamore Management Consultants	Healthcare Consultancy	11
MedeAnalytics International Limited	Healthcare Performance Analytics	11
Matrix Knowledge Group	Research	10
Lightfoot Solutions Ltd	Change Management Consultancy	10
Northgate	Technology Solutions	9
The Checklist Partnership	Predictive Modelling Solutions	9
SG2	Performance Analytics	8
Matrix Research and Consultancy Ltd	Research	8
Northgate Information Solution	Technology Solutions	8

Data Release Listing – Receiving Organisations (Exceptions)

24 data releases were identified during the overall analysis that were registered to an individual person. This is likely to be down to an error in record keeping or procedural exception – the DRA/DSA was signed to an individual instead of the organisation. These are summarised in the table below:

Data Source (Functional Area)	Financial Year Approved	Organisation Name
Clinical Audit	2009/10	Named Individual at University Hospital Birmingham NHS Foundation Trust
Clinical Audit	2010/11 client's signature not dated	Named Individual at University Hospital Birmingham NHS Foundation Trust
Clinical Audit	2011/12	Named Individual at University Hospital Birmingham NHS Foundation Trust
Clinical Audit	2012/13	Named Individual at University Hospital Birmingham NHS Foundation Trust
Clinical Audit	2011/12	Named Individual at The Heart Hospital, University College London Hospital
Clinical Audit	2009/10	Named Individual at (Burton Hospitals NHS Trust)
Clinical Audit	2010/11	Named Individual at (Burton Hospitals NHS Trust)
Clinical Audit	2011/12	Named Individual at (Burton Hospitals NHS Trust)
Clinical Audit	2012/13	Named Individual at (Burton Hospitals NHS Trust)
Clinical Audit	2012/13	Named Individual at (Burton Hospitals NHS Trust)
HES	2010/11	Named Individual A
HES	2010/11	Named Individual at DH
HES	2010/11	Named Individual at UCL
Mental Health	2008/09	Named Individual at Pinewood House
Workforce	2006/07	Named Individual at The University of Manchester
Workforce	2011/12	Named Individual at The University of Manchester
Workforce	2012/13	Named Individual at The University of Manchester
Workforce	2011/12	Named Individual at The University of Manchester
Workforce	2005/06	Named Individual at The University of Manchester
Workforce	2011/12	Named Individual at The University of Manchester
Workforce	2012/13	Named Individual at University of Oxford
Workforce	2012/13	Named Individual at University of York
Workforce	2005/06	Named Individual B
Workforce	2009/10	Named Individual C

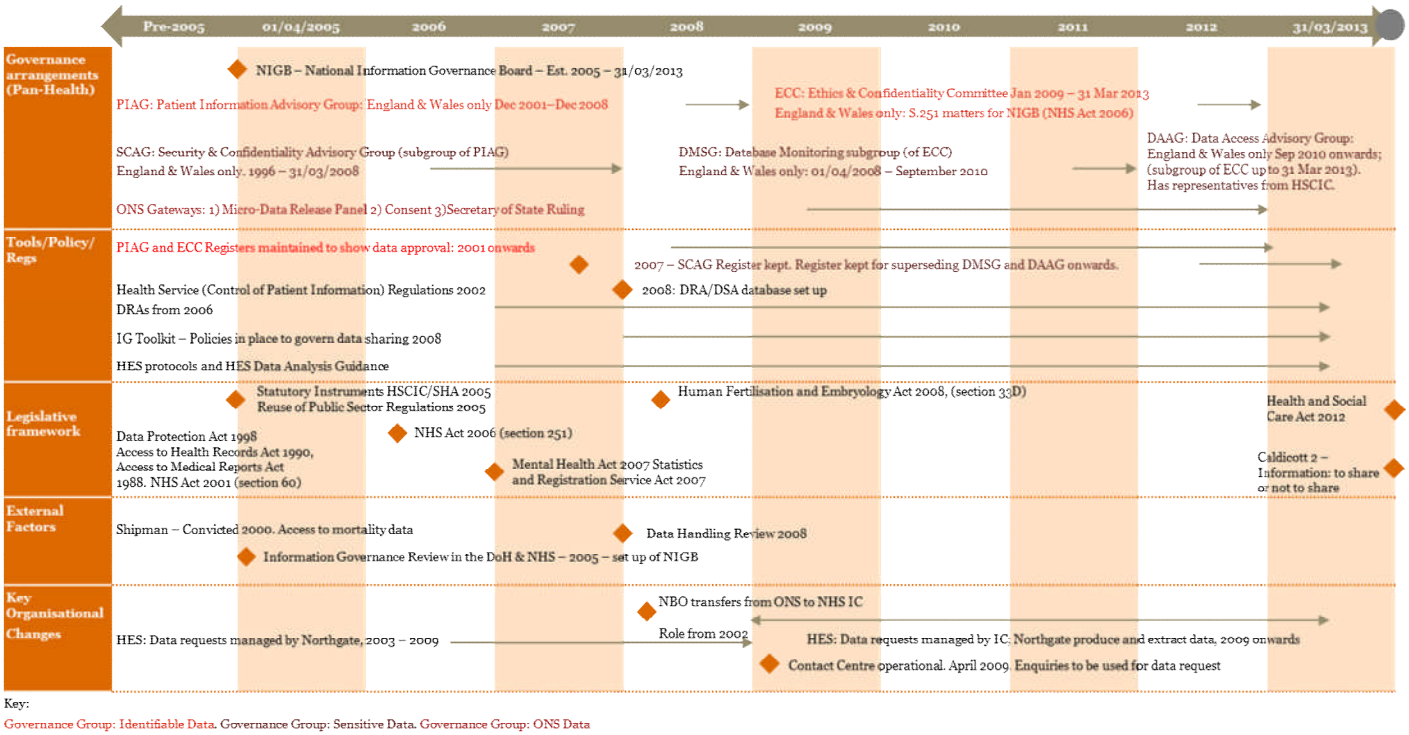
Data Release Listing – Limitations

Given the time period under review, and despite full co-operation of the HSCIC management and staff, there are some inherent limitations with the manner in which the data release listing has been compiled, specifically:

- For HES data releases made between 1 April 2005 and 2009 when the process for handling all data was outsourced to Northgate, the availability of records is limited in terms of how individual data releases have been recorded;
- For MRIS data releases, it has not been possible to identify individual releases of data given the 'event-driven' nature of MRIS study data. It has been possible to identify the number of agreements in place with organisations to cover approved data releases; and
- For a number of functional areas, there are limited records of data releases maintained. The data release listing has therefore been compiled using the centrally maintained list of DRAs/DSAs by the IG team. There is a risk that this list may not provide a comprehensive list of all data actually released during the time period under review.

Governance Timeline

The diagram below summarises the timeline of prevailing governance arrangements, processes and controls in relation to the release of data, for the period under review. This provides the framework by which data releases have been tested as part of this review.



The prevailing governance arrangements in place over data releases made during the period under review have been established and form the basis of the testing framework for each of the functional areas under review. These arrangements can be summarised as follows:

Approval Committees – required for identifiable and/or sensitive data releases

- For identifiable data –Patient Information Advisory Group (PIAG) until January 2009, when this became the Ethics and Confidentiality Committee (ECC);
- For sensitive data – Security and Confidentiality Advisory Group (SCAG) until 1 April 2008, when this became the Database Monitoring Sub-Group (DMSG). From September 2010 this became the Data Access Advisory Group (DAAG);
- For MRIS research study data releases – in addition to the appropriate Approval Committee governance, the research study must have Ethics Committee Approval; and
- For ONS data – legal gateways in place for the release of birth or mortality data.

Data Reuse and Data Agreements – required for all identifiable/sensitive, pseudonymised data releases

- Requests for data received across functional areas of the NHS IC were subject to local processes in place to review, challenge, and apply for the appropriate data sharing or reuse agreements;
- Policy and process around DRA/DSAs were formalised in 2008. Prior to this date agreements were used, however not consistently recorded and stored centrally.

Summary findings – Functional Area Analysis and Compliance Testing

Through analysis of the data release listing and sample testing of compliance, the exceptions identified do not indicate significant or systemic failings in terms of the processes, controls and overarching governance arrangements around data releases made by the NHS IC between 1 April 2005 and 31 March 2013.

Analysis and sample testing did identify a number of 'procedural exceptions', which are summarised in the findings below. However, due to the timescales of the review, it is difficult to ascertain whether these exceptions are a result of limitations in the manner that records have been maintained or procedural non-compliance.

1. *Compliance with Approval Committee governance arrangements for identifiable and/or sensitive data*

- Analysis and testing has highlighted 92% (109 of 118 tested) compliance with the prevailing governance arrangements for the release of patient identifiable and/or sensitive data during the period under review. The nine exceptions (seven from 1 April 2005 to 31 March 2009 and two from 1 April 2009 to 31 March 2013) relate to HES data releases;
- For HES data administered by Northgate between 1 April 2005 and 1 April 2009, the manner in which records have been maintained in hard copy format, it was not possible to confirm within the timescales of the review, that the appropriate Approval Committee authorisation was in place for any of the sample data releases tested (please refer to detailed finding HES2); and
- For HES data releases post 1 April 2009, 93% (28 out of 30 tested) compliance. It is not possible to confirm whether the two exceptions are as a result of poor record keeping or non-compliance with governance arrangements (please refer to detailed finding HES2).

2. *No record of complaints made against the NHS IC for inappropriately sharing data*

- This review examined the process by which complaints could be raised by an individual if they believed their data had been used/released inappropriately by the NHS IC; and
- Fewer than 20 complaints were identified as being recorded by the NHS IC contact centre during its lifetime and subsequent review of available documentation highlighted no specific complaints in respect of inappropriate data releases.

3. *Compliance with Ethics Committee Approvals for MRIS research study related data releases*

- Sample testing highlighted 77% (46 out of 60 tested) compliance with the requirement for Ethics Committee Approvals for MRIS research related data releases;
- The 14 exceptions noted relate to longer standing studies, all of which were approved and established prior to MRIS becoming part of the NHS IC in 2008 and the requirements for Ethics Committee approval being formalised; and
- Of the 14 studies identified as without Ethics Committee approval by this review, further investigation with the universities in question has confirmed that three do have Ethics Committee approvals although this is not recorded centrally, 10 of the studies have closed and one still has no evidence (please refer to detailed finding MRIS1).

4. *Compliance with ONS Legal Gateway requirements*

- Although sample testing identified 98% (59 of 60 tested) compliance with the requirements of the ONS Legal Gateway, one study was identified that did not have appropriate approvals. This prompted further investigation across all MRIS agreements, which identified a further eight research studies that did not have the appropriate ONS Legal Gateway approvals in place for the release of mortality data. These nine studies have been suspended by MRIS pending ONS Gateway approval.

5. *Data Sharing and Data Re-Use Agreements (DSAs & DRAs)*

- Analysis and sample testing has indicated that DRAs and DSAs were in place and predominantly being used for data releases made for the period under review;

- However, the sample testing has identified a number of procedural exceptions relating to existence, completeness and accuracy of DRAs/DSAs in some the functional areas under review; and
- These exceptions include: two out of 60 tested HES agreements had not been signed by both the data requestor and the Caldicott Guardian; two out of 15 tested MHMDS releases were non-compliant with DSAs; eight of the 15 Social Care DSAs sampled remain incomplete; one of the 20 Clinical Audit DSAs could not be located and others tested displayed minor procedural exceptions relating to sign-off protocols; 16 of the Workforce population of 62 do not have evidence of approval or agreement, and two out of 15 tested displayed minor procedural exceptions relating to sign-off protocols; and 15 of the Population Health – Screening and Immunisations population of 32 do not have any record of a DSA (please refer to detailed findings HES4, SUS1, MHMDS2, SC1, SC2, CA1, CA3, CI1, CI2, WF1, WF4, PH-L1, PH-S&I1 and PH-S&I2).

6. *HES data releases*

- Between 1 April 2005 and 1 April 2009, all aspects of the HES data release service were run by Northgate. Records for this period are limited and present the risk that total HES data releases may be under reported (please refer to detailed finding HES1);
- For pseudonymised HES data released by Northgate prior to 1 April 2009, although 100% (30 out of 30) of the sample tested had some form of data agreement in place, the testing highlighted weaknesses around evidence of approvals, and an inconsistency in the level of detail relating to how data should be handled, secured and controlled by requesting organisations (please refer to detailed finding HES3);
- Further review of the Northgate contract was undertaken, specifically clause 2.5.8, which states "The Contractor shall obtain the permission of the Authority to disclose data when access to them is requested by another person. In any disclosure to a third party, the Contractor shall impose a non-disclosure undertaking which prohibits disclosure of the data to any other person by that third party." In the assessment of HES processes for the period 1 April 2005 to 1 April 2009, it has been possible to identify that a non-disclosure undertaking was in place for the items that were tested. Based on the information made available for the review, it has not been possible to identify specific evidence, for the sample of 37 tested, of case by case permission or approval from the NHS IC prior to the data being released by Northgate. However, following further discussions with the HSCIC and Northgate, it has been identified that the process used during this period did not require Northgate to seek specific approval from the NHS IC for releases of pseudonymised data; and
- Post 1 April 2009, testing highlighted 100% compliance with DRA/DSA requirements and 93% (28 out of 30) compliance with Approval Committee governance. This is consistent with an observed improvement in the overall quality and level of record keeping and documentation (please refer to detailed finding HES3).

7. *Limitations in terms of record keeping across functional areas*

- Many of the functional areas reviewed have historically maintained limited records of what data has been released. As a result, in these functional areas data release listings for this review have been compiled using the list of DRAs and DSAs maintained centrally by the NHS IC Information Governance team; and
- As the Information Governance team are 'reactive' in terms of granting agreements, there is a risk that the list of DRAs and DSAs may not be a complete list of all data that has been released by a specific functional area (please refer to detailed findings MHMDS1, SC1, CA1, CI1, WF1, PH-S2, PH-L1, PH-S&I1).

8. *Availability of records for the time period under review*

- There have been a number of instances where due to the period under review, 1 April 2005 to 31 March 2013, that detailed records of data releases have been limited; and
- This has been due to a combination of factors including the short timeframe in which the review has been completed, inconsistent and, in places, limited record keeping by the NHS IC, and the NHS IC records management policy of not retaining records after five years. (please refer to detailed findings SUS1 and CA2).

9. *Evidence of data release approval and release process*

- Although the review has confirmed that local processes and controls were in operation across the functional areas of the NHS IC during the period under review, a general lack of consistency has been observed; and
- In addition, there is a common theme around the lack of evidence maintained by functional areas to confirm approvals, date of approvals and date of data releases (please refer to detailed findings NBO1, NBO3, MHMDS3, MHMDS4, SC3, SC4, CA4, CI3, WF2, WF3, WF5, PH-S3, PH-L2, PH-S&I3).

b) Summary Findings – Data Releases – National Back Office

The NBO provide a service under specific legislation to the UKBA, Police, SOCA and Courts. This review identified that a total of **12,954** recorded responses to trace requests were made by the NBO in relation to the person trace service between 1 April 2008 (when the service transferred from the ONS to the NHS IC) and 31 March 2013. These releases can be summarised as follows:

- Police requests relating to serious offences (the NHS IC maintained a list of offences considered serious for which data is released against) and SOCA, relating to serious offences requested by the agency – **total of 3,949 trace request responses**;
- UKBA primarily linked to data requested for the purpose of the prevention or detection of immigration offences and/or protection of the NHS from potential abuse from immigrants to the UK– **total of 7,766 trace request responses**; and
- Court orders relating to information requested to be used in court proceeding or the tracing of families in divorce proceedings – **total of 1,239 trace request responses.**

Summary Findings – Analysis and Compliance Testing

NBO Trace Requests (please refer to detailed findings NBO1, NBO2 and NBO3)

- As this service is provided under specific legislation, there was no requirement for DRAs/DSAs. Records maintained of all NBO responses to trace requests confirm whether the request had been accepted, rejected or refused. However, there is no evidence or audit trail maintained to support this process other than the record of the final decision. From compiling responses to trace requests across NBO, it was possible to observe that a proportion of trace requests were either refused or rejected, which indicates that the processes and controls are operating;
- Processes and controls governing these trace requests had remained stable since the transfer of the service to the NHS IC in 2008; and
- For NBO related trace requests made to the Police, UKBA and SOCA, electronic records had been maintained from 1 August 2010. Prior to this, paper records were maintained and subsequently destroyed in accordance with the NHS IC IG policies for retention and disposal of records in place at that time. Therefore, responses to trace requests between 1 April 2008 and July 2010 have not been included within this review.

4. Detailed Findings – Health and Social Care Data

The detailed findings from the review for the functional areas relating to the release of health and social care related data are provided in the following section of this document. For each of the functional areas determined as in scope (please refer to Section 2: Method Statement), the detailed findings have been structured around the following headings to provide consistency:

Heading	Description
Highlights	Provides summary highlights for each functional area reviewed.
Context and Background	Provides a summary and background to each functional area, including the prevailing governance arrangements and controls in operation.
Summary of Approach	Approach adopted to perform the data release review specific to each functional area. This also includes a summary of the testing approach adopted against the prevailing governance and control arrangements. Further details of the sample testing methodology can be found in Appendix 6.
Analysis and Commentary	Analysis and commentary on the data releases made by the functional area during the period under review and a summary of testing performed.
Detailed Findings	Test exceptions and other findings identified as part of the review.

4.1 Hospital Episode Statistics

- *Total of 1,667 HES data releases identified between 1 April 2005 and 31 March 2013;*
- *Between 1 April 2005 and 1 April 2009 all aspects of the HES data release service were run by Northgate. Records for this period are limited and present the risk that total HES data releases may be under reported;*
- *Due to the lack of detailed records between 1 April 2005 and 31 March 2009, some exceptions have been identified in relation to linking identifiable data releases to Approval Committee authorisations, and the completeness of DRA/DSAs;*
- *There are limitations with the agreements available during 1 April 2005 and 31 March 2009 to support the approval by Northgate or the NHS IC of the release and subsequent handling of the data; and*
- *Post April 2009, overall record keeping and compliance with Approval Committee governance and DSA/DRA protocols was more robust, with only a small number of exceptions noted.*

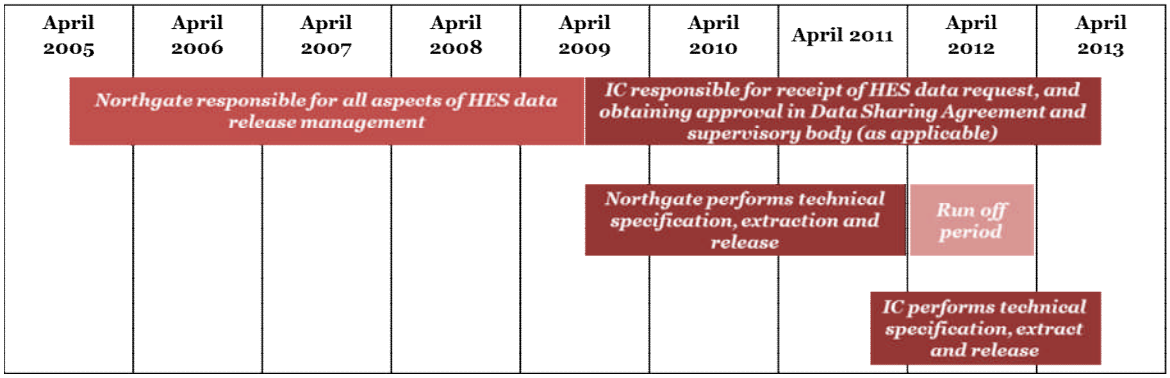
Context and background

HES data comprised of the admitted patient, outpatient and accident and emergency records for all NHS hospitals in England. There were over 125 million records processed annually.

The data was collected throughout a patient's time at hospital and was submitted to allow Trusts to be paid for the care they deliver. HES data was designed to enable secondary use, for non-clinical purposes, of this administrative data.

If an entity wished to obtain HES data, they needed to make a formal request stating the specific HES data that they required and if it was sensitive or patient identifiable for which an appropriate legal basis was also required. There were approximately between 100 and 200 HES requests made per year.

The handling of HES data requests and subsequent data releases changed throughout the lifetime of the NHS IC and is illustrated below:



Governance arrangements

The prevailing governance and control arrangements relating to the release of HES data evolved as the processes, which are illustrated further in Appendix 7, for handling the data changed over the period under review. The below table summarises the primary governance mechanisms identified as being in place for HES data releases:

Ref	Entity	Applicable time period	Identified control
1	Northgate	April 2005 to October 2012	For each release administered by Northgate, an Extract and Tabulation Checklist was completed at three specific points in the extract process stages. 1. Specification – assessment to ensure that all necessary detail had been completed and as applicable any selected sensitive or PID fields were highlighted for further authorisation; 2. Syntax Check – review to ensure that the specification syntax was correct; and 3. Output – review to ensure that the results and their format were consistent with the original request and agreed specification.
2	Northgate	April 2005 to April 2009	Prior to running the extract and releasing data, the requestor was required to sign up and agree to the agreements administered by Northgate and the HES Non-Disclosure Agreement (NDA) form in respect of the requested data. It was the responsibility of the requestor to document the controls in place that they were to have over the data, in line with the requirements laid out on the form.
3	NHS IC (IG)	April 2005 to April 2009	Upon a sensitive or PID field being identified as part of a request, IG was required to ensure that an appropriate legal basis was in place.
4	Information Governance	April 2009 to April 2013	Upon review of the draft DRA, if any sensitive of PID fields were selected by the requestor, IG checked to ensure that an appropriate legal basis was in place for this data to be released. Where it was not already in place, they notified the requestor what was required and put the release on hold until evidence of an applicable legal basis was provided.
5	Data Linkage Extract Service (DLES)/IG	April 2009 to April 2013	For all data extract requests that were made, a formal DRA was created that was required to be signed by the customer and followed by, or on behalf of the Caldicott Guardian, prior to the release of the data.

