National Institute of Health Research
Health Informatics Collaborative (Critical Care)

# Standard Operating Procedure for Data Release

# **Document control**

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# 1. Introduction

This document specifies the framework for releasing data collated for the Critical Care theme of the National Institute of Health Research's Health Informatics Collaborative (NIHR HIC). These data are portions of the electronic health records related to an episode of critical care. They have been assembled to enable clinical and health science research teams to interrogate these rich data streams with the aim of improving the care of future patients.

While supporting this academic programme, we need to protect the existing patients from whom these data have been abstracted. The data are stored securely using the Identifiable Data Handling Solution at University College London (UCL IDHS) which is certified to the ISO27001 information security standard and conforms to the National Health Service (NHS) Information Governance Toolkit.

We have followed the principles of patient confidentiality from the NHS Code of Practice in preparing this document. (1)

To protect – look after the patient's information. The data handling and storage is discussed elsewhere. The scope of this document is limited to anonymisation steps for data release.

To inform – ensure that patients are aware of how their information is used. We will make this document, and the methods we use for anonymisation publically available. We have already, and will continue to engage with patients and their representatives to ensure that the processes of using these data are transparent.

To provide choice – allow patients to decide whether their information can be disclosed or used in particular ways. We will provide easily accessible opt-out mechanisms for patients who do not wish to have their data released.

To improve – always look for better ways to protect, inform, and provide choice. We will review this document annually, and through external audit, re-identification challenges, and public scrutiny continually improve these processes.

We envision two scenarios in which data may be released from the IDHS.

- 1. Raw data for analysis
- 2. Summarised data for research publication

The first of these carries the greatest risk with respect to information security. The second refers to the release of data summaries, tables, and figures where the individual records are not exposed. The same standards of security will apply to both scenarios but the inherent aggregation of data in the latter will mean that most data has already been pre-processed to meet these standards.

# 2. Principles

# (a) Definition of personal data

We will be following the guidance provided by the Information Commissioner's Office (ICO) in 'Anonymisation: managing data protection risk code of practice' (2012). (2) The legal basis for this guidance comes from the Data Protection Act (DPA) 1988, and Recital 26 of the European Data Protection Directive (95/46/EC) which in turn is based on the following principles.

- "Personal data has to be about a living person, meaning that the DPA does not apply to mortality or other records about the deceased"
- that "information or a combination of information, that does not relate to and identify an individual, is not personal data"

Importantly, the guidance from the ICO states that there is "clear legal authority for the view that where an organisation converts personal data into an anonymised form and discloses it, this will not amount to a disclosure of personal data".

#### (b) Definition of likelihood of re-identification

The DPA does not require that it is impossible to re-identify an individual from disclosed data, but that defines personal data as those where is the risk of re-identification is "*likely*". We are expected to take three factors into account.

- the likelihood of identification being attempted
- the likelihood of identification being successful
- the quality of the data after the anonymisation has taken place.

Medical data will present a likely target for re-identification, and more so where it includes information on VIPs (e.g. public figures, politicians, celebrities). Although, we can minimise this risk by removing the records of VIPs from released data, the risk remains to others.

We therefore have concentrated on making the likelihood of re-identification unsuccessful. This has to be balanced against the utility of the data after anonymisation has been performed which, in turn, requires measures of the disclosure risk, and of information content.\*

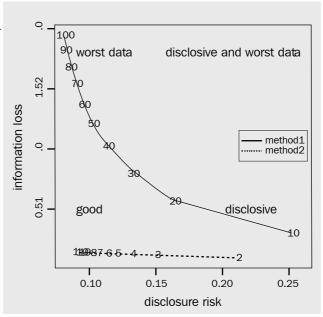
<sup>\*</sup> Data releases are to be *anonymised* not *pseudonymised*, where the latter term indicates that a unique is available that could be used to re-identify the data. Pseudonymisation will be used for transferring data between organisations where data linkage must be undertaken, and where one of the organisations does not hold all the necessary permissions to handle those data.

# (c) Measuring disclosure risk

There is a trade off between information loss and disclosure risk so that as the risk of disclosure decreases then so does utility of the data.

To define this we need to measure the information content, and quantify the disclosure risk. Ignoring direct identifiers which must be removed, then it is still possible to re-identify individuals using other charactertics. We describe this risk using two terms.

**K-anonymity** counts the number of individuals identified by the intersection of key variables. We would wish this to be ten or greater. For example, if we release individual data describing



'species', and 'favourite sandwich filling', then the intersection of 'bears' and 'marmalade' would uniquely identify Paddington Bear. If we generalise 'favourite sandwich filling' to 'prefers sweet sandwiches' then because Pooh Bear likes honey as well as Paddington liking marmalade, the *k-anonymity* would rise to two.

**L-diversity** counts how varied other sensitive fields are within a *k-anonymous* group. Continuing the example above, if we had a data item 'fictional character', then a child wondering if Pooh really lived in the 100 acre wood would be able to confirm that, since all individuals in the group are fictional, this cannot be true.

These concepts can be used to classify data fields into the following categories.

| Direct identifiers         | These must be removed from the data.  |
|----------------------------|---|
| Key variables              | A k-anonymity threshold must be set which defines the group size that would result if the key variables were used together to attempt to re-identify individuals. |
| Sensitive fields           | These are fields that would reveal information about individuals in the data set even when the k-anonymity threshold was not breached.                            |
| Non-identifiying variables | These are the remaining variables after defining the direct identifiers, key, and sensitive variables.  |

# 3. Anonymisation methodology

We have adapted guidance for National Statistical Offices (e.g. the UK's Office of National Statistics) produced by the International Household Survey Network in its 'Introduction to Statistical Disclosure Control'. (3)

We have divided the steps that may be taken to anonymise the data into the specific (with respect to these data), and the general (that apply to all data). A template flow diagram that summarises these steps is provided. Each data release will be expected to adapt this template where necessary, and then seek specific approval for those adaptions.

#### (a) General measures

The following steps will be perfored before assessing any information loss.

#### Step (1) Removal of direct identifiers

All unique identifiers including NHS number and hospital number will be removed from the data before release.

