



# The HES Protocol

(June 2009)

Instructions for handling the data\*

<sup>\*</sup>These instructions form part of the binding agreement on all users of HES data whether directly, through the HES Interrogation System, or indirectly, through the request of extracts and tabulations.

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## 1 Introduction and background

#### 1.1 Who is the HES Protocol for?

- 1.1.1 The HES Protocol applies to everyone with access to HES data. This includes everyone:
  - responsible for processing HES data, eg nominated staff at The NHS Information Centre for health and social care (The NHS IC) and at Northgate Information Solutions
  - querying HES data via the HES Interrogation System, eg analysts at The NHS IC and users of the HES data warehouse
  - requesting extracts and tabulations of HES data
  - using HES data for research.
- 1.1.2 All users must follow the protocol and any associated documentation for handling HES data.

#### 1.2 Sign-up requirements

- 1.2.1 All users of HES Interrogation System must familiarise themselves with the HES User Guide (available from HESonline [http://www.hesonline.nhs.uk]) and the HES Protocol, and sign and return the declaration in Appendix A of the HES Protocol.
- 1.2.2 All users will be required to re-sign the HES Protocol on an annual basis, or whenever the protocol is revised, to re-affirm their commitment to its principles.
- 1.2.3 All external users of HES extracts and sensitive tabulations sign a non-disclosure declaration based on the HES protocol. These declarations are customised as needed.
- 1.2.4 Access to the HES dataset will not be given (or continued) unless the latest version of the HES Protocol or the supplied non-disclosure form is signed. The HES team reserve the right to refuse or to withdraw access to the HES Interrogation System, or HES data provided as extracts or tabulations.

#### 1.3 The purpose of the HES Protocol

- 1.3.1 The NHS IC seeks to make information available to serve the public interest, while protecting the confidentiality of those described by it, such as patients, GPs, consultants and other clinicians. It is important that the people who are described by the data are confident that their data is being:
  - · collected and held legally
  - · handled confidentially, with due care and respect for privacy
  - managed in accordance with relevant legislation, eg Data Protection Act 1998.
- 1.3.2 Given the scope of HES data and the variety of uses to which it could be put, it is essential that the security procedures within this document are understood and applied consistently. Therefore, the HES Protocol:
  - describes the sensitivities of the HES dataset
  - defines the limits up to which data can be released without risk of encountering problems with those sensitivities
  - gives rules for releasing HES data
  - outlines some of the data quality and integrity issues.

## 2 Sensitivities of HES data and protecting the individual

#### 2.1 Patient information

- 2.1.1 The data held within HES relate to the care of individual patients while in hospital. Some clinical information, such as certain diagnoses (eg AIDS) or procedures (eg abortions), could potentially be very sensitive if related to an individual patient. While all health information is sensitive, some data items can be more sensitive than others or can more easily enable identification of individuals. For example:
  - the set of data items including postcode, sex and date of birth (collectively referred to as 'the potential identifiers') could, in combination and with outside knowledge, help to identify an individual patient
  - the NHS number or the healthcare organisation's local patient identifier can uniquely identify a patient if the relationship between the data item and the patient is known. This relationship is not kept within HES.
- 2.1.2 In HES, the patient's ethnic group is not a restricted data item. The patient has the option to select their ethnic group or not to state the ethnic group to which they consider they belong.

#### 2.2 Clinician-related data

- 2.2.1 In addition to patient-specific data items, there is sensitivity around practitioner-specific data. This includes the General Medical Council (GMC) code of the consultant and the registered GP. These data are routinely available but only in an anonymised format.
- 2.2.2 Even anonymised data may, however, be recognised as relating to known practitioners and should therefore be used with care. For example:
  - The consultant code in HES may refer to a consultant-led team of doctors or an individual consultant
  - Data aggregated by specialty may, in certain circumstances, report on an individual consultant
  - In a single-handed GP practice the GP Practice Code will identify an individual GP.

#### 2.3 Are individuals identified?

- 2.3.1 The privacy of the individual is one of the basic principles behind the HES Protocol. Measures are in place to make sure that the identity of a patient is never discovered using HES, even though potential identifiers (see 2.1) are held. These data items are held for grouping and linkage purposes in order to identify and group conditions, and analyse treatment patterns and patient pathways.
- 2.3.2 Patients' NHS numbers were added to the HES dataset in 1997-98 to reduce the dependence for access to potential identifiers. However, the NHS number is now treated as a potential identifier and is therefore handled as a sensitive data item in HES. Where direct access to this and other sensitive data items is allowed, they are normally anonymised (see Appendix B). This allows differentiation of patients for the purposes of comparative analysis, while still concealing the potential identity of individual patients.
- 2.3.3 PSEUDO\_HESID is a data field in HES. It was established to give each patient in the HES data warehouse an identifier that is unique to them and HES. This was implemented to prevent much of the need for the disclosure of potential identifiers purely for matching purposes, although they will still be needed for matching with data outside of HES, eg Office for National Statistics (ONS) mortality data, which are being systematically added to HES.

