

NHS Hospital Data and Datasets:

A Consultation



IMPROVE
PATIENT SAFETY
AND HEALTH
OUTCOMES

CITIZEN DATA=
CHOICE AND
ACCOUNTABILITY



REDUCE
DUPLICATION
INCREASE
EFFICIENCY



WORLD
CLASS
RESEARCH FOR
ECONOMIC
GROWTH



INTELLIGENT
COMMISSIONING



ANTICIPATE
RISK OF DISEASE AND
DEVELOP PROACTIVE
CARE PACKAGE

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Foreword

NHS England's purpose is to secure high quality care for all, now and for future generations. We believe that the NHS should support everyone to live longer and healthier lives, regardless of their background or personal circumstances. Clearly, the only way to determine whether we are achieving our aims is to use high quality information about the care being provided to patients.

NHS England has therefore embarked on an unprecedented programme to increase the transparency of information available about the NHS. Our intention is to expose any unwarranted variations in the care being delivered across the country, in terms of its safety, patient experience, effectiveness, equity and efficiency. We believe that this information can empower citizens and patients to play a far more active role in the design of local health and care services. Together, we are convinced that greater transparency and participation will result in safer, more effective, and more compassionate health care for us all.

So what data sets do citizens and commissioners require in order to know whether a hospital is providing safe, efficient, and equitable care? Which specific data items should the Health and Social Care Information Centre extract from hospitals' electronic systems and make available to citizens, providers, regulators, and researchers? And how can we support

hospitals to provide more complete data sets while minimising the burden of data collections on frontline staff? This consultation is your opportunity to help answer these questions, and to guide us in shaping the future of NHS hospital data and data sets.

Currently, the principal source of hospital data is the Hospital Episode Statistics (HES) dataset. HES is an invaluable national resource that is envied across the world. It has underpinned tens of thousands of clinical audits and research studies, which have led to demonstrable improvements in patient care. However, HES suffers from a number of shortcomings and it simply does not meet the needs of a modern health service.

NHS England is leading a programme to bring the NHS data service up to modern standards. Known as the care.data programme, this work is guided by three fundamental principles. First, the new data service will meet the highest information governance standards. From the outset, our proposals are being designed for full compliance with the Data Protection Act, the Human Rights Act, the NHS constitution, the Caldicott2 review of information governance, and the common law duty of confidentiality wherever it applies.

Secondly, we are expanding the range of care settings from which data will be drawn

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and linked. Put simply, commissioners cannot ensure that there is joined-up care being provided to their patients unless they have access to joined-up data. Therefore, beginning in November 2013, commissioners will have access to a data set that contains linked information from all GP practices and all hospitals. Over the next few years, we will progressively add data from all other care settings, including community health services and social care. This transformation will see Hospital Episode Statistics (HES) evolve into a care episode service (CES).

The third principle, which we are exploring in this consultation, is that commissioners must have access to a far richer range of hospital data. At the moment, HES is essentially limited to demographic, diagnostic, and procedural information. The quality of HES data is variable, and there are serious shortcomings in the outpatient and A&E data in particular. Moreover, commissioners have little or no access to information about patients' experiences of care, nor to information about outcomes, hospital prescriptions, investigations, or observations.

As the Francis report into the failings at Mid Staffordshire Hospital noted, *"A coordinated collection of accurate information about the performance of organisations must be available to providers, commissioners, regulators and the public, in as near real time as possible, and should be capable of use by regulators in assessing the risk of non-compliance. It must not only include statistics about outcomes, but must take advantage of all safety related information, including that capable of being derived from incidents, complaints and investigations."*

This consultation is a step towards fulfilling these requirements on a national scale. At the end of the consultation period we will analyse the responses received and then hold a series of stakeholder events. This process will culminate in our publishing a technical specification of the new data set that hospitals will be required to supply, starting in April 2014. We expect all of these additional data be extracted from care records and therefore they will be data that are routinely collected as part of the patient's care. The technical specification will include information about data standards and formats, together with standards of data completeness and consistency. One of the key standards will be the use of the NHS number as the primary identifier.

We fully recognise that relatively few hospitals are likely to have all of the required information ready for immediate extract. As the Francis report noted, however, *"All healthcare provider organisations should develop and publish real time information on the performance of their consultants and specialist teams in relation to mortality, morbidity, outcome and patient satisfaction, and on the performance of each team and their services against the fundamental standards."*

The benefits of a richer hospital dataset are legion. As citizens, we will be able to compare the quality of care provided by different hospitals, different hospital teams and wards, and by individual clinicians. Commissioners will become much better informed about the needs and experiences of their populations, and will be able to hold their local providers to account for the care they provide. Researchers will be

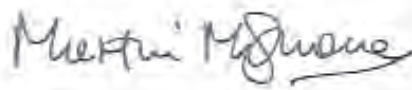
able to analyse patterns and trends across the country, develop more sophisticated analytical and predictive tools, and conduct more rigorous evaluations. Most importantly, patients and their clinicians will be able to view, share, and analyse the care they received or provided. Overall, we envision a virtuous cycle where richer datasets and greater transparency will lead to greater participation and better care for all.

We are seeking responses to our consultation from a wide range of stakeholders, including patients, clinicians, hospital managers, commissioners, and researchers. We encourage you to go online (<https://consultations.infostandards.org/nhs-england/hes/>) and tell us how we can best improve the comprehensiveness and accuracy of hospital data while minimising the burden on hospitals and clinical staff.

Professor Sir Mike Richards, Director for Reducing Mortality (Domain 1)



Dr Martin McShane, Director for Long-term Conditions (Domain 2)



Professor Keith Willett, Director for Acute Episodes of Care (Domain 3)



Neil Churchill, Director of Patient Experience (Domain 4)



Dr Mike Durkin, Director of Patient Safety (Domain 5)



Dr Mark Davies, Director of Clinical and Public Assurance, Health and Social Care Information Centre (HSCIC)



Executive Summary

Key Points

- This document accompanies an online, public consultation: <https://consultations.infostandards.org/nhs-england/hes/>.
- The data currently collected from hospitals is sufficient neither for commissioners to make properly informed decisions nor for clinicians and patients to understand the quality of care provided
- Using its powers under the Health and Social Care Act 2012, NHS England proposes directing the Health and Social Care Information Centre (HSCIC) to collect a far more complete data set from hospitals, beginning in April 2014
- Appendix B of this document provides a potential, illustrative data set that could be extracted from hospitals' electronic systems
- This consultation seeks opinions and advice from a wide variety of stakeholders about
 - » The advantages, disadvantages, and feasibility of extracting each of the items listed in the illustrative data set
 - » Any items that should be added to or deleted from the data set
 - » Ways to minimise any additional burden on hospital staff
 - » How to maximise the quality, completeness, and timeliness of the data extracted
- Later this year, we will publish the technical specification for the hospital data set, and we will direct the HSCIC to begin extracting it from hospitals starting in April 2014
- Although it will be extremely challenging or impossible for some hospitals to provide a complete data extract in this timeframe, the Francis report into the failings at Mid Staffordshire Hospital stressed the urgent need to improve hospital data
- Those hospitals that fail to provide the required data on time will therefore need to work with their local commissioners on implementing a rapid remediation and improvement plan

The NHS has some of the best data systems in the world; however, the central flows of data from hospitals are currently limited in terms of their scope, their utility, and their accuracy. NHS England is launching a public consultation about what data should be extracted from hospital systems from April 2014 onwards in order to improve their usefulness for a variety of purposes.

The *Hospital Episode Statistics* (HES) database is the principal source of patient-level information for commissioners, providers and health services researchers. HES records information about every inpatient, outpatient, and accident & emergency (A&E) encounter in England.

However, NHS hospitals collect a wide range of additional information electronically that is not currently extracted. For example, some leading NHS hospitals collect patient-level nursing observation data, prescribing data, and patient satisfaction data. Although these data sets are used extensively within hospitals, their full potential is not yet being achieved. NHS England believes that these data sets and others should be standardised, extracted, and collated for use by citizens, patients, commissioners, other providers, and researchers for the benefit of all.

As a recent OECD report put it, the “... *effective use of health data that has already been collected... can help to deliver better quality of care, reduce medical errors, and streamline administration*”.¹ NHS England is therefore working closely with the Health and Social Care Information Centre (HSCIC) and

other stakeholders to design a modern data service for the NHS. Known as “care.data”, it will bring together patient-level information from all healthcare settings to generate a joined-up view of the care being provided to patients. Commissioners need this type of joined-up data to ensure that their patients are receiving seamless, integrated care and to prevent unnecessary duplication and gaps in care provision. The care.data programme will see the transformation of Hospital Episode Statistics (HES) into the Care Episode Service (CES), which will include:

- A greatly enriched hospital dataset
- Mental health data
- GP data
- Community health services data
- Social care data
- Clinical audit data
- Disease registry data

The entire care.data project will comply with the highest standards of information governance. Specifically, it will be designed to meet the requirements of the:

- Data Protection Act
- Human Rights Act
- NHS Constitution
- Caldicott2 review of information governance
- Common law duty of confidentiality, wherever it applies

HES has a number of shortcomings in terms of its timeliness, consistency and completeness. Our intention is to build on the strengths of HES while addressing these

¹ OECD, 2013. Strengthening Health Information Infrastructure for Health Care Quality Governance. http://www.oecd.org/els/health-systems/Strengthening-Health-Information-Infrastructure_Preliminary-version_2April2013.pdf

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problems, so that health service data will in future be used more widely and more rapidly to improve patient care. In particular, the expansion of HES into CES will allow more detailed and more sophisticated analyses to be conducted of patients' interactions with the health and care system. These analyses should ensure that services are planned and audited more effectively, and that resources are deployed more efficiently and more equitably across the country.

Ultimately, our vision is to improve the electronic recording and usage of data in hospitals, which in turn will increase the coverage, timeliness, and quality of the data extracted centrally for secondary uses. Many hospitals already have electronic processes in place to meet our likely new demands. Others will rapidly need to implement new technologies if they are to provide the necessary data while reducing the burden on clinicians – a key preliminary recommendation of the NHS Confederation's bureaucracy review. [38] Throughout this consultation, it is important to remember that for patients, technologies such as electronic prescribing and digital ward observation systems can have both direct benefits at the clinical level, as well indirect benefits through data linkage, analysis, aggregation, and greater transparency.

Consultation

Under the Health and Social Care Act 2012, NHS England has the power to direct the HSCIC to establish information systems and for providers to have regard to the standards published. As part of the process of issuing new directions, NHS England is required to consult widely with stakeholders. We plan to do so both through this consultation but also through a series of events and workshops with key stakeholders after the end of the consultation period. An important part of this process will be to consider how we can make the best use of the information available while carefully considering what data are truly needed for different specific purposes. Later this year, we will publish a technical document and collection of standards that will specify what additional hospital data will flow from hospitals into the HSCIC beginning in April 2014 as part of the care.data hospital dataset. This technical document will include standards for improving the quality, consistency, and completeness of the data extracted.