Summary of approach

Given the changes made to HES processes during the lifetime of the NHS IC, initial review activity focussed on identifying the processes involved in the production of HES data.

The HES data extract and release listing was compiled using four separate sources of data and primary identifiers to provide a listing of 1,667 releases (following the removal of duplicate records). The sources used were as follows:

- Northgate Information Solutions ("Northgate") third party database – a spreadsheet containing details of all data releases from the contract inception in 2003 to close in 2012;
- Ad hoc HES (AHES) database – Access database used by the DLES team to record details of HES requests from April 2009. The database contained detail from April 2009 to October 2012;
- Customer Relationship Management (CRM) report – a spreadsheet of HES data releases as per CRM for period of November 2011 to March 2013; and
- Information Governance Data Re-Use Agreements register – a spreadsheet listing of data releases and associated information governance documented information.

HES data releases were detailed by data types (admitted patient, outpatient and accident and emergency)for the CRM report only. This has not been possible for the other data sources due to insufficient data available. In addition, with the exception of the Information Governance Data Re-Use Agreements register, the information provided did not include details of the date of approval for the release, and thus the creation date from each source has been used for the testing of compliance against the governance and control arrangements. The variability in the level of data available has impacted the analysis performed.

Due to the significant change in the management of HES data releases, two separate samples were selected for testing to reflect the move from a wholly outsourced HES service to one with greater NHS IC involvement:

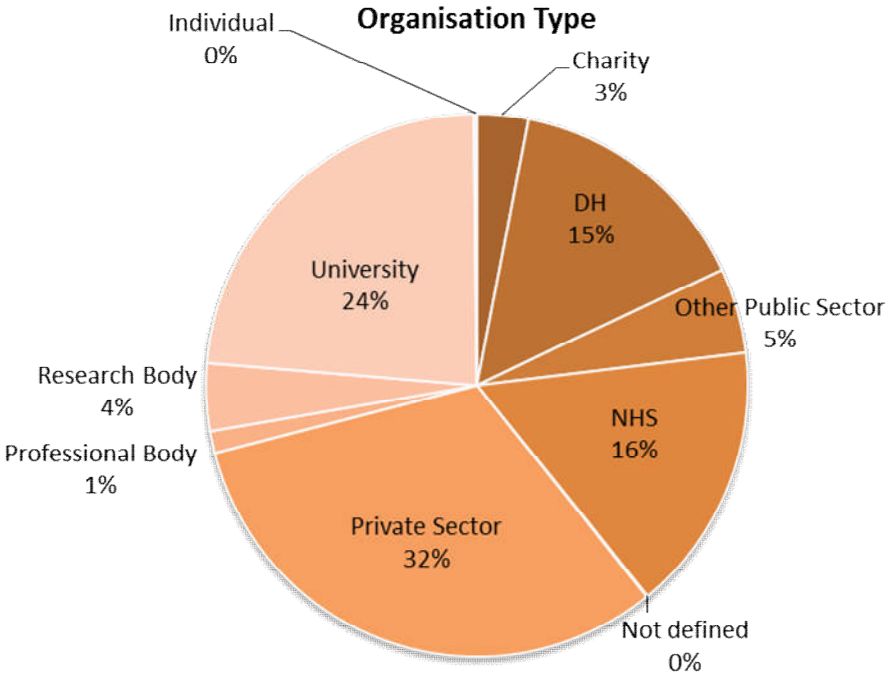
- April 2005 to April 2009 – due to limitations in time and the information available at the time of the review, it was not possible to identify the nature of data released i.e. pseudonymised, sensitive or identifiable. Therefore, the sample was haphazardly selected; and
- April 2009 to April 2013 – the sample specifically focussed upon pseudonymised, sensitive or identifiable.

Analysis and commentary

Data Release Listing

Further analysis has been undertaken on 1,667 data requests and releases made to each of the organisation types as illustrated below:

- Following requests since 1 April 2005, just under a third (529) of the data releases were made to private sector organisations and a nearly a quarter (392) to universities:



- The top ten organisations by volume of created data releases were as follows:

Organisation Name	Organisation Type	Data Releases
Information Centre (for control of internal sharing of data)	Department of Health ALB	53

Organisation Name	Organisation Type	Data Releases
Department of Health	Government Department	51
University of York	University	44
CHKS Limited	Private Sector	36
University of Oxford	University	33
Care Quality Commission	Department of Health (ALB)	28
UCL	University	24
National Cancer Services Analysis Team	NHS	22
NHIS Ltd	Private Sector	22
The University of Manchester	University	21

- The top five private sector organisations requesting HES data were as follows:

Organisation Name	Activity	Data Releases
CHKS Limited	Healthcare Intelligence	36
NHIS Ltd	Optimisation of healthcare organisations	22
Beacon Consulting	Pharmaceutical consultancy	18
Civil Eyes Research Ltd	Health services benchmarking	18
McKinsey and Company	Management consultancy	16

- A total of 99 HES data releases were identified whereby the associated financial year of approval was unable to be determined based on the available information during the compilation of the listing. The available information has found that whilst a specific financial year cannot be determined the releases are all associated with the time period between 1 April 2005 and 31 March 2009.

- For one HES release, issued in 2010/11, it has not been possible to determine the organisation that received the data based on available information and subsequent investigation. The released information was not flagged as containing sensitive or identifiable data. Further discussion with Northgate has indicated that this could relate to an internal Northgate request for data; however this could not be confirmed.

Testing

The testing approach adopted was:

Sample 1 – Northgate data releases 1 April 2005 to 31 March 2009

For data releases made prior to April 2009, it was not possible to identify the nature of the release based on the information provided for the purposes of the review. However, this is detailed within hardcopy evidence obtained by the NHS IC and archive boxes maintained by the DLES team obtained from Northgate. The contents of these boxes had not been indexed, thus limiting the sample selection method. Therefore, individual copies detailing the release were selected and reviewed to determine for inclusion in testing, specifically the following:

- Those dated between 1 April 2005 and 31 March 2009; and
- Those that did not request any sensitive or patient identifiable data.

Where a sensitive or identifiable request had been made and included within the sample, details of these were retained and tested as a separate population against the prevailing governance requirements. In total, 30 pseudonymised and seven sensitive/identifiable were selected for testing. Following the identification of a sample, the release and associated paperwork were assessed to determine that:

- The request was reviewed prior to release to ensure its accuracy and alignment to the original specification;
- Evidence has been observed to support the approval of the release by a senior staff member, either Northgate or the NHS IC; and
- Following a release, a signed agreement was in place with the requestor, and applicable member of Northgate or the NHS IC, which detailed the use, handling and storage of the data by the requestor.

Sample 2 – Pseudonymised, sensitive or PID releases

The HES listing post 1 April 2009 details the nature of the release (pseudonymised or identifiable) based upon the assigned coding. Therefore the sample could be effectively selected and tested using the criteria detailed in sample 1. In total, 30 pseudonymised and 30 sensitive/identifiable data releases were selected for testing. In addition, evidence was sought to validate that the release had been authorised by the relevant approval committee prevailing at the time of the release.

The following table summarises the testing results. Any exceptions identified are provided the detailed findings table below:

Time Period	Nature of Data Provided	Sample Size	Compliance with Prevailing Governance and Controls
1 April 2005 to 31 March 2009	Pseudonymised	30	• 100% (37 of 37) evidence of review prior to release • 0% (0 of 37) evidence of approval by Northgate or NHS IC • 0% (0 of 7) evidence of approval of sensitive or identifiable data • 57% (21 of 37) of agreements detailing appropriate use of the data • 16% (6 of 37) of agreements detailing handling of the data • 68% (25 of 37) of agreements detailing security and retention of the data
	Identifiable and sensitive	7	
1 April 2009 to 31 March 2013	Pseudonymised	30	• 100% evidence of review prior to release • 97% (58 of 60) with a supporting signed agreement • 93% (28 of 30) evidence of approval of sensitive or identifiable data • 100% (58 of 58) of available agreements detail handling, use and retention
	Identifiable and sensitive	30	

All of the 97 items tested had undergone some form of review prior to the data being released. However, the testing performed highlighted a lack of supporting evidence meaning that it was not possible to verify that an action had been performed as no supporting documentation had been maintained or retained. In particular, the level of evidence available to support the operation of controls surrounding data releases whereby the request was administered wholly by Northgate (1 April 2005 – 31 March 2009) was limited.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
HES1	**Limitations in the level of information available in respect of HES data releases between April 2005 and 31 March 2009** The management of the HES service was wholly outsourced to Northgate during the period 1 April 2005 to 31 March 2009. As of this date, the process for managing requests for HES data was brought in-house by the NHS IC with the remaining technical extract and release process being fully in-sourced by October 2012.

Detailed Findings and Testing of Compliance with Governance Arrangements

Ref	Finding
	Based on the information made available for the purposes of the review, it was not possible to identify a number of key pieces of data, thus limiting the assessment. These specifically include: • Date of approval; and • Type of HES data provided – outpatients, A&E, ONS etc. For releases requested subsequent to 1 April 2009 a richer dataset is available for analysis. However, although it is possible to determine the nature of the data provided, it is not always possible for the specific type of HES data released to be determined. This information only became available for data requests created from 2012 onwards due to an improved means of coding requests by the DLES team. As a result the total volume of HES releases is likely to be underreported.
HES2	**Lack of evidence to support appropriate authorisation of sensitive or PID HES data released** During testing of the data releases under the period which the HES data release service was run by Northgate, seven releases of sensitive or identifiable data were identified and tested. It was not possible to evidence supporting records that the releases had undergone review by the NHS IC and/or that applicable authorisation had been granted by the relevant governing committee. The releases were as follows: **Organisation Name** / **Organisation Type** / **Issue Date** Mid Cheshire Hospitals NHS Trust / NHS / 02/10/2006 Binleys / Private Sector / 11/10/2006 National Cancer Service Analysis Team / NHS / 08/03/2007 Mid Anglia GP Accident Service / Charity / 28/06/2007 South Manchester Univ. Hospital Trust NHS / NHS / 27/12/2007 Decision Resource Inc. / Private Sector / 15/05/2008 University of Liverpool / University / Not defined Further review of the Northgate contract, specifically clause 2.5.8 which stated "The Contractor shall obtain the permission of the Authority to disclose data when access to them is requested by another person. In any disclosure to a third party, the Contractor shall impose a non-disclosure undertaking which prohibits disclosure of the data to any other person by that third party." In the assessment of HES processes for the period April 2005 to April 2009, it has been possible to identify that a non-disclosure undertaking was in place for the items which were tested. Based on the information made available for the purposes of the review, it has not been possible to identify specific evidence, for the sample of 37 tested, of case by case permission or approval from the NHS IC prior to the data being released by Northgate. However, following further discussions with the HSCIC and Northgate, it has been identified that the process used during this period did not require Northgate to seek specific approval from the NHS IC for releases of pseudonymised data. In addition, a sample of 30 sensitive data or identifiable data releases tested for the period 1 April 2009 to 31 March 2013 identified two releases that did not have evidence available to support the required approval from the relevant committee or organisation. The identified releases were as follows:

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
	<table><tr><th>Organisation Name</th><th>Organisation Type</th><th>DRA Approval Date</th><th>Required Approval</th></tr><tr><td>Cooperation and Competition Panel</td><td>DH</td><td>02/08/2010</td><td>ONS or DMSG</td></tr><tr><td>University of Leeds</td><td>University</td><td>02/08/2011</td><td>ONS</td></tr></table>
HES3	**Exceptions identified in testing of HES releases administered wholly by Northgate (1 April 2005 – 31 March 2009)** For all 37 of the HES data releases tested from April 2005 to April 2009 (30 pseudonymised and seven sensitive/PID), evidence was present to support that all items had undergone a review by Northgate as evidenced on the Extract and Tabulations checklist. However, the following gaps in governance and controls were identified: • For none of the items tested (100%) was it possible to observe evidence to support that there had been any approval by Northgate or the NHS IC prior to release i.e. there was no corresponding signature from Northgate or the Caldicott guardian, in addition to that of the requestor on the Northgate data agreement or HES NDA; and • Upon review of the agreements administered by Northgate and HES NDA, there was inconsistency in the level of information provided in respect of how a recipient would ensure appropriate controls were in place over the data: – 9 of the 30 and 7 of the 7 items tested did not have any details documented as to how the requestor of the data would ensure that the data is used in an appropriate manner and in keeping with the original reason for the request; – 30 of the 30 and 1 of the 7 items tested, there was no evidence to support any requirements placed on the requesting organisations to document and sign-up to appropriate controls to be implemented to handle the data once received; – 11 of the 30 and 1 of the 7 items tested did not have any details documented as to how the data will be secured or the length it will be retained by the requestor; and – 1 of the 7 agreements detailed the retention period as three years. However, the agreement did not justify the need for the data to be retained more than 12 month, which was a requirement within a specific field of the agreement.
HES4	**Formally signed DRA unable to be located for data releases in the period post 1 April 2009** The approach to testing governance arrangements for releases subsequent to 1 April 2009 was similar to that of releases prior to April 2009. The largest difference being the way in which the sample was selected and the mechanism of testing itself, utilising more electronic based sources of evidence. Overall, there has been improvement in the level of evidence maintained enabling identification and assessment of the prevailing governance arrangements. However, for two releases out of 60 tested, it was not possible to evidence a signed DRA by both the requestor and the Caldicott Guardian. A copy of the draft unsigned Word version of each agreement was observed on the NHS IC IG maintained repository.

4.2 Secondary Uses Service

- *Total of 509 SUS data releases identified between 1 April 2005 and 31 March 2013;*
- *SUS releases to Health Solutions Wales and Imperial College London (Dr Foster Unit), SUS PbR extracts and SUS PbR releases to the Audit Commission were deemed in scope;*
- *The NHS IC introduced a formalised process to ensure DRA/DSAs were used since 2008. As a result, it has not been possible to identify whether agreements exist for SUS PbR releases to the Audit Commission and other organisations prior to this date; and*
- *Compliance with prevailing governance arrangements, including Approval Committee authorisation for identifiable data and DSA/DRAs, post 2008.*

Context and background

The purpose of SUS was to capture, process and enable access and reporting on all data relating to NHS commissioned activity in England. SUS provided a single repository for patient-based data and information for management and clinical purposes other than for direct patient care – secondary use. A monthly feed of SUS data populated the HES database. The management of the SUS service had been wholly outsourced to British Telecom (BT) for the period under review.

Data was submitted by healthcare providers in respect of admitted patient care, outpatients, accident and emergency and critical care.

Governance arrangements

There were differing datasets of SUS releases, which had varying governance arrangements as detailed in the table below:

SUS Release	In Scope?	Detail
Individuals accessing and obtaining SUS data direct from the SUS database using their NHS Registration Authority Smart Card	No	This was deemed out of scope as it was outside of the remit of the NHS IC. Organisations gained access to the SUS data through the NHS Registration Authority. Individual users of the organisation were granted role specific access by local information governance and registration agents. An organisation was only able to see SUS data that they had submitted.
Legacy releases direct from BT, who managed SUS on an outsource basis, to Health Solution Wales and Imperial College London (Dr Foster Unit)	Yes	In addition to the individual users gaining access to their SUS data, there were two legacy releases made by BT for a number of years, which commenced by the NHS IC in December 2006 and contained a fuller set of SUS data. The releases made were as follows: • Health Solution Wales – received monthly data on admitted patient care information on Welsh residents who had been treated in English hospitals; and • Imperial College London (Dr Foster Unit) – received a rolling monthly extract of the last 24 months of admitted patient care and outpatient data flows. Both organisations had in place a formal legal basis (section 251) for the data that they were receiving. These releases were based on a legacy agreement rather than specific requests.

SUS Release	In Scope?	Detail
SUS PbR extracts	Yes	Towards the end of 2011, the SUS PbR extract process was introduced, which was similar to HES extract requests. As with HES releases, a formal request process was required to be followed for SUS PbR extracts, managed by the DLES team. The volume of these requests was found to be small as the service had only been in place since the end of 2011. Requests may have been part of wider HES data extract requests or solely for SUS PbR data.
SUS PbR releases to the Audit Commission	Yes	Two datasets had been released to the Audit Commission in support of their audit activities of healthcare providers: • A quarterly release of pseudonymised SUS PbR data for inclusion in the Audit Commission's Benchmarker tool, used to assist in identifying specific areas of focus for an audit. This release had been in place since mid-2006, although a precise date could not be provided; and • A random sample of data requests that the Audit Commission utilised in their assessments, which was at an individual record level and contain sensitive data/PID. The Audit Commission had statutory authority for receipt of this data to complete data quality audits as required. Rather than individual agreements per release, annual DSAs were implemented with the Audit Commission stipulating the use of the data and an outline of the specific legal basis. No separate governing authority was required to approve the request.

Summary of approach

A series of meetings took place with key stakeholders to identify the associated processes involved in SUS data production. Due to changes within the NHS IC structure over time, it was not possible to speak to any individuals who were part of the predecessor organisation in 2005.

The listing has been compiled based upon the individual datasets for the in scope SUS releases:

SUS Release	Detail
Legacy releases direct from BT, who managed SUS on an outsource basis, to Health Solution Wales and Imperial College London (Dr Foster Unit)	• Confirmation was received from BT that the initiation of these monthly data extracts released to Health Solution Wales and Imperial College London (Dr Foster Unit) commenced in December 2006 by the NHS IC. The total number of releases to each of the legacy organisations was estimated to be 76, one for each month of the period. • There were no agreements in place as the data was provided at the inception of the NHS IC. The legal basis under section 251 has been validated.
SUS PbR extracts	• A listing has been maintained by the DLES team of such requests made and using information obtained from CRM, a population of extract requests has been determined. • A total of 10 SUS PbR extracts occurred during the NHS IC and

SUS Release	Detail
	a sample of five selected for testing to confirm evidence of review, approval and signed agreements.
SUS PbR releases to the Audit Commission	• Two datasets have been released to the Audit Commission in support of their audit activities of healthcare providers: – A quarterly release of SUS PbR data for inclusion in the Audit Commission's Benchmarker tool for which a total of 27 releases was calculated to have occurred – one per quarter since 1 April 2006; and – A random sample of data requests that the Audit Commission utilised in their assessments. Since the releases began in 2011, there were approximately 160 releases a year, equating to a total of 320 releases identified up to April 2013. • An annual DSA was available from 2009/10 for each year since, which covered the individual releases.