#### Step (2) Remove living subjects (where possible)

The DPA only applies to living individuals. Where possible, data will only be released for patients who are known to have died. Where the analysis depends on comparisons of survivors and non-survivors, these additional data must be specifically requested.

#### Step (3) Date and time metadata

All data items within the data carry a two metadata timestamps. One relates to when that data file was created, and is used for internal audit of the data (i.e. when a data item has been updated). This will be discarded before any data release. The second relates to the date and time when an observation was recorded. These carry a re-identification risk as they narrow down the number of observations that might relate to any particular individual. We will convert all of these to data and time differences from critical care admission before data release. For example, a heart reate measurement will be defined as occurring 24 hours after ICU admission, but it will not be possible to know the day, month or year of that measurement. Where a researcher intends to study a phenomenom that depends on these characteristics (e.g. the 'weekend' effect) then the minimum data and time information necessary for the analysis will released.

#### Step (4) Remove high risk individuals and specific opt-outs

The participating hospitals will inevitably care for well known public figures from time to time, and to avoid attempts at their re-identification we will prospectively remove their health records from any data release. The MIT team running the MIMIC critical care database in Boston resorted to a similar strategy when they discovered that users were trying to identify the health records of the victims of the Boston Marathon bombings in 2013.

Specific patients may also have notified the data controller through the CCHIC team that they do not wish their data to be shared. These records would also be removed before release.

#### Step (5) Aggregate continuous and date-time key variables

Because we cannot group patients by a continuous measure, the concept of kanonymity only applies to categorical variables (e.g. we can group patients by eye colour, but hair length). Where a key variable is continuous then we will run an initial conversion to a categorical version by aggregating. The unit of aggregation will be the natural unit of the measurement (e.g. years for age, or kilogrammes for weight), and the initial aggregation will be some multiple of that unit (e.g. 2 years, and 5 kg respectively). This multiples will be initially small in order to minimise information loss, but will be increased during the iterative specific anonymisation step until the necessary kanonymity and I-diversity is reached.

# (b) Specific anonymisation methods

The remaining key and sensitive variables will be processed using the thresh-

Identifiable Remove high risk individuals and anonymisation natient ont outs Specification Convert dates from absolute to relative measures Specify k-anonymity Delete direct identifiers Data requested [Field list and date range] Micro-aggregation of all key Initial anonymisation continuous and date-time configuration variables Specific Micro-aggregation steps Measure k-anonymity Local suppression and l-diversity Adjust anonymisation configuration No L-diversity Additional safeguards (e.g. remove living subjects) Yes Measure information loss Record data release

olds for k-anonymity and l-diversity. Where these thresholds are exceeded, micro-aggregation, recoding or local suppression will be applied more aggressively until the pre-specified threshold is reached. These anonymisation methods 'coursen' the data thereby increasing k-anonymity. Measures such as post-randomisation, shuffling, and adding noise will be held in reserve because it is not possible to accurately measure k-anonymity after their use.\*

**Recoding** Categorical variables are combined into super-categories that contain less information than the original variable (e.g. age in years is recodeded to age in ten year bands). Top and bottom recoding is a special case of the above where the sparsely populated extremes are recoded into bands (e.g. age in years over

<sup>\*</sup> Anonymisation methods that add noise do not 'coursen' the data, and therefore allow a natural increase in the k-anonymity. Other measures of re-identification risk would need to be used.

100 is recoded to 80+) thereby minimising the risk of re-identification without losing information in already populous categories.

**Local suppression** This is method normally applied to key variables that when present reduce the k-anonymity measure below the desired threshold. By replacing the values of a small number of these observations with missing values, then it increases the k-anonymity measure, and makes it more difficult to triangulate any particular individual.

**Post-randomisation** Categorical data is perturbed by randomly re-assigning observations to a different category. The user specifies the probabilities that an observation in one category is transformed to another. For example, if eye colour is a category then you might specify that 'blue' eyes have a 10% chance of being relabeled as 'grey' and a 1% chance that they are relabeled as 'brown'. In this way, the user specifies the trade-off between information loss and disclosure risk.

**Micro-aggregation** This method is applied to continuous variables. The variable is divided into categories by an automatic algorithm and then replaced with a summary statistic for that category. Height, for example, might be recoded into quintiles and replaced with the median value for each quintile. Various automatic grouping algorithms exists which differ, as usual, in the trade-off between information loss and disclosure risk. Most are 'computationally' expensive (i.e. take time to run on even a fast computer).

**Adding noise** Adding noise is another method for handling disclosure risk for continuous key variables. Each observation is perturbed by sampling from a noise distribution, and adding that amount of noise to the measure. The parameters of the noise distribution are adjusted to preserve, where possible, the mean and the variance of the original data.

**Shuffling** This is a more complex 'multivariate' approach to adding noise that attempts to preserve relationships between variables as well as the summary characteristic of the original variable. In brief, if we were trying to reduce the disclosure risk for patient weight it would be important to take account of height and sex before adding noise. We would then build a regression model in the original to predict weight from height and sex. Instead of using the predictions from the model, we would rank the predicted values, and the original values. We would then replace the original value with a prediction of the same rank. Continuing the example, assuming tall men weight the most, we would use the actual weight of the tallest man to replace the original value of the heaviest person in the original data even if that person was female.

# (c) Measure information loss

We will aim to preserve the structure of the data where possible. For example, rather than recoding age into age bands (a categorical variable), we will preferentially add noise so that the variable remains continuous. In order that researchers can understand the fidelity of the data we will also aim to report measures of information loss. In the first instance, we will reproduce a standard severity of illness model (e.g. APACHE II (4)), and then report differences in measures of fit between the identifiable and non-identifiable data sets.

# 4. Governance

# (a) Central data management

Critical Care's Health Informatics Collaborative (CC-HIC) is a collaboration between the five Biomedical Research Centre's at Cambridge, Guy's and St Thomas', Imperial, Oxford, and UCL. A theme board comprising the clinical and programme management team oversees a working group at UCL who manage the programme on behalf of the board. The management structure is as follows:

- Data controller: Professor Mervyn Singer (UCL)
- Data custodian: Professor Graham Hart (UCL)

The data controller reports to the CC-HIC board, and may nominate others to manage the data releases such that they meet the standards described here. These individuals must be made known to the CC-HIC board so that a direct line of responsibility is maintained.