NHS England will continue to offer support and guidance throughout the process, and we look forward to working collaboratively with providers, commissioners, patient groups and other important stakeholders.

Please use the online consultation (<https://consultations.infostandards.org/nhs-england/hes/>) to tell us how we can best ensure that the new data set results in the maximum benefit for patients while placing the minimum burden on hospitals.

Introduction

This document launches an open consultation on hospital data and datasets in the NHS. Its publication follows the commitment in the Everyone Counts planning guidance, issued by the NHS Commissioning Board in December 2012,² to improve the quality of the data made available to clinical commissioning groups (CCGs). In parallel with this consultation, we are publishing *Good Data: A Guide for Clinical Commissioners*, which serves both as a general guide for data quality and as a specific resource for CCGs as they develop their data strategies.

High quality data will underpin the modernisation of our national health service, ensuring that it becomes truly patient-centred and clinically led, and which properly measures and improves the outcomes patients achieve. NHS England's data strategy has two pillars. First, we will ensure that local decision-makers have access to prompt, pertinent, reliable data. Secondly, we will encourage participation, use and engagement at all levels of the health service through increased openness and greater transparency. Together, these two pillars of our strategy are designed to:

- increase patient safety
- improve outcomes
- reduce waste

- minimise health care inequalities
- remove unwarranted variation
- empower citizens and staff; and
- deliver high quality health care for all.

The Francis enquiry³ into the failings and neglect at Mid Staffordshire hospital provides an additional sense of urgency in the improvement of hospital data (see Box 1).

Box 1: Recommendations of the Francis enquiry concerning hospital data

In order to monitor safety and prevent unacceptable standards of care, the report called for:

- Reliable data, linked to individuals and provider organisations, to enable the comparison of treatment outcomes
- Real time recording of treatments and medications to reduce errors and to aid with quality management
- Healthcare professionals, individually and collectively, to introduce measures that fairly reflect their performance
- Relevant information to be accessible to the public to facilitate accountability and to support choice.

In order to improve the quality, efficiency, and experience of care while reducing healthcare inequalities, NHS England believes it is imperative for additional information to

² NHS Commissioning Board, 2012. Everyone Counts: Planning for Patients 2013/14 www.england.nhs.uk/everyonecounts.co.uk

³ Francis R, 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

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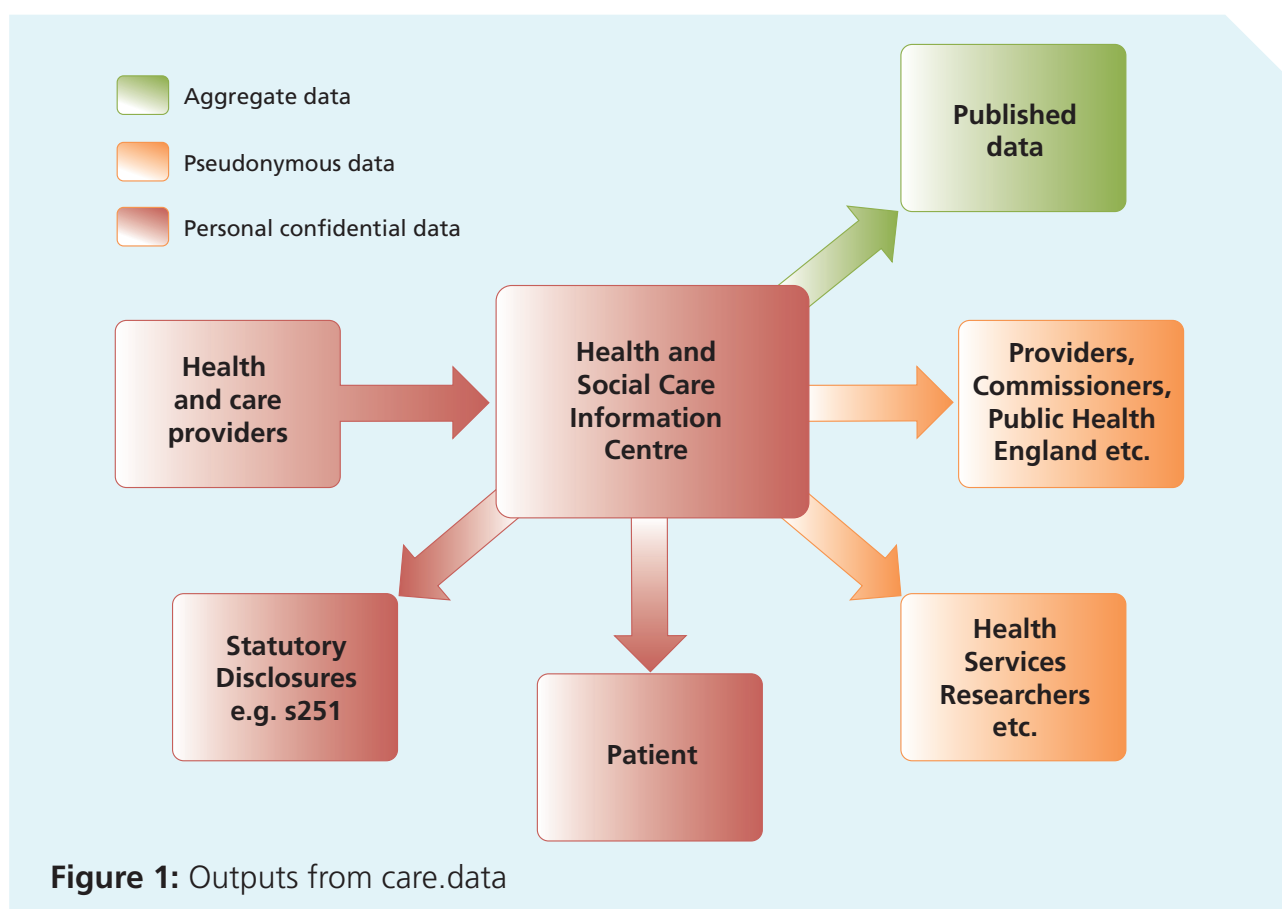


Figure 1: Outputs from care.data

be extracted from hospitals, so that it can be made available in appropriate formats to commissioners, providers, researchers, and patients (see Figure 1).

In Figure 1, **green** flows of data will be published in aggregated form, with small number suppression, in line with guidance published by the Information Commissioner's Office (ICO);⁴ **amber** data will only be disclosed by the HSCIC to accredited users such as NHS commissioners and providers. Although amber data do not include identifiers, there is a potential risk of malicious re-identification through so-called 'jigsaw attack'. In view of this risk, such

data will only be disclosed in a controlled environment where robust safeguards are in place, as set out in the ICO guidance and the Caldicott2 Information Governance Review. All such disclosures will be on the basis of legally binding agreements, and will be either in the form of aggregate reports and/or pseudonymous, record-level data. In the future, patients may be able to view or download their own identifiable (**red**) disclosures from the HSCIC once appropriate safeguards are in place. This initiative is analogous to Medicare's Blue Button in the United States, where Medicare recipients can download their claims data.⁵

⁴ ICO, 2012. Anonymisation: managing data protection risk code of practice. http://www.ico.org.uk/Global/~media/documents/library/Data_Protection/Practical_application/anonymisation_code.ashx

⁵ See <http://www.medicare.gov/manage-your-health/blue-button/medicare-blue-button.html>

We are therefore seeking views on what data should be recorded electronically by hospitals and what data should flow into the HSCIC for secure linkage and onward publication or disclosure to patients, commissioners, providers, and researchers in a range of appropriate formats. Specifically, the purpose of this consultation is to seek advice and suggestions about:

- **Priority areas** for new hospital data collections and extractions, including advice about which data items will lead to the most rapid improvements in patient safety.
- **Examples of good practice** from within and outside the NHS relating to electronic data capture and extraction in hospitals
- Details of the **guidance and support** that will be required by hospitals as they expand the dataset they submit to the HSCIC
- Suggestions for how best to improve the **quality and completeness** of data collected by hospitals
- Setting **reasonable timeframes** for these additional collections and extractions.

As a result of this consultation, we expect the breadth and quality of information extracted from hospitals to improve significantly. As we expand the range of data we make available to commissioners and other accredited users, it is essential that patients retain and increase their trust in how securely the NHS protects their data. The care.data service will be fully compliant with the Data Protection Act, as well as with the common law duty of confidentiality wherever it applies,⁶ with human rights legislation, the

NHS constitution, and the second Caldicott review of information governance. One of the recommendations of this review was that access to patients' personal confidential data should be limited to (a) the clinical team providing direct care to the patient, and (b) the HSCIC, which is the new "statutory safe haven". Consequently, NHS commissioners and health services researchers will in general only be permitted access to data sets that have been rendered pseudonymous (i.e., where individuals are distinguished by using a unique identifier – a pseudonym – that does not reveal their 'real world' identity).⁷

Currently, all secondary care providers are required to collect data that have been approved by the *Information Standards Board*. These collections include the *Systemic Anti-Cancer Therapy* dataset and the *Cancer Outcomes and Services* dataset, which are already improving outcomes for cancer patients. This consultation is the beginning of our commitment to build on these successes and to develop a comprehensive clinical data set for secondary care.

Currently, all secondary care providers are required to collect data that have been approved by the *Information Standards Board*. These collections include the *Systemic Anti-Cancer Therapy* dataset and the *Cancer Outcomes and Services* dataset, which are already improving outcomes for cancer patients. This consultation is the beginning of our commitment to build on these successes and to develop a comprehensive clinical data set for secondary care.

⁶ Note that there are statutory restrictions on the HSCIC about how it publishes and disseminates information.

⁷ Where access is to PCD, this access will only be when there is a legal basis for this information to flow.

Introduction

We begin with a description of the current hospital datasets used in England, followed by a brief description of the international context. Next, we set out a vision of the types of data that might potentially be extracted in future, as well as the range of issues that will need to be considered regarding implementation and the support required by hospitals. Finally, we provide a link to the online consultation, and details of next steps. A series of appendices provide additional details of current hospital data collections, how HES data are used, and some international case studies as well as a glossary of terms and a list of references

If you would like any additional information about this consultation, please contact england.cdo@nhs.net.

Current Hospital Datasets

Hospitals currently submit numerous datasets to central collections using a range of tools such as UNIFY and Omnibus. Many of these collections are at an aggregate level (e.g. intensive care unit influenza data, and information about breastfeeding). Others are at patient level (e.g. commissioning data sets [CDS]). In addition to these central collections, there may also be local data flows at aggregate and record level. One of the key aims of this consultation is to focus on the development of the Hospital Episode Statistics (HES) database into the Care Episode Statistics (CES) database and how this can be improved and augmented by other data streams and sources.

What is HES?

Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England. These data are collected during a patient's time at hospital and are submitted to the HSCIC to allow hospitals to be paid for the care they deliver. HES data are designed to enable secondary uses, of these administrative data (i.e., uses of the data for non-clinical purposes).