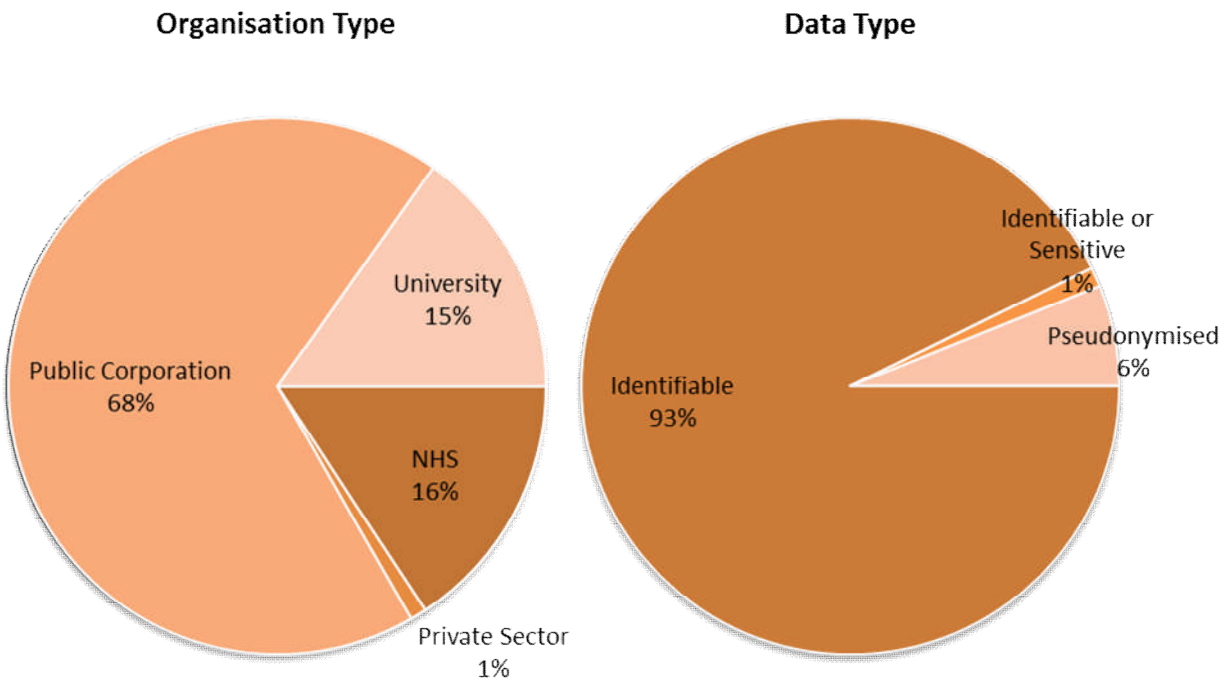
Analysis and commentary

Data Release Listing

Analysis has been undertaken on 509 data requests and releases made to each of the organisation types as illustrated below:

- Nearly two thirds of SUS data releases have been made to the Audit Commission and all contained either pseudonymised or identifiable data, although it was not possible to identify for six releases whether they were identifiable or sensitive:

Release type	Organisation Name	Organisation Type	Data Releases
Welsh Patient data (Legacy)	Health Solution Wales	NHS	76
Rolling 24 month data (Legacy)	Imperial College (Dr. Foster Unit)	University	76
SUS PbR Extract requests	See table below	NHS, Public and Private Sector	10
Benchmarker tool data	Audit Commission	Public Corporation	27
Random sample data	Audit Commission	Public Corporation	320
		Total	**509**



- A total of 10 SUS PbR extract requests have been received by the DLES team since they were introduced in 2011:

Financial Year created	Organisation Name	Organisation Type	Type of request
2011/2012	East Midlands SHA	NHS	Sensitive or PID
2011/2012	Ramsay Health – Westbourne Centre	Private Sector	Pseudonymised
2012/2013	Milliman	Private Sector	Pseudonymised
2012/2013	Civil Eyes Research Ltd	Private Sector	Sensitive or PID
2012/2013	BUPA	Private Sector	Sensitive or PID
2012/2013	McKinsey & Company	Private Sector	Pseudonymised
2012/2013	Clatterbridge Hospital	NHS	Sensitive or PID
2012/2013	NHS Central Midlands Commissioning Support Unit	NHS	Sensitive or PID
2012/2013	London Cancer Alliance	NHS	Pseudonymised
2012/2013	Imperial College London	University	Sensitive or PID

- Based on the small number of direct requests that were made, no specific in-depth statistical analysis is possible; and
- The total volume of SUS releases was estimated due to the lack of records at a data release level. There is therefore a risk of inaccuracy in this analysis.

Testing

Testing has been performed across the in scope releases identified to assess the following:

- The request was subject to review prior to the release to ensure its accuracy and alignment to the original specification;
- Evidence was available to support the approval of the release by a senior staff member;

- If the request was for data that was either sensitive or PID, there was an appropriate legal basis in place for the data to be issued; and
- Where a release was made, a signed agreement was in place between the requestor and the NHS IC, which stipulated how the requestor would use, handle and store the data.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
SUS1	**Lack of evidence to support DSAs prior to 2009** The NHS IC introduced a formalised process to ensure DRA/DSAs were used since 2008. As a result, it has not been possible to identify whether agreements existed for SUS PbR releases to the Audit Commission and other organisations prior to this date. During testing of the SUS PbR extract requests, no exceptions were identified.

4.3 Medical Research Information Service

- *Total of 591 approved customers to receive MRIS data releases identified between 1 April 2008 and 31 March 2013;*
- *Compliance with prevailing governance arrangements, including Approval Committee authorisation for identifiable data and DSA/DRAs, for 95% of the sample;*
- *77% (46 of 60 tested) of the sample identified in terms of longer standing studies having the appropriate Ethics Committee approvals; and*
- *More significant exception identified around specific studies having the required ONS Legal Gateway approval to release ONS related data. One study within the sample, which led to a further eight upon investigation, have been suspended pending ONS gateway approval.*

Context and background

MRIS or the DLES teams supported medical research through the provision of 'event driven' patient specific data to research customers. The majority of research groups were HEIs. Patient cohorts, supported by either Section 251 or consent, were tracked over a period of time. Data was released if an event had occurred that related to the scope of a study (e.g. death, cancer, move location, change of demographic data) at regular intervals agreed by the customer. There was also some data released to support clinical audit.

A record of the open agreements was maintained in a number of key systems within MRIS. Supporting documentation relating to each of the studies; including signed DSAs, application forms, appropriate ethical and governance support had also been maintained.

Governance arrangements

Applications were reviewed by the Applications Team to confirm that they had received ethical support from Research and Ethics Committees, evidence of patient consent or Section 251 Support and governance committee approval where applicable.

Where MRIS studies required the provision of ONS mortality data an additional legal basis would normally have been necessary in addition to a section 251, either in the form of permission under section 42(4) Statistics and Registration Service Act 2007 or through the researcher receiving 'Approved Researcher accreditation' from the ONS 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. On approval of accreditation as an Approved Researcher, the applicant's request for ONS mortality data was submitted by ONS to the ONS Microdata Release Panel (MRP).

To gain ONS MRP approval, requests must have met the MRP criteria and been consistent with the aims and principles of the Code of Practice and the Protocol on Data Access and Confidentiality that ONS had in place.

Once the application has been approved, a DSA was prepared which would be signed by the requestor and approved by the Caldicott Guardian or Head of IG on behalf of the Caldicott Guardian.

These are the relevant governance arrangements that are currently in place now. Governance arrangements, including ethical approval and relevant NIGB committees, were not as formalised in the past. Many MRIS studies were longstanding studies that pre-dated MRIS coming into the NHS IC in 2008; the oldest of the studies dated back to 1969. Technically, these studies were therefore originally agreed by predecessor organisations to the NHS IC. However, they have been included in the review in order to provide a comprehensive picture of the data releases made by MRIS under the NHS IC.

Although confidentiality agreements/DSAs would have been issued for data that was shared in relation to the agreements, these were not as detailed with guidance on how to store, handle, share and destroy data. However, it must be noted that for all open agreements at the time of transition, new DSAs should have been

issued or the studies would have been closed. Further ONS approval in relation to mortality data releases only came into place in 2009/10 and thus studies ended before this date would not have gone through these particular gateways.

Summary of approach

A scoping meeting was held with MRIS Delivery Manager, which identified the following:

- The data release listing for MRIS was developed with the Business Support Manager through compiling an initial list of DSAs for the period under review. It should be noted that the listing therefore represents the number of approved customers for the receipt of MRIS data;
- Each of the records was manually reviewed by the MRIS team to obtain the specific detail needed for the data release listing. Completeness and accuracy testing was undertaken to provide some comfort over the process, however there remains a risk of incompleteness and inaccuracy associated with this approach; and
- Testing of compliance with overarching governance procedures was undertaken by selecting a sample of MRIS data releases.

Analysis and commentary

Data Release Listing

The table below provides a breakdown of the number of agreements in place to receive data from MRIS by organisation type, for which just over half of the data releases were made to universities. It should be noted that although these were the organisations that received MRIS data, the commissioning bodies for related research studies were often the DH or NHS.

Organisation Type	Number of Data Releases
University	320
NHS	169
Research Body	39
Charity	22
Private Sector	13
Government Agency	11
DH	9
Government Department	5
Public Body	2
Professional Body	1
Total number of agreements for MRIS data	**591**

- 54% of all MRIS agreements for data to be released were with universities for research purposes with the institutions listed in the table below being the highest consumers of MRIS data for the period under review:

Top 10 Universities	Data Releases
London School of Hygiene & Tropical Medicine	28
The University of Birmingham	25
Clinical Trial Service Unit (CTSU)	24
University of Oxford	22
Institute of Cancer Research	12
The University of Manchester	12
University of Bristol	11
UCL	9

Top 10 Universities	Data Releases
Imperial College London	8
University of Cambridge	7

- In addition to universities, MRIS released data to a variety of other organisations, including research bodies, charities, other government departments and agencies. MRIS also released data to a number of private sector organisations during the period under review.
- Data releases made to private sector organisations are summarised in the table below:

Organisation Name	Data Releases
AstraZeneca	3
British Nuclear Group	3
Capita Surveys and Research	1
Causation Ltd	2
CAVATAS Central Office	1
Global SHE Operations, AstraZeneca	1
Occupational Health and Screening Services	1
The Boots Company Ltd	1

- The data released to these organisations was for the purpose of patient tracking, was sensitive and typically provided NHS Registration data, cancer data, and mortality data; and
- Of the 591 data release agreements made by MRIS:
  - 565 (96%) contained patient identifiable data or sensitive; and
  - 26 (4%) contained pseudonymised data.

Testing

A sample of 60 identifiable and sensitive releases was selected for testing. Each release was tested against three main criterion to evidence that there has been the appropriate level of review and challenge in place regarding requests prior to the release:

- Initial Ethics Committee approval from a valid Research Ethics Committee (REC) – 77% (46/60) of the sample has supporting evidence to confirm the relevant approval from a REC. However, for one of these, ONS gateway approval was required as it contained mortality data but this has not been obtained;
- Governance committee approval e.g. PIAG, ECC, etc. – 100% of the sample agreed to committee approval or patient consent where applicable; and
- DSA signed by/on behalf of the Caldicott Guardian – 95% of the sample had a signed DSA in place and for the three that did not, these studies were confirmed as either closed or suspended due to no signed DSA.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
MRIS1	**Ethics Committee Approval** For 14/60 of the studies tested (23%), there was no evidence of specific ethics approval from a valid Research Ethics Committee on file. It must be noted that many MRIS studies were longstanding studies that pre-dated MRIS coming into the NHS IC in 2008; the oldest of the studies dated back to 1969. Technically, these studies were therefore originally agreed by predecessor organisations to the NHS IC and therefore requirement for valid ethical approval before the study went ahead was not a formal requirement. However, they have been included in the review in order to provide a

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
	comprehensive picture of the data releases made by MRIS under the NHS IC. Of the 14 studies identified as without Ethics Committee approval by this review, further investigation has confirmed that three do have Ethics Committee approvals 10 of the studies have closed and one still has no evidence
MRIS2	**ONS Legal Gateway Approval** For one study there was no evidence of appropriate approval via ONS gateways for the release of mortality data. Following identification of this exception, further testing on the full data release listing identified a further eight releases that did not have the appropriate ONS gateway approval for the release of mortality data. As a result of the review, these releases have been suspended until this is obtained. The studies identified as exceptions are as follows:

Approval Date	Organisation Name	Legal Basis for Provision of Data if Sensitive and/or Identifiable
15/05/1985	Institute of Child Health	Section 251 Support
Pre-2008	Strangeways Research Laboratories	Section 251 Support
04/06/1996	University of Birmingham	Section 251 Support
25/11/1997	Oxford University	Section 251 Support
05/01/1999	Imperial College London	Section 251 Support
01/11/2000	University of Birmingham Clinical Trials Unit	Section 251 Support
16/04/2003	University of Oxford	Section 251 Support
20/07/2004	CSEU, Institute of Cancer Research	Section 251 Support
01/07/1996	Addenbrookes Hospital	Section 251 Support

4.4 Mental Health Minimum Data Set

- *Total of 28 MHMDS data in scope releases identified between 1 April 2005 and 31 March 2013;*
- *Compliance with prevailing governance arrangements, including Approval Committee authorisation for sensitive data and DSA/DRAs, with only one exception identified from sample testing performed;*
- *The listing was compiled using the records maintained locally by the functional area and centrally used the records of agreements held by the NHS IC IG team, which gives rise to the risk that the listing may not be complete; and*
- *There is no recorded evidence or audit trail of when data releases were approved or released.*

Context and background

MHMDS contained record-level data about the care adults and older people received using secondary mental health services, which encompassed services provided in outpatient clinics and the community as well as hospitals. MHMDS consolidated information about each patient across the mental health care pathway, and could be used to support a variety of secondary use functions and a comprehensive national picture of the use of specialist mental health services in England.

The information was captured across the mental health pathway by the provider and compiled into one record. Data was submitted to Connecting for Health in Exeter, which was pseudonymised and sent to the NHS IC to create extracts. Extracts of record-level MHMDS data to a pre-determined specification were produced starting with 2006/07 data. With the increase in requests for data, a service providing sensitive or non-sensitive data was introduced in 2011, which also included a change to the data set. This service was managed by the Mental Health team. During 2013, the handling of extract requests including this service was taken over by DLES.

The first publication from the NHS IC was made in 2008, covering MHMDS data up to 2006/07. Three main historic customers were recipients of annual MHMDS data being: Dr Foster Intelligence Ltd, CQC and Public Health Observatories.

Governance arrangements

All customers were subject to an approval process resulting in a DSA prior to the release of the data. Only one annual DSA per organisation was required covering pseudonymised data.

From 2007-11, a request for data would be received and reviewed by the team. The team would draft a DRA/DSA and submit to the NHS IC IG team for review. The relevant governance bodies prevailing at the time would be involved accordingly where the data was deemed sensitive and further approval was required.

In 2011 following the provision of an extract service, two separate DSAs were required per organisation dependent upon the sensitivity of the pseudonymised data:

- For non-sensitive data, the Senior Information Risk Owner (SIRO) signed-off the DSA; and
- For sensitive data, DAAG approved the release.

Summary of approach

The listing of data releases was compiled by the Business Support Manager using the records maintained in relation to DRAs/DSAs and also the list of MHMDS specific agreements since 2009 held by the functional area. The listing was cross referenced to the listing of DRAs/DSAs held by the NHS IC IG team for completeness using MHMDS specific wording, recipient organisations and key contacts. Any differences e.g. status of DSA/DRA, and additional releases identified as MHMDS specific were confirmed and included. Any out of scope releases were removed from the listing.

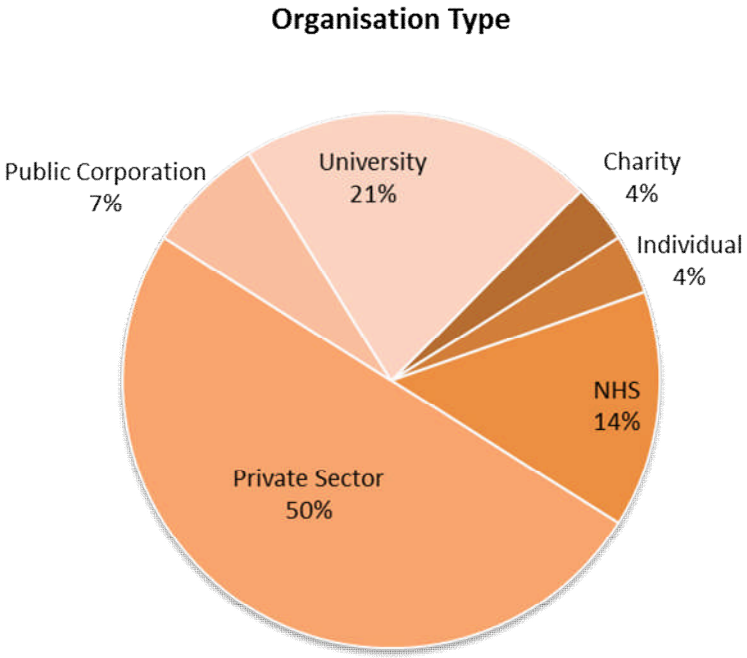
The finalised listing contains 21 original DRA/DSAs and seven amendments to such agreements, for which the agreement does not detail data handling/usage but does refer back to the original agreement. Based on this, a sample of ten releases pertaining to an original agreement and five amendments to the original agreements were selected for testing against the prevailing governance arrangements.

Analysis and commentary

Data Release Listing

Further analysis has been undertaken on the 28 data requests and releases made to each of the organisation types as illustrated below:

- Half (14) of the data releases have been made to private sector organisations, six of which were to Parallel (a web design company):

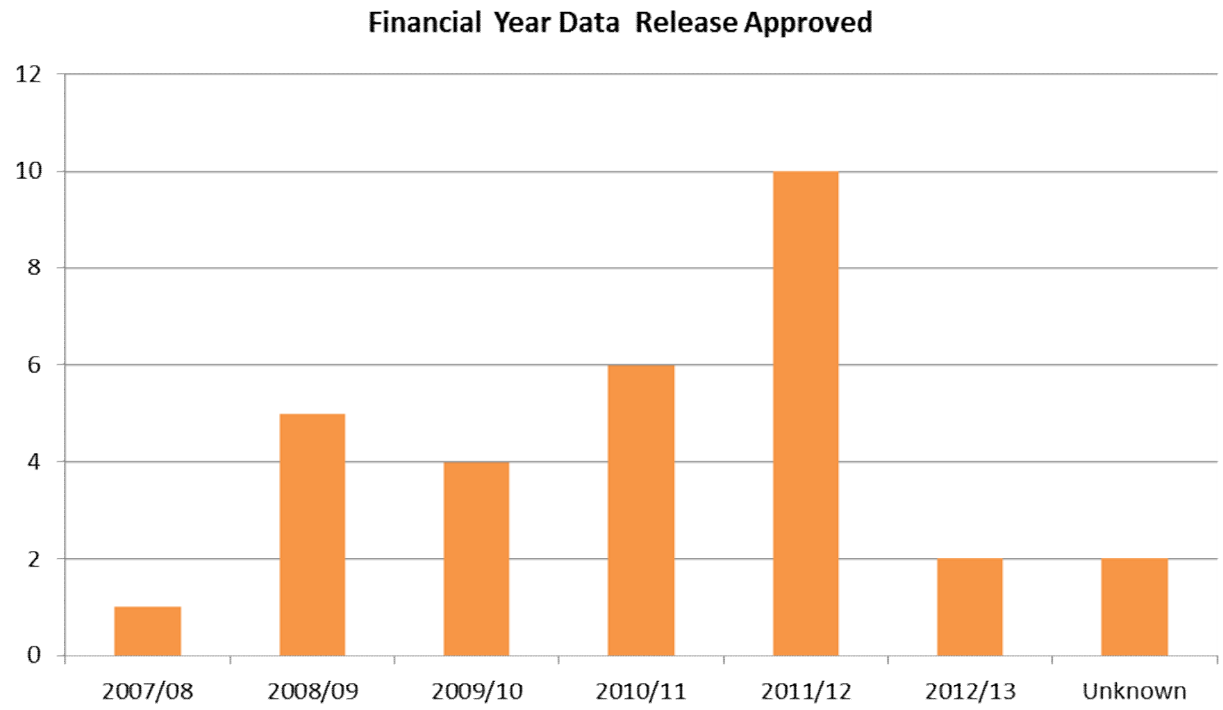


- All releases within the compiled listing were pseudonymised; however, three of these requests from universities for research purposes contained sensitive data and therefore required DAAG approval:
- Many of the recipient organisations have only had one or two data releases. The organisations that received more than two can be broken down as follows:

Organisation Name	Organisation Type	Data Releases
Parallel Web Design – many of these requests were to populate the MHMDS website.	Private sector	6
Dr Foster Intelligence Ltd – data requested for the development of a new indicator, quality audit purposes and incorporation into the dataset for a range of Dr Foster Intelligence information tools for mental health trusts and other NHS bodies.	Private sector	4

- For two releases made, it was not known when the request for the release was finally approved. The details of these releases are below:
  - **CHKS Ltd**– the release did not contain sensitive or identifiable data, and the purpose was to be used by CHKS as part of a product or services to be sold by the organisation to their customers; and

– **Parallel Web Design** – the release did not contain sensitive or identifiable data, and the purpose was to populate the existing MHMDS online website with additional analyses of 2006/07 data by Primary Care Trust (PCT).



- More requests were received in 2011/12 when the Mental Health team developed a more formal extract service to meet demand. Few requests have been received since the DLES team took over the service in 2013.

Testing

- 15 releases were selected for testing, which comprised of ten releases pertaining to an original agreement and five amendments to agreements;
- The majority of amendments did not contain any details relating to data handling or reuse and referred back to the original agreements. Therefore, sample testing of such amendments were agreed back to the original agreement;
- All releases, except for one, equating to 93% of the sample, were agreed to signed original agreements, which detailed data handling, use and retention;
- Three releases required DAAG approval and thus included in the sample, with the remaining 12 haphazardly selected; and
- All releases requiring DAAG approval were corroborated to meeting minutes accordingly to support the approval. However, local controls were implemented at a functional level to review, challenge and approve all other releases for which there was no supporting documentation.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
MHMDS1	**Listing Compilation** Limited record keeping by the functional area detailing the data releases that have been made during the period in question was identified. The data release listing was compiled using DSA/DRA records available and functional level specific records, which raises a risk of incompleteness. The following exceptions was noted: • Three items had been missed from the list compiled by the functional area, of which two required DAAG approval.
MHMDS2	**Accuracy of Records** Discrepancies were identified between the listing of releases compiled by the functional area and the listing of agreements held by NHS IC IG team, which encompassed additional releases and differing statuses of agreements. Two releases were not marked as completed but confirmation was provided from the functional area that the data had been released, although it was not possible to evidence: • One release could not be traced to a signed DRA. It was marked as approved, not completed, on the IG listing but the functional area confirmed that they supplied the data. The release was non-sensitive, pseudonymised data that was released in August 2012 to CHKS Ltd; and • One release was identified and confirmed by the functional area but was marked as not completed on the NHS IC IG team listing and had no signed DSA either. The release made in January 2009 was non-sensitive, pseudonymised data to Parallel Web Design.
MHMDS3	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, unless this was escalated to DAAG given the sensitive nature of the data, thus limiting the testing. The review and approval process was performed at a functional level, with no evidence prior to request for a DSA/DRA. A signed agreement was deemed as approval.
MHMDS4	**Audit Trail of Data Release Date** Limited formal audit trail to corroborate the date that the data was actually released to the organisation for the releases included within the listing. A log was maintained but this was predominantly for the recipients of annual data and PCTs.