In addition, we undertake to:

- review this policy annually
- submit the policy and procedures to an annual internal information security audit
- submit the policy and procedures to an annual external information security audit
- keep all other approvals up-to-date (e.g. Research Ethics, and Clinical Advisory Group approval)

# (b) Data user's responsibilities

Data users will be expected to sign an end user license agreement that is modelled on that used by the UK Data service (see https://www.ukdataservice.ac.uk). It can be summarised with the following sixteen points.

- 1. to use the data in accordance with the EUL and to notify the Critical Care Health Informatics Collaborative of any breach you are aware of
- 2. not to use the data for commercial purposes without obtaining permission and, where relevant, an appropriate licence if commercial use of the data is required
- 3. that the EUL does not transfer any interest in intellectual property to you
- 4. that the EUL and data collections are provided without warranty or liability of any kind
- 5. to abide by any further conditions notified to you
- 6. to give access to the data collections only to registered users with a registered use (who have accepted the terms and conditions, including any relevant further conditions). There are some exceptions regarding the use of data collections for teaching and the use of data collections for Commercial purposes to be set out in an additional Commercial Licence.
- 7. to ensure that the means of access to the data (such as passwords) are kept secure and not disclosed to anyone else
- 8. to preserve the confidentiality of, and not attempt to identify, individuals, households or organisations in the data

- 9. to use the correct methods of citation and acknowledgement in publications
- 10. to send the Critical Care Health Informatics Collaborative bibliographic details of any published work based on our data collections
- 11. that personal data about you may be held for validation and statistical purposes and to manage the service, and that these data may be passed on to other parties
- 12. to notify the Critical Care Health Informatics Collaborative of any errors discovered in the data collections
- 13. that personal data submitted by you by you are accurate to the best of your knowledge and kept up to date
- 14. to meet any charges that may apply
- 15. to offer for deposit any new data collections which have been derived from the materials supplied
- 16. that any breach of the EUL will lead to immediate termination of your access to the services and could result in legal action against you

# 5. Process

The following process will be followed for each data release.

- The data request will be reviewed and approved as per the Data Access request SOP. The request must include a list of fields, and a time period for the data.
- 2. The fields will be compared to the master list of direct identifiers, key variables, and sensitive variables (see Appendix [b] List of fields and anonymisation approach [Page 14]).
- 3. A k-anonymity threshold of at least **twenty** will be applied as an initial default (meaning that the smallest group that could be re-identified using the key variables to 'triangulate' would contain twenty individuals).\*
- 4. An anonymisation configuration file will be submitted that describes the desired data fidelity (e.g. that age is reported rounded to the nearest five years, that the day of hospital admission is known but the month and year suppressed etc.).
- 5. The data requested will be processed as per Section [3] Anonymisation methodology page [6].
- 6. If the k-anonymity threshold is not met (either directly or because of inadequate l-diversity in sensitive fields) after processing then those seeking access to the data will be invited to discuss their configuration requests. Guidance will be offered as to which fields might be further aggregated or suppressed.
- 7. Once the k-anonymity and l-diversity criteria have been met then the data can be made available for release.
- 8. An audit trail of the data release will be created containing the following information.
  - Date and time of data processing
  - Unique reference to the source data
  - Code reference of anonymisation package (git commit ID)
  - Code reference of the configuration file for the anonymisation
  - Personal details of the data user
  - Personal details of the data controller (or designated nominee) who is approving the data release

<sup>\*</sup> This is the *mininum* size, but the typical group size would be larger. Now consider two re-identification scenarios: the prosecutor and the journalist. In the former, an intruder seeks to re-identifiy a specific individual. Here the average group size is more relevant. In the latter, an intruder (the journalist) simply wants to show that the anonymisation has failed and they have re-identified an arbitrary individual. Here the minimum group size is more important.

# (a) Example data release form

This is intended to document the steps taken to anonymise the data for release. The justification, and other due diligence steps for approving a release will be part of the paper work generated from the Data request SOP.

| Date and time data processed      | 2016-10-25 1908h   |
|-----------------------------------|--|
| Unique references for source data | UCLH-IDHS/data/NHIC/live/ccdata.XML  |
| Anonymisation code reference      | https://github.com/UCL-HIC/ccanonym/commit/<br>e3b67ea353ccae9de144bf6782b068f32ac530c0  |
| Configuration file code reference | edec77d2a34c0b394ae870eac0aeb542c20c9181   |
| Data user                         | Dr Steve Harris, Critical Care Department<br>University College Hospital London<br>235 Euston Road<br>London<br>NW1 2BU  |
| Data controller                   | Professor Mervyn Singer University College London The Cruciform Building Gower Street Wolfson Institute for Biomedical Research London WC1E 6BT United Kingdom |
| Initial minimum k-anonymity       | 1  |
| Initial k-anonymity median (IQR)  | 15 (5 to 60)   |
| Final minimum k-anonymity         | 5  |
| Final k-anonymity median (IQR)    | 52 (12 to 101)   |

# 6. Additional recommendations

# (a) Abscence of guidance

Fields and data that are not specifically mentioned are assumed to be non-disclosable. This is to prevent the accidental release of sensitive information as the database is updated. In other words, the algorithm for generating a data release will take a 'rule-in' approach whereby a field must be both specified for release, and have been assigned an anonymisation classification (direct identifier, key variable, or sensitive field).

# (b) Audit

Both internal and external audits of the anonymisation processes are planned. We have asked the UCL IDHS team to perform the internal audit, and the team running the MIMIC-III database at the Massachussets Institute of Technology (MIT) in Boston, USA to perform the external audit. They will review both this documentation, and the code based used to perform the anonymisation.

# (c) Re-identification testing

In addition, we will undertake to perform a 'penetration test' whereby a third party is asked to either identify an individual from these data, or to identify some sensitive characteristic of an individual. The test will follow the 'motivated intruder principle' which means that methods that additionally use other publically available data to assist with re-identification (e.g. using newspaper reports of a celebrity's hospital admission to narrow down the data range when trying to identify their health record).