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- 2.3.4 The PSEUDO\_HESID can be used to link together records for a single patient from 1997-98 onwards, and has the potential to link admitted patient to outpatient records from 2002-03 onwards and to A&E records from 2007-08 onwards.
- 2.3.5 The PSEUDO\_HESID succeeds the HESID and has been developed to bring it into line with general encryption standards under the guidance of the Ethics and Confidentiality Committee (ECC, formerly PIAG) of the National Information Governance Board. The algorithm, which derives the PSEUDO\_HESID, has been enhanced to match as many patients as possible, even in cases in which data quality is poor.
- 2.3.6 To meet ECC's standards on data sharing, customers who request PSEUDO\_HESID as part of an extract will receive a field called EXTRACT HESID which is unique to the customer.
- 2.3.7 Most users of the HES data warehouse will never need to access the potential identifiers. Any user who wishes to gain access to identifiable or sensitive items must first seek clearance from ECC or the Database Monitoring Sub-Group (DMSG) and will need to sign up to additional conditions to gain access.
- 2.3.8 Where users are granted access to sensitive data items they must not query, extract, store or link these data items with their equivalent anonymised data items, without the express consent of the HES team. On no account should an attempt be made to decipher the process of creating anonymised data items. Such an act would be treated as a serious breach of security.

#### 2.4 Are the data securely kept?

2.4.1 HES data is stored in a secure data centre where there is restricted access to the environment. The data is held securely under a combination of software and hardware controls, as approved by DMSG.

#### 2.5 ECC, DMSG and other legal issues

- 2.5.1 HES data is not obtained directly from the patients but from hospital provider systems via the Secondary Uses Service (SUS). It is not feasible to obtain explicit consent from patients for the multitude of uses to which HES data can be put. The NHS IC has sought and received approval from ECC to hold a temporary exemption (under Section 251 of the Health and Social Care Act 2006) from obtaining explicit consent. Work is underway within The NHS IC to manage the continued approval for the use of HES data within the appropriate regulations. The role of ECC is to make sure that information collected about patients is treated fairly, confidentially and on a firm legal footing.
- 2.5.2 DMSG is a sub-group of ECC and exists to oversee the protocols for the use of HES data and, in relation to HES data, to respond to requests for advice and linkage work with NHS Care Records. They also monitor information governance issues in relation to national databases and in particular monitor security aspects of information management. DMSG considers applications for access to sensitive but non-identifiable data held in the national databases and advises ECC in relation to this work.
- 2.5.3 HES data are deemed 'personal' under the terms of the Data Protection Act 1998 and are therefore subject to its fair processing requirements. The HES team has taken legal advice over the years to make sure that the ever developing HES Interrogation System and service complies with the provisions of the Act.

## 3 Guidelines on releasing HES information

#### 3.1 Fundamental principles of releasing HES data

- 3.1.1 There are three basic principles to follow when releasing HES data:
  - 1. Protecting the privacy and confidentiality of individuals
  - 2. Making the data available, both routinely and on request, as widely as possible (subject to The NHS Information Centre policy, the HES Protocol and legislation)
  - 3. Seeking advice (from a colleague, a senior officer or a member of the HES team) whenever there is any doubt about whether data can be released.

#### 3.2 Recognition of an individual and breaching confidentiality

- 3.2.1 All users of HES data must consider the risk of identifying individuals in their analyses prior to publication/release. You should be on the alert for any rare and unintentional breach of confidence, such as responding to a query relating to a news item that may add more information to that already in the public domain.
- 3.2.2 Data should normally be released at a high enough level of aggregation to prevent others being able to 'recognise' a particular individual. If you recognise an individual while carrying out an analysis you must exercise professionalism and respect their confidentiality. If you believe this identification could easily be made by others you should alert a member of the Information Governance team within The NHS Information Centre for further advice [information.governance@ic.nhs.uk]. Similarly, if you recognise an individual from existing analyses you should alert the author of the analysis as well as the Information Governance team within The NHS Information Centre for further advice.
- 3.2.3 While appropriate handling of an accidental recognition is acceptable, the consequences of deliberately breaching confidentiality could be severe. Action would be taken by The NHS Information Centre against both your organisation and you as an individual.

#### 3.3 General release guidelines

- 3.3.1 Table 1 summarises the general rules for protecting the identity of individuals data classified as 'OK' in the table may be released without restriction. Note that where more than one rule is relevant, apply the strictest. It also highlights where further consideration is necessary before releasing data. The rules are explained further in the paragraphs following the table.
- 3.3.2 All analyses must carry the appropriate footnotes from the HES User Guide (obtained from the HESonline website) concerning definitions, grossing, small numbers, data quality and so on. It is particularly important that the data source (Hospital Episode Statistics, The NHS Information Centre for health and social care) is clearly referenced. These footnotes must be retained when any analyses are passed on, even if only part of the analysis is used.

#### 3.4 Release of tabulations with small numbers or record level extracts

- 3.4.1 Where the release of small numbers or record level extracts is necessary, authority and advice must be sought from the Information Governance team at the NHS Information Centre. Where approved, a data sharing agreement (DSA) will need to be completed. Also see appendix C1 and C2 for non-disclosure and public health observatories (PHOs) declaration forms. For further information on small numbers please see the 'Further explanations' in section 4.
- 3.4.2 Strict requirements are in place for the provision of small numbers or record level extracts once the release has been approved. Information will normally be sent on disk by secure courier and encrypted (see section 5.2).