4.5 Social Care

- *Total of 26 Social Care data releases identified between 1 April 2005 and 31 March 2013;*
- *The listing was compiled using the records maintained locally by the functional area and centrally used the records of agreements held by the NHS IC IG team, which gives rise to the risk that the listing may not be complete; and*
- *Limited recorded evidence or audit trail of when data releases were approved or released.*

Context and background

The Social Care team collected and published a wide range of information (for example: social care activity, expenditure, workforce and surveys that are participated by survey users) on adult social care that could be used to help monitor and deliver services. The majority of the data received from the 152 local authorities was aggregated, but survey data was at a record-level. The data was typically used for:

- Social care publications;
- Research purposes specifically requested by organisations; or
- By the local authority only for MI purposes and further validation prior to publication.

Instances where Social Care shared data were:

- Providing local authorities with early access to data via NASCIS (National Adult Social Care Intelligence Service) for MI purposes using terms and conditions as in some cases the data would have been further revised prior to publication;
- Long term relationships with CIPFA (Chartered Institute of Public Finance and Accountancy), who until recently did part of the validation process on expenditure data due to a long term agreement around 'joint ownership' of the collection;
- Via DSAs, often with DH or academia/charities, to allow them to analyse the data prior to publication and/or use the data with small numbers included; and
- Via a DSA with TEASC (Towards Excellence in Adult Social Care) through which they shared reports with small numbers with local authorities for MI purposes.

Governance arrangements

Requests for data were received directly by the team for review and challenge. If the request was deemed appropriate, it was submitted to the NHS IC IG team for approval and drafting of a DSA.

Summary of approach

The listing of data releases was compiled by the Social Care Section Head using the records maintained by the team and the NHS IC IG team, including draft DRAs/DSAs and archived repositories.

The data release listing was cross referenced to the listing of DRAs/DSAs held by the NHS IC IG team for completeness. No further additional releases were identified. Any out of scope releases were removed from the listing.

The listing originally provided contained 64 releases (21 from records maintained by the functional area and 43 from review of the NHS IC IG team listing of DRA/DSAs). All releases were defined as aggregated small numbers not supressed.

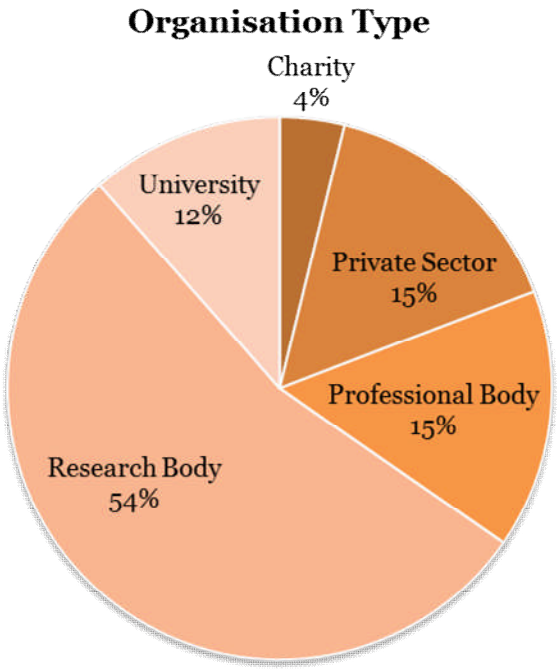
The finalised listing contains 11 original DRA/DSAs and 15 amendments to such agreements, for which the agreement did not detail data handling/usage but did refer back to the original agreement. Based on this, a sample of ten releases pertaining to an original agreement and five amendments to the original agreements were selected for testing against the prevailing governance arrangements.

Analysis and commentary

Data Release Listing

Further analysis has been undertaken on 26 data requests and releases made to each of the organisation types as illustrated below:

- Approximately half (14) of the data releases have been made to research bodies, of which 12 of these have been to Professional Social Services Research Unit (PSSRU):



The recipient organisations can be broken down as follows:

Organisation Name	Organisation Type	Data Releases
PSSRU	Research Body	12
Amadeus Software Limited	Private Sector	3
CIPFA	Professional Body	3
NatCen	Research Body	2
University of Kent	University	2
Age UK	Charity	1
Care Performance Partners Limited (CaPP)	Private Sector	1
School of Health and Related Research (ScHARR), University of Sheffield	University	1
Skills for Care	Charity	1

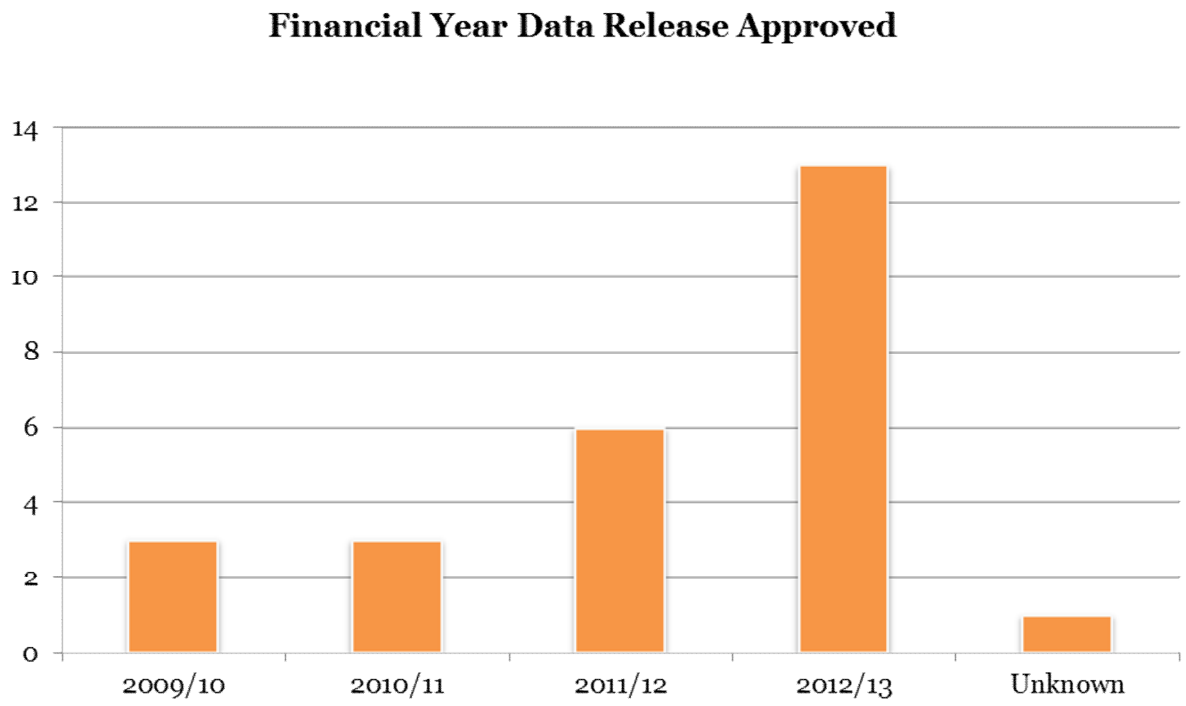
The details of the requests for private sector organisations and professional bodies are below:

- **Amadeus Software Limited** – whilst there were three data releases, there was one DSA and two amendments to it. The original DSA was put in place in June 2012 (both amendments were approved July 2012) as the consultants at Amadeus were contracted to build the SAS (statistical analysis software) processes for the NHS IC's internal Data Management Environment (DME) project. Use of historically

submitted raw data was required in order to robustly test user acceptance of the newly developed process prior to the adoption for the processing internally of the 2011-12 data return on 6 July 2012; and

- **CaPP** – this private sector organisation required data to contribute to a report for the TEASC Board in June 2012;
- **CIPFA** – these three data releases include one original DSA (approved August 2010), one amendment and one extension to it (approved August 2010 and June 2011 respectively), all of which were for CIPFA publications.

- For one release made to Skills for Care, it was not known when the request was finally approved.



Testing

- 15 releases were haphazardly selected for testing, which comprised of 10 releases pertaining to an original agreement and five amendments to agreements, for which they were agreed back to the original agreement;
- The majority of amendments did not contain any of the data handling or use and referred back to the original agreements. Therefore, sample testing of such amendments were agreed back to the original agreement;
- All releases, equating to 100% of the sample, were agreed to signed original agreements, which detailed data handling, use and retention; and
- As all the releases were not PID, local controls were implemented at a functional level to review, challenge and approve the releases for which there was no supporting documentation.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
SC1	**Listing Compilation** Limited record keeping by the functional area detailing the data releases that have been made during the period in question was identified. The data release listing was compiled using

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
	DSA/DRA records available and functional level specific records, which raises a risk of incompleteness.
SC2	**Accuracy of Records** As the listing of releases was compiled by the functional area using the listing of agreements held by the NHS IC IG team and draft DRA/DSAs, there are no reliable records to confirm whether data was provided following the discrepancies identified: • One data release identified by the functional area using the records maintained was marked as never completed on the NHS IC IG team listing. The functional areas is unable to confirm whether data was ever provided as there is only a draft DSA available; and • Seven data releases identified by the functional area from the NHS IC IG listing of DRA/DSAs are marked as never completed. However, the functional area has no reliable records to identify whether data has been released or not and have not been included within the listing.
S3	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, thus limiting the testing. The review and approval process was performed at a functional level, with no evidence, prior to request for a DSA/DRA. A signed agreement was deemed as approval.
S4	**Audit Trail of Data Release Date** No formal audit trail to corroborate the date that the data was actually released to the organisation. For 18 of the 26 releases, this was unknown and for the remainder, only the month could be provided based upon the approval date of the DRA/DSA.

4.6 Clinical Audit

- *Total of 88 Clinical Audit in scope data releases identified between 1 April 2005 and 31 March 2013;*
- *35 other potential releases have been identified but could not be confirmed as they were not marked as completed on the NHS IC IG team listing and have no evidence of a final signed-off agreement. These were omitted from the listing. However, upon further investigation some of these have been reconciled to the listing of approvals of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) data access requests summary made publically available by Health Quality Improvement Partnership (HQIP);*
- *Compliance with prevailing governance arrangements, including Approval Committee authorisation for identifiable data and DSA/DRAs; however, a number of exceptions were noted around the completeness of DSA/DRAs;*
- *Records are not available pre-2008 in line with NHS IC Records Management policies, so the release listing does not include data released prior to this period; and*
- *There is no recorded evidence or audit trail of when data releases were released.*

Context and background

Clinical audits were nation-wide processes designed to understand and enhance care provided to patients. There were several national clinical audits collecting information and producing annual reports.

The NHS IC may have been commissioned by organisations, such as the HQIP, to run these audits. Where this was the case, agreement was required from such organisations to share the data, as they were the data controller.

Data requests came from a wide range of customers, such as universities, medical royal colleges and other professional bodies. However, each audit area usually had a number of established partners. Although the data collected for the purpose of audit usually contained PID, it was often released as pseudonymised or aggregated.

Governance arrangements

Data from the audits was released under Section 251 where relevant. Individual clinical audits applied for an umbrella Section 251 approval enabling the NHSC IC to disclose data to partner institutions without the need to obtain further approvals for individual releases for a given period of time.

A Data Access Request (DAR) was completed by the data requestor and submitted to the relevant Clinical Audit team for which the data related to. The Clinical Audit team reviewed the request and if deemed appropriate, a DRA/DSA was drafted and submitted for review by the Information Asset Owner (IAO) within Clinical Audit and finally to the NHS IC IG team. Following IG approval, the Clinical Audit team would issue the DRA/DSA to the requestor for sign-off and in addition to the data controller where it was not the NHS IC.

Final sign-off of the DRA/DSA was obtained from the NHS IC IG team on behalf of the Caldicott guardian. Each Clinical Audit had its own records and documentation within specific repositories for the request.

Summary of approach

The listing of data releases was compiled by each Clinical Audit Manager using the records maintained within the functional area repositories, their experience and corporate memory given that many of the Clinical Audit Managers have changed roles or left over the lifetime of the NHS IC. The DRA/DSA listing held by the NHS IC IG team was also assessed.

It has not been possible to compile a listing of data released prior to 2008 as records were paper-based and disposed of in accordance with the NHS IC IG data retention policies.

The Clinical Audit team provided relevant DSA numbers for each release, which were used and reviewed to compile the listing and capture the details required. Therefore, 100% of the population could be traced to an agreement.

The listing was cross referenced to the listing of DRAs/DSAs held by the NHS IC IG team for completeness. 35 agreements were identified as being recorded as not completed on the IG listing, the majority of which related to amendments that were never finalised.

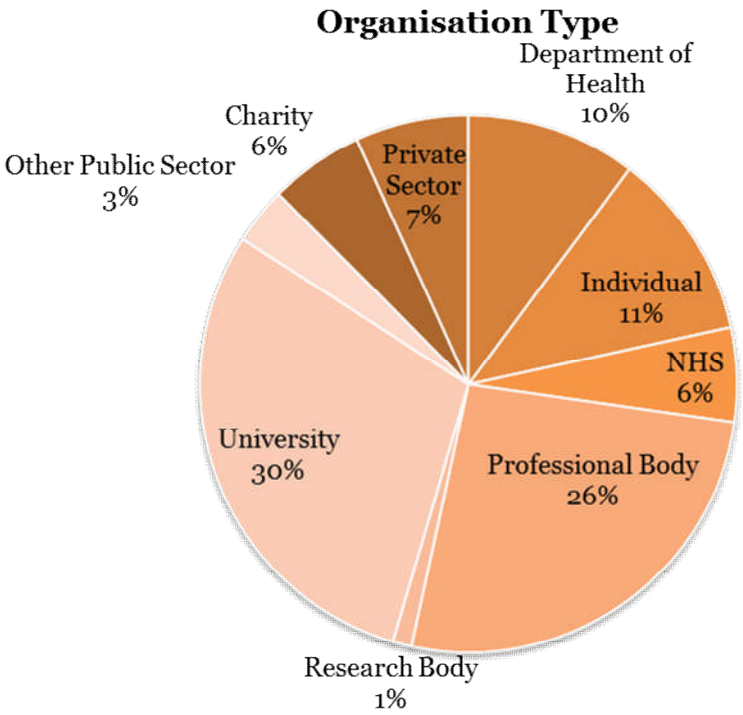
The finalised listing contains 88 original DRA/DSAs and 18 amendments to such agreements, for which the agreement did not detail data handling/usage but referred back to the original agreement. Based on this, a sample of 20 releases pertaining to an original agreement was selected for testing against the prevailing governance arrangements.

Analysis and commentary

Data Release Listing

Further analysis has been undertaken on 88 data requests and releases made to each of the organisation types as illustrated below:

- Approximately half (49) of the data releases have been made to either professional bodies (23) and universities (26), as partners in the clinical audits, which include:

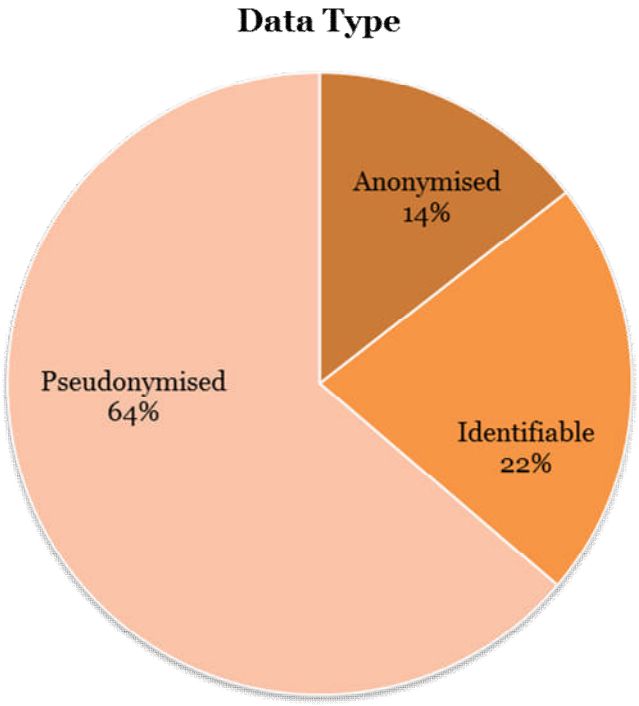


- Many of the recipient organisations have only had one to three data releases. The organisations, as contract partners, that have received more than three can be broken down as follows:

Organisation Name	Organisation Type	Data Releases
Clinical Effectiveness Unit (CEU)	Professional Body	11
Division of Epidemiology and Public Health, University of Nottingham	University	9

Organisation Name	Organisation Type	Data Releases
Individual (Burton Hospitals NHS Trust)	Individual	5
Quantics – the purposes of these releases were requested for analyses to support the functions of the National Hip Fracture Database (NHFD) annual report and Casemix adjusted outcomes, development of the database, user queries related to the audit and further observation and research work. This organisation was commissioned by the RCP (Royal College of Physicians), as contract holders for that audit to provide analysis.	Private Sector	5
Royal College of Surgeons CEU	Professional Body	5
Individual at University Hospital Birmingham NHS Foundation Trust	Individual	4

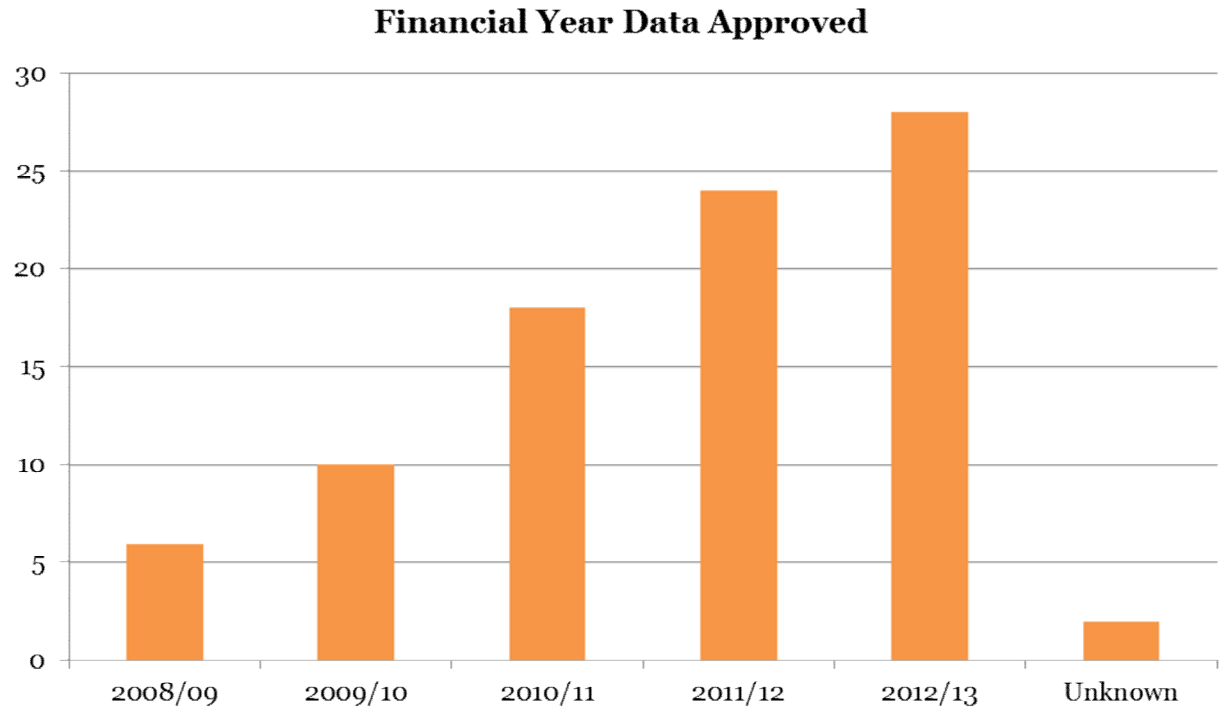
- 15 of the data releases contained identifiable data and 44 of them were pseudonymised:



- For two releases, it was not known when the request for the release was finally approved by the Caldicott Guardian. The details of these releases are below:

  – **University of Oxford** – whilst this original agreement did not evidence final approval, the amendment to the agreement did. The release did not contain sensitive or identifiable data, and the data was required to carry out research for which the output was to be in the form of a clinical decision support platform, intended to act as a software tool to assist the clinicians in coming to informed, timely, safe and effective decisions in lung cancer care; and

  – **The Royal College of Surgeons** – a signed copy of this amendment was not available; however, the original agreement was appropriately signed. The release was an extension of an amendment that did contain sensitive data for which a Section 251 was obtained. The data was originally obtained from the Intensive Care National Audit and Research Centre (ICNARC) Casemix programme dataset and linked to the prospective O-G cancer audit dataset for use in the production of the audit report. The linked dataset was to be anonymised and provided to the CEU for analysis.