A complication arises where the motivated intruder has prior knowledge that might help them re-identify another individual (or even themselves). The best example of this with these data is where a health care professional might attempt to use their own knowledge of a patient's health care episode to identify further details from these data. In this context, the ICO guidance would consider this behaviour to be prohibited by the professional ethics of the health care intruder, and outside the remit of the 'motivated intruder'.

# (d) Transparency

This SOP should be made publically available so that the processes that we have undertaken can be understood and scrutinised. We also propose to make this a standing agenda item for review with public and patient partners.

# (e) Privacy Impact Assessment

This data release SOP should be seen as part of a wider privacy impact statement (PIA) detailing the privacy risks and proposed solutions that have been considered in preparing CCHIC data for use.

# 7. Appendix

# (a) Code repository for anonymisation process

This is stored on github in a private repository (https://github.com/UCL-HIC/ccanonym). We recomend making this repository public to enable better public scrutiny of the anonymisation steps. Some of this work is a simple wrapper for the R package sdcMicro (http://cran.fhcrc.org/web/packages/sdcMicro/). (5)

# (b) List of fields and anonymisation approach

Patient identiable information are defined according to the NHS code of practice on Confidentiality (1) as:

- patient's name, address, full post code, date of birth;
- pictures, photographs, videos, audio-tapes or other images of patients;
- NHS number and local patient identifiable codes;
- anything else that may be used to identify a patient directly or indirectly. For example, rare diseases, drug treatments or statistical analyses which have very small numbers within a small population may allow individuals to be identified.

With respect to the above, we have classified fields held by the CCHIC project below.

| Anonymisation              | NHICcode          | dataItem  |
|----------------------------|-------------------|---|
| Direct identifier          | NIHR HIC ICU 0001 | PAS number  |
| Direct identifier          | NIHR_HIC_ICU_0002 | Site code (ICNARC CMP number)   |
| Direct identifier          | NIHR_HIC_ICU_0005 | Critical care local identifier / ICNARC admission number              |
| Direct identifier          | NIHR_HIC_ICU_0073 | NHS number  |
|                            |                   |   |
| Direct identifier          | NIHR_HIC_ICU_0100 | Transferring unit admission number                                    |
| Direct identifier          | NIHR_HIC_ICU_0101 | Transferring unit identifier (in)                                     |
| Direct identifier          | NIHR_HIC_ICU_0033 |   |
| Key variable (categorical) |                   | Code of GP  |
| Key variable (categorical) |                   | Postcode  |
| Key variable (categorical) |                   | Sex   |
| Key variable (categorical) | NIHR_HIC_ICU_0058 | Ethnicity   |
| Key variable (continuous)  |                   | Age   |
| Date-time variable         | NIHR_HIC_ICU_0032 | Date of admission to your hospital                                    |
| Date-time variable         | NIHR_HIC_ICU_0034 | Date of last critical care visit prior to this admission to your unit |
| Date-time variable         | NIHR_HIC_ICU_0035 | Date of original admission to/attendance at acute hospital            |
| Date-time variable         | NIHR_HIC_ICU_0036 | Date of original admission to ICU/HDU                                 |
| Date-time variable         | NIHR_HIC_ICU_0037 | Date of ultimate discharge from ICU/HDU                               |
| Date-time variable         | NIHR_HIC_ICU_0042 | Date of death on your unit  |
| Date-time variable         | NIHR_HIC_ICU_0044 | Date of declaration of brain stem death                               |
| Date-time variable         | NIHR_HIC_ICU_0050 | Date fully ready for discharge  |
| Date-time variable         | NIHR_HIC_ICU_0051 | Time fully ready for discharge  |
| Date-time variable         | NIHR_HIC_ICU_0406 | Date of discharge from your hospital                                  |
| Date-time variable         | NIHR_HIC_ICU_0408 | Date of ultimate discharge from your hospital                         |
| Date-time variable         | NIHR_HIC_ICU_0411 | Date & Time of admission to your unit                                 |
| Date-time variable         | NIHR_HIC_ICU_0412 | Date & Time of discharge from your unit                               |
| Key variable (continuous)  | NIHR_HIC_ICU_0017 | Height  |
| Non-identifying            | NIHR_HIC_ICU_0018 | Height (Source)   |
| Key variable (continuous)  | NIHR_HIC_ICU_0019 | Weight  |
| Non-identifying            | NIHR_HIC_ICU_0020 | Weight (Source)   |
| Sensitive                  | NIHR_HIC_ICU_0016 | Biopsy proven cirrhosis   |
| Sensitive                  | NIHR_HIC_ICU_0062 | HIV/AIDS  |
| Sensitive                  | NIHR_HIC_ICU_0075 | Portal hypertension   |
| Key variable (categorical) | NIHR_HIC_ICU_0399 | Primary reason for admission to your unit                             |
| Key variable (categorical) | NIHR_HIC_ICU_0088 | Secondary reasons for admission to your unit                          |