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**TABLE 1: Summary of release guidelines** 

|                      |   | Level of aggregation  |   |  |  |
|----------------------|---|---|---|--|--|
| Topic of<br>Interest | Area  | National, regional, Strategic Health<br>Authority,<br>DHA/HA of residence | Strategic HA/DHA/HA of treatment, postcode district, LA, electoral ward, Trust, PCT of responsibility/residence, Super Output Areas, Special Has  Generally no, suppress. Consult the HES team if a suitable alternative analysis cannot be found within the guidelines and the request is still required. If agreed (this may need approval from the DMSG), the customer must sign a non-disclosure agreement.  Note: PHOs have authority to release data containing small numbers, according to these guidelines (see section 4.12.2) |  |  |
| Small numbers        | 1 - 5 acceptable in any individual cell?                          | OK (agreed by DMSG)   |   |  |  |
| In addition to sma   | all numbers in a cell, certain diag                               | gnoses and procedures are especially ser                                  | nsitive:  |  |  |
| Surgical             | Abortions   |   |   |  |  |
| Procedures           | - OPCS4: Q09.1, Q10.1,  |   | on using and releasing abortion statistics and  |  |  |
|                      | Q10.2, Q11.1, Q11.2,  |   | ortions are published by the Department of  |  |  |
|                      | Q11.3, Q11.5, Q11.6,  | Health.   |   |  |  |
|                      | Q14.1-Q14.6, Q14.8, Q14.9,  |   |   |  |  |
|                      | R03.1, R03.2, R03.8, R03.9  | (See section 4.7 for fu   | rther details)  |  |  |
|                      | Neurosurgery for mental   | No - refer to The NHS   | Information Centre Contact Centre   |  |  |
|                      | disorders   | (see section 4.5 and 5  | for further details)  |  |  |
|                      | ECT   | No - refer to The NHS Information Centre Contact Centre                   |   |  |  |
|                      | - OPCS4: A83  | (see section 4.5 and 5  | for further details)  |  |  |
|                      | Other   | OK  | OK  |  |  |
| Deaths               |   | OK, but ensure footnotes are given with output.                           | Must consult HES Team before issuing.   |  |  |
| Diagnoses            | AIDS / HIV - ICD9: 0794 - ICD10: B20 to B24, Z20.6, Z21 and Z71.7 | OK  | No  |  |  |

|   |   | Level of aggregation  |  |  |
|---|---|---|--|--|
| Topic of<br>Interest                      | Area  | National, regional, Strategic Health<br>Authority,<br>DHA/HA of residence | Strategic HA/DHA/HA of treatment, postcode district, LA, electoral ward, Trust, PCT of responsibility/residence, Super Output Areas, Special Has   |  |
|   | Abortions - ICD9: 635 to 638 - ICD10: O04 to O08  |   | on using and releasing abortion statistics and ortions are published by the Department of  |  |
|   | (See section 4.7 for further details)             |   |  |  |
|   | STDs<br>- ICD9: 090 to 099<br>- ICD10: A50 to A64 | ОК  | No   |  |
|   |   |   | Information Centre Contact Centre for further details)   |  |
|   | Other   | OK  | OK   |  |
| Consultant,<br>Registered GP,<br>Referrer |   |   | although still needs care as consultants can be recognisable from the anonymised on available. Use of original (raw) codes requires DMSG approval. |  |

#### 3.5 Provisional monthly data

- 3.5.1 Each month The NHS IC publishes provisional headline information from monthly HES data and makes the underlying data available to HES users.
- 3.5.2 The headline information that is made publicly available is for the period up to 4 months before the publication month. For example in May 2009 The NHS IC published provisional monthly information for the period up to January 2009. Data for the period up to February 2009 was included in the monthly HES data available to HES interrogation users but there had only been three weeks for the NHS to submit this data so it was not complete.
- 3.5.3 Each month, this latest month's data is made available to HES users for management purposes only and must not be made publicly available.
- 3.5.4 Table 2 summarises which data is available each month.

| Table 2: Summary of monthly data available |                                 |                                      |  |
|--|---------------------------------|--------------------------------------|--|
| Publication Month                          | Latest data publicly available* | Latest data for management purposes* |  |
| May 2009                                   | Jan 2009                        | Feb 2009                             |  |
| Jun 2009                                   | Feb 2009                        | Mar 2009                             |  |
| Jul 2009                                   | Mar 2009                        | Apr 2009                             |  |
| Aug 2009                                   | Apr 2009                        | May 2009                             |  |
| Sep 2009                                   | May 2009                        | Jun 2009                             |  |
| Oct 2009                                   | Jun 2009                        | Jul 2009                             |  |
| Nov 2009                                   | Jul 2009                        | Aug 2009                             |  |
| Dec 2009                                   | Aug 2009                        | Sep 2009                             |  |
| Jan 2010                                   | Sep 2009                        | Oct 2009                             |  |
| Feb 2010                                   | Oct 2009                        | Nov 2009                             |  |
| Mar 2010                                   | Nov 2009                        | Dec 2009                             |  |
| Apr 2010                                   | Dec 2009                        | Jan 2010                             |  |

<sup>\*</sup> Subject to change

3.5.5 HES users must not publish data for the latest available month in the public domain. If data from the latest available month is shared with third parties, for NHS or public body management purposes, it must not be disseminated more widely. More information about monthly HES data is available on HESonline; a footnote which must accompany any dissemination of the latest available month of data is available in the HES User Guide.