HES has collected data for all admitted patients since 1989; outpatient data since 2003; and A&E data since 2007. Each year, HES adds an additional 19 million inpatient records, 90 million outpatient records, and

18 million A&E records. Across these three care settings there are a number of common sections. For example, patient identity, activity characteristics, and clinical diagnoses are recorded across all three. In addition, there are several setting-specific sections, such as A&E investigations and A&E treatments.

Although it is an enviable national resource, HES does not currently support the measurement of hospital quality to the degree that is required, especially regarding the measurement of outcomes. Quality improvement was not the original purpose of HES; rather, its development to date reflects its origins as an administrative database. This consultation offers the opportunity to redesign and expand HES so that it supports the full range of secondary uses.

What information is contained in HES?

HES is derived from the secondary uses service (SUS) data warehouse, which in turn is fed by commissioning data set (CDS) submissions from hospitals. Although HES contains many hundreds of fields, not all the submitted data fields from CDS flow through into HES, and HES contains additional data fields that are not contained in SUS. These additional fields are derived from the data and include for example flags to indicate whether other fields contain valid data, and geographical derivations from postcodes. Overall, HES contains:

Current Hospital Datasets

- **administrative** information (such as appointment dates and method of admission);
- **demographic** and **biographic** information about the patient (e.g., age, sex, ethnicity); and
- **clinical** information (viz., diagnoses and operations).

HES extracts are taken from the SUS data warehouse each month of the year, with each extract being cumulative for the financial year. HES therefore represents a series of fixed positions aligned to the extracted data, while SUS is continually

updated whenever new data are submitted. For this reason, there may be differences between HES and SUS for the same time period. Further information about the processing and outputs of HES can be found in Appendix A.

Organisations that provide NHS funded care are mandated by the NHS standard contract to submit data to the HSCIC. Specifically, the providers must send the data using the relevant CDS to SUS, with CDS providing the basic structure for the submission. Table 1 indicates some of the main data items collected through CDS.

Table 1: Examples of data items collected in SUS (items highlighted in green are common components across two or more care settings).

Inpatient	Outpatient	A&E
NHS Number	NHS Number	NHS Number
Start Date (Spell)	Appointment Date	Arrival Date
		Arrival Time
Age at CDS Activity Date	Age at CDS Activity Date	Age at CDS Activity Date
Code of Provider	Code of Provider	Code of Provider
Code of Commissioner	Code of Commissioner	Code of Commissioner
Primary Diagnosis	Primary Diagnosis	Primary Diagnosis
Primary Procedure	Primary Procedure	Primary Procedure
Episode Start Date		A&E Investigation – First
Episode End Date		A&E Treatment - First
Age on Admission		

HES records healthcare activity in units called *finished consultant episodes*, *hospital spells*, and *attendances* (see Box 2).

Box 2: Examples of Currencies used for Recording Hospital Activity

Finished Consultant Episode

A finished consultant episode (FCE) is a completed period of inpatient activity for a patient under one consultant within one healthcare provider. If a patient is transferred from one consultant to another, then the episode ends and another begins - even if this new spell is within the same provider unit.

Hospital Spell

A hospital spell is the period from the date of admission to hospital to the date of discharge, which can be made up of one or many FCEs.

Attendance

An attendance refers to both an outpatient appointment and a visit to A&E. It is the unit of a visit to either care setting.

What is HES used for?

HES is designed for secondary uses (i.e., uses that are not related to direct patient care). Such uses may include analyses to identify patterns and trends in health outcomes, summary statistics, predictive modelling, evaluation, and linkage to other datasets. Currently, HES is unable to support this full range of secondary uses, especially the monitoring and improvement of quality.

Further information about HES and examples of its use can be found in Appendix D.

What hospital data do stakeholders need?

Commissioners, clinicians, managers, and patients require high quality information in order to design, contract for, improve and assure the care provided to the population. However, the information currently available

to these stakeholders is severely restricted. Commissioners and managers have access to the SUS data set, which provides them with basic information about the secondary care and tertiary care services delivered to their population of patients. However, SUS suffers from problems of poor data quality and completeness, especially for A&E and outpatient care. More importantly, SUS is completely lacking in data for many important dimensions of care. For example, SUS does not record information about the nursing care received by patients, the investigation results for inpatients and outpatients, nor the medications prescribed and received in hospital. Further information about data quality and completeness can be found in Appendix D.

All NHS hospitals collect large volumes of electronic data through their daily interactions with patients that are not available in SUS. All hospitals, for example, have a patient administration system (PAS) that records additional details such the patient's ward; a picture archiving and communications system (PACS); and a pathology system that contains information about blood tests and other laboratory results. A minority of hospitals also collect additional data such as nursing observations and prescriptions electronically. These systems have led to demonstrable improvements in patient safety. There are therefore strong reasons for all NHS hospitals to introduce, without delay, electronic prescribing systems and electronic systems for monitoring and analysing patients' vital signs.

These systems have been shown to lead to direct benefits to patients both directly and indirectly. By extracting and analysing

Current Hospital Datasets

the data from thousands of patients in ways that protect patient confidentiality, it is possible to determine whether patients' health care needs are being met, for example by comparing the quality, equity and cost-effectiveness of different hospital services.

Because of the limitations of the current data sets, additional data sets have been created for essential clinical, research, quality and other purposes, most notably clinical registers and national clinical audits, as well as research databases. These all contain high quality clinical data useful for a variety of secondary purposes and very much the improvement in quality of patient care and outcomes. Some of these are mandatory, such as some clinical audits.

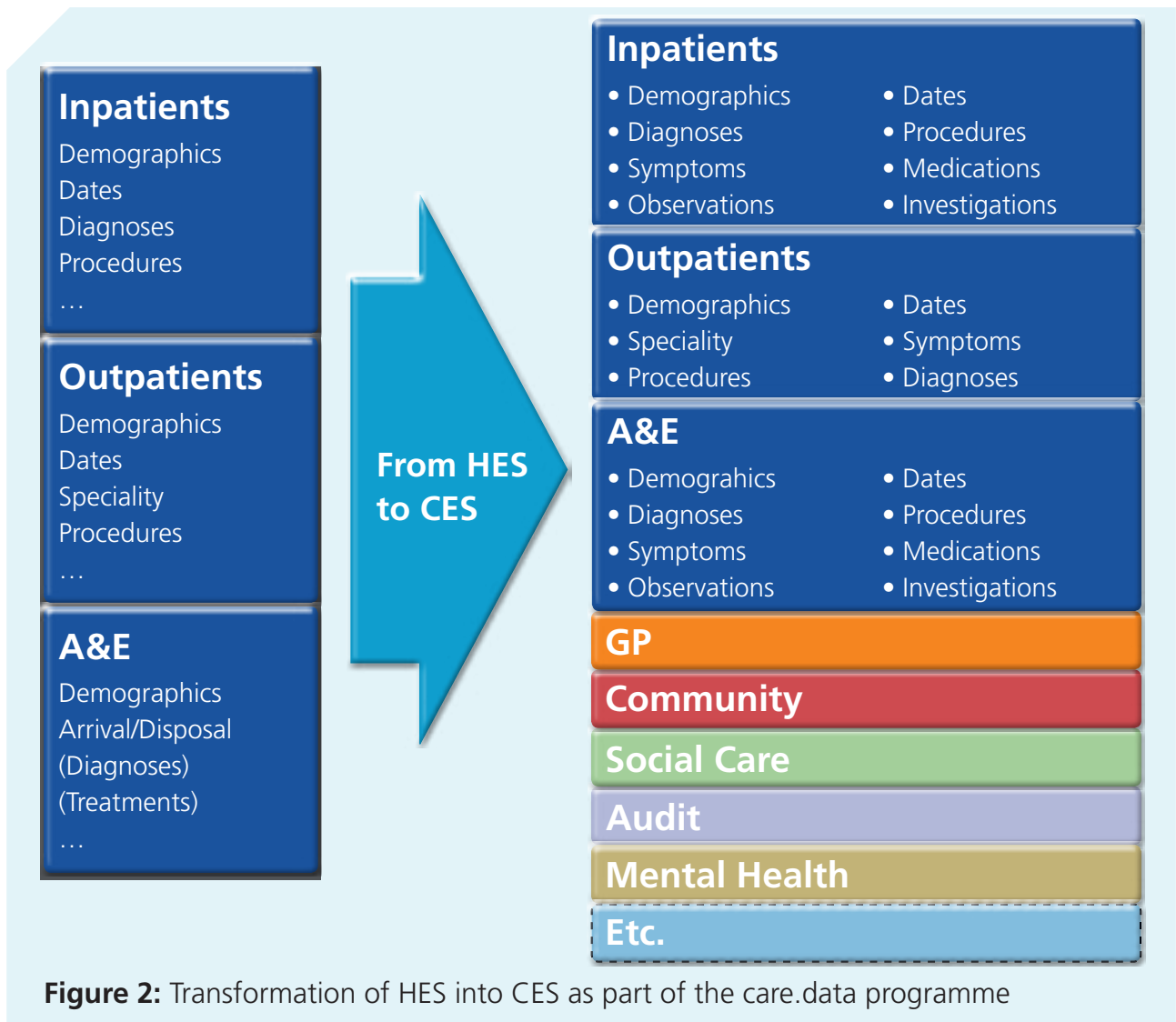
NHS England is addressing the deficiencies in the information that is currently available to commissioners, clinicians, patients and providers by designing a new comprehensive and integrated data service for the NHS.

Known as "care.data", this system will receive information from all care settings before linking it securely and anonymising, pseudonymising, and aggregating the data for different purposes ready for use by commissioners, health care providers, researchers, and citizens. By creating an environment where information flows more securely and more effectively, and contains a wider volume of data items, the programme aims to stimulate continuous improvements through greater transparency and participation, leading to higher quality, greater efficiency, better patient experience, and fewer inequalities.

Future Hospital Extracts

It is vital that commissioners and other stakeholders see a complete view of the care being provided to their population or provider setting, including care that spans across different care settings. Historically, patients who required care from multiple providers often experienced undue fragmentation and duplication in their care. Only by analysing linked information

can commissioners ensure that their patients are receiving properly integrated care and clinicians ensure their care is of high quality. Therefore, in addition to expanding the information available about inpatient, outpatient and A&E care, the care.data programme will also ensure that commissioners and others receive data from the full range of care settings, including



Future Hospital Extracts

primary care, mental health, clinical audit, and social care data. This expansion and modernisation will transform Hospital Episode Statistics (HES) into Care Episode Statistics (CES). See Figure 2.

Additional data to be included in CES

Hospitals collect a vast amount of data above and beyond that submitted to SUS, including patients' ward and theatre details, pharmacy, and pathology data. If these data were submitted centrally they would provide

a much more detailed picture of the patients and any variations in the healthcare provided. Other types of data, which might be useful to analyse, are rarely recorded by hospitals if at all. Table 2 lists a range of potential additional data that we are exploring as part of this consultation.

Appendix B details a dataset which provides an example of the level of detail we will be aiming for all providers across these domains.