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| Key variable (categorical)      |  | Ultimate primary reason for admission to unit  |
|---------------------------------|--|--|
| Key variable (categorical)      |  | Other condition in past medical history  |
| Non-identifying                 | NIHR_HIC_ICU_0004                      | Treatment function code  |
| Non-identifying                 | NIHR_HIC_ICU_0006                      | CCU bed configuration 02   |
| Non-identifying                 | NIHR_HIC_ICU_0007                      | Level 2 (HDU) days   |
| Non-identifying                 | NIHR_HIC_ICU_0008                      | Level 3 (ICU) days   |
| Non-identifying                 | NIHR_HIC_ICU_0009                      | Organ support maximum  |
| Non-identifying                 | NIHR_HIC_ICU_0010                      | Acute myeloid/lymphocytic leukaemia or myeloma   |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0011<br>NIHR_HIC_ICU_0013 | Admission for pre-surgical preparation  Adult ICU/HDU within your critical care transfer group (in)                        |
| Non-identifying                 | NIHR_HIC_ICU_0014                      | Adult ICU/HDU within your critical care transfer group (iii)  Adult ICU/HDU within your critical care transfer group (out) |
| Non-identifying                 | NIHR_HIC_ICU_0015                      | Antimicrobial use after 48 hours in your unit  |
| Non-identifying                 | NIHR_HIC_ICU_0021                      | Cardiopulmonary resuscitation within 24 hours prior to admission to unit   |
| Non-identifying                 | NIHR_HIC_ICU_0022                      | Basic Cardiovascular support days  |
| Non-identifying                 | NIHR_HIC_ICU_0023                      | Advanced Cardiovascular support days   |
| Non-identifying                 | NIHR_HIC_ICU_0024                      | Chemotherapy (within the last 6months) steroids alone excluded   |
| Non-identifying                 | NIHR_HIC_ICU_0025                      | Chronic myelogenous /lymphocytic leukaemia   |
| Non-identifying                 | NIHR_HIC_ICU_0026                      | Chronic renal replacement therapy  |
| Non-identifying                 | NIHR_HIC_ICU_0027                      | classification of surgery  |
| Non-identifying                 | NIHR_HIC_ICU_0029                      | Congenital immunohumoral or cellular immune deficiency state   |
| Non-identifying                 | NIHR_HIC_ICU_0030                      | Critical care visit post-discharge from your unit  |
| Non-identifying                 | NIHR_HIC_ICU_0031                      | Critical care visit prior to this admission to your unit   |
| Non-identifying                 | NIHR_HIC_ICU_0038                      | Date body removed from your unit   |
| Non-identifying                 | NIHR_HIC_ICU_0039                      | Time body removed from your unit   |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0043<br>NIHR_HIC_ICU_0045 | Time of death on your unit Time of declaration of brain stem death   |
| Non-identifying                 | NIHR_HIC_ICU_0048                      | Date treatment first withdrawn   |
| Non-identifying                 | NIHR_HIC_ICU_0049                      | Time treatment first withdrawn   |
| Non-identifying                 | NIHR_HIC_ICU_0053                      | Delayed admission  |
| Non-identifying                 | NIHR_HIC_ICU_0054                      | Delay  |
| Non-identifying                 | NIHR_HIC_ICU_0055                      | Dependency prior to admission  |
| Non-identifying                 | NIHR_HIC_ICU_0056                      | Dermatological support days  |
| Non-identifying                 | NIHR_HIC_ICU_0057                      | Hospital housing location (out)  |
| Non-identifying                 | NIHR_HIC_ICU_0059                      | Gastrointestinal support days  |
| Non-identifying                 | NIHR_HIC_ICU_0060                      | Heaptic encephalopathy   |
| Non-identifying                 | NIHR_HIC_ICU_0063                      | Home ventilation   |
| Non-identifying                 | NIHR_HIC_ICU_0065                      | Hospital housing location (in)   |
| Non-identifying                 | NIHR_HIC_ICU_0066                      | Level of care at discharge from your unit  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0067                      | Liver support days Location (in)   |
| Non-identifying                 | NIHR_HIC_ICU_0068<br>NIHR_HIC_ICU_0069 | Discharge location (location out)  |
| Non-identifying                 | NIHR_HIC_ICU_0070                      | Lymphoma   |
| Non-identifying                 | NIHR_HIC_ICU_0071                      | Metastatic disease   |
| Non-identifying                 | NIHR_HIC_ICU_0072                      | Neurological support days  |
| Non-identifying                 | NIHR_HIC_ICU_0077                      | Prior location (in)  |
| Non-identifying                 | NIHR_HIC_ICU_0080                      | Radiotherapy   |
| Non-identifying                 | NIHR_HIC_ICU_0081                      | Discharge status (Reason for discharge from your unit)   |
| Non-identifying                 | NIHR_HIC_ICU_0082                      | Referred for solid organ or tissue donation  |
| Non-identifying                 | NIHR_HIC_ICU_0083                      | Renal support days   |
| Non-identifying                 | NIHR_HIC_ICU_0084                      | Residence post discharge from acute hospital   |
| Non-identifying                 | NIHR_HIC_ICU_0085                      | Residence prior to admission to acute hospital   |
| Non-identifying                 | NIHR_HIC_ICU_0086                      | Basic respiratory support days   |
| Non-identifying                 | NIHR_HIC_ICU_0087                      | Advanced respiratory support days  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0089<br>NIHR_HIC_ICU_0090 | Sector of other hospital (in) Sector of other hospital (out)   |
| Non-identifying                 | NIHR_HIC_ICU_0090                      | Severe respiratory disease   |
| Non-identifying                 | NIHR_HIC_ICU_0092                      | Solid organ or tissue donor  |
| Non-identifying                 | NIHR_HIC_ICU_0095                      | Status at discharge from your hospital   |
| Non-identifying                 | NIHR_HIC_ICU_0097                      | Dead or alive on discharge   |
| Non-identifying                 | NIHR_HIC_ICU_0098                      | Status at ultimate discharge from hospital   |
| Non-identifying                 | NIHR_HIC_ICU_0098                      | Steroid treatment  |
| Non-identifying                 | NIHR_HIC_ICU_0103                      | Treatment withheld/withdrawn   |
| Non-identifying                 | NIHR_HIC_ICU_0104                      | Type of adult ICU/HDU (in)   |
| Non-identifying                 | NIHR_HIC_ICU_0107                      | Very severe cardiovascular disease   |
| Non-identifying                 | NIHR_HIC_ICU_0108                      | Heart rate   |
| Non-identifying                 | NIHR_HIC_ICU_0109                      | Heart rhythm   |
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| Non-identifying                 | NIHR_HIC_ICU_0110                      | Mean arterial blood pressure - Art BPMean arterial blood pressure           |
|---------------------------------|--|---|
| Non-identifying                 | NIHR_HIC_ICU_0111                      | Mean arterial blood pressure - NBPMean arterial blood pressure              |
| Non-identifying                 | NIHR_HIC_ICU_0112                      | Systolic Arterial blood pressure - Art BPSystolic Arterial blood pressure   |
| Non-identifying                 | NIHR_HIC_ICU_0113                      | Systolic Arterial blood pressure - NBPSystolic Arterial blood pressure      |
| Non-identifying                 | NIHR_HIC_ICU_0114                      | Diastolic arterial blood pressure - Art BPDiastolic arterial blood pressure |
| Non-identifying                 | NIHR_HIC_ICU_0115                      | Diastolic arterial blood pressure - NBPDiastolic arterial blood pressure    |
| Non-identifying                 | NIHR_HIC_ICU_0116                      | Central venous pressure   |
| Non-identifying                 | NIHR_HIC_ICU_0117                      | Cardiac output - LiDCO Plus   |
| Non-identifying                 | NIHR_HIC_ICU_0118                      | Cardiac output - LiDCO Rapid  |
| Non-identifying                 | NIHR_HIC_ICU_0119                      | Cardiac output - PICCO  |
| Non-identifying                 | NIHR_HIC_ICU_0120                      | Cardiac output - PA Catheter  |
| Non-identifying                 | NIHR_HIC_ICU_0121                      | Cardiac output - Doppler  |
| Non-identifying                 | NIHR_HIC_ICU_0122                      | Lactate - ABG   |
| Non-identifying                 | NIHR_HIC_ICU_0123                      | Lactate - Lab   |
| Non-identifying                 | NIHR_HIC_ICU_0125                      | Central venous saturation   |
| Non-identifying                 | NIHR_HIC_ICU_0126                      | Airway  |
| Non-identifying                 | NIHR_HIC_ICU_0129                      | SpO2  |
| Non-identifying                 | NIHR_HIC_ICU_0130                      | SaO2 - ABG  |
| Non-identifying                 | NIHR_HIC_ICU_0132                      | PaO2 - ABG  |
| Non-identifying                 | NIHR_HIC_ICU_0134                      | PaCO2 - ABG   |
| Non-identifying                 | NIHR_HIC_ICU_0136                      | pH - ABG / VBG  |
| Non-identifying                 | NIHR_HIC_ICU_0138                      | HCO3 - ABG / VBG  |
| Non-identifying                 | NIHR_HIC_ICU_0141                      | Temperature - Central   |
| Non-identifying                 | NIHR_HIC_ICU_0142                      | Temperature - Non-central   |
| Non-identifying                 | NIHR_HIC_ICU_0143                      | Position  |
| Non-identifying                 | NIHR_HIC_ICU_0144                      | Invasive or non-invasive (ventilation)                                      |
| Non-identifying                 | NIHR_HIC_ICU_0145                      | Total respiratory rate (monitor)  |
| Non-identifying                 | NIHR_HIC_ICU_0146                      | Total respiratory rate (ventilator)   |
| Non-identifying                 | NIHR_HIC_ICU_0147                      | Mandatory Respiratory Rate  |
| Non-identifying                 | NIHR_HIC_ICU_0148                      | Minute volume Peak airway pressure  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0149                      |   |
| Non-identifying                 | NIHR_HIC_ICU_0150<br>NIHR_HIC_ICU_0151 | Inspired fraction of oxygen Positive End Expiratory Pressure                |
| Non-identifying                 | NIHR_HIC_ICU_0152                      | Airway pressure   |
| Non-identifying                 | NIHR_HIC_ICU_0153                      | Frequency (Hz)  |
| Non-identifying                 | NIHR_HIC_ICU_0154                      | Cycle Volume  |
| Non-identifying                 | NIHR_HIC_ICU_0155                      | Base flow   |
| Non-identifying                 | NIHR_HIC_ICU_0156                      | GCS - total   |
| Non-identifying                 | NIHR_HIC_ICU_0157                      | GCS - motor component   |
| Non-identifying                 | NIHR_HIC_ICU_0158                      | GCS - eye component   |
| Non-identifying                 | NIHR_HIC_ICU_0159                      | GCS - verbal component  |
| Non-identifying                 | NIHR_HIC_ICU_0160                      | Sedation score (hourly)   |
| Non-identifying                 | NIHR_HIC_ICU_0161                      | Renal replacement mode  |
| Non-identifying                 | NIHR_HIC_ICU_0162                      | Urine output  |
| Non-identifying                 | NIHR_HIC_ICU_0164                      | Urea  |
| Non-identifying                 | NIHR_HIC_ICU_0166                      | Creatinine  |
| Non-identifying                 | NIHR_HIC_ICU_0168                      | Sodium  |
| Non-identifying                 | NIHR_HIC_ICU_0169                      | Sodium ABG/VBG  |
| Non-identifying                 | NIHR_HIC_ICU_0171                      | Potassium   |
| Non-identifying                 | NIHR_HIC_ICU_0172                      | Potassium ABG/VBG   |
| Non-identifying                 | NIHR HIC ICU 0174                      | Bilirubin   |
| Non-identifying                 | NIHR_HIC_ICU_0175                      | Glucose ABG/VBG   |
| Non-identifying                 | NIHR_HIC_ICU_0176                      | Glucose bedside test  |
| Non-identifying                 | NIHR_HIC_ICU_0178                      | Haemoglobin ABG/VBG   |
| Non-identifying                 | NIHR_HIC_ICU_0179                      | Haemoglobin   |
| Non-identifying                 | NIHR_HIC_ICU_0182                      | White cell count  |
| Non-identifying                 | NIHR_HIC_ICU_0183                      | Neutrophil count  |
| Non-identifying                 | NIHR_HIC_ICU_0184                      | Platelets   |
| Non-identifying                 | NIHR_HIC_ICU_0186                      | Site  |
| Non-identifying                 | NIHR_HIC_ICU_0187                      | Organism  |
| Non-identifying                 | NIHR_HIC_ICU_0188                      | Sensitivity   |
| Non-identifying                 | NIHR_HIC_ICU_0242                      | Fentanyl  |
| Non-identifying                 | NIHR_HIC_ICU_0252                      | Milrinone   |
| Non-identifying                 | NIHR_HIC_ICU_0395                      | CCU bed configuration 03  |
| Non-identifying                 | NIHR_HIC_ICU_0396                      | CCU bed configuration 05  |
| Non-identifying                 | NIHR_HIC_ICU_0397                      | CCU bed configuration 90  |
| Non-identifying                 | NIHR_HIC_ICU_0398                      | Admission type  |
| • =                             |  |   |