### 4 Further explanations

#### 4.1 Small numbers

- 4.1.1 'Small numbers' in HES are the numbers 1 to 5. Low-level analyses are more likely to contain small numbers, which might facilitate identification of individual patients, especially at a local level. They might also allow identification of a hospital consultant, where local knowledge identifies a single consultant treating patients in a particular specialty.
- 4.1.2 Small numbers are not necessarily a problem when they cover a broad geographical area, because the patient would not normally be identifiable (Table 1 shows the acceptable levels). However, data that are likely to be more sensitive, eg deaths (see 4.2.1), should still be treated with care if they are likely to identify individuals. Small numbers within local authorities (Las), wards, postcode districts, PCTs and trusts may allow identification of patients and should not be published without The NHS IC Information Governance team approval.
- 4.1.3 When publishing HES data, you must make sure that cell values from 1 to 5 are suppressed at a local level to prevent possible identification of individuals from small counts within the table. (Zeros (0) do not need to be suppressed.) If only one cell requires cell suppression, you must suppress at least one other component cell (the next smallest) to avoid calculation of suppressed values from the totals. You should replace these values with '\*' and add a note:

'\*' in this table means a figure between 1 and 5

- 4.1.4 It is possible to use a spreadsheet formula, or macro, to make these changes (the HES team can help with this).
- 4.1.5 The rules on suppression of low cell counts should be considered wherever small numbers are encountered, irrespective of whether the count is directly a count of patients. The rules cover several types of analysis (eg episodes, admissions and deaths) and measures based on small numbers, such as bed days. While a bed day measure may not appear to be disclosive, a small number of bed days implies a small number of cases so similar suppression is needed.
- 4.1.6 Certain other measures, such as average times waited or length of stay, appear not to give any disclosive information on the number of cases, but at times they may do so, eg a mean of 5 days with up to 5 cases implies no case exceeded 25 days. In such cases, the averages might not be disclosive, but judgement still needs to be taken as to whether they imply something more about individual cases.
- 4.1.7 An alternative to suppressing values from 1 and 5 is to consider a higher level of aggregation for one or more items, eg move from trust level to SHA of treatment, or from diagnosis at the 4-character level to the 3-character level, or group using wider age bands. A higher level of aggregation is the preferred option if several cells are affected by the suppression rule.
- 4.1.8 Another option is to provide the data at the requested low level (if necessary for purpose), but anonymising the level of aggregation, ie replace identifying codes or labels with arbitrary reference numbers.
- 4.1.9 If the alternatives to suppressing values don't suit your needs, and you are unable to find a suitable compromise, contact the HES team for advice via The NHS Information Centre Contact Centre [enquiries@ic.nhs.uk].

#### 4.2 Deaths

- 4.2.1 Deaths analysis can be sourced from the HES dataset itself or from ONS death registration records supplied by ONS for linkage with HES. The DISMETH (Discharge method) and DISDATE (Discharge date) fields in HES are limited in that they do not capture deaths occurring post discharge from hospital. This can cause incompleteness or bias in some comparative analyses. Linking HES with the ONS registered deaths data addresses this issue.
- 4.2.2 ONS mortality data is present in public records and could therefore lead back to a patient being identified in a HES analysis thus making the HES contents more vulnerable to disclosure of additional facts about the individual otherwise not in the public domain. DMSG have reviewed this situation and concluded that adherence to the HES small numbers policy is sufficient to address any small additional risk posed by the linkage. However, users of ONS mortality data in HES should take extra care to ensure that any output tables run no risk of disclosure.
- 4.2.3 Queries concerning deaths should always be handled with caution and discussed with a member of the HES team, where necessary. Requests for counts of deaths by operative procedure and/or diagnosis for individual NHS trusts are especially sensitive.
- 4.2.4 HES deaths from whichever source data should not be used to infer the quality of care provided by NHS trusts; many factors not included within the HES dataset will have an effect on the care of the patient. If HES deaths data are used as part of such comparative analysis users should ensure that the relevant footnote (see HES User Guide, obtained from the HESonline website) is included.
- 4.2.5 Cause of death data cannot be obtained from HES at the moment; refer to the mortality statistics [http://www.statistics.gov.uk/CCI/nscl.asp?ID=6444] produced by ONS from death certification, or to the Compendium of Health Statistics [http://www.ohecompendium.org] produced by the Office of Health Economics.

#### 4.3 Re-admissions

- 4.3.1 Queries on re-admissions (to the same or another hospital) can be carried out using the HESID data item. However, analysis of re-admissions figures on their own cannot inform on quality of care, since other factors not described in the HES data can affect the care of the patient.
- 4.3.2 It is important to note that re-admissions can result from a variety of reasons and may not be clinically related to an earlier admission. However, most indicators assume that all providers are equally affected by this and other confounding factors to make the analysis meaningful comparatively if not in absolute terms.
- 4.3.3 Always include the relevant footnote (see HES User Guide, obtained from the HESonline website) with any analysis and contact The NHS Information Centre Contact Centre (enquiries@ic.nhs.uk) if you have any difficulties.