Table 2: Extra domains

Type of information	Details
Identifier	<ul style="list-style-type: none"> NHS Number is the sole identifier in use for all submissions
Clinical	<ul style="list-style-type: none"> Extra clinical details such as presenting complaint, issues on discharge
Prescribing	<ul style="list-style-type: none"> Prescribing information including medications and infusions prescribed during stay, take home medications etc.
Tests	<ul style="list-style-type: none"> Tests and imaging performed in hospital Results of test and imaging
Ward	<ul style="list-style-type: none"> Ward information such as where the patient stayed, the and the time of transfers between wards
Feedback	<ul style="list-style-type: none"> Patient feedback (patient reported outcomes, patient experiences)
Incidents	<ul style="list-style-type: none"> Incidents that occurred in hospital, such as falls and medication errors
Nursing	<ul style="list-style-type: none"> Nursing observations performed (observations recorded in hospital) Nursing observation results (results of the observations recorded in hospital) Responsible nurse (the nurse responsible for the care of a patient) Associated AHPs (other health care professionals who cared for the patient in hospital)
Discharge	<ul style="list-style-type: none"> Discharge details (arrangements made with GP, social care etc.) Issues on discharge (issues present at the time of discharge such as pressure ulcer)
Audits	<ul style="list-style-type: none"> Clinical audit data and registers which span a wide range of care There are currently a wide range of these datasets which could be incorporated

Collecting information about each of these additional domains could lead to both direct and indirect improvements in patient care.

Visualisation of patient records

An individual's HES record can be displayed graphically as a timeline (see Figure 3). Known as a *Theograph*, this data visualisation provides an overview of a patient's encounters with all hospital providers.⁸

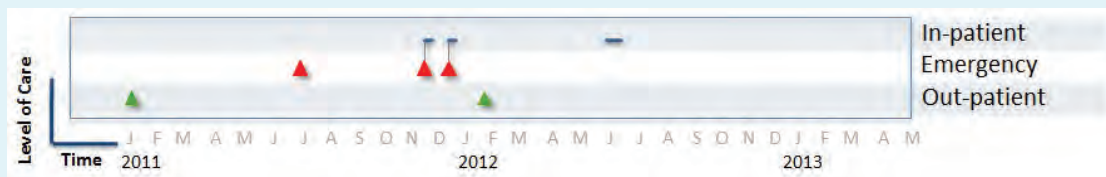


Figure 3: Mock-up HES Theograph for one individual's hospital encounters, spanning two years

By the end of the transformation of HES into CES, a patient's Theograph will contain details from additional care settings, such as GP visits and social care services (See Figure 4).

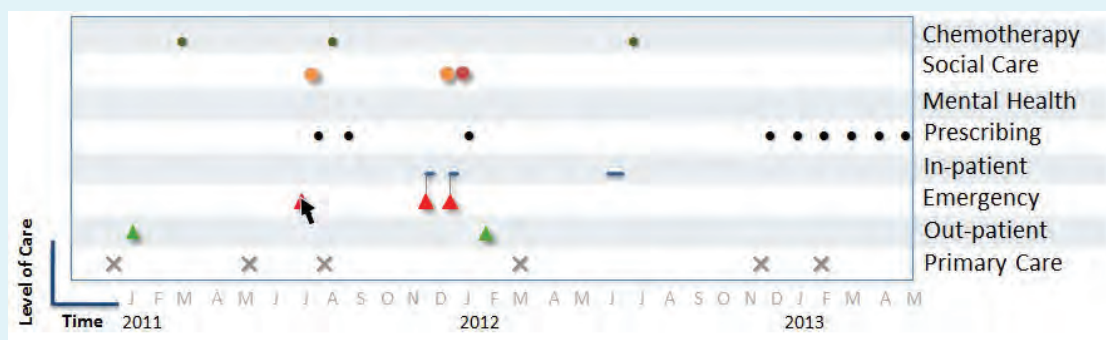


Figure 4: Mock-up CES Theograph for one individual's hospital, primary care, and social care encounters, spanning two years

⁸ From the Greek meaning the picture seen by the Gods (i.e., a comprehensive view of every hospital encounter for a patient, spanning all providers nationwide)

Future Hospital Extracts

Depending on the outcome of the current consultation, the underlying data available within each hospital encounter will also become much richer, leading to the concept of *nested Theographs* (i.e., minute-by-minute Theographs showing a patient's real-time recording of treatments and medications etc., as called for in the Francis report). See Figure 5.

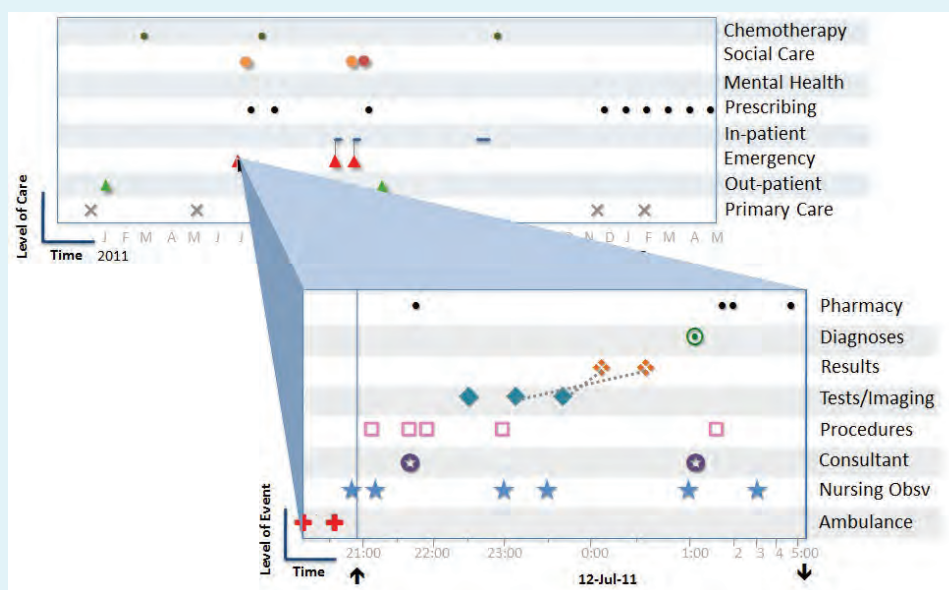


Figure 5: Mock-up CES Theograph, showing minute-by minute details of the care received during an A&E attendance

Direct improvements in care

Direct improvements in patient care are known to occur when a hospital implements an electronic system that allows healthcare professionals to record information electronically at the point of care. For example, electronic prescribing systems can directly improve patient safety in a variety of ways, including:

- The ability to communicate accurate and understandable prescriptions between hospital doctors, pharmacists, and nurses
- Automated prompts that offer information on what drugs are, should be, or should not be prescribed
- Algorithms that alert prescribers to contradictions, adverse reactions, and duplicate therapies
- Bar-code systems that prevent wrong-patient, wrong-drug, and wrong-dose errors

Similarly, electronic nursing documentation systems have been shown to contribute to direct improvements in patient safety.^{9,10,11} In particular, electronic observations data can help improve the safety of shift handovers and the detection of the early signs of impending critical illness.

An additional benefit of implementing such systems, however, is that the data recorded can then also be extracted by the HSCIC for secondary uses, leading to indirect improvements in patient care.

Indirect improvements in care

Indirect improvements in care are known to result from the linkage of a patient's data to the rest of his or her data generated in other care settings; collation with other patients' records; and analysis for patterns, variations, and trends. Indirect improvements can occur across a range of types of data and for a variety of types of user of data including patients, clinicians, commissioners, providers and researchers. (See boxes 3 – 7).

Box 3: Patient access to data

Patients will have access to detailed information on the performance of hospitals, clinics, wards and consultants. This transparency will provide them with better information with which to make a more informed choice about where to receive their care. The collection of feedback data from patients will allow patients to see which organisations provided a better level of service from the perspective of other patients.

Patients will have access to improved clinical, prescribing and test data to provide them with a more comprehensive record of the care they received, highlighting any perceived errors in their record, and will give the option of sharing their data with family members, carers, clinicians and other trusted third parties.

⁹ Kierkegaard P., 2013. The Benefits of Electronic Prescriptions "E-Prescription across Europe". Health and Technology, 3 (1), pp. 1-15

¹⁰ Raleigh, 2010. Getting the Measure of Quality Opportunity and challenges. <http://www.kingsfund.org.uk/sites/files/kf/Getting-the-measure-of-quality-Veena-Raleigh-Catherine-Foot-The-Kings-Fund-January-2010.pdf>

¹¹ Munkvold, G., & Ellingsen, G., 2007. Common Information Spaces along the illness trajectories of chronic patients 4 (2) pp. 1 - 10

Future Hospital Extracts

Box 4: Commissioner access to data

Commissioners will be able to use the wealth of aggregated and pseudonymised data to determine what care they are purchasing on behalf of their population.

Improved electronic collections of clinical, ward, prescribing, test and outcome data will allow commissioners to build a more detailed picture of the care being offered by providers. It will help them ensure that they are using resources optimally by targeting services where they are needed and where the outcomes are best.

Commissioners will be able to use electronic feedback data to identify any weaknesses in services that need to be addressed as well as understanding the strengths and efficiencies of different providers.

Box 5: Provider access to data

Offering clinicians, with a legitimate relationship to a patient, access to extended electronic collections will increase patient safety as staff have access to wider patient information and medical history, including test, prescribing and incident data.

Box 6: Researcher access to data

Researchers will gain access to a much richer source of anonymous, pseudonymous, and aggregated data to analyse, including areas of care for which there is currently little or no data made routinely available.

Clinical data would allow researchers to look at the activities taking place for patients with given conditions to compare the outcomes of treatments and investigations to determine the best therapies.

Prescribing data will allow researchers to monitor patterns in prescribing and also provide the potential to link it with outcome data to see which drugs are proving effective across a range of patients. This information could also be linked with demographic data to explore any patterns relating to drug effectiveness by age, sex and other characteristics.

Test result data add further dimensions to research studies, for example by examining how test results have varied over time, and how they were associated with other factors such as prior history and treatment.

Box 7: Clinician access to data

Clinicians will gain access to a wider set of linked data, and the data will be of far greater granularity and clinical relevance. This new resource will underpin strategic changes in the design and delivery of clinical services. Clinicians will be able to monitor the quality of the care they deliver, learn from the care provided by their peers, and use the lessons learnt to inform and drive changes and clinical redesign.

Information Standards and Collections

The content and flow of HES data are governed by a set of standards. These standards are currently developed by the HSCIC, approved by the Information Standards Board for Health and Social Care (ISB HaSC), and then published as an Information Standards Notice (ISN). Both *information standards* and *information collections* are important for ensuring that data are processed in a consistent way. (See Boxes 8 and 9).

Box 8: Information standards

An information standard defines an item of information and how it will be used. The Health and Social Care Act 2012 specifies that an information standard must be created with appropriate consultation and with accompanying implementation guidance. The process of standards commissioning and development is currently undergoing a process of change. A new body, the Informatics Services Commissioning Group (ISCG) will provide a cross-sector view of the standards being commissioned in health and care. Box 9 details some of the responsibilities of NHS England in relation to standards according to the Act.