Testing

- 20 releases were selected for testing, all of which pertained to an original agreement. The releases were haphazardly selected based upon the nature of the data;
- The majority of amendments did not contain any of the data handling or use and referred back to the original agreements. Therefore, sample testing of such amendments were agreed back to the original agreement;
- All releases, except for one, equating to 95% of the sample, were agreed to signed original agreements, which detailed data handling, use and retention; and
- 90% of the sample required PIAG/ECC approval and thus included in the sample. All these releases were corroborated to meeting minutes accordingly to support the approval. However, local controls were implemented at a functional level to review, challenge and approve all other releases prior to submission to the NHS IC IG team, for which there was no supporting documentation to evidence this.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
CA1	**Listing Compilation** The data release listing was compiled using the data contained within specific folders for each clinical audit and general corporate memory. Discrepancies were identified between the details captured for the listing using these records and the DRA/DSA listing held by the NHS IC IG team. Many of the agreements for the releases identified were not marked as completed with no corresponding date of Caldicott Guardian signature in the DRA/DSA listing: • 27 agreements were marked as not completed; and • Eight agreements marked as final/draft, for which three of these agreements were evidenced but only signatures were obtained from HQIP as data controllers. It was not possible to determine whether agreements had been approved and data shared or not. As such, these have been omitted from the listing. However, at the time of report writing, additional

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
	sources of information were highlighted being the National Clinical Audit and Patient Outcomes Programme (NCAPOP) data access requests summary made publically available by HQIP. This register details the status of approval for the NHS IC's agreements. Given the time constraints and further work required, it has not been possible to verify whether these were actual releases or not.
CA2	**Availability of records** It has not been possible to compile the list prior to 2008 and identify data releases where the NHS IC IG data retention rules have been complied with as records are only kept for a review of a minimum retention period of five years from the date of completion of audit.
CA3	**Supporting DSAs** Of the 88 releases included within the listing that needed to be traced to an agreement to compile the listing, the following exceptions were noted: • One was not signed by, or on behalf of, the Caldicott Guardian. However, there was a signed amendment to that agreement; • Four were signed by, or on behalf of, the Caldicott Guardian, prior to the signature of the relevant Clinical Audit Manager; • Six did not have a supporting date of signature from either the NHS IC or the data requestor; and • One amendment to an existing agreement did not have a scanned signed copy. All other releases were agreed to signed and dated agreements, which detailed data handling, use and retention.
CA4	**Audit Trail of Data Release Date** No formal audit trail to corroborate the date that the data was actually released to the organisation where this was via email, courier or external drives. In addition, limitations within the functionality of the system used to release data (Data Depot) meant that individual data releases were not matched with relevant DSAs and there was no easy way to link the two, particularly given the lack of bulk export functionality and time constraints to conduct this review.
CA5	**Date of Death Interpretation** Clinical Audit Managers treated date of death as sensitive, non-identifiable information, which agrees to the FAQs on legal access to PCD pages on the HSCIC website. However, there is inconsistency with this definition across the organisation. The HSCIC, within their DLES pages on the website, define data of death as PCD in which individuals are clearly identified, or there is a high risk of individuals being identified. This includes PID, such as: • NHS number; • Name; • Address; • Postcode; • Date of Birth; and • Date of Death.

4.7 Clinical Indicators

- *Total of 50 Clinical Indicator in scope data releases identified, which commenced in quarter one of 2011/12;*
- *Compliance with prevailing governance arrangements, including Approval Committee authorisation for identifiable data, ONS gateways and DSA/DRAs, with only minor exceptions identified;*
- *The listing was compiled using the records maintained locally of requests received, for which the list is used help the team manage relations with customers when they request new data. However, some discrepancies were identified between this listing and the agreements held centrally by the NHS IC IG team; and*
- *Some exceptions noted of the lack of evidence or audit trail of when data releases were approved or released.*

Context and background

The Clinical Indicators team produced a number of indicators for health and social care professionals, as well as information specialists, researchers and citizens. They were quantitative measures that captured information about care. The Summary Hospital-level Mortality Indicator (SHMI) was the only indicator that had been identified as containing identifiable data, and is therefore in scope for this review. Other indicators contained data that was released at an aggregate level via the indicator portal, as a sole repository for range of health indicators.

Development of the SHMI began in 2010 following a request from the DH. The SHMI was first published in October 2011. It was an aggregated indicator that was produced from HES data linked to ONS death registrations data as it reported on mortality at Trust level across the NHS in England and therefore included identifiable data.

Governance arrangements

SHMI is an official statistic commissioned by the Secretary of State for Health, which is produced and published on a quarterly basis. Where a release of SHMI data was to an organisation commissioned by the Secretary of State (SoS) to support the development of the SHMI, DH on behalf of the SoS provided the approval and legal basis under which the data was released. This approval falls under the Statistics and Registration Service Act 2007 section 42(4) 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.

Where necessary, the NHS IC IG team dealt with obtaining the relevant approvals prior to putting in place the DRA. Guidance was sought from the NHS IC IG team on what type of agreement (either a DRA or a DSA) was appropriate for each data request. Some data shared were aggregated but not suppressed for small numbers, as determined by the purpose for which the data were needed and expressed in each agreement for the use of the data.

Drafting of new agreements and communication with the data requestor was predominantly carried out by the NHS IC IG team. The NHS IC IG team retained copies of the signed final agreements.

Summary of approach

A record was maintained of all data released since June 2011, which detailed existing and expired agreements. The information contained within this record included, for example: agreement numbers and status, details of agreement amendments, general description of the type of data requested, data transfer methods and key contacts. This record has been used to compile the listing of releases.

The listing provided contained 50 releases, which was cross referenced to the listing of DRAs/DSAs held by the NHS IC IG team for completeness. 10 amendments to the agreements were identified that did not share further

data, and as such they have not been included within the listing.

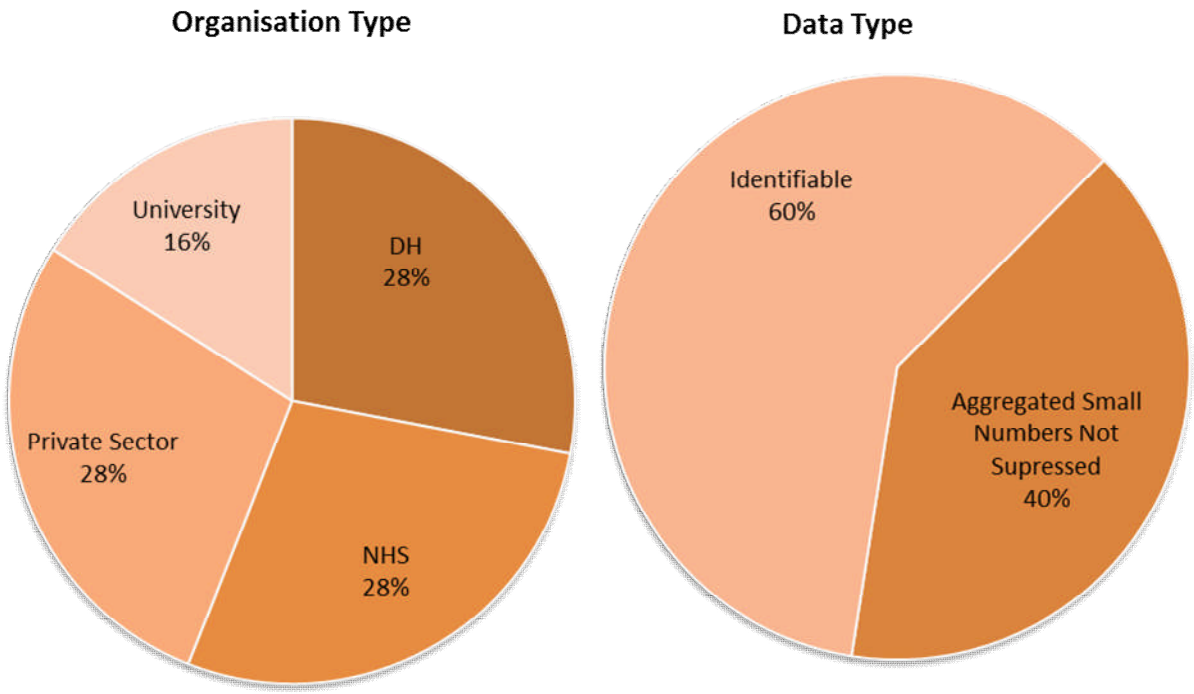
The finalised listing contains 16 original DRA/DSAs, for which there has been 33 individual releases. There have been amendments extending the end date or the data field provided for 11 of these agreements and for which there has been 17 releases. The amendments to the original agreement did not detail data handling/usage but referred back to the original agreement. Based on this, a sample of five releases pertaining to an original agreement and five amendments to the original agreements were selected for testing against the prevailing governance arrangements.

Analysis and commentary

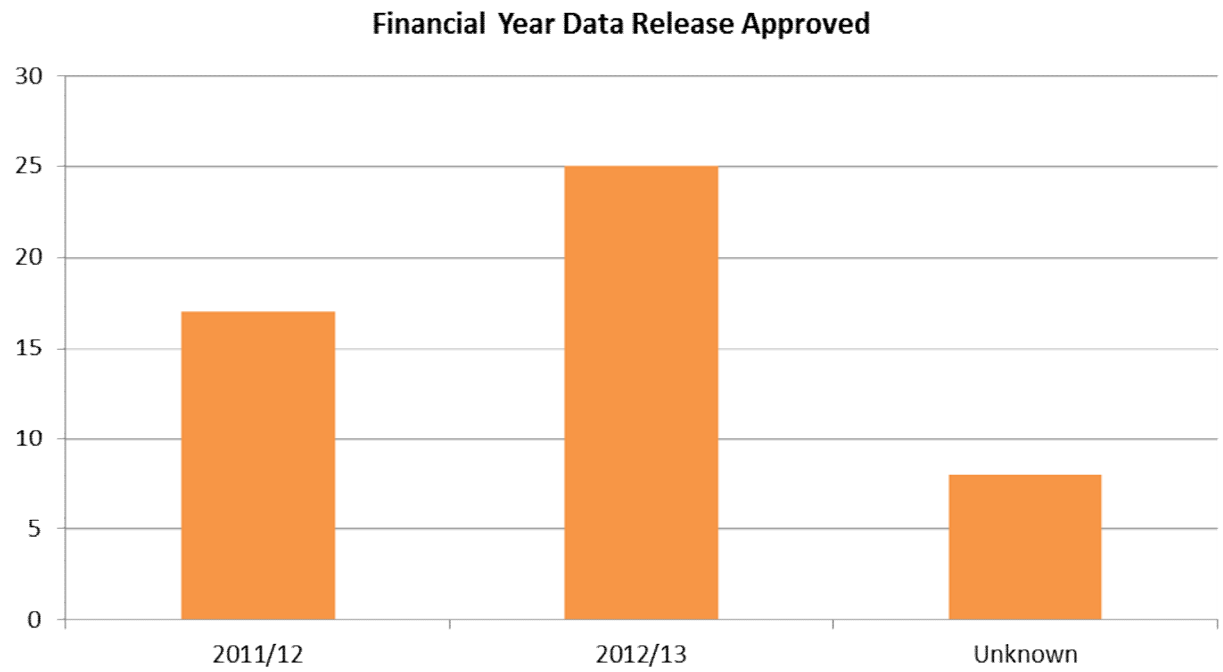
Data Release Listing

Further analysis has been undertaken on 50 data releases made to each of the organisation types as illustrated below:

- Data was released to four different types of organisations, of which the identifiable releases were made to the following:
  - CHKS Limited;
  - University Hospitals Birmingham;
  - Dr Foster Intelligence Ltd; and
  - Dr Foster Unit, Imperial College.
- The organisations listed above only received identifiable data, which was commissioned by the SoS to provide third party support for the development of the SHMI:



- For eight releases across the organisations listed above, it is not known when the request for the release was finally approved:



- The recipient organisations of all the data releases can be broken down as follows:

Organisation Name	Organisation Type	Data Releases
CHKS Limited	Private Sector	8
Dr Foster Unit, Imperial College	University	8
University Hospitals Birmingham	NHS	8
Dr Foster Intelligence Ltd	Private Sector	6
Advancing Quality Alliance (AQuA)	NHS	6
East Midlands Quality Observatory (EMQO)	DH	5
Yorkshire and Humber Quality Observatory (YHQO)	DH	5
Quality Intelligence East (branch of Midlands and East SHA quality observatory)	DH	4

Testing

- Five agreement and five amendments pertaining to an original agreement were selected for testing;
- The majority of amendments did not contain any of the data handling or use and referred back to the original agreements. Therefore, sample testing of such amendments were agreed back to the original agreement;
- All releases, equating to 100% of the sample, were agreed to signed original agreements, which detailed data handling, use and retention;
- ONS approval was required for 50% of the sample (five releases) as the SHMI data was linked to ONS data. Three of these were amendments to the original agreements that added a non-identifiable, non-sensitive data field to the data provided and therefore ONS approval was not required. However, the remaining two were new agreements for which there was no supporting evidence of approval from ONS; and
- Local controls were implemented at a functional level to review, challenge and approve all other releases for which there was no supporting documentation.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
CI1	**Accuracy of Records** The listing provided by the Clinical Indicators team based upon their own records identified discrepancies between the DRA/DSA listing held by the NHS IC IG team: • Six agreements and one amendment, equating to eight releases were included within the Clinical Indicator listing but the NHS IC IG team listing defined these as not complete/no signature. Only a draft copy was maintained, not a final agreement; • One amendment was included within the Clinical Indicator listing but not at all on the listing held by the NHS IC IG team. This amendment was issued but not returned. It changed the purpose for which the data could be used to allow discussions of the data with individual trusts. This amendment may have never been signed as the Dr Foster Unit was an academic unit and had little need to discuss the data with trusts. Any data releases would still be authorised under terms of the original DRA; and • One amendment to the fields of the data provided was included within the Clinical Indicator listing but did not have a status input into the relevant field on the NHS IC IG team listing.
CI2	**Supporting DSA** It was identified that seven data releases were made to Parallel Interactive Media for uploading to a web-based tool, which allowed NHS Medical Directors and Analysts to preview and validate their SHMI prior to publication. These releases contained aggregated date not suppressed for small numbers. A DRA/DSA was not in place, but the Clinical Indicators team deemed this acceptable given that the data was essentially provided for the purpose of management validation and the contract with Parallel stipulated clauses prescribing appropriate confidentiality arrangements, data protection and NHS information governance rules for which data was provided. The NHS IC Procurement Team was responsible for this contract. However, inspection of the DRA/DSA listing held by the NHS IC IG team identified that 14 DSAs, five of which were amendments, existed with Parallel, the purpose of which related to MHMDS and QOF data.
CI3	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, thus limiting the testing. A signed agreement was deemed as approval. However, as noted CI1, nine of these agreements were draft with no signature and therefore it was not possible to validate the approval.
CI4	**Timing of Data Releases** Based upon the sample testing performed, it was identified that when the data disclosed under a DRA, the actual release often occurred prior to obtaining all signatures, albeit by a few days. No exceptions were found for the DSAs tested. Agreements relating to SHMI were fairly standardised and therefore once the requestor and IAO signature were obtained and returned to the NHS IC IG team for final sign-off by the Caldicott Guardian, advice was sought as to whether the data could be released immediately and prior to the final signatures being obtained. For one amendment, this was signed by the IAO ten working days after the Caldicott Guardian.

4.8 Workforce

- *Total of 62 Workforce in scope data releases identified between 1 April 2005 and 31 March 2013;*
- *The majority of the data releases contained identifiable information with no authorisation from Approval Committees as such releases were approved based on legacy processes transferred at the inception of the NHS IC and assumption made that the legal basis was covered as part of the relevant NHS Act prevailing;*
- *Some minor record inaccuracies identified during the course of the review; and*
- *There is limited recorded evidence or audit trail of when data releases were approved and released by the functional area, particularly where these pre dated the existence of the NHS IC IG team in 2008.*

Context and background

The Workforce team was part of the wider Workforce and Estate and Facilities department at the NHS IC. Estates and Facilitates did not release any in scope data. The Workforce team shared data based upon the workforce across the NHS, including statistical publications.

The Workforce team historically provided data for two main organisations: HMRC and the Centre for Workforce Intelligence (CfWI) as a national authority providing advice and information to the health and social care system. Additional ad hoc releases were predominantly, but not limited to, Academic Institutions and Researchers that may contain identifiable data.

Workforce information of GPs and dentists was passed to HMRC on an individual record basis and allowed HMRC to perform linkage of this data to tax records and send aggregated linked earnings results back to the NHS IC for publication as agreed with senior stakeholder groups for GPs and Dentists.

Governance arrangements

From 2005–2008 and prior to the foundation of the NHS IC IG team, all customer data requests (with the exception of HMRC) were logged by the Workforce team within their own records as an ad hoc request. A paper data release form was signed by both parties prior to the data release. For the same period, HMRC releases were covered by a Service Level Agreement (SLA) between the NHS IC and the HMRC and an additional paper release form.

From 2008 to the present, all customers including HMRC were subject to an approval process resulting in a DSA prior to the release of the data.

Data releases with CfWI were governed by a Data Sharing Framework. Individual data requests were submitted using a data request form and if within the scope of the framework, data was then provided.

No authorisation was sought from Approval Committees for identifiable data as this was assumed to have been previously provided as part of a legacy processes transferred at the inception of the NHS IC. An assumption was also made that such authorisation was covered within the prevailing NHS Act at the time.

Summary of approach

The listing of non-HMRC data releases was compiled by individual teams within Workforce using reports run from the records maintained of ad hoc data requests. These were collated by the Workforce Section Head. Annual HMRC data releases were identified by the Workforce Section Head using records maintained.

The listing was cross referenced to the listing of DRAs/DSAs held by NHS IC IG team for completeness. Any differences were considered by the Workforce Section Head and additional releases added to the listing if in scope. These included either original agreements or additional amendments where only the most recent had been included. Any out of scope releases were removed from the listing.

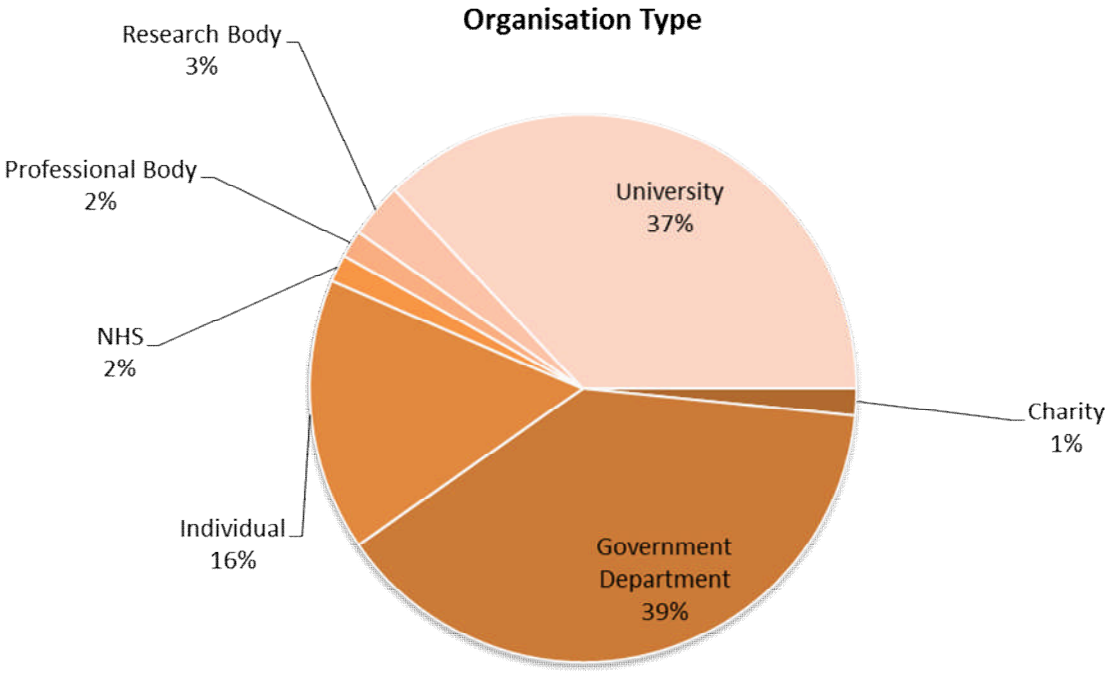
The finalised listing contains 62 releases, 16 of which have no records to perform testing over and 46 covered by DRA/DSAs. These include 27 amendments to such agreements, some of which may include changes to personnel. The amendment did not detail data handling/usage but referred back to the original agreement. Based on this, a sample of seven releases pertaining to an original agreement and eight amendments to the original agreements were selected for testing against the prevailing governance arrangements.