#### 4.4 Consultant team / clinician data

- 4.4.1 Since 1997-98, the consultant code has been included with each episode record. It gives the general medical council (GMC) code of the lead consultant responsible for the care of the patient. Analysis carried out with this data item is referred to as being 'by consultant team' as it incorporates (although does not currently distinguish between) the work of the whole team including junior doctors, anaesthetists, nurse practitioners and other members of staff.
- 4.4.2 Consultant code is currently handled as a sensitive data item (See Appendix B) and is routinely available only in an anonymised format. However, even the anonymised consultant data should be used with care if there is sufficient information to recognise individual

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consultants, for example if there are only a few people within a specialty in a Trust. Should the original codes (ie non-anonymised) be required this will need approval from DMSG.

#### 4.5 Mental health

4.5.1 All analyses involving either neurosurgery for mental disorders or electroconvulsive therapy (ECT) must be referred to The NHS Information Centre Contact Centre (see Section 5). Specific help on mental health HES data can also be obtained via The NHS Information Centre Contact Centre [enquiries@ic.nhs.uk].

#### 4.6 Maternity

4.6.1 Specific help on maternity HES data can be obtained via The NHS Information Centre Contact Centre [enquiries@ic.nhs.uk].

#### 4.7 Abortions

- 4.7.1 Only 20% of abortions are performed as a surgical procedure in NHS hospitals so the number of abortions recorded in HES data is different to published official abortion statistics. Hence, any release of HES abortion data should be done with extreme caution, following the disclosure guidance for abortion statistics and released with the appropriate caveats. Guidance on release of abortion statistics can be found in Disclosure Review for Health Statistics, Guidance for Abortion Statistics

  [http://www.statistics.gov.uk/downloads/theme\_health/abortion\_stag\_final.pdf].
- 4.7.2 Some areas of interest as described in the guidelines:
  - Small numbers and cells that may breach confidentiality:
    - From consideration of the risk scenarios the unsafe cells for abortion statistics are those for which:
      - The count is zero unless no other value is logically possible
      - The count is below 5 for a Government Office Region in England, the country of Wales or a larger area
      - It is less than 10 and the area concerned is smaller than Government Office Region in England or the country of Wales
      - It is less than 10 and the variables are considered highly sensitive
      - The count is associated with at most 2 practitioners
      - It is associated with at most 2 hospitals.
  - Other highly sensitive variables:
    - Young ages (<15)</p>
    - Late gestation (over 24 weeks)
    - Procedure by gestation
    - Medical conditions.

Please note that in the event of any requirement to access small numbers and/or sensitive information relating to abortions you must contact the Abortion Statistics department at the Department of Health:

Tel: 0207 972 5537

Email: abortion.statistics@dh.gsi.gov.uk

#### 4.8 IVF and AIDS

4.8.1 IVF data are now included in the HES dataset, but all identifiers should be removed. The source of official statistics on IVF and fertility treatment is the Human Fertilisation and Embryology Authority (HFEA) [http://www.hfea.gov.uk].

4.8.2 AIDS data have special sensitivities. The source of official statistics, epidemiology and surveillance of infectious diseases (including HIV/AIDS) is the Centre for Infections (CfI) at the Health Protection Agency (HPA) [http://www.hpa.org.uk/infections/default.htm].

#### 4.9 Postcode

- 4.9.1 The full postcode of a patient's home address is a sensitive data item and requires DMSG approval for its use. The postcode district (the first part of the postcode only, eg W1, N14 and GU25) is generally available to users of the HES Interrogation System.
- 4.9.2 Many geographic fields have been derived from postcode and are routinely available (see the HES Data Dictionary <a href="http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=571">http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=571</a>]). In addition, Northgate Information Solutions can generate specialised geographical breakdowns for extracts and tabulations, subject to small number restrictions.

#### 4.10 Census Output Areas

- 4.10.1 Output Areas (OAs) were devised by ONS to identify small geographical areas that cover similar population sizes, according to the 2001 Census. They are defined by adjacent postcodes as at census day. There are 165,665 OAs in England. Too small for meaningful statistics in their own right, their main purpose is as building blocks for a range of other measures.
- 4.10.2 The full ten-character census output area code (oacode) is a sensitive data item in HES. Access to this field requires DMSG approval. The lowest level of census output code routinely available in HES is oacode6 (six-character census output area code).
- 4.10.3 The increased number of small-area codes routinely available in HES, now including oacode6 as well as currward (current ward) and ward81 (frozen census ward 1981) or ward91 (frozen census ward 1991), raises concerns that yet smaller areas might be identified by differencing. This could enable identification of selected small slithers of land (in HES, these might represent single postcodes).
- 4.10.4 As part of their conditions of access, users of the HES data warehouse must not try to produce smaller areas by differencing.