From initial recording through to the flow, storage and analysis of information, standards are vital for ensuring the consistency of data across different care settings and different NHS organisations.

Box 9: Information collections and extractions

An information collection sets out what information will be collected from a provider. An information collection is defined as a requirement to provide information in a specified form, manner and periodicity. For example, the "HIV and AIDS Reporting System (HARS)" (ISB1570) is an information collection that specifies the items that are to be collected by providers for the HIV/AIDS data set.

In contrast, a data extraction is an automated extraction of information from a system.

Future Hospital Extracts

Collections and extractions represent an important resource for a range of users, including:

- *Patients* – to enable patients to access to their own records, allowing them to become more involved with their care and enabling them to make more informed decisions about how and where they would like to receive care;
- *Clinicians* – to help understand their patients and their needs, to compare the care provided, to identify potential safety issues, and to predict risk;
- *Commissioners* – to consider what services have been used, how much of a particular service has been used, the impact of different services, and to predict future service requirements; and
- *Researchers* – to analyse the data to determine patterns and trends, and to make comparisons about care.

An important outcome of this consultation will be to provide direction on which areas of hospital activity might require the development of new standards and new collections or extractions. Any additions or amendments to the data collected from NHS hospitals would need prioritisation and approval from the subgroup of ISCG responsible for information standards, collections and extractions. The proposed standard would require detailed consultation prior to publication. At the end of this process, the approved new items would be included in a data collection.

International Context

The world's leading health care systems all report data for public health and statistical review. The ways in which their data are collected varies between administrative databases, health registries, clinical records, and national survey or census datasets. However, as with England's HSCIC, the data custodians of advanced health care systems tend to work in secure facilities where they link data from different data sources and release the data in different tiers of richness for different classes of users. For example, pseudonymised data may be released to pre-approved researchers for analysis, while minimum data sets of healthcare quality and safety indicators are released more widely.

The Office of Economic Cooperation and Development (OECD) has for many years recognised the potential of data to improve the quality, equity and efficiency of healthcare, while also driving economic growth, and contributing to the public good¹². In 2011-12, the OECD conducted a

survey on Health information infrastructures, which examined the current state of health care data around the world, as well as the associated opportunities and challenges of exploiting healthcare data while protecting privacy. The report concluded that linked data are an essential part of any health information infrastructure. It states that with the risk classification to identify privacy issues, even very sensitive data can be used for research and monitoring to help improved health, health care quality and health system performance.

Appendix E contains a number of examples from around the world of how smarter use of hospital data, and its linkage to datasets from other care settings, are being used to improve care. These case studies are intended to provide a flavour of good practice from around the UK and internationally. They are by no means comprehensive, and as part of the consultation we would welcome information about other good examples.

¹² OECD, 2013. Strengthening Health Information Infrastructure for Health Care Quality Governance. http://www.oecd.org/els/health-systems/Strengthening-Health-Information-Infrastructure_Preliminary-version_2April2013.pdf

Implementation and Support

NHS England is committed to improving the comprehensiveness, quality and completeness of the data collected from hospitals while at the same time decreasing the effort that providers must expend in recording and sending this information to the HSCIC. This twin aim is important for ensuring that we both improve the quality of information available to NHS commissioners while at the same time ensuring that the burden on providers in collecting this information is reduced. We believe that this balance can only be achieved by moving to electronic recording of information at the point of care.

The initial phase of the NHS Confederation's *Bureaucracy and Regulatory Review* found that over a third of NHS staff were spending between one and three hours a day collecting and recording data. This bureaucracy takes staff away from their front-line roles, and often involves unnecessary duplication and overlap in the recording of information.

The NHS Confederation's initial report made several recommendations about reducing data burdens on staff, including:

- developing the HSCIC into a world-class data hub;
- minimising locally-driven collections; and
- encouraging information to be shared across the NHS.

Reducing burdens will be a key priority for the ISCG, for the subgroups of the ISCG, and for NHS England. Part of this consultation and future work will look at simplifying the collections that are currently undertaken while increasing the amount of data being collected. As providers move to automatic extraction of information, the burden of collecting information will diminish.

The burden of increasing the amount of data that hospitals submit centrally will vary between providers depending on the sophistication of their electronic systems. Another aim of this consultation is therefore to seek a range of views on the advantages and disadvantages associated with each potential additional type of data, including the potential benefits to patient safety and the burden associated with supplying each type of data.

Finally, in addition to seeking views on extending the data collected, we are also aiming to gather views on how to improve the quality of the existing data. There are several potential levers that could be used, including legal powers, imposing financial implications, scorecards etc. Each of these options has pros and cons, which we will explore as part of the consultation.

Consultation

This consultation seeks views on the steps that NHS England could take to improve response rate and completeness of the data collected from hospitals.

The consultation is available as a web questionnaire, which can be completed and submitted online at <https://consultations.infostandards.org/nhs-england/hes/>.

The questions in the online consultation include:

- » Section 1 – Respondent's details
- » Section 2 – Existing data that are not currently extracted
- » Section 3 – Data that are not recorded or submitted
- » Section 4 – Issues with data submissions to HES
- » Section 5 – Priorities
- » Section 6 – Timeframes
- » Section 7 – Consistency and completeness of data
- » Section 8 – Additional Information

At the end of the consultation period, NHS England will collate the responses received ready for analysis. Following the preliminary analysis, NHS England will convene a series of workshops with a broad range of stakeholders to review the findings and to begin formulating recommendations that reflect the consultation findings and meet the needs of NHS patients, providers, commissioners and researchers.

Later in the year, a technical specification will be published indicating what additional hospital data will flow into the HSCIC. This document will include timelines for the submission of data and the use of different mechanisms to improve the quality, consistency, and completeness of the data submitted. Any additions or amendments to the data collected from NHS hospitals will require detailed consultation followed by standardisation and publication. This process will be done in collaboration with a range of stakeholders from across the health and social care area.

Appendix A: HES processing and outputs

Hospitals submit patient data via CDS data flows into the SUS data warehouse. Extracts are taken from SUS each month on pre-arranged dates and represent a snapshot of SUS on that day. Because SUS is continually updated as new data flows into it a comparison of HES and SUS for the same time period will likely have differences.

SUS is the single comprehensive repository for healthcare data which enables a range of reporting and analyses to support the NHS in the delivery of its services. Data within SUS is at patient level and can be identifiable, anonymised, or pseudonymised as required for users' needs. Healthcare providers can access SUS data directly via the data warehouse or via the extract mart for their own data. Figure 6, (below) shows the flow of hospital data through to HES.

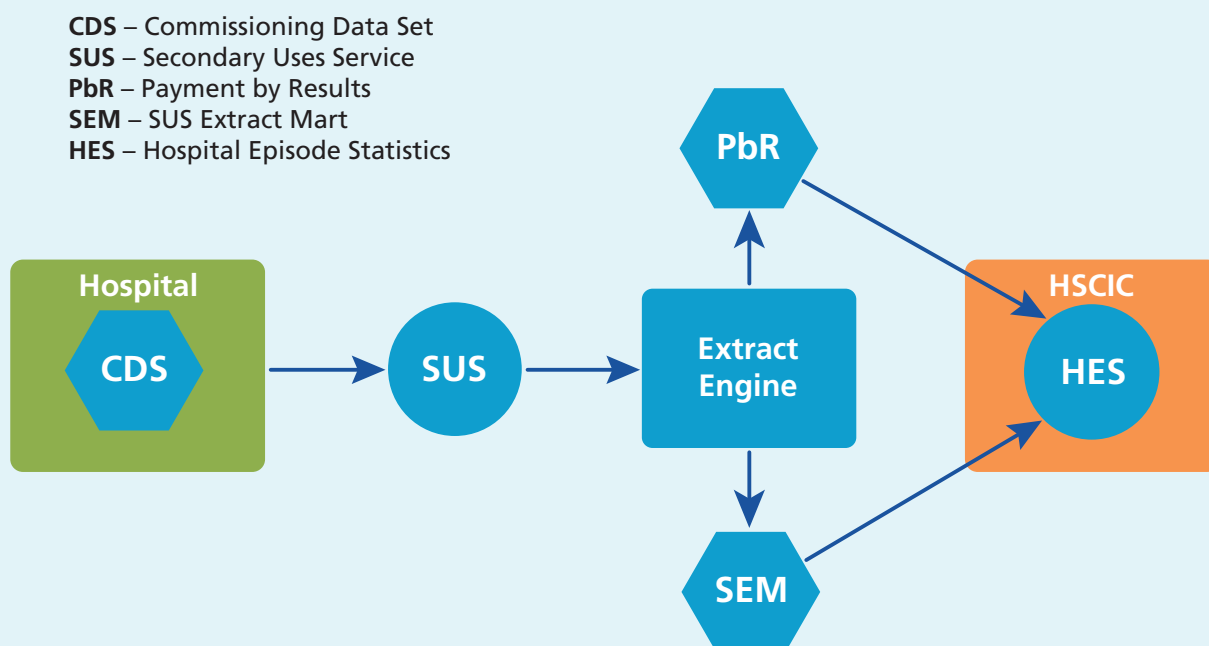


Figure 6: Flow chart showing the path of hospital extracts into HES.

Current HES Outputs

The confidentiality of patients is always a prime consideration in any release of HES data, whether at aggregate or record level. Aggregate data are non-record level (i.e. a summary table of data for more than one patient). For sub-national data, a small-numbers rule is applied that suppresses any figure below 5 to provide an additional protection to patient confidentiality. This type of aggregated data can be released as open data.

HES data are released for both official and bespoke purposes, as intended by its creation for secondary (i.e. non-clinical) uses.

Official publications

As HES data conform to national information standards, they can be used to construct indicators and comparators. Moreover, reports about data quality and completeness ensure statistical relevance, and enable providers the opportunity to improve the quality of submissions. For these reasons, the HES dataset is used to produce accredited National and Official Statistics, to answer parliamentary questions, and to calculate indicators which are used nationally, such as the Outcomes Framework.

The HSCIC publishes HES APC and OP reports as National Statistics each year. These annual publications include a summary report alongside a selection of Excel tables used to highlight specific breakdowns of information. The target audience for these publications are NHS staff who use the data to inform policies, strategies, and processes for improving patient care.

In addition to the publications of HES that are designated as National Statistics, the HSCIC also publishes other HES statistical reports as Official Statistics. These include the annual publication of HES A&E data (which is still classed as experimental).

Other Official Statistical publications about hospital care (not just HES) include:

- Accident & Emergency (patient journey, diabetes inpatient activity, finalised patient reported outcome measures [PROMs])
- Deaths within 30 days of a hospital procedure or of an emergency admission to hospital
- Emergency readmissions to hospital within 28 days of discharge
- Provisional A&E quality indicators,
- Hospital prescribing, and
- Summary hospital-level mortality indicator (SHMI).

Note that HES is only made openly available at an aggregate level. The only ways to access pseudonymised, record-level HES data are via a bespoke output or via the HSCIC HES Data Interrogation System. This system, which is only available to NHS organisations, enables NHS analysts to interrogate the data directly and to produce their own tabulations of the data.