Analysis and commentary

Data Release Listing

Further analysis has been undertaken on 62 data requests and releases made to each of the organisation types as illustrated below:

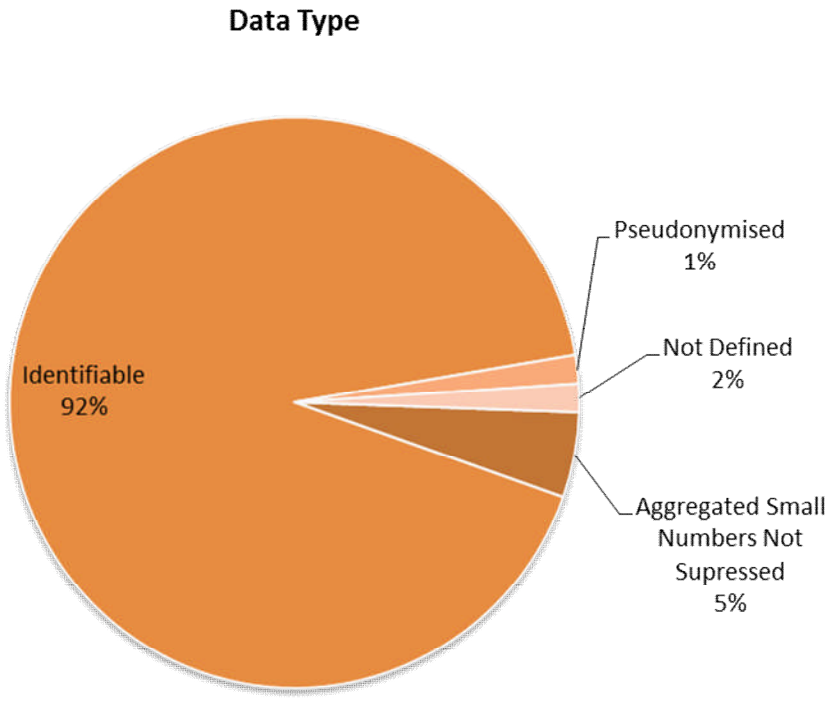
- The data releases have predominantly been made to the HMRC (24) or to universities (23):



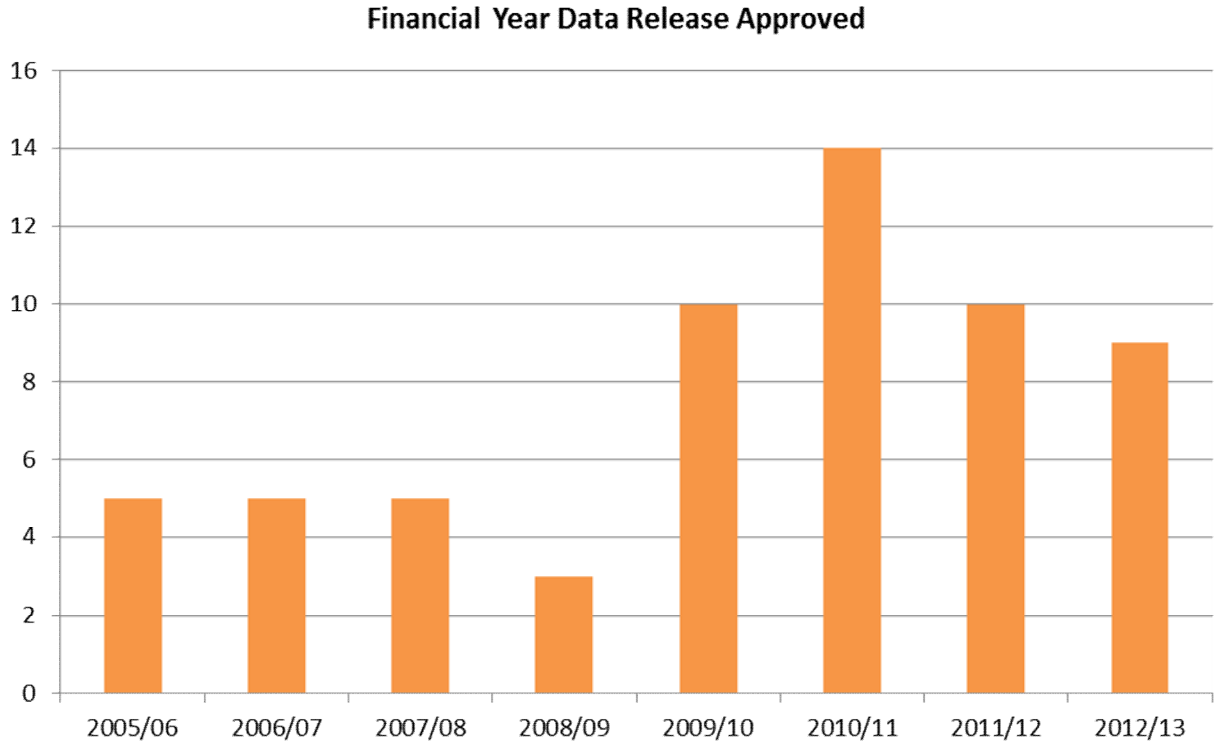
- Many of the recipient organisations have only had one or two data releases. The organisations that have received more than two can be broken down as follows:

Organisation Name	Organisation Type	Data Releases
HMRC	Government Department	24
Individuals requesting releases	Individual	10
Kings College London	University	8

- The majority of these releases included identifiable data:



- For 16 releases within the population, there is no record of their approval or corresponding agreement but the approval date could be obtained from the database used to record data releases:



Testing

- 15 releases were selected for testing, which comprised of seven releases pertaining to an original agreement, and eight amendments to agreements;

- The majority of amendments did not contain any of the data handling or use and refer back to the original agreements. Therefore, sample testing of such amendments were agreed back to the original agreement;
- All releases, except for two, equating to 87% of the sample, were agreed to signed original agreements, which detailed data handling, use and retention; and
- The majority of the releases tested were for identifiable data and two for sensitive data. However, no further approval was required from approval committees as the legal basis was assumed to be covered within the prevailing NHS Act e.g. NHS Act 2006, and such releases were based on legacy processes transferred at the inception of the NHS IC. However, local controls were implemented at a functional level to review, challenge and approve the releases for which there was no supporting documentation.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
WF1	**Accuracy of records** A discrepancy was identified relating to an amendment where Workforce data was released but the original agreement requested only HES data and therefore there was no evidence of communication of data handling/retention for the Workforce specific data release. The Workforce Section Head explained that the Workforce specific element was contained within another DSA but this was only available in draft and no signed copy. One additional release could not be traced to a signed DSA. The level of completion was blank on the IG listing and the function could not trace whether data was supplied or not.
WF2	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, thus limiting the testing. A signed agreement was deemed as approval.
WF3	**Audit Trail of Formal Approval** Of 62 releases identified by the function and through cross checking performed, 16 releases had no record of approval or agreement, either paper or electronic, and are prior to 2008/09: • 14 of these pre-dated the NHS IC IG team and the releases would have been accompanied by a signed paper release form. However none of these were retained. This could be as a result of the NHS IC data retention rules, but the functional area has no clear way of identifying the applicable rules that would have been in place and whether they were followed; and • Two of these releases relating to data shared with HMRC were from 2008 and should have DSAs in place. However, only a draft DSA was available for them.
WF4	**Data Request Purpose** For five of the 14 pre-IG releases that were identified in WF3, no data is available about the purpose that the data was requested for, in particular as there were no agreements available.
WF5	**Audit Trail of Data Release Date** No formal audit trail to corroborate the date that the data was actually released to the organisation for any of the releases included within the listing.

4.9 Population Health – Surveys

- *Total of five Population Health Surveys data releases identified as in scope between 1 April 2005 and 31 March 2013 given the early access to data not yet published;*
- *There are inconsistencies as to how data requested was reviewed and approved, dependent upon the channel used by the requestor given that the request could be received by either the NHS IC or the contractor; and*
- *There is no recorded evidence or audit trail of when data releases were approved or released.*

Context and background

The Surveys team commissioned a number of surveys across a variety of public health at a national level e.g. Health Survey for England (HSE). Some surveys were transferred from the DH at the inception of the NHS IC for the Population Health team to manage, which could span a number of years to undertake and analyse. The collection and analysis of the survey data were outsourced to a number of third party contractors, but most of the contracts were held with NatCen (an independent research agency). A preferred supplier listing of contractors existed that was compiled subject to OJEU rules.

The contractors collected the record level data that was PID and held this in line with their contractual obligations. All contractors must have met the NHS IG Toolkit minimum compliance levels. The NHS IC received the aggregate data for inclusion within the publications. All published data was anonymised and supporting tables were made publicly available in data archives (UK Data Service).

Informed consent from the survey participants was obtained where this may have been linked to other data sets, and was stated within the consent form that was signed by the participant. The participants could request to have their data removed up to the point of publication.

Governance arrangements

Data requests could be submitted to the NHS IC or direct to the commissioned contractor. The latter of these channels meant that the NHS IC did not have any oversight or involvement of the release. Those requests received by the NHS IC were discussed at monthly management team meetings (if it related to an annual survey) or via email with the contractor (if it related to an ad hoc survey). The NHS IC IG team were consulted who approved all agreements. Availability of such agreements dates back to 2008/09.

Summary of approach

Discussions with the Surveys Section Head revealed that the Surveys team kept records of agreements, which were stored separately for each survey rather than in one central repository or as a full list. The list of data releases was compiled using the agreements across all the surveys and cross-referenced to the listing of agreements held by the NHS IC IG team using related wording. This was also to identify if there were any omissions predating current team members.

The vast majority of data requests were sent to the contractors who were commissioned to collect and analyse the data on behalf of the NHS IC. The NHS IC did receive some requests directly and processed these themselves rather than referring them to the contractor. The Surveys team had no oversight of data requests and subsequent releases made by the contractors and thus wrote to all contractors commissioned during the lifetime of the NHS IC to identify what releases had been made on behalf of the NHS IC to support the identification of gaps/omissions in the data release listing. Confirmation was provided from all that no PID had been released. Enclave arrangements existed that allowed data requestors to review data onsite under restricted access by the contractor.

The original listing provided contained a number of releases that were deemed out of scope, for example, the requests for data related to survey materials, such as questionnaires, interview scripts, and training materials and involved no actual data transfer.

The finalised listing contains four original DRA/DSAs and one amendment to such agreements, for which the agreement did not detail data handling/usage but referred back to the original agreement.

Analysis and commentary

Data Release Listing

The listing provided contained five releases that were approved from 25 February 2009 to 14 March 2012. The releases related to three specific surveys:

- Two of the releases were for the Infant Feeding Survey (IFS):
  - Both requested by Child and Maternal Health Intelligence Unit (ChiMat).
- Two of these requests related to the HSE England from differing organisations:
  - University; and
  - Research body.
- One release to a university for data pertaining to Attitudes to Mental Illness survey

Testing

- 100% of the population was agreed to signed original agreements, which detailed data handling, use and retention; and
- Since all releases were giving early access to survey data at an aggregate level that was due to be published shortly, it was deemed that no formal review of the requests was necessary.

For exceptions identified, see detailed findings section below.

Detailed Findings	
Ref	**Finding**
PH – S1	**Oversight of Contractors** There were inconsistencies as to how the data requested was reviewed and approved, dependent upon the channel used by the requestor given that the request could be received by either the NHS IC or the contractor. This inconsistency is currently adopted by the HSCIC and no review has occurred to align the process. If the request was directed to the contractor, there were no agreements in place and the NHS IC (and currently the HSCIC) had no involvement. However, if the NHS IC received the request, the Surveys team would handle this and put in place an agreement as appropriate. These processes are currently still implemented. Whilst responses from the contractors (with the exception of one from CHiMAT) confirmed that no data was released that contained PID and data sharing rules were stipulated within the terms and conditions, no independent assurance was received.
PH – S2	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, thus limiting the testing. A signed agreement was deemed as approval.
PH – S3	**Audit Trail of Data Release Date** No formal audit trail to corroborate the date that the data was actually released to the organisation for the releases included within the listing.

4.10 Population Health – Lifestyles

- *Total of one Population Health Lifestyles in scope data release identified between 1 April 2005 and 31 March 2013; and*
- *There is no recorded evidence or audit trail of when the data release was approved based on the prevailing governance arrangements.*

Context and background

The Lifestyles Statistics Section of Population Health dealt with three survey outputs and publishing of other lifestyles national statistical publications. Established quality assurance processes were in place prior to publication of such surveys, which were also subject to a risk assessment and required Statistical Governance sign-off. There were very few data requests given that the surveys were made publically available and most others collections were aggregated returns.

Summary of approach

The Lifestyles Statistic Section Head confirmed that there was no complete listing of data releases that has been maintained within the team over the NHS IC lifetime. The listing has been has been compiled from viewing DRA/DSA documentation maintained by the functional area and the NHS IC IG team. All enquiries were logged via the Contact Centre in CRM. Only National Child Measurement Programme (NCMP) data was identified as in scope based on the sensitive nature of it e.g. gender and ethnicity, although the data was pseudonymised within the dataset.

This data was collected and held by the NHS IC, and jointly owned with the DH. All data and subsequent requests for it were subject to NCMP regulations for the gathering and further processing of information under NCMP, which were set by the NHS.

Analysis and commentary

Data Release Listing

One NCMP based release was originally identified to a university. However, upon closer inspection, it was confirmed that there was no signed and therefore finalised DSA as the request was refused following discussion with DH lawyers. The NHS IC IG team had classified this DSA as not completed within their records.

A cross reference to the DRA/DSA listing maintained by the NHS IC IG team identified an additional release that had been omitted from the original listing but was classed as completed by the NHS IC IG team. The Lifestyle team explained that there was some confusion with this release as the same request was made in 2011 but refused following advice from DH lawyers. However, the earlier request was granted following discussions with DH lawyers. The interpretation of the NCMP regulations has changed over time.

Testing

This in scope release pertaining to NCMP data was provided to the Department for Children, Schools and Families following approval on 30 October 2009 based upon the signed DSA, which detailed data handling, use and retention. This was classed as non-sensitive and non-identifiable data by the NHS IC IG team but held details of ethnicity, height and weight.

For exceptions identified, see detailed findings section below.

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
PH – L1	**Listing Compilation** Limited record keeping held by the functional area detailing the data releases that have been made during the period in question given the few request received. The data release listing was compiled using DSA/DRA records available as to hold separate records to the NHS IC IG team is deemed duplicated effort.
PH – L2	**Audit Trail of Data Release Approval** It was not possible to evidence the approval of the data release following discussions with the DH lawyers. Discussions between the NHS IC IG team and DH lawyers have taken place on the interpretation of the regulations over the years, of which anecdotal feedback suggests that this has been inconsistent and progressively stricter. Furthermore, the DSA was signed by, or on behalf of the Caldicott Guardian, prior to the functional area sign-off by three working days.
PH – L3	**Accuracy of Records** The NHS IC IG listing categorised the releases identified for Lifestyles as non-sensitive However, based upon the definition provided by the HSCIC of PCD, these should be defined as sensitive they contain ethnicity details.

4.11 Population Health – Screening and Immunisations

- *Total of 32 Population Health Screening and Immunisation in scope data releases identified between 1 April 2005 and 31 March 2013;*
- *Limited level of record keeping around data releases made prior to February 2010. From here on, agreements were implemented and there has been compliance with prevailing governance arrangements, with only minor exceptions identified;*
- *As of November 2011, data enquiries and releases have been recorded in an Enquiries Log; and*
- *There is limited recorded evidence or audit trail of when data releases were approved.*

Context and background

Screening data was collected from pathology labs, colposcopy clinics and breast screening units and was sent to the NHS IC via the NHS Cancer Screening Programmes Quality Assurance Reference Centres (QARCs). Screening data also came from the Open Exeter system (NHAIS) to the Screening and Immunisations team. Almost all screening data were aggregate, although there was a small amount of non-identifiable patient-level data.

Immunisation data was sent to the NHS IC by the Health Protection Agency. These data were aggregated at PCT/Local Authority level. Small numbers were suppressed in some published tables but in most tables no suppression was applied meaning that there was a risk of self-identification. However, data that were not supressed were not considered sensitive.

The current Screening and Immunisations Section Head took responsibility for the team in February 2010 when the services were transferred from the Workforce Team. From this point onwards, DSAs were implemented and were therefore not previously available. Previous members of the Workforce team were engaged to assist with the compilation of the list.

Prior to February 2010, the current Section Head had responsibility for the Health Poverty Index (HPI) and has included any requests relating to this within the screening and immunisations listing as it is no longer supported by the HSCIC and anticipated that it would not be identified by another functional area.

Summary of approach

The listing of data releases was compiled by the Screening and Immunisations Section Head using the enquiries log to identify small numbers based releases, which date back to November 2011. The log is completed upon receipt of enquiries forwarded by the Contract Centre or the team being contacted directly. Responses are held in the enquiries folder. Prior to November 2011, the teams have reverted to archived group and personal emails to identify releases.

The listing was cross referenced to the listing of DRAs/DSAs held by IG for completeness using Screening and Immunisations specific wording, recipient organisations and key contacts. No further in scope releases were identified. Any out of scope releases were removed from the listing.

The finalised listing contains 32 original releases, of which four are included within the same request and DSA but were for different screening data sets. There are also nine amendments to such agreements, for which the agreement did not detail data handling/usage but referred back to the original agreement. Based on this, a sample of ten releases pertaining to an original agreement and five amendments to the original agreements were selected for testing against the prevailing governance arrangements.

Analysis and commentary

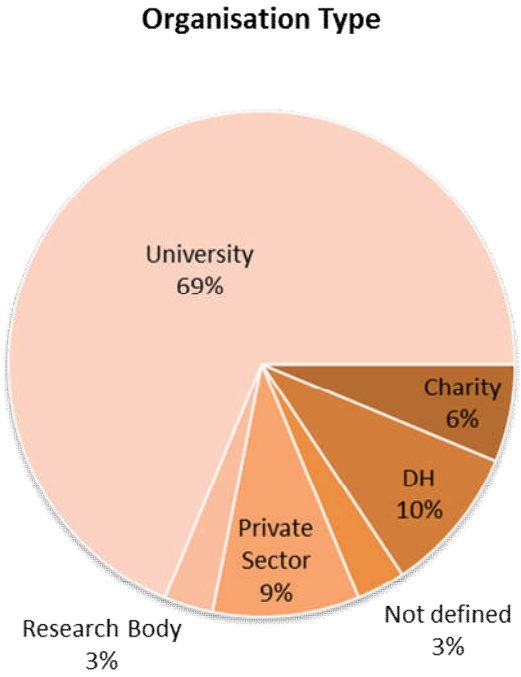
Data Release Listing

The final listing includes 32 in scope data releases that are broken down as follows:

- eight releases under original agreements, for which two relate to the same agreement but the data was from two different data sets;
- nine releases under amendments to original agreements, of which six of these were released under the same amendment but related to different data sets; and
- 15 releases without any agreements, four of which were retrospectively included within a later agreement.

Further analysis has been undertaken on 32 data requests and releases made to each of the organisations types illustrated below:

- Just over a third (22) of the data releases have been made to universities for research purposes or to provide a more detailed evaluation of screening programme performance:



- Three releases have been made to two private sector organisations, being:
  - Glaxosmithkline Cancer Research for an unknown purpose; and
  - York Health Economics Consortium Ltd (YHEC) to contact users of the HPI and health professionals for their views as part of the wider HPI review, which has been deemed identifiable.

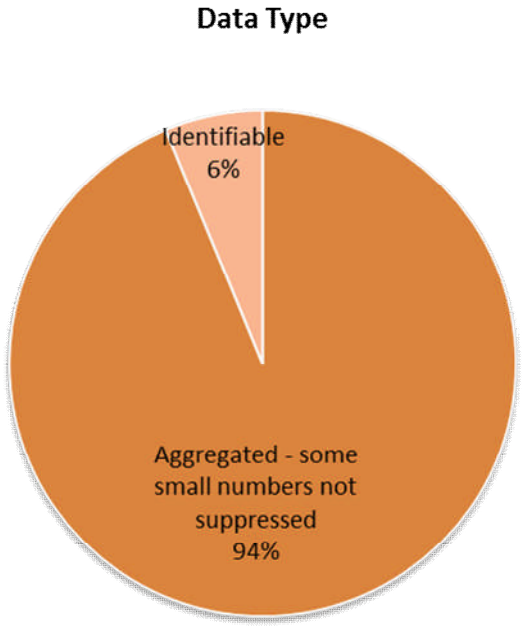
- The listing highlighted one release whereby from a review of the available information maintained by the NHS IC, it was not possible to ascertain the organisation that had received the data. A subsequent investigation into this release was undertaken by the HSCIC which provided details that indicate the release was made to a Primary Care Trust in the North West of England for the purposes of research.