#### 4.11 What if the request fails the guidelines but is still required?

- 4.11.1 There may be exceptional circumstances where access to sensitive data items or small numbers is needed for an analysis. There are procedures in place for when such circumstances contravene the guidelines presented here. This may include seeking approval from DMSG.
- 4.11.2 In the case of extracts and tabulations, data requests that contravene the guidelines in this Protocol will need to be fully justified, scrutinised by the related data custodian and submitted to the HES team for consideration.
- 4.11.3 In the case of the HES data warehouse, users requesting access to sensitive data items must complete and return a form requesting access to one or more sensitive data items, state the justification for access and give the length of time access is required. The form is available from the HES team.
- 4.11.4 In both of the instances above, a non-disclosure agreement (Appendix C1) must be signed before the data are released or access is given. The non-disclosure agreement will allow the data to be used in analysis; the raw data must not be published or passed on and must be destroyed once the work is complete.

#### 4.12 Record level data requests, detailed or complicated analyses

- 4.12.1 The HESonline website [http://www.hesonline.nhs.uk] offers free access to selected HES data, and explains how to apply for bespoke tabulations, or an extract of record-level data (see the Extract Pack and Tabulation Pack on the HESonline website).
- 4.12.2 In addition, PHOs are able to provide tabulations of local data, including tables containing cells with small numbers and record-level extracts of regional data for local NHS organisations (non-sensitive data only). The customer will need to justify the need for this data and sign a non disclosure agreement (see Appendix C2). If a PHO is unable to provide the data required, because of prohibitive cost or the request exceeds the PHO's remit, then the request should be referred to The NHS IC.
- 4.12.3 In September 2006, DMSG granted PHOs access to the full national HES dataset, including the sensitive fields. The access is for research, benchmarking, planning, monitoring and similar analyses, either alone or working with, or on behalf of, groups of PHOs. These record-level data are not available for general release by PHOs; customers must always refer to The NHS IC and the HESonline website if national and/or sensitive data are required.

### 5 Security

#### 5.1 PC security

- 5.1.1 All users of the HES Interrogation System access HES through a standalone PC workstation (unless separately agreed otherwise). To help remove the possibility of unauthorised access to HES through the workstation, the following simple precautions should be adhered to:
  - Do not share your password with anyone or write it down in an obvious manner
  - Use a password protected screen saver and set it to a delay of no more than 5 minutes
  - Log off from the HES Interrogation System when leaving the PC for more than 30 minutes unless this is impractical, e.g. if you are submitting an urgent query that will be running while you are away from your workplace (although you should normally use Broadcast Agent to schedule jobs that are expected to run while you are not present).
- 5.1.2 If you store HES data extracts or HES tabulations that contain sensitive data on your local workstation or network, you must ensure that unauthorised users cannot gain access to the data. This can be achieved by minimising the data that you store locally, by storing the data in a protected or personal area and by using file password protection.
- 5.1.3 Any information stored outside of HES should be kept only for as long as it is needed and then the data must be destroyed. For example, if information is saved onto a CD or data stick in order to transfer it from a standalone PC to a network the data should be password protected and destroyed after the transfer is complete.

#### 5.2 Data transfer

- 5.2.1 Data with small numbers or record level extracts will be encrypted using 256-bit AES encryption or better (eg WINZIP V9 or later) with a complex password containing numbers, capital and lowercase letters, and symbols with a length of at least 12 characters.
- 5.2.2 The password will only be released to the named person on the Data Sharing Agreement and will be supplied before the information is sent. Once confirmation of the password being received safely is provided, the information will normally be dispatched on disk by secure courier. Passwords may be dispatched by email (to a known email address only), by phone, or face-to-face.

#### 5.3 Further information and contacts

- 5.3.1 We welcome your views on the HES Protocol and its application, and on the HES data warehouse itself.
- 5.3.2 For more information on HES please see the 'HES User Guide' on the HESonline website <a href="http://www.hesonline.nhs.uk">[http://www.hesonline.nhs.uk</a>]. For more information on the HES Protocol please contact the NHS Information Centre, Contact Centre:

Tel: 0845 3006016 Email: <u>enquiries@ic.nhs.uk</u> Fax: 0113 2547239

# Appendix A: Declaration form

### **Declaration**

|                              | irm that I have read and understood the ir<br>ESonline website)   | formation in the HES User Guide (available on  |
|------------------------------|---|--|
| The F<br>instru              | HES Protocol: Instructions for handling the ctions given in it at all times. I accept that retand that failure to sign this annual declar | ontents of 'Hospital Episode Statistics (HES), data (June 2009)' and agree to follow the I will have to re-sign annually, on reminder. I tration will result in access rights to HES being |
| table                        |   | r of the HES team if I am unsure whether a tant before releasing any data that I believe be used to identify an individual patient.  |
| HES                          |   | relating to the release of data given in <i>The</i> offence and will result in action being taken  |
| Title:                       | Full name:  |  |
| Position in org              | ganisation:   |  |
| Organisation:                |   |  |
| Signed:                      |   | Date:  |
| Witnessed by                 | (this should be a senior officer or line ma   | nager):  |
| Title:                       | Witness' full name:   |  |
| Witness' Posi                | tion in organisation:   |  |
| Signature of v               | vitness:  | Date:  |
| When comple                  | ted, please return to:  |  |
| The NHS IC I                 | nformation Governance Team  |  |
| Email:<br>Telephone:<br>FAX: | information.governance@ic.nhs.uk<br>0845 300 6016<br>0113 254 7299  |  |