Bespoke outputs

Although some HES data are published at aggregate level as open data (e.g., in publications), it would be impossible for the HSCIC to publish every permutation of data that might be of interest to users. Bespoke tabulations of data can therefore be

Appendix A: HES processing and outputs

requested from the HSCIC Data Linkage and Extract Service. This service typically releases 70 bespoke tabulations of HES each year.

In addition to the Official Statistics published by the HSCIC, the underlying HES data are available from the HSCIC Data Linkage & Extract Service.

Each year this service typically releases:

- 130 bespoke extracts of HES
- 50 bespoke linkages to HES

A subscription service for monthly releases of standard provisional extracts is also provided. There are approximately 20 subscribers to this data feed, each receiving between 2 and 5 datasets per month.

Appendix B: Example Data Set

Table 3 provides potential examples of the data items and data sets that might be included with the care.data extract following this consultation.

Table 3: Examples of potential items that might be extracted from hospitals' electronic systems

Type of information	Example Items	Coding Language
Identifier	<ul style="list-style-type: none"> • NHS Number 	<ul style="list-style-type: none"> • id
Clinical	<ul style="list-style-type: none"> • Presenting complaint code • Issue on discharge flag • Reason for admission 	<ul style="list-style-type: none"> • SNOMED CT • Boolean • SNOMED CT/structured text
Prescribing	<ul style="list-style-type: none"> • Medication code • Form • Quantity • Dosage • Route of administration • Reason for administration • Prescriber ID • Prescription date/time 	<ul style="list-style-type: none"> • dm+d • structured text • number • structured text • SNOMED CT • SNOMED CT/structured text • Identifier • datetime
Tests	<ul style="list-style-type: none"> • Test Code • Result • LabID • Ordered by • Ordered date/time 	<ul style="list-style-type: none"> • SNOMED CT • SNOMED CT/structured text • id • id/name • datetime
Ward	<ul style="list-style-type: none"> • Ward ID • Ward description • Arrival date/time • Departure date/time 	<ul style="list-style-type: none"> • id • structured text • datetime • datetime
Feedback	<ul style="list-style-type: none"> • Patient Reported Experience Measure (PREM) 	<ul style="list-style-type: none"> • dataset
Incidents	<ul style="list-style-type: none"> • Incident code • Incident date/time • Adverse 	<ul style="list-style-type: none"> • SNOMED CT • datetime • boolean

Appendix B: Example Data Set

Type of information	Example Items	Coding Language
Nursing	<ul style="list-style-type: none"> • Temperature • Heart/pulse rate • Respirations • Blood pressure • Capillary refill time • Pain assessment • Level of consciousness • Height • Weight 	<ul style="list-style-type: none"> • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text • SNOMED CT/structured text
Discharge	<ul style="list-style-type: none"> • Discharging consultant • Discharging speciality • Expected discharge date/time • Date/time of discharge • Discharge method • Discharge destination 	<ul style="list-style-type: none"> • id/structured text • code • datetime • datetime • code • code
Audits	<ul style="list-style-type: none"> • All national clinical audits mandated by NHS England 	<ul style="list-style-type: none"> • dataset

Appendix C: Uses of HES Data

HES provides information to support of a wide range of users, including ministers and Department of Health officials, NHS commissioners, NHS providers, public health, other government bodies, researchers, and private companies.

Official uses

The Department of Health has a wide range of uses for HES data including modelling and predicting the correct allocation of funding for GPs.¹³ As the primary source of national hospital data, HES enables the Department of Health to keep track of hospital usage and performance.

NHS Commissioners

HES data are an invaluable resource for NHS commissioners. They provide a secure, pseudonymous view of clinical, demographic, geographical, and administrative information that is centred on individual patients (i.e. allows one pseudonymous individual's interactions with the health service to be tracked over time across all providers).

HES can be used to estimate a range of statistics, including the incidence of certain conditions and treatments, durations of stay, waiting times, and access to different types of medical, surgical, and maternity for different population subgroups. These estimates are important for writing strategic

papers and preparing budget reports, as well as for identifying gaps within service areas and benchmarking. The data can be filtered by demographic, geographical or provider categories in order to provide comprehensive analysis for targeting service usage. They can also be more fully risk-adjusted to allow more meaningful comparisons to be drawn

NHS providers

Information is made available to providers from the SUS extracts for their own area; however, HES allows providers to benchmark their activity with other local areas, regions and nationwide. For example, hospitals can compare their local patient experience data to the national PROMS-HES linked data (see Box 10).

Box 10: NHS Providers validating local data

NHS providers are able to validate their local data collections against national data. HES allows providers to benchmark across a wider geographical area than their access to SUS data allows.

It has been suggested that HES data could replace the need for some local reporting (e.g., surgeons' log books). Reductions to, and the policing of additional data collections is required in order to achieve sustainable reductions to the burden of

¹³ Person-based Resource Allocation (PBRA), <http://www.nuffieldtrust.org.uk/our-work/projects/person-based-resource-allocation-pbra>

Appendix C: Uses of HES Data

the NHS as determined in the preliminary recommendations of the NHS Confederation in March 2013¹⁴.

The review of bureaucracy and regulatory burden in the NHS has been actively gathering insights and evidence to support the need for change. This review found that over a third of NHS staff were spending “between one and three hours a day collecting and recording data.”¹⁵ This duplication and overlap in reporting requirements requires a more effective and streamlined process.

Public health

HES is an invaluable source of information for public health monitoring and evaluation. HES data are used for comparative analyses to study health variations, assess service interventions, benchmark providers, and undertake equity audits. For example, Public Health England commissions the linkage of cancer registry data with HES each year to provide a range of information on patterns of cancer survival and their impact on the population. This linkage provides insight into the extent and the causes of inequalities in the outcome of cancer treatment. It also allows public health specialists to evaluate the population impact of strategies designed to improve survival or to reduce inequalities in outcomes.

Other government uses

Other government departments also use HES to aid policy decisions in complementary areas. For example:

- Road traffic accident injury data from the Department for Transport is linked to HES each year and made available to researchers to help improve road design and thus reduce the burden on A&E departments from traffic accidents.¹⁶
- The Department of Communities & Local Government used HES to help establish a social impact bond for homeless people in London [9]
- The Department of Health commissions the use of HES to model the allocation of GP funding.¹⁷

Researchers

Health economists, health services researchers, and policy analysts use HES to understand patterns, trends in hospital activity, as well as the associated costs and benefits.

University researchers are heavy users of HES data for clinical trial cohorts. HES data pre and post-clinical trial can be used to track any changes to patients’ medical conditions that might be triggered or improved by the clinical trial. HES can also be used to identify cohorts of patients with particular conditions that can then be tracked over time with no need for the researcher to ever know the identity of those patients.

In some cases, HES has replaced the requirement for researchers to visit hospitals to collect follow-up data on their cohort. For example the Self Harm Intervention Family Therapy (SHIFT) trial run by Leeds

¹⁴ HSCIC, 2012. http://www.hscic.gov.uk/media/1352/Publications-Calendar-Full-list-of-offical-statistics/doc/20120413_OfficialStatisticsList.doc

¹⁵ Billings J., Mijanovich T., Wennberg D., 2006. Case finding for patients at risk of readmission to hospital: development of algorithm to identify high risk patients. *BMJ Group*. 333 (327)

¹⁶ Dept for Transport, 2011 <http://assets.dft.gov.uk/statistics/releases/road-accidents-and-safety-annual-report-2011/rrcgb2011-06.pdf>

¹⁷ Person-based Resource Allocation (PBRA), <http://www.nuffieldtrust.org.uk/our-work/projects/person-based-resource-allocation-pbra>

University Clinical Trials Research Unit has been exploring the feasibility of replacing researcher hospital visits with HES data¹⁸. This arrangement not only saves time and effort for the researchers but also lessens the burden on hospitals to manually extract the data they require. For patients, the move to a national data source ensures that the clinical trial is more accurate in reporting outcomes as it captures all relevant data (e.g. readmissions with clinical complications) rather than data only for those patients that used local hospitals after the trial.

Examples of research using HES:

- **Predictive modelling.** A study by Billing and colleagues used HES data to develop a method of identifying patients at high risk of readmission to hospitals within 12 months. Data from HES were used to analyse all admissions in NHS trusts in England over five years. A set of variables for previous hospital resource use and diagnostic history from HES was used to predict emergency admissions that occurred in the 12 months after discharge.¹⁹
- **Trend analysis.** A study by Blunt and colleagues examined hospital admission rates in England. Approximately 35% of all hospital admissions in the NHS in England were classified as emergency admissions, costing in the region of £11 billion a year. This study used HES data to examine monthly emergency admissions over a five-

year period. The use of a pseudonymised patient ID in HES facilitated patient-level tracking on factors such as readmission.²⁰

- **Health intervention evaluations.** The Partnership for Older People Projects (POPP) was established by the Department of Health with the aim of encouraging local councils to work in partnership with the NHS and local organisations to improve the health, wellbeing and independence of older people. New data linkage techniques developed with the HSCIC allowed person-level data about hospital activity to be obtained and used without compromising confidentiality. A study by Steventon and colleagues examined patterns of hospital use of the individuals who received the POPP interventions, and matched controls who did not receive the intervention. Rather than relying on aggregated data within their primary care trust area, the HES data allowed the researchers to access to person-level information while maintaining the highest standards of information governance and protecting the confidentiality of the individuals who received the interventions.²¹

Private companies

Information intermediaries are private companies that use HES data to populate visualisation and analytical tools that are marketed to the NHS and other health organisations such as pharmaceutical companies. For example, companies involved in the production of hospital equipment

¹⁸ Shift, 2013 <http://ctr.u.leeds.ac.uk/shift>

¹⁹ Billings J, 2006. Case finding for patients at risk of readmission to hospital: development of algorithm to identify high risk patients. *BMJ Group*. 333 (327), pp.1-52

²⁰ Trends in emergency admissions in England 2004 - 2009. Nuffield Trust. <http://www.nuffieldtrust.org.uk/talks/slideshows/trends-emergency-admissions-england-2004-2009>

²¹ The quality of nationally submitted health and social care data. 2012 <http://www.hscic.gov.uk/catalogue/PUB08687>

Appendix C: Uses of HES Data

often request tabulations of HES data. This information can help them assess the market for specific devices or equipment and to direct their resources to meet the needs of the NHS. HES data are also used to populate commercial research databases such as QResearch,²² CPRD,²³ and THIN.²⁴ These databases provide life sciences researchers

with access to a rich source of data that would not otherwise be available. Note that private companies are only granted access to de-identified raw data, with robust safeguards in place to prevent re-identification. They must sign an agreement as part of their contract with the HSCIC not to disclose the data to other bodies.

²² QResearch, <http://www.qresearch.org/SitePages/Home.aspx>

²³ CPRD, <http://www.cprd.com/intro.asp>

²⁴ EPIC, <http://www.epic-uk.org/>

Appendix D: HES data quality

Data quality can be assessed according to six dimensions: completeness, validity, consistency, timeliness, accuracy and uniqueness (see Box 11).