| Non-identifying                 | NIHR_HIC_ICU_0400                      | Brain stem death declared                                 |
|---------------------------------|--|---|
| Non-identifying                 | NIHR_HIC_ICU_0405                      | Timeliness of discharge from your unit                    |
| Non-identifying                 | NIHR_HIC_ICU_0407                      | Date of first critical care post-discharge from your unit |
| Non-identifying                 | NIHR_HIC_ICU_0409                      | APACHE II Score   |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0410<br>NIHR_HIC_ICU_0413 | APACHE II Probability Fluid Balance (hourly)              |
| Non-identifying                 | NIHR_HIC_ICU_0414                      | Amikacin  |
| Non-identifying                 | NIHR_HIC_ICU_0415                      | Amoxicillin   |
| Non-identifying                 | NIHR_HIC_ICU_0416                      | Azithromycin  |
| Non-identifying                 | NIHR_HIC_ICU_0417                      | Benzylpenicillin  |
| Non-identifying                 | NIHR_HIC_ICU_0418                      | Cefotaxime  |
| Non-identifying                 | NIHR_HIC_ICU_0419                      | Ceftazidime   |
| Non-identifying                 | NIHR_HIC_ICU_0420                      | Ceftriaxone   |
| Non-identifying                 | NIHR_HIC_ICU_0421                      | Cefuroxime  |
| Non-identifying                 | NIHR_HIC_ICU_0422                      | Chloramphenicol   |
| Non-identifying                 | NIHR_HIC_ICU_0423                      | Ciprofloxacin   |
| Non-identifying                 | NIHR_HIC_ICU_0424                      | Clarithromycin  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0425<br>NIHR_HIC_ICU_0426 | Clindamycin<br>Co-Amoxiclav                               |
| Non-identifying                 | NIHR_HIC_ICU_0427                      | Colistin  |
| Non-identifying                 | NIHR_HIC_ICU_0428                      | Co-Trimoxazole  |
| Non-identifying                 | NIHR_HIC_ICU_0429                      | Demeclocycline HCL  |
| Non-identifying                 | NIHR_HIC_ICU_0430                      | Doxycycline   |
| Non-identifying                 | NIHR_HIC_ICU_0432                      | Ertapenem   |
| Non-identifying                 | NIHR_HIC_ICU_0433                      | Erythromycin  |
| Non-identifying                 | NIHR_HIC_ICU_0434                      | Ethambutal HCL  |
| Non-identifying                 | NIHR_HIC_ICU_0435                      | Flucloxacillin  |
| Non-identifying                 | NIHR_HIC_ICU_0436                      | Fuscidic acid   |
| Non-identifying                 | NIHR_HIC_ICU_0437                      | Gentamicin  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0438                      | Isoniazid<br>Levofloxacin                                 |
| Non-identifying                 | NIHR_HIC_ICU_0439<br>NIHR_HIC_ICU_0440 | Linezolid   |
| Non-identifying                 | NIHR_HIC_ICU_0441                      | Meropenem   |
| Non-identifying                 | NIHR_HIC_ICU_0442                      | Metronidazole   |
| Non-identifying                 | NIHR_HIC_ICU_0443                      | Moxifloxacin  |
| Non-identifying                 | NIHR_HIC_ICU_0444                      | Neomycin  |
| Non-identifying                 | NIHR_HIC_ICU_0445                      | Nitrofurantion  |
| Non-identifying                 | NIHR_HIC_ICU_0446                      | Ofloxacin   |
| Non-identifying                 | NIHR_HIC_ICU_0447                      | Pentamidine   |
| Non-identifying                 | NIHR_HIC_ICU_0448                      | Phenoxymethylpenicillin                                   |
| Non-identifying                 | NIHR_HIC_ICU_0449                      | Piperacillin/Tazobactam Pyrazinamide                      |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0450<br>NIHR_HIC_ICU_0452 | Rifampacin  |
| Non-identifying                 | NIHR_HIC_ICU_0453                      | Rifater   |
| Non-identifying                 | NIHR_HIC_ICU_0454                      | Rifinah   |
| Non-identifying                 | NIHR_HIC_ICU_0456                      | Sodium Fusidate   |
| Non-identifying                 | NIHR_HIC_ICU_0457                      | Teicoplanin   |
| Non-identifying                 | NIHR_HIC_ICU_0458                      | Tigecycline   |
| Non-identifying                 | NIHR_HIC_ICU_0459                      | Tobramycin  |
| Non-identifying                 | NIHR_HIC_ICU_0460                      | Trimethoprim  |
| Non-identifying                 | NIHR_HIC_ICU_0461                      | Vancomycin  |
| Non-identifying                 | NIHR_HIC_ICU_0462                      | Propofol  |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0463<br>NIHR_HIC_ICU_0464 | Midazolam<br>Remifentanil                                 |
| Non-identifying                 | NIHR_HIC_ICU_0465                      | Adrenaline  |
| Non-identifying                 | NIHR_HIC_ICU_0466                      | Dobutamine  |
| Non-identifying                 | NIHR_HIC_ICU_0467                      | Dopamine  |
| Non-identifying                 | NIHR_HIC_ICU_0468                      | Enoximone   |
| Non-identifying                 | NIHR_HIC_ICU_0469                      | Levosimendan  |
| Non-identifying                 | NIHR_HIC_ICU_0470                      | Noradrenaline   |
| Non-identifying                 | NIHR_HIC_ICU_0471                      | Vasopressin   |
| Non-identifying                 | NIHR_HIC_ICU_0549                      | Spontaneous Respiratory Rate                              |
| Non-identifying                 | NIHR_HIC_ICU_0550                      | Tidal volume  |
| Non-identifying                 | NIHR_HIC_ICU_0552                      | Duration of therapy (hours per day)                       |
| Non-identifying Non-identifying | NIHR_HIC_ICU_0553<br>NIHR_HIC_ICU_0554 | Total effluent per day Dialysate                          |
|                                 |  | J. G. J. G.           |