# Appendix B: Access to sensitive HES data items

| Data Item 'hidden' from view   |          | Data item available to all   |  |  |
|--------------------------------|----------|--|--|--|
| HES object name HES field name |          | Anonymised version(s)  |  |  |
| Patient data                   |          |  |  |  |
| Date of birth                  | DOB      | Aggregated: Age at start of episode, Age at end of episode, various age ranges         |  |  |
| Legal status on admission      | LEGLCAT  | No anonymised version available  |  |  |
| Legal group on admission       | LEGALGPA | No anonymised version available  |  |  |
| Local patient ID               | LOPATID  | PSEUDO_HESID   |  |  |
| NHS number                     | NEWNHSNO | PSEUDO_HESID   |  |  |
| Postcode                       | HOMEADD  | Aggregated: Postcode district, many derived geographical data items                    |  |  |
| Augmented Care Period          | ACPLCID  |  |  |  |
| Practitioner data              |          |  |  |  |
| Consultant team code           | CONSULT  | Pseudonymised  |  |  |
| Referrer code                  | REFERRER | Pseudonymised  |  |  |
| Registered GP                  | REGGMP   | Pseudonymised  |  |  |
| Geographically derived data    |          |  |  |  |
| Census Output Area, 2001       | OACODE   |  |  |  |
| Ordnance Survey grid reference | GRIDLINK | TO BE INVESTIGATED FURTHER (WILL BE DETERMINED BY GRANULARITY IN THE GIS PACKAGE USED) |  |  |
| Birth data                     |          |  |  |  |
| Mothers date of birth          | MOTDOB   | Aggregated: Mother's age at date of delivery   |  |  |
| Baby's date of birth           | DOBBABY  |  |  |  |
| Psychiatric data               |          |  |  |  |
| Legal status at census date    | LEGLSTAT | No anonymised version available  |  |  |
| Legal group at census date     | LEGALGPC | No anonymised version available  |  |  |
| Detention category             | DETNCAT  |  |  |  |

<sup>\*</sup> Note:

<sup>1. &#</sup>x27;Hidden' means the data item is held in a separate part of the data warehouse, inaccessible except to authorised users.

<sup>2.</sup> The 'Hidden' data items are accessible if acceptably justified and the due authorisation procedure is followed.

# Appendix C1: HES Non-Disclosure Agreement Form - Sensitive tabulations

This form is appropriate for requesting tabulations of HES data that are sensitive. For example, the table may contain consultant level data or have small numbers, which cannot be suppressed in the normal manner, in the cells.

| Organisation: |  |
|---------------|--|
|---------------|--|

Responsible lead contact:

Data custodian (senior officer):

HES reference (for HES Team use):

#### **Project:**

(please provide a description of the intended project and how you propose to use and/or publish the analysis of the HES data – publication of the raw data is prohibited)

#### HES data to be provided:

(attach an example outline or sketch of the table required if possible/appropriate)

#### Sensitivities:

(retain or delete as appropriate to the data required)

#### Consultant team data:

- Pseudonymised consultant code is unpublished and must not be released in any way that may enable the identification of individual consultants.
- Should identifiable consultant data (ie the raw GMC code, not anonymised) be investigated, which will only be provided in case of justifiable concern about outcomes, the consultant(s) concerned should be made aware that this is happening.

#### Patients must not be identified:

- Patient information from HES must not be used to identify (or recognise) individual patients and must be handled with proper regard to the confidentiality of individuals.
- Any published HES figure(s) at a local level must be based on no fewer than 6 cases or else suppressed (eg replaced with an asterisk, with a note "\* in this table means a figure between 1 and 5". Zero is allowed). Low-level analyses might facilitate the identification of individual patients, especially with local knowledge. Care should be taken to ensure that values may not be more closely calculated by differencing from sub-totals. For practical purposes, any geographic reference smaller than Strategic Health Authority should be considered local.

#### Deaths data:

HES data cannot be used to determine the cause of death of a patient while in hospital. Deaths
recorded on the HES database are classified according to the main diagnosis for which the
patient was being treated during their stay in hospital, and may not necessarily be the underlying
cause of death. The Office for National Statistics (ONS) collects information on the cause of
death, wherever it occurs, based on the death certificate, and should be the source of data for
analyses on cause of death.

#### I agree:

- that there is a business need for this work requiring data with the sensitivities indicated above.
- to abide by the instructions given against the sensitivities.
- that the data will be stored with proper safeguards to prevent unauthorised access. Note: This
  condition is subject to unannounced site inspections by The NHS Information Centre for health
  and social care (The NHS IC) staff to ensure that measures are satisfactory.
- that the work will not be used for other purposes without the permission of the HES team.
- that the data will not be copied or transferred to any third party without the written consent of the HES Team. Note: output based on the data may be shared provided it abides by the rules above.
- to give prior notice of intention to publish HES data to the HES Team and where feasible provide a copy of the published work. Any published work containing HES data must acknowledge the source: "Hospital Episode Statistics, The NHS Information Centre for health and social care".
- to inform the HES Team immediately if custodianship of the data should change.

| Signed | <br> |
|--------|------|
|        |      |
| Name   | <br> |
|        |      |
| Date   | <br> |

#### **HES Information Governance:**

Email: information.governance@ic.nhs.uk

Tel: 0113 254 7054 Fax: 0113 254 7299

Please complete and return this form to the address above or fax it. The HES data can only be sent once the signed agreement is received.