- Many of the recipient organisations only had one or two data releases. The organisations that received more than two can be broken down as follows:

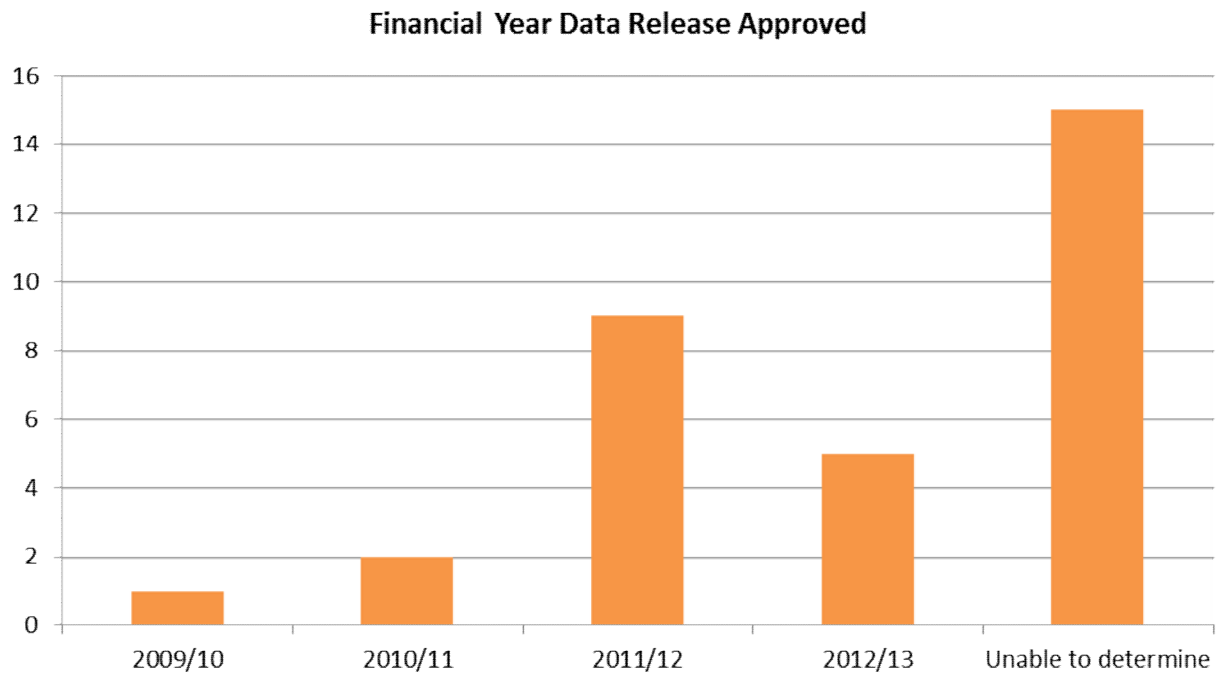
Organisation Name	Organisation Type	Data Releases
Cancer Epidemiology Unit, University of Oxford	University	6
DH Policy Research Unit in Cancer Awareness, Screening and	University	6

Organisation Name	Organisation Type	Data Releases
Early Diagnosis, Queen Mary University of London		
Cancer Screening Evaluation Unit (CSEU), Institute of Cancer Research	University	5

- The majority of these releases contained aggregated data with some small numbers not suppressed, although the two to YHEC did contain identifiable data:



- For 15 releases within the population, there was no record of their approval or corresponding agreement given that no agreements were used until the current Section Head came into post in February 2010. However, four of these were retrospectively covered within a later agreement:



Testing

- As 15 releases had no evidence of an agreement and nine releases were amendments to the agreements, all have been selected for testing;
- Where a DSA is stated, 100% of those have been agreed to the original agreement, which detailed data handling, use and retention; and
- Local controls were implemented at a functional level to review, challenge and approve the releases for which there was no supporting documentation.

For exceptions identified, see detailed findings section below.

Detailed Findings	
Ref	**Finding**
PH – S&I1	**Listing Compilation** Limited record keeping held by the functional area detailing the data releases that have been made during the earlier part of the review period in question, being prior to February 2010. The data release listing was compiled using DSA records and the Enquiries Log, archived emails and records available. Since November 2011, the Enquiries Log has recorded details of enquiries received and data released.
PH – S&I2	**Supporting DSA** As DSAs were only available post February 2010, there are 13 releases predating this that did not have any supporting DSAs, two of which contained identifiable data. However, there were two that are after this date and still did not have a supporting DSA (see exception below). For the 15 releases without a DSA, none of these were recorded on the DRA/DSA listing held by the NHS IC IG team and had no approval date of the release. However, four of these were retrospectively included within a DSA that was implemented in October 2010. This DSA stated that "It is recognised that that the data covered by this agreement has previously been shared since 1992 (originally provided by the Department of Health) on an informal basis."
PH – S&I3	**Audit Trail of Data Release Approval** No formal audit trail to support the approval process, thus limiting the testing. A signed

Detailed Findings	
Ref	**Finding**
	agreement was deemed as approval, where available. Two releases have been identified as containing identifiable but not sensitive data, and although they do not have supporting evidence to confirm appropriate approval, being a DRA/DSA, there was a contract in place. These related to the HPI and released to YHEC: • For one, the NHS IC IG team advised this was not necessary because the people agreed to be contacted. The NHS IC IG recommended that the data processors of personal information i.e. YHEC, could only use this information on behalf of the NHS IC, who were the data controllers. This condition was covered in the contract that used the NHS IC's standard terms and conditions prevailing at the time and governing PID; and • For one, it contained the contact details of health professionals. However, there was speculation that most of this data was available within the public domain and therefore out of scope but it could be confirmed.

5. Detailed Findings – NBO Trace Request Service

In addition to the functional areas releasing large and complex health and social care data described in section 4 of this document, this review has also considered the trace request service provided by NBO.

The detailed findings are provided in the following section of this document, which have been structured around the following headings to provide consistency:

Heading	Description
Highlights	Provides summary highlights for each functional area reviewed.
Context and Background	Provides a summary and background to each functional area, including the prevailing governance arrangements and controls in operation.
Summary of Approach	Approach adopted to perform the data release review specific to each functional area. This also includes a summary of the testing approach adopted against the prevailing governance and control arrangements. Further details of the sample testing methodology can be found in Appendix 6.
Analysis and Commentary	Analysis and commentary on the data releases made by the functional area during the period under review and a summary of testing performed.
Detailed Findings	Test exceptions and other findings identified as part of the review.

5.1 National Back Office

- *Total of 12,954 NBO recorded trace responses made between 1 April 2008 and 31 March 2013;*
- *Electronic records have only been maintained from August 2010 onwards for UKBA, Police and SOCA, therefore the analysis does not include trace responses made to these organisations between 1 April 2008 and 31 July 2010;*
- *It is not possible to test formal approval and authorisation of trace responses due to the level of records maintained within NBO;*
- *However, the analysis demonstrates that review, challenge and approval processes appear to be operating within NBO due to the proportion of requests that are rejected or refused (9%); and*
- *Of the number of traces accepted and approved, 51% result in no trace.*

Context and background

NBO became part of the NHS IC from 1 April 2008, transferring in from the ONS. It was primarily focused around the maintenance of Patient Demographic Data, including (but not limited to) name, address, date of birth and NHS number, which was used by clinical systems across the country. The primary systems in use were the 'Chris' database and more latterly, following the National Programme for IT, the Personal Demographics Service (PDS) system, which was a component part of the Spine. The PDS system enabled a patient to be readily identified by health and social care staff quickly and accurately, and did not hold any clinical or sensitive data items such as ethnicity or religion. This service included resolving data quality incidents and providing matching and cleansing services for all users of the patient demographic data within the NHS and wider health economy.

In addition to managing demographic records, there was a NBO team that responded to specific trace requests that originated from outside of the NHS/health family, including requests under the DPA (section 29(3)) and Court Orders.

Trace requests in scope for the review were as follows:

- Police requests relating to serious offences (the NHS IC maintained a list of offences considered serious for which data is released against) and SOCA, relating to serious offences requested by the agency;
- UKBA primarily linked to data requested for the purpose of the prevention or detection of immigration offences and/or protection of the NHS from potential abuse from immigrants to the UK,; and
- Court orders relates to information requested to be used in court proceeding or the tracing of families in divorce proceedings.

Data releases deemed out of the scope of the review were as follows:

- The 1939 Register Service – data including (but not limited to) occupation and gender was released against individuals from the information collected for the purposes of National Registration. This could be applied for publically by any individual and there were no restrictions, however, data was only released if the person was recorded as deceased in the NHS IC records. Due to the fact that there were no restrictions on application, it was considered that this was data that was in the public domain and therefore placed out of scope; and
- Death Registration Enquiries – the NBO service released data to professional organisations quoting an Ofsted, Charity or Registration Number to confirm if biological parents or adoptees had deceased. The information was available in the public domain and therefore out of scope for this review.

The volume of trace requests was significant in this area, c500 every month. Requests were received directly by NBO and were not routed through the NHS IC Contact Centre. For Police, SOCA and UKBA data releases, a spreadsheet was maintained that recorded every request for trace, and whether it was rejected, refused or accepted.

All Court Order requests were maintained on system. However, detail behind the outcome of requests that was sent to the requestor was kept within Court Order hard copy and electronic archive files in Southport.

Listed below are the reasons behind rejection and refusal of trace requests:

Police: Requests were rejected where it was not addressed correctly (that is to the NHS IC) or where the counter signatory requirements had not been met. Requests were refused where the reason they were seeking an individual did not meet the NHS IC criteria for suspects of 'serious crime';

SOCA: Requests were rejected where it was not addressed correctly (that was to the NHS IC) or where the counter signatory requirements had not been met. The NBO also did not accept requests from SOCA individuals themselves, only from the gateway/single point of contact. If the requirements for submission had been met, SOCA requests were not refused. If a trace request was accepted it did not necessarily mean it was possible to trace the individual and if not, data would not have been released.

Court Orders: Requests were rejected where the Court Order was not directed correctly (that was to the NHS IC) or where the order was not the original order or did not have a Court stamp/judge signature. If the requirements for submission had been met, there was no refusal of Court Orders; and

UKBA: Requests were rejected where it was not addressed correctly (that was to the NHS IC) or where the counter signatory requirements had not been met. Requests were refused where the reason they were seeking an individual did not meet the NHS IC criteria for definitions of NHS abuse.

Governance arrangements

There was a specialised team in the NHS IC for dealing with NBO trace requests. Each request was considered for acceptance/rejection. If a request was rejected (this may have been due to it being directed to the wrong organisation), it went no further along the release process. If the request was accepted, it was then considered for approval/refusal. If a request was refused (this may have been due to, for example, with Police requests that the crime did not meet the NHS IC definition of a serious crime), it went no further along the release process. Once a request had been accepted and approved, it was considered whether the details/individual could be traced on the systems. If the individual had been traced, the details were released.

The spreadsheets/hard copy files maintained by the team recorded whether a request had been accepted/rejected and approved/refused. All Police requests received were subject to supervisor scrutiny before considered acceptable (or not). Also, NBO processes included quality assurance checks, which ensured a percentage of work processed was checked before the response to the enquiry was despatched. However, there was no evidence retained within NBO of the approval and authorisation process that could be sample tested.

Summary of approach

A scoping meeting was held with NBO Operations Manager, which identified the following:

- The trace request listing for UKBA, Police and SOCA was developed using records maintained within NBO. It was noted that electronic records had only been maintained from August 2010 for each of these areas. Prior to that, paper records were maintained and subsequently destroyed in line with the IG policies for retention and disposal of records in place at that time. Therefore, trace responses made between April 2008 and July 2010 have not been included within the listings;
- There was no central record maintained in relation to trace requests against Court Orders and all requests were recorded on a legacy system called FoxPro. The trace response listing was compiled by reviewing every entry on FoxPro and reconciling to hard copy and electronic archive files, to gather information relating to whether data was released. These records dated back to 1 April 2008;
- No detailed testing could be performed over the listings and approval process as records maintained by NBO did not provide this level of detail. Further analysis on the number of requests, rejections, refusals and ultimate releases was undertaken; and
- Completeness testing was undertaken to provide comfort over the trace response list.

Analysis and commentary

Response to trace request listing

The response to trace request listing compiled during this review was based on records maintained by NBO, in which for SOCA, UKBA and Court Orders multiple individual traces were maintained as one record. To enable a comprehensive view, further analysis was undertaken to identify the total number of individual trace requests contained within the records maintained by NBO. The table below provides the total number of individual trace requests from Police, SOCA, UKBA and Court Orders, received and processed by NBO:

Totals	Police and SOCA 2010-2013	UKBA 2010-2013	Court Order 2008-2013	Total
Total receipts	**14,591**	**12,587**	**1,566**	**28,744**
Rejected, not refused	554	348	141	1,043
Refused, not rejected	493	8	0	501
Rejected and refused	810	27	0	837
Rejected, unknown if refused	1	0	0	1
Accepted and approved	12,733	12,204	1,425	26,362
Approved – Trace	3,104	6,304	1,239	10,647
Approved – No Trace	8,784	4,438	186	13,408
Approved – No record	845	1462	0	2,307
No of requests with no trace response due to rejection, refusal or no trace	10,642	4,821	327	15,790
Total number of trace responses	**3,949**	**7,766**	**1,239**	**12,954**

- This analysis shows that of a total number of trace requests of 28,744;
  - 26,362 were accepted and approved;
  - Of these 10,647 resulted in a trace and data being released, and 2,307 being approved but no record maintained within NBO of whether a trace was successful; and
  - 15,790 resulted in no trace response due to refusal, rejection or no trace being possible.
- It should be noted that electronic records had only been maintained from August 2010 for Police, SOCA and UKBA. Prior to that, paper records were maintained and subsequently destroyed in line with the IG policies for retention and disposal of records in place at that time. Therefore the analysis does not include trace responses made to these organisations between 1 April 2008 and 31 July 2010; and
- Records of Court Orders have been maintained since 1 April 2008, and therefore trace responses for the period up to 31 March 2013 form part of the analysis.

Testing

- Although it is not possible to test the formal approval and authorisation process relating to trace requests due to the level of records maintained within NBO, the analysis demonstrates that review, challenge and approval processes appear to be operating within NBO.

For exceptions identified, see detailed findings section below:

Detailed Findings and Testing of Compliance with Governance Arrangements	
Ref	**Finding**
NBO1	**Records of approval process for NBO data releases** No records are kept of the approval process within NBO in relation to data releases made to Police, UKBA or Court Order; therefore it is not possible to test this process in detail. From compiling data releases across NBO, it is possible to observe that a proportion of requests were either refused or rejected. DSAs were not required as the trace service is provided under legislation.
NBO2	**Records relating to data releases to SOCA, UKBA and Police** Electronic records have been maintained from August 2010 for each of these areas. Prior to that, paper records were maintained and subsequently destroyed in accordance with the NHS IC IG policies for retention and disposal of records, in place at that time. Therefore, releases between April 2008 and July 2010 have not been included within the listings. This has limited the analysis of data released to these organisations to the time period 1 August 2010 to 31 March 2013.
NBO3	**Records relating to number of successful traces** A number of data releases (2,307) have been identified for Police, SOCA and UKBA where the record of whether a trace has been successful and therefore data released, are incomplete. It is therefore not possible to confirm whether data was released. For the purposes of this analysis, these have been included within the trace requests listing for NBO.

Appendix 1. Terms of Reference

NHS Information Centre Data Release Review

Context

Sir Nick Partridge, a Non-Executive Director on the HSCIC Board and former Chief Executive of the Terrence Higgins Trust, has agreed to conduct a review of all the data releases made by the HSCIC's predecessor organisation, the NHS Information Centre (NHS IC), and to report on this to the HSCIC Board.

Price Waterhouse Coopers ("PwC") has been commissioned to review all data releases approved by the NHS Information Centre between 2005 and 31 March 2013. The review will examine the arrangements that were in place for the release of data, and will provide insight and key observations that will allow the HSCIC to learn from its predecessor's experience and ensure the HSCIC's processes are as robust, open and transparent as possible.

The review will be made available to the HSCIC Board at the end of April 2014, to be discussed at its meeting on 15 May 2014, prior to a publication at the end of May 2014.

Scope and objectives

The objectives of the review are to:

- Identify and produce a list of those data releases approved during the lifetime of the NHS IC;
- Analyse a sample of the identified data releases to provide insight, trends and key observations;
- Assess the arrangements that were in place from a sample of the data releases regarding the appropriate use, data handling and data retention controls as defined to the data requestor;
- Identify the prevailing governance and control arrangements, roles and responsibilities in operation within the NHS IC during the period of 1 April 2005 through to 31 March 2013 to review, challenge and approve data releases; and
- Assess compliance with the prevailing governance and control arrangements in place from request through to release for a sample of data releases selected for testing.

Out of scope

Data released in an anonymised form, that are readily available in the public domain and for which Data Sharing Agreements were not required are not included in this review. As a result, the following should be considered to be out of scope:

- Parliamentary Questions/Freedom of Information requests;
- Media/statistical publications;
- DH and the NHS/social care family specifically for management or validation purposes;
- 'Open Data' that is already publicly available;
- Aggregate data returns.

Data released by other predecessor organisations will also not be included.

Appendix 2. Review Governance

Data Release Review Steering Group:

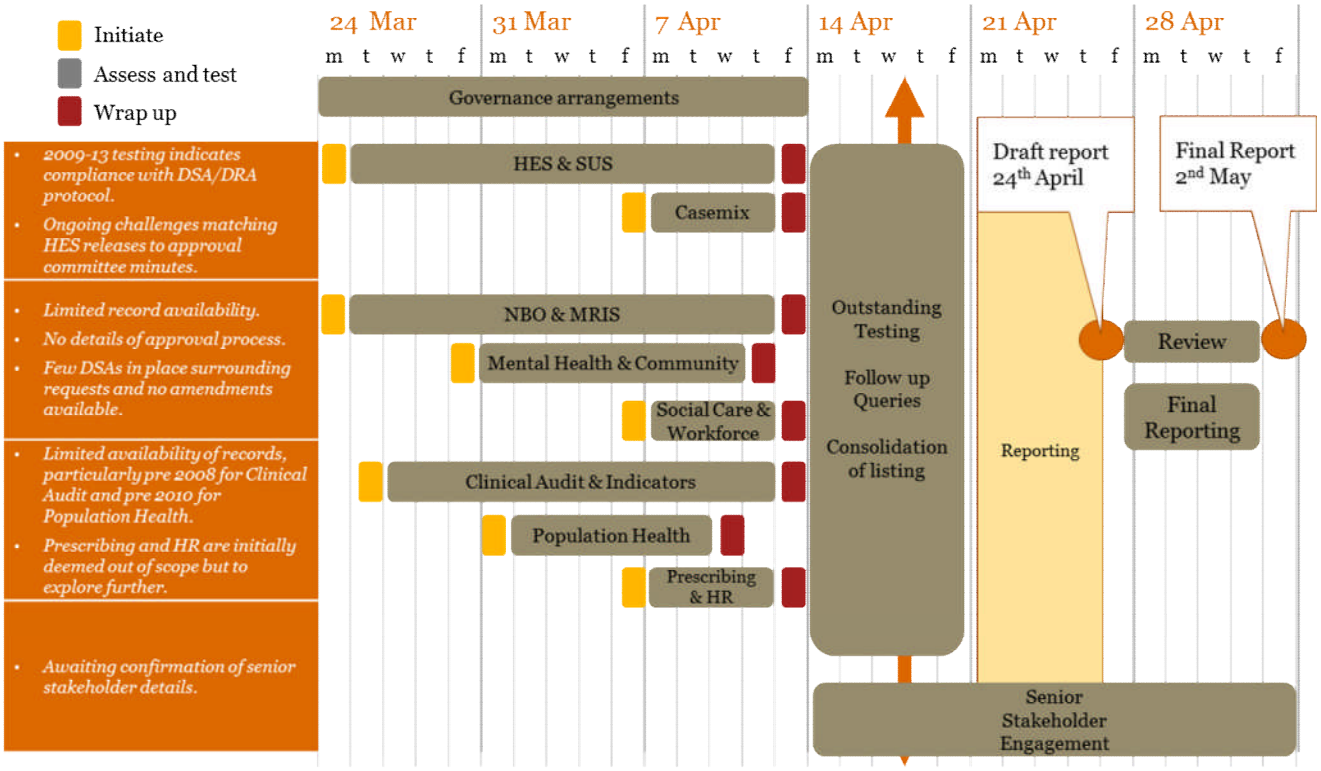
Title	Role
Non-Executive Director HSCIC	Review Sponsor
Programme Head – Operations and Technical Standards	Review Lead
Head of Data Services	Review Steering Group
Director of Benefits and Utilisation	Review Steering Group
Director of Information Analysis	Review Steering Group
Director of Business Services	Review Steering Group
Head of Corporate Assurance	Review Steering Group
Director of Communication	Review Steering Group
Head of Population Health and Social Care	Review Steering Group
Head of Media and Public Affairs	Review Steering Group
Statistics Head of Profession	Review Steering Group