| Non-identifying | NIHR_HIC_ICU_0555 | Replacement fluid during RRT                    |
|-----------------|-------------------|---|
| Non-identifying | NIHR_HIC_ICU_0556 | Type of anticoagulation                         |
| Non-identifying | NIHR_HIC_ICU_0557 | C reactive protein                              |
| Non-identifying | NIHR_HIC_ICU_0558 | Thiopentone / Thiopental                        |
| Non-identifying | NIHR_HIC_ICU_0559 | Clonidine                                       |
| Non-identifying | NIHR_HIC_ICU_0560 | Dexmedetomidine                                 |
| Non-identifying | NIHR_HIC_ICU_0561 | Ketamine  |
| Non-identifying | NIHR_HIC_ICU_0563 | Morphine  |
| Non-identifying | NIHR_HIC_ICU_0564 | Dopexamine                                      |
| Non-identifying | NIHR_HIC_ICU_0565 | Terlipressin                                    |
| Non-identifying | NIHR_HIC_ICU_0568 | Type of adult ICU/HDU (out)                     |
| Non-identifying | NIHR_HIC_ICU_0573 | Destination post discharge within your hospital |
| Non-identifying | NIHR_HIC_ICU_0906 | Esmolol   |
| Non-identifying | NIHR_HIC_ICU_0907 | Metoprolol                                      |
| Non-identifying | NIHR_HIC_ICU_0908 | Dexamethasone                                   |
| Non-identifying | NIHR_HIC_ICU_0909 | Hydrocortisone                                  |
| Non-identifying | NIHR_HIC_ICU_0910 | Methylprednisolone                              |
| Non-identifying | NIHR_HIC_ICU_0911 | Sedation yes/no                                 |
| Non-identifying | NIHR_HIC_ICU_0913 | PaO2/FiO2 ratio                                 |
| Non-identifying | NIHR_HIC_ICU_0915 | Fluid Balance (daily)                           |
| Non-identifying | NIHR_HIC_ICU_0918 | Glucose (laboratory)                            |
| Non-identifying | NIHR_HIC_ICU_0930 | Status at ultimate discharge from ICUHDU        |
| Non-identifying | NIHR_HIC_ICU_0931 | Advanced respiratory support                    |
| Non-identifying | NIHR_HIC_ICU_0932 | Basic respiratory support                       |
| Non-identifying | NIHR_HIC_ICU_0933 | Advanced Cardiovascular support                 |
| Non-identifying | NIHR_HIC_ICU_0934 | Basic Cardiovascular support                    |
| Non-identifying | NIHR_HIC_ICU_0935 | Renal support                                   |
| Non-identifying | NIHR_HIC_ICU_0936 | Neurological support                            |
| Non-identifying | NIHR_HIC_ICU_0937 | Liver support                                   |
| Non-identifying | NIHR_HIC_ICU_0938 | Dermatological support                          |
| Non-identifying | NIHR_HIC_ICU_0939 | Gastrointestinal support                        |
|                 |                   |   |