Box 11: Definition of data quality dimensions

Completeness

All of the necessary data are present; no fields remain empty.

Validity

Data are compliant with the formatting rules provided (e.g. max/min values, alphanumeric codes, field length, date order, etc.)

Consistency

The same entries remain the same between systems and within systems (e.g. NHS number is always used as the primary identifier, units of laboratory tests always comply to the same established standard).

Timeliness

The time period between an item of data becoming available for its intended use and the time it relates to.

Accuracy

Data are sufficiently correct for their intended purpose, representing clearly and in detail the activity being delivered.

Uniqueness

The degree to which the data exclude duplicate records

In this appendix, we shall consider each of these six dimensions in turn. Note that work is already underway to improve the capacity and capability of the HSCIC to handle big data.

Completeness

The usability of a dataset is often limited by incompleteness in the data. For example, missing fields reduce linkage success rates. The standard fields used for data linkage by the HSCIC are NHS number, date of birth, gender, and postcode. Although data may be linked with a subset of these identifiers, having all fields available increases the robustness of the linkage and provides greater confidence of a correct match. Unfortunately, a single person may have multiple records within HES due to incomplete personal identifiable data. If the completeness of the data is low, it indicates that there may be an issue with collecting the information and/or with its availability in provider systems. Within HES, data completeness is considerably higher for inpatient data than outpatient and A&E. See Box 12 for potential reasons why this may be the case.

Appendix D: HES data quality

Box 12: Why inpatient data may be more complete than data from other hospital settings.

Lower time constraints

For inpatients, a ward clerk typically has more time and fewer patients to deal than do the clerks and administrators for outpatients and A&E.

Greater financial incentive

The costs that can be reclaimed from NHS commissioners are greater for inpatient stays than for outpatient or A&E episodes.

Maturity of systems and processes

Inpatient data have been collected for longer than outpatients and A&E, so the processes and systems in place, such as scheduled referrals, are established and well-developed.

Validity

The quality of HES data depends on the quality of the SUS data from which it is derived. The validity of key fields in inpatient SUS is generally high, ranging from 100 per cent for *treatment function* to 92.3 per cent for *site of treatment*.²⁵ Outpatient and A&E SUS show similar figures for data validity in *key fields*, which are often mandatory. However, the validity of other fields remains poor; notably in the A&E dataset. This deficiency may be because the A&E dataset is still classed as 'experimental'. Some A&E fields will require significant improvements before the data are fully useable (e.g., diagnosis).

Consistency

Providers usually have national coding standards built into their own PAS. Fortunately, the use of such systems is high. However some providers use local coding systems, which they then map across to the national system. Moreover, most hospitals still use paper-based clinical notes, with the coding process occurring from clinical notes well after the point of care. These complexities create opportunities for errors to arise.

Timeliness

At present, the monthly provisional HES dataset is released with a 4 month lag (e.g. data for April 2013 is released in August 2013). This is due to the submission deadlines that providers have to work to and the processing required to derive HES from the SUS data. Recent changes to the processing of HES data should mean that the time lag reduces over the next year or so due to increased processing efficiencies.

Although currently subscribers to the standard monthly HES feeds can expect to receive the data on the day of release, it is more common for extract customers to have to wait several weeks from the point of requesting data to actually receiving it. This delay is due, in part, to the information governance requirements involved in releasing that data, but also the capacity of the team and the infrastructure delivering the service.

²⁵ The NHS information centre., 2012. The quality of nationally submitted health and social care data. England – First Annual Report, 2012, Experimental Statistics. 1 (1), pp. 1 - 44.

These time lags prevent HES data being used as efficiently as it could be by NHS providers and commissioners. Providers generally prefer to use their own data for most analyses, as they are timelier, with HES data only used for benchmarking purposes. Likewise, commissioners tend to use SUS extracts to upload into their own data warehouses in order to analyse data and will use HES for benchmarking. For both types of users, HES data tends to be used more often via third party information intermediary applications.

Accuracy

Data accuracy is often assessed by clinical audits, such as the Audit Commission's PbR data assurance framework. Over the last five years since the Commission has been undertaking these reviews, the quality of the data has improved. Payment error rates have improved by over 2 per cent and underpinning clinical coding error rates have reduced by 9 per cent. The average error rate identified from the audits is now 7 per cent, suggesting that data items reviewed are 93 per cent accurate. However, this figure masks a considerable variation amongst individual NHS trusts. For example, two providers were found to have error rates in excess of 20 per cent.²⁶

Uniqueness

Published figures from the HSCIC's *SUS Data Quality Dashboards* Dashboards show that there is a low level of duplicate records in SUS. For example, in the third quarter of the 2011/12 financial year the figures were 0.05%, 0.03% and 0.02% for inpatient, outpatient and A&E, respectively.

Transparency

Due to the sensitive nature of the data, HES is released at record level only where a contractual agreement is in place that restricts the use and further distribution of the data. A rising issue with the flow of patient data is a lack of awareness by the public about those flows. Most patients do not know what data are collected and held about them and, more importantly, how they are used for secondary purposes (i.e., for uses not related to direct patient care). It is important that patients be made aware of how their data are being used and how such usages can lead to improvements in the quality, efficiency, and equity of care.

²⁶ The NHS information centre., 2012. The quality of nationally submitted health and social care data. England – First Annual Report, 2012, Experimental Statistics. 1 (1), pp. 1 - 44.

Appendix E: International Case Studies

In this appendix we have drawn together a range of case studies from across the UK and internationally of how richer hospital datasets have been used to improve patient care. We would be grateful if you would let us know via the online consultation of any other notable case studies.

1. United States

1(a) Kaiser Permanente – Big Data equals volume, variety and velocity

Kaiser Permanente (KP) is an integrated, managed care consortium, based primarily in California. It has an international reputation for using innovative practices and technology, including embracing the concept of big data, to improve the quality and efficiency of patient care.^{27 28} Kaiser Permanente has shown how the use of consent-based integrated health information across all medical providers can improve efficiency in patient care. A 2009 study found that immediate access to complete, integrated, current patient information (including inpatient, outpatient, imaging and pharmacy data) was associated with a 26% reduction in patient visits and an eightfold increase in the number of consultations that could be conducted via telephone.²⁹

Kaiser Permanente have been keen to demonstrate to patients the benefits of data sharing and usage, to prevent them seeing it purely as some kind of ‘big brother’ scheme.³⁰ Such benefits include a reduction in unnecessary face-to-face appointments (as judged by the patient), which was enabled by a greater sharing of data, and has reduced costs for KP but has also proved a better experience for the patients, who can now often speak to the clinician from home or work rather than attend a clinic. The increased availability of information is also allowing a smoother admission and discharge process for the patient as clinicians can plan better with the information available.

1(b) Blue Button

The Blue Button approach is a simple concept: a patient is provided with a highly visible, clickable button to download his or her medical records in digital form from a secure website offered by their providers, insurers, pharmacies or payers. After downloading their information, patients can examine it, check it, and share it with their doctors and others as they see fit. By allowing patients greater access to their information, Blue Button is helping individuals to participate more meaningfully

²⁷ BBC, 2002 <http://news.bbc.co.uk/1/hi/health/1764713.stm>

²⁸ Versel, 2013 <http://www.informationweek.co.uk/healthcare/electronic-medical-records/big-data-helps-kaiser-close-healthcare-g/240150269>

²⁹ Chen, 2009. The Kaiser Permanente Electronic Health Record: Transforming And Streamlining Modalities Of Care. <http://content.healthaffairs.org/content/28/2/323.full.pdf>

³⁰ Big Data Helps Kaiser Close Healthcare Gaps, 2013. <http://www.informationweek.co.uk/healthcare/electronic-medical-records/big-data-helps-kaiser-close-healthcare-g/240150269>

in their health and health care. The wealth of personalised data contained in electronic medical or claims records also presents a unique opportunity for other data uses in order to improve patient care.³¹

1(c) Department of Veterans Affairs

The Veterans Health Administration within the U.S. Department of Veterans Affairs (VA) is widely regarded as a modern, responsive, efficient, and effective health care organization. Through a new program called the *Innovation Initiative*, the VA has committed to being on the cutting edge of health care delivery and laying the foundation for safe, secure, and efficient interoperability of health records.³²

The VistA system created by the VA is one of the most successful examples of an integrated health information technology system. Developed by the VA from a clinical perspective, VistA has been continuously enhanced over the past 25 years. It has been successfully deployed and utilized by administrative and clinical staff working in VA medical centres, clinics, and nursing homes across the country, and is now being widely deployed in private health systems, public hospitals, and medical offices in the United States and overseas.

The VA's secondary uses data include some 3.2 billion clinical orders, 1.8 billion prescriptions, and 2 billion clinical text notes, all of which can provide critical

information for research purposes and case studies in order to improve patient care. One recent development of data usage is a "prediction engine", which uses semantic search capabilities to mine structured and unstructured data stored in veterans' electronic health records. This engine can answer natural language queries from physicians will help clinicians to estimate risks relating to their patients based on previous patterns observed in the data.³³

1(d) BioSense – Real Time Surveillance

BioSense began in 2003 as an attempt to create an integrated, national public health surveillance system for the early detection and rapid assessment of potential bioterrorism-related illness. It is now being expanded and updated by the Centers for Disease Control and Prevention to cover a wide range of public health tracking issues at the state, local, and national level. This collaborative system between all levels of government, hosted on the cloud, is an example of how integrated data can be used to track health issues in real time, as they evolve.³⁴

1(e) GenISIS – Creating Value from Genomic Information

GenISIS and the *Million Veterans Program* are projects supported by the Department of Veterans' Affairs to make greater use of veteran genomic information and ultimately improve patient care. Having full genomic information on veterans will give doctors

³¹ Blue Button Data, 2012 <http://bluebuttondata.org/about.php>

³² Broderick A., 2013. The Veterans Health Administration: Taking Home Telehealth Services to Scale Nationally. http://www.commonwealthfund.org/~media/Files/Publications/Case%20Study/2013/Jan/1657_Broderick_telehealth_adoption_VHA_case_study.pdf

³³ Bresnick J., 2013. VA to use NLP, HER data mining in VistA "prediction engine". <http://ehrintelligence.com/2013/02/04/va-to-use-nlp-ehr-data-mining-in-vista-%e2%80%9cprediction-engine>

³⁴ Government Business Council, 2012. 5 of the Most Innovative Government Big Data Projects. http://www.govexec.com/media/gbc/docs/netapp_bigdata_publish.pdf

Appendix E: International Case Studies

far greater information when treating their patients. The projects will also make vast amounts of genomic data available for secondary research and analysis, potentially leading to new or improved treatments. The short-term goal for GenISIS is to create and support a knowledge base that will facilitate independent research projects and collaborative repurposing of data. The long-term vision is focused on improving patient care by integrating clinical care and research activities for improved patient outcomes.³⁵

1(f) Outcome Payments for Clinicians

The linking of patient activity with outcomes data is allowing organisations in the United States to move away from fee-for-service plans towards payment based on patient outcomes. Similarly, this approach is being introduced in pharmaceutical contracts, with risk-sharing agreements where the payment for drugs is based on measurable improvements in patient health. These schemes would not be possible without the effective linking of activity and outcome data at a patient level.³⁶

2. Australia

The Data Linkage Australia (DLA) Project

The *Western Australian Data Linkage System* (WADLS) consists of over thirty population health datasets, including hospital morbidity and discharge data, birth and death records, mental health services data, cancer registrations and midwives' notifications. Recent extensions of the project include

data from the state electoral roll, and Commonwealth data sets such as Medicare, the pharmaceutical benefits scheme, and aged care. Through computerised probabilistic matching, WADLS creates a dynamic master linkage key between over 30 population-based, administrative and research health data collections. WADLS provides data linkage and related services to researchers and academics from the health industry, academic community, and government organisations. It has led to over 600 distinct studies of clinical needs and patterns, costs of care, and the outcomes of health services.