# Appendix C2: PHO and customer declaration of use and non-disclosure

This form is a declaration that the conditions for use of the HES data requested will be adhered to. It should be completed by a senior person within the organisation with responsibility for data protection and security issues. This person will be responsible for safeguarding the HES data and for ensuring that all users of the data will abide by the conditions of supply. When complete please return to the PHO shown below. HES data will not be supplied until the completed form has been received. Access for each user is dependent on receipt of their signed Declaration (Section 4 of this appendix).

| When complete, this form should be returned to:                 |
|---|
| <pho address="" and="" insert="" name="" return="" to=""></pho> |
|   |
|   |
|   |
| 1. Data requested   |
| Please outline here the data required.                          |
|   |
|   |
|   |
|   |
|   |
|   |
|   |
|   |
|   |

#### 2. Responsible Person Declaration and User List

I understand and agree to abide by the following conditions under which the HES data tabulation/extract requested is to be supplied to me by the (insert PHO name).

|    | $\sim$ | n | $\sim$ | ~ |  |
|----|--------|---|--------|---|--|
| Si |        |   | -      |   |  |
|    |        |   |        |   |  |
|    |        |   |        |   |  |

| Name:                     |  |
|---------------------------|--|
| Organisation:             |  |
| Position in organisation: |  |
| Signature:                |  |
| Date:                     |  |

The following people will have access to the HES data supplied. A signed Declaration for each person is attached.

I will keep a copy of this list and notify the PHO of any changes. I will forward a signed Declaration for any new users added.

| I |  |
|---|--|

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#### 3. Conditions of Supply

- 1. The HES data will only be used for the following purpose(s):
  - Local NHS management
  - Planning and target setting
  - Performance management
  - Clinical governance
  - Benchmarking
  - Comparative analysis
  - Needs assessment and fair access to healthcare
  - Epidemiology
  - Monitoring of health improvement and the effective delivery of healthcare
  - Medical/health research

# If your purpose for requiring the data is not covered above, please discuss with the PHO prior to completing this declaration.

- 2. Any reports, papers or statistical tables published or released to other organisations/individuals will fully protect the identity of individuals in accordance with the current guidance stated in the HES Protocol from The NHS Information Centre for health and social care (The NHS Information Centre) (see the HESonline website [http://www.hesonline.nhs.uk]). Where there is doubt about the release of data/information, the advice of the PHO will be sought, who may in turn contact The NHS Information Centre. If, subsequent to release it appears that there is a risk of disclosure, the PHO will be informed immediately.
- 3. No contact will be made with any individual(s) who could be identified from the data supplied.
- 4. The data will not be released to any other individual or organisation not directly connected with the work specified at 1 above (except in the form of non-disclosive statistical tables or conclusions) without prior approval from the PHO. All tables released must include the relevant footnotes provided, even if only part of the table is used.
- 5. The information will be processed in accordance with the principles and conditions set out in the Data Protection Act 1998 and with proper safeguards to ensure confidentiality. The data will be held in a secure environment where any access can be traced. The PHO will have the right to inspect and audit the security arrangements in place, without prior notification.
- 6. No attempt will be made to link the information supplied to any other data relating to identifiable individuals without the prior approval of the PHO. The prior agreement of the PHO will also be required for any extension of this work using (or derived from) the data supplied by the PHO, beyond that which was originally notified.
- 7. All information supplied by the PHO (and any copies or potentially identifying tables produced from it) will be securely destroyed (the PHO can supply you with details on how to do this) when no longer required for the purposes for which it was supplied, or after one year whichever is the earlier. The PHO reserve the right to check that this has been done. Should the data be required for longer than one year, approval must be sought *in advance* from the PHO.
- 8. The PHO will inform the Information Governance Team at The NHS Information Centre for health and social care of all declarations signed, the data requested and the uses to which

the data will be put. It may also be necessary on occasion to seek their advice or approval before data are released.

9. I, by having signed this form, take responsibility for ensuring the conditions of this agreement are fully complied with. I will ensure that the PHO is informed of the name of any person who has access to the HES data supplied by the PHO and that the named individuals have signed a Declaration. I will inform the PHO immediately should I no longer be responsible for the data within this organisation and will ensure that a substitute Declaration is signed. I understand that the PHO has the right to check on the custodianship of the data.

#### 4. Individual Declaration

To be completed by each user before access to the data is allowed.

I have read the conditions under which the PHO has supplied the HES data, and agree to abide by them. I will immediately inform the person responsible of any actions that risk breaching the conditions of supply.

#### Signed

| Name:                     |  |
|---------------------------|--|
| Organisation:             |  |
| Position in organisation: |  |
| Signature:                |  |
| Date:                     |  |

Please return to the person responsible for the HES data.

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