Data Release Review Steering Group Meetings:

Date of Meeting
21 March 2014
28 March 2014
4 April 2014
11 April 2014
17 April 2014
25 April 2014

Appendix 3. Delivery Plan

The delivery plan for the data release review is summarised below:



Appendix 4. Insight Workshop 14 March 2014 – Attendees

Role
Programme Manager, Workforce and Facilities
Higher Information Analyst, Community and Mental Health
Head of Data Services
Assistant Director of Information Governance
Section Head, Workforce and Facilities
Operations Manager, Audit Support Unit
Business Support Manager, Community and Mental Health
Head of Primary Care, Strategy
Higher Information Analyst, Population Health
Statistics Head of Profession, Statistical Governance
Programme Manager, Population Health

Appendix 5. Insight Workshop 14 March 2014 – Outcomes

Functional areas around data release				
WHO (functional area)	**WHAT (what type of data)**	**WHY (who would request the data typically)**	**Any key third parties involved?**	**Identifiable, or potentially identifiable ?**
HES Team & SUS Team	• HES Data • SUS data • PbR data • Clinical data sets This includes: • Inpatient • Outpatient • A&E • Critical • Maternity • PROMS • DIDS	• Intermediaries (e.g. Dr Foster) • Universities • Providers • Commissioners • Charities • Individual researchers • Other private sector (e.g. insurance) • DH/ALBs/gov't/regulators • Pharmaceutical/mental health companies	Northgate	Identifiable
Mental Health & Community Team	• Mental Health Minimum Data Set • IAPT (Improving Access to Psychological Therapies)	• As per HES, except without providers/commissioners	Exeter	Potentially identifiable
Social Care Team	• Social care data • User experience	• Research	n/a	Potentially identifiable
HR	• Staff data	• TBC	n/a	Potentially identifiable
Workforce Team	• NHS Workforce data • ESR records • Census • GP data from Exeter system • Dental • Ophthalmic • GP workforce	• Government • Wider NHS family • Higher Education institutions	n/a	Potentially identifiable
NBO	• Southport data (central register MRIs) Came into NHS IC from ONS	• Research	Southport	Potentially identifiable
MRIS	• Cohort data for research	• Researchers	n/a	Identifiable
Prescribing Team	• Prescription level data • Cost analysis • Dispenser/prescriber	• Pharmaceutical companies • Mental health companies/organisations	n/a	Potentially identifiable

Functional areas around data release				
WHO (functional area)	**WHAT (what type of data)**	**WHY (who would request the data typically)**	**Any key third parties involved?**	**Identifiable, or potentially identifiable ?**
	data • QOF (Quality and Outcomes Framework) database	• Department of Health and NHS family		
Clinical Audit	• Clinical audit data • Clinical datasets on certain types of clinical episode: e.g. • Diabetes • Cancer • Stroke etc.	• Researchers and research organisations • Department of Health and NHS family	HQIP	Identifiable
Case mix team	• Case mix data (linked to PbR)	• Standardise data by looking at populations • Department of Health & NHS family	n/a	Potentially identifiable
Surveys Team	• National Child Measurement Programme • Surveys data • National child measurement programme data • Population health surveys	• Researchers • Government bodies	Survey contractors e.g. • NATCEN • BMRB • ONS • IFF • GFK/NOP	Potentially identifiable
Information Governance	• ONS data (Micro Release Data Panel) • Data protection subject access requests • Data requests and copyright • Section 251 data	• All	n/a	Identifiable
Secondary Uses Service	• Patient record level data • PCD	• Intermediary – Imperial College and Dr Foster unit	BT	Identifiable
Dr Foster	• Various levels of clinical indicator data	• Was in a Joint Venture with DFI	Yes – DFI	Potentially identifiable
Clinical Indicators Team	• Pseudonymised/anonymised patient record data for NHS Trusts • Population/mortality data	• NHS Family • Intermediaries	n/a	Potentially identifiable

Appendix 6. Sample Testing Methodology

PwC has performed sample testing across the individual listings for each functional area to assess the compliance by the NHS IC to prevailing governance processes and controls. A 'haphazard' approach to selecting the sample was adopted, which has been defined below:

"Haphazard selection, in which the auditor selects the sample without following a structured technique. Although no structured technique is used, the auditor would nonetheless avoid any conscious bias or predictability (for example, avoiding difficult to locate items, or always choosing or avoiding the first or last entries on a page) and thus attempt to ensure that all items in the population have a chance of selection. Haphazard selection is not appropriate when using statistical sampling."[2]

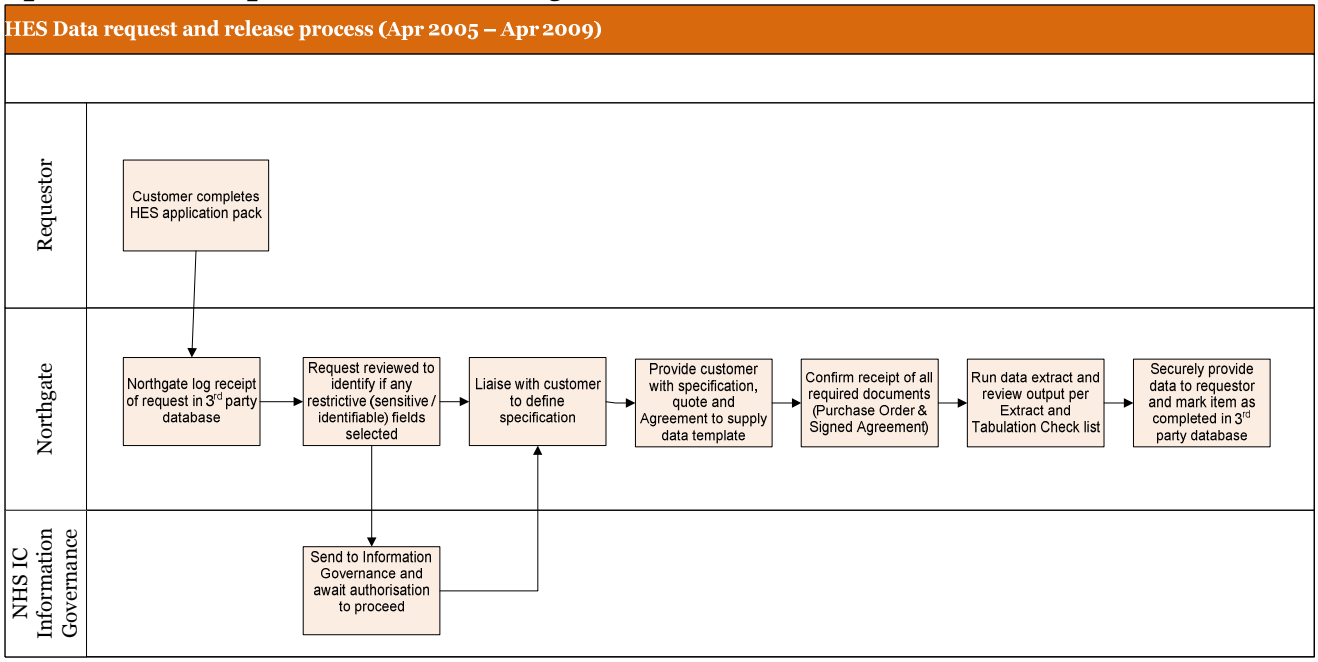
Testing samples have been select in line with the standard PwC methodology, which is based on the size of the population and the obtaining a 'high level of assurance'. This is illustrated in the table below:

Population Size	Sample Size – Number of Items to Test for 'High Assurance'
1	*1*
4	2
12	5
52	15
250	40
Over 250	60

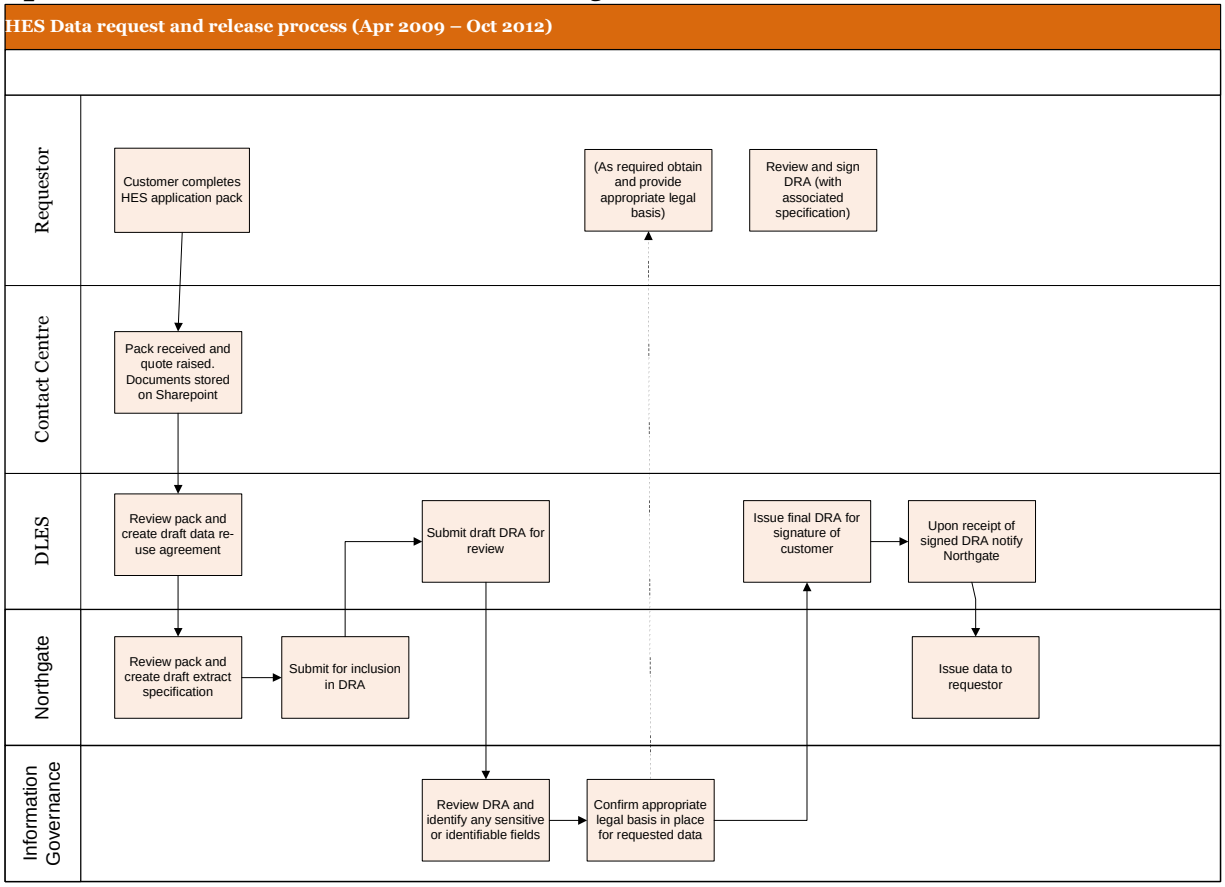
[2] International Standard on Auditing 530 Audit Sampling – Appendix 4

Appendix 7. HES Process Maps

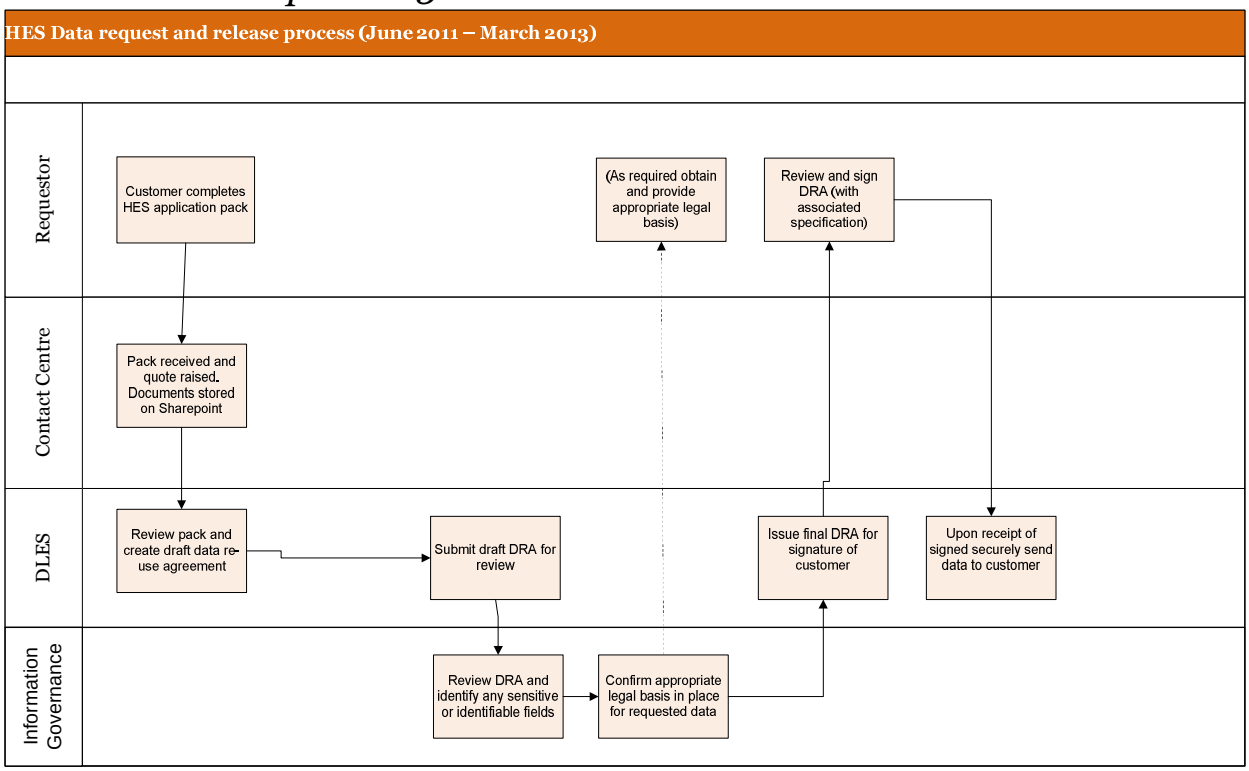
April 2005 – April 2009 – Northgate



April 2009 – October 2012 – Northgate and NHS IC



Summer 2011– April 2013 –NHS IC



Appendix 8. Glossary of Key Terms

Term	Definition
Approved Research/Microdata Release	For use when neither SoS nor Informed Patient Consent are applicable for provision of ONS Data. Accreditation as an Approved Researcher and approval from the ONS Microdata Release Panel is required. Approval for release of the data through this legal gateway is granted by ONS under the Statistics and Registration Service Ace 2007 sections 23 and 39 (4) (i).
Bespoke data linkage	Subject to the relevant approvals, this product is available with HES, PROMS, DID, ONS mortality data, and any routinely linked data sets at a frequency of customer choice. Linkage could be between two or more sets of HSCIC data, customer data and data held by HSCIC, or between two or more sets of customer data.
Bespoke Extracts	Bespoke record-level extracts from HES, PROMS, SUS PbR, DID, ONS mortality data, and any of the routinely linked data sets. These can be provided on a one-off or regular basis as required. This is in the form of an extract of pseudonymised data that meets customer specifications. Identifiable data may be provided where an appropriate legal basis is in place.
Business Impact Level (BIL) 1	Aggregated De-identified data for publication – data that can be publicly disclosed as it has been anonymised and there is a low risk of individuals being identified.
Business Impact Level (BIL) 2	Pseudonymised at record level De-identified data for limited disclosure or access – data that has been through a process of pseudonymisation; however there remains a risk of individuals being identified.
Business Impact Level (BIL) 3	Personal confidential and sensitive data Personal confidential data – data in which individuals are identified, or there is a high risk of individuals being identified.
Data Types	A breakdown of the datasets that have been provided to the customer, which can be a single dataset or a combination of the following: - HES Inpatient, HES Outpatient, HES A&E, HES Critical Care, PROMS (Patient Reported Outcome Measures), MHMDS (Mental Health Minimum Dataset), DIDS (Diagnostic Imaging Dataset), SUS PbR Spells (Secondary Users Services Payment by Results), SUS PbR Episodes (Secondary Users Services Payment by Results)
Informed Patient Consent	Where the individual to whom the data relates has given explicit consent. Customer must supply copies of the consent materials used to gain individual explicit patient consent which should include consent forms plus any literature such as information leaflets or posters.

Term	Definition
Identifiable Data	This includes data such as: - NHS number, Name, Address, Postcode, Date of Birth, Date of Death
Identifiable Data (definition within HES and the MHMDS)	Identifiable data Fields: NHS Number, Date of Birth, Postcode of patient, Birth date – baby, Mother's date of birth
NHS/Social Care family	Arm's Length Bodies, Providers and Commissioners of NHS funded care.
Non Sensitive	No identifiable sensitive information
Patient Identifiable Data (PID)	This includes data such as: NHS number, Name, Address, Postcode, Date of Birth, Date of Death
Patient Status and Tracking	The demographic status of a specific group of patients or information collected from tracking patients over a period of time, including regular updates using PDS, ONS cancer data and ONS mortality data.
Personal Confidential Data (PCD)	Data in which individuals are clearly identified, or there is a high risk of individuals being identified. This includes patient identifiable data and also includes sensitive data which may include: - Racial or ethnic origin, Political opinions, Religious or other similar beliefs, Physical or mental health condition, Sexual Life, Criminal Record
S251	Section 251 of the NHS Act 2006 allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes.
Secretary of State (SoS, S42)	SoS can be used if the information requested consists of statistics and is disclosed for the purpose of assisting the person in producing or analysing statistics or in the performance of functions exercisable by it in relation to the health service. These persons are: The Secretary of State, The Welsh Ministers, The National Health Service Commissioning Board, A clinical commissioning group, A local authority, A local health board, An NHS trust established under section 19 of the Nation Health Service (Wales) Act 2006, The National Institute of Health and Care Excellence, The Health and Social Care Information Centre, A Special Health Authority, The Care Quality Commission, Such other persons as the appropriate authority may specify in a direction given for the purposes of this section. Customers must supply a commissioning or funding letter from the relevant body.
Sensitive	Sensitive data may include items such as: - Racial or ethnic origin, Political opinions, Religious or other similar beliefs, Physical or mental health condition, Sexual life, Criminal Record
Sensitive Data (definition within HES and the MHMDS)	Sensitive data Fields: - Consultant Code, Local Patient Identifier, Patient's Census Output Area, Code of Patient's Registered or Referring General Medical Practitioner, Person Referring Patient, Augmented Care Period Local ID, Detention Category, Legal Group of Patient, Legal Status Classification, Legal Category of Patient, Ordnance Survey Grid Reference.
Service Types	Medical Research Information Centre – a cohort is flagged on the system and

Term	Definition
	events and death details can be provided: - Bespoke Extract, Standard Monthly Extract Service, Data Linkage and Bespoke Extract, Bespoke Tabulation.
Standard Extracts	Standard extracts of HES, SUS PbR, DID, MHMDS, and any routinely linked data sets provided monthly on a subscription basis. Identifiable data may be provided where an appropriate legal basis is in place.
Tabulation	Statistical tables of data, customised to meet customer requirements. For HES, MHMDS, and the HES routine linkage to DID.

Appendix 9. Glossary of Acronyms

Acronym	Definition
ALB	Arm's Length Body
BT	British Telecom
CRM	Customer Relationship Management
DAAG	Data Access Advisory Group
DAR	Data Access Request
DDA	Data Deposit Agreement
DIDS	Diagnostic Imaging Dataset
DLES	Data Linkage Extract Service
DMSG	Database Monitoring Sub-Group
DRA	Data Reuse Agreement
DSA	Data Sharing Agreement
DSF	Data Sharing Framework
ECC	Ethics and Confidentiality Committee
FOI	Freedom of Information
HEI	Higher Education Institution
HES	Hospital Episode Statistics
HMRC	Her Majesty's Revenue and Customs
HPI	Health Poverty Index
HQIP	Healthcare Quality Improvement Partnership
HRA	Health Research Authority
HRA CAG	Health Research Authority Confidentiality Advisory Group
IAO	Information Asset Owner
IAPT	Improving Access to Psychological Therapies
IG	Information Governance
MHMDS	Mental Health Minimum Data Set
MMES	Monthly Managed Extract Services
MRIS	Medical Research Information Services
MRP	Microdata Release Panel
NBO	National Back Office
NCMP	National Child Measurement Programme
NIGB	National Information Governance Board
ONS	Office for National Statistics
PbR	Payment by Results
PCD	Patient Confidential Data
PIAG	Patient Information Advisory Group
PID	Patient Identifiable Data
PROMS	Patient Reported Outcome Measures
SHMI	Summary High-Level Mortality Indicator
SOCA	Serious Organised Crime Agency
SUS	Secondary Use Service
TEASC	Towards Excellence in Adult Social Care
UKBA	UK Border Agency

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