A recent development in Australia is a new programme for Internet-based *Person-Controlled Electronic Health Records* (P-CEHRs). The system links demographic data, medical history, medications and allergies, which can be viewed by patients through a secure portal. Plans are in place to expand to incorporate referrals, test results, and prescriptions. It is expected that the data functionality will continue to increase as more healthcare providers adopt the P-CEHR system data exchange.³⁷

3. Finland

Finland is currently using the PERFECT (Performance, Effectiveness and Cost of Treatment Episodes) system to monitor the quality, cost-effectiveness and outcomes of episodes of medical care. The project is heavily dependent on high quality and

³⁵ Government Business Council, 2012. 5 of the Most Innovative Government Big Data Projects. http://www.govexec.com/media/gbc/docs/netapp_bigdata_publish.pdf

³⁶ Kayyali B, 2013. The big-data revolution in US health care: Accelerating value and innovation. http://www.mckinsey.com/insights/health_systems/the_bigdata_revolution_in_us_health_care

³⁷ Thornett A, 2012. Getting the benefit from electronic patient information that crosses organisational boundaries. http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1803-226_V03.pdf

linkable data, including hospital inpatient, outpatient and birth records. In addition to data similar to those currently available in HES in England, PERFECT also examines prescribed medicines and social care data. In a 2012 study by the National Institute of Health and Welfare, the quality of Finnish data was found to be high.³⁸

4. Iceland

The Decode system in Iceland stores encrypted health data that are not individually identifiable. When fully operational, this database will contain quantitative information from health records (such as blood pressure measurements) but no narrative information (such as free text from hospital notes). For research purposes, a person may consent to the linking of their genetic information with their health services information.

A researcher will be able to post queries to the database through the Decode system, for example to test for correlations among clinical, demographic, epidemiological, and disease data. Longitudinal studies are also expected to become possible since the encryption system uses a unique identifier (the Icelandic personal identifier).³⁹

5. Scotland

SHIP (Scottish Health Informatics Programme) is a Scotland-wide research platform for the collation, management, dissemination and analysis of anonymised electronic patient records (EPRs).

This programme aims eventually to provide researchers with remote access to de-identified data securely so that they can be accessed at a distance and allow the researchers to use advanced statistical techniques. SHIP also aims to ensure that data are shared across third parties, thereby facilitating research involving data linkage.⁴⁰ These research facilities are supported by NHS Scotland, and provide the basis for future studies using EPRs.

The programme is focused on data linkage for research and statistical purposes. It does not cover the sharing of personal information about an individual between organisations.⁴¹ The programme is also exploring how data from other government services might be linked, such as unemployment rates and data from the Scottish Health Survey. The National Research Ethics Service reviews all aspects of the Scottish Health Survey, including data linkage. Survey respondents are asked to consent to their name, address and date of birth being sent to the Information Services Division of NHS Scotland. These identifiers are then used to link a person's responses to the Health Survey to their records including medical diagnoses, inpatient and outpatient visits, and other information about cancer registration, GP registration and mortality.

6. Wales

The Secure Anonymised Information Linkage (SAIL) Databank is in essence a large, secure data warehouse. The SAIL system links

³⁸ OECD, 2013. Strengthening Health Information Infrastructure for Health Care Quality Governance. http://www.oecd.org/els/health-systems/Strengthening-Health-Information-Infrastructure_Preliminary-version_2April2013.pdf

³⁹ Anderson R, 1998. The DeCODE Proposal for an Icelandic Health Database. <http://www.cl.cam.ac.uk/~rja14/Papers/iceland.pdf>

⁴⁰ Scottish Government, 2012. A Scotland-wide Data Linkage Framework for Statistics and Research: Consultation Paper on the Aims and Guiding Principles. <http://www.scotland.gov.uk/Publications/2012/03/3260/0>

⁴¹ NHS Scotland. SHIP, 2013. www.nhsresearchscotland.org.uk/230_Health+Informatics.html

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together a wide range of person-based data using anonymisation techniques.⁴² SAIL is continually expanding, both in types of dataset and in geographical coverage. The databank, which adheres to strict data protection principles, is becoming an invaluable resource for health-related research and service development.

The system links anonymised data at individual and household level across many health and health-related datasets. It uses a high-performance computing infrastructure that was created by the national e-health research facility for Wales, and is part of the UK e-health research infrastructure.

Datasets included within SAIL are:

- Inpatients, outpatients & day cases
- Child health (heights, weights, immunization records, maternal info etc)
- Births & Deaths
- Cancer incidence (Cancer Registry for Wales -WCISU)
- National screening programs, i.e. cervical screening
- Education data from the National Pupil Database for below 18 whilst other age ranges are in discussion.
- Congenital Abnormalities
- Ambulance Service data (Dispatch & Patient Clinical Record)
- A&E data from Trusts
- GP –full historic extracts (all patients, all conditions)
- Pathology results from NHS Trusts (all departments)
- Social Services unified assessment data (older people, mental health, learning disability, children)
- Housing data from Local Authorities
- Swansea biomedical datasets
- Cardiology Images

⁴² Data Linkage Australia. www.datalinkage-wa.org.au

Appendix F: Glossary of Terms

CDS – Commissioning Data Set is the basic structure used for the submission of commissioning data to the Secondary Uses Service for outpatient and A&E attendances, critical care activity, admitted patient care and elective admission list data

DQD – Data Quality Dashboards are interactive Excel workbooks that are populated with provider and national data, and which can be used by a provider to chart or graph against information standards. The dashboards can be configured to show data quality performance against regional and national averages. Dashboards also support the improvement and completeness of data flows by reporting on the validity of key data items.

ESS – European Statistical Service is a partnership between the Statistical Office of the European Union (Eurostat) and the National Statistical Institutes and other national authorities that are responsible in each Member State for the development, production and dissemination of European statistics.

FCE – Finished Consultant Episode is a completed period of inpatient care for a patient under one consultant within one healthcare provider. If a patient is transferred from one consultant to another, even if this is within the same provider unit, then the episode ends and another one begins. Any number of FCEs make up the Spell.

GS1 – Global Standards One uses a unique set of identification numbers to enable the identification, capture, and sharing of information on medicine, medical devices, assets and returnable equipment automatically. GS1 assists patient safety and supply chain efficiencies using a unique barcode system.

HES – Hospital Episode Statistics is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England

HSCIC – Health and Social Care Information Centre is a data, information and technology resource for the health and care system, and plays a fundamental role in driving better care, better services and better outcomes for patients

Inpatient – is secondary care activity that can be planned or emergency. This is usually where a patient is admitted to a ward for a period of time but not necessarily overnight.

ICD 10 – International Classification of Diseases is a comprehensive classification of causes of morbidity and mortality. All inpatient episodes and attendances that contain diagnoses must be recorded to the mandated version of ICD. The ICD-10 refers to the tenth revision.

Appendix F: Glossary of Terms

IG – Information Governance How organisations manage the way information and data are handled. It covers the collection, use, access and decommissioning of data, as well as the requirements and standards that organisations and their suppliers need to achieve in order to fulfil the obligations that information is handled legally, securely, efficiently, effectively and in a manner that maintains public trust.

IGT – Information Governance Toolkit is an online system that allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards. It also allows members of the public to view participating organisations' IG Toolkit assessments. Note that the use of the toolkit is mandated for health service bodies since the toolkit is an information standard.

KPI – Key Performance Indicators are a set of quantifiable measures that a company or industry uses, or specific activities to gauge or compare performance in terms of meeting their strategic and operational goals.

MHMDS – Mental Health Minimum Data Set contains record-level data about the care of adults and older people using secondary mental health services

OECD – Office of Economic Co-operation and Development is an international economic organisation of countries founded in 1961 to stimulate economic progress and world trade. It provides a platform to compare policy experiences, seek answers to common problems, identify good practices and co-ordinate domestic and international policies of its members

ONS – Office for National Statistics is the UK's largest independent producer of official statistics and the recognised national statistical institute of the UK. This includes the collection, compilation, analysis and dissemination of a range of economic, social and demographic statistics relating to the United Kingdom

OP – Outpatient is a patient who attends a hospital clinic for an appointment

PbR – Payment by Results is an incentive-based method of payment first introduced in the NHS in 2003/04 to improve the fairness and transparency of hospital payments, and to stimulate provider activity and efficiency. Rather than relying on locally negotiated contracts based on local prices and block payments providers are paid for the number and type of patients treated in accordance with nationally published rules and tariffs. The activity with a national tariff has increased year on year to now include the majority of inpatients, outpatients and Accident & Emergency.

PROMs – Patient Reported Outcome Measures assess the quality of care delivered to NHS patients from the patient perspective. Currently covering four clinical procedures, PROMs calculate the health gains after surgical treatment using pre- and post-operative surveys.

PDS – Personal Demographics Service is the national electronic database of NHS patient demographic details such as name, address, date of birth and NHS Number

QIPP – Quality, Innovation, Productivity and Prevention is a collection of case studies, tools and resources aimed at improving quality and productivity across the NHS and social care. Case studies are evaluated based on quality improvements, savings, evidence and implementation and are peer reviewed.

SEM – SUS Extract Mart is an extract available to SUS users that provides a pseudonymised dataset of activity for a given period. SUS is used by NHS providers and commissioners.

Sit reps – Situation reports are reports submitted to the department of health by trusts to show the situation at a point in time, highlighting problem areas such as capacity and incidents

SNOMED CT – Systematised Nomenclature of Medicine – Clinical Terms provides a comprehensive set of clinical phrases or terms including groups with relationships. It is the most comprehensive terminology currently available. SNOMED-CT can be used across all care settings and all clinical domains, and it is used internationally.

Spell is the period from the date of admission to hospital to the date of discharge. A hospital spell may consist of more than one FCE

SUS – Secondary Uses Service is the single, comprehensive repository for healthcare data which enables a range of reporting and analyses to support the NHS in the delivery of healthcare services

Unify is the data collection system used by the Knowledge and Intelligence team in the Department of Health to collect a wide range of performance information

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