# (c) Relevant legislation\*

# (i) Data Protection Act 1998

This act makes provision for the regulation of the processing of information relating to individuals, including the obtaining, holding, use or disclosure of such information.

All data subjects have a right of access to their health records, therefore all records should be traceable whilst in your care.

Always bear in mind that the eight Data Protection Act principles require that personal data must:

- · be processed fairly and lawfully
- be obtained or processed for specific lawful purposes
- be adequate, relevant and not excessive
- be accurate and kept up to date
- not be kept for longer than necessary
- be processed in accordance with rights of data subjects
- be kept secure

<sup>\*</sup> The details of the relevant legislation have been adapted from those in the Data Governance Policy prepared for the National Institute of Academic Anaesthesia (2014) which is in turn adapted from the Health Quality Improvement Partnership's (HQIP) report "An Information Governance Guide for Clinical Audit" (2011)

• not be transferred outside the European Economic Area (EEA) unless there is adequate protection.

# (ii) Access to Health Records 1990

This Act has been superseded by the Data Protection Act but still applies to access to the records of the deceased. An Act to establish a right of access to health records by the individuals to whom they relate and other persons; to provide for the correction of inaccurate health records and for the avoidance of certain contractual obligations; and for connected purposes.

#### (iii) Human Rights Act 1998

This act gives further effect to rights and freedoms guaranteed under the European Convention on Human Rights.

The Human Rights Act requires that any invasion of an individual's private life is first subject to a test of necessity and proportionality. It is also underpinned by the Data Protection Act 1998.

#### (iv) Criminal Justice and Immigration Act 2008

The Secretary of State may by order provide for a person who is guilty of an offence under section 55 of the Data Protection Act 1998 (c. 29) (unlawful obtaining etc. of personal data) to be liable. If you use, obtain or disclose information recklessly and in contravention of the Data Proctection Act 1998 you may receive a fine or prison sentence of up to two years if you are successfully prosecuted under this Act.

# (v) The Health Service (Control of Patient Information) Regulations 2002 (SI 1438)

These regulations were made under Section 60 of the Health & Social Care Act 2001 and continue to have effect under Section 251 of the NHS Act 2006. These regulations established class support mechanisms that support the use of information, one of which allows the use of patient information under strict controls, 'for the audit, monitoring and analysing the provision made by the health service for patient care and treatment'.

#### (vi) Common Law Duty of Confidentiality

This is a key issue in matters of sharing or using personal and/or sensitive information. For NHS purposes using personal information can be justified where the recipient needs the information because he or she is or may be concerned with the patient's care or treatment; the use of the information can also be justified for wider purposes such as improving quality of treatment, promoting effective healthcare administration or research. Where information is shared, there is an implied understanding that the information will not be used except where it is strictly needed to help the professional provide the service. Each member of the team, and any person who provides administrative or secretarial support, has an obligation to treat the information as confidential. The obligation of confidence owed by a professional covers not only information provided by the patient, but also information relating to the patient which the professional obtains from others.

# (d) References

- 1. Health DO. Confidentiality: NHS code of practice.; 2003a.
- 2. Graham C. Anonymisation: Managing data protection risk code of practice. Information Commissioner's Office; 2012b.
- 3. Templ M, Meindl B, Kowarik A, Chen S. Introduction to statistical disclosure control (SDC). IHSN Working Paper No 007 2014, Oct 28:1-25.
- 4. Knaus WA, Draper EA, Wagner DP, Zimmerman JE. APACHE II: A severity of disease classification system. Crit Care Med 1985, Oct 0;13(10):818-29.
- 5. Templ M, Kowarik A, Meindl B. Statistical disclosure control for micro-data using the R package sdcmicro. Journal of Statistical Software 2015, Oct 7;67(1):1-36.