



Honest Broker Service Disclosure Control and Publication Policy

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Background

The aim of the Honest Broker Service (HBS) is to enable non-identifiable data to be safely shared to maximise the uses and health service benefits which can be gained from it, including planning, commissioning of services and public health monitoring. The HBS enables access to anonymised, aggregated and in some cases pseudonymised health and social care data to the Department of Health (DoH), Health and Social Care (HSC) organisations and for anonymised data for health and social care related research. HBS anticipates that data generated by its work will be used by others, and that this will be through collaboration with researchers and service staff. To help track the outputs and impact of research carried out using Honest Broker Service data, the HBS contribution must be acknowledged in all publications.

Purpose and scope

This document replaces the previous HBS Disclosure Control Protocol & Policy Agreement. It applies to all data sets provided for research purposes, and all published research outputs created by researchers using data accessed via the Honest Broker Service. It addresses all research outputs which have already been generated and are intended for publication or other form of dissemination.

Disclosure Control

Certain disclosure control measures will be applied to all output information released to HBS users by the Honest Broker Advice Service (HBAS). This is to ensure that no individual can be identified within them. If data is to be released in tabular form, then the HBAS will ensure that any information that could potentially identify a service user is aggregated, suppressed or removed as appropriate.

The pre-release disclosure control protocol includes:

- The Health and Care Number (HCN) is a unique pseudonymised variable representing each service user registered for healthcare services in Northern Ireland. This variable alone allows linkage between all health care related datasets without need to refer to other common identifiers such as name of service user; however lookups exist between HCN and other personal details on multiple systems so HCN is considered a personal identifiable data field.
- To ensure the anonymisation of data the HCN is double encrypted and recoded into an Anonymised Linkage Field referred to as the Study_ID. Each Study_ID represents an individual allowing linkage of individual records on the research datasets however these will be meaningless and cannot be reverse engineered to identify an individual as the lookups between HCN and Study_ID are deleted during the recoding process.
- All other common identifiers are removed from the data. In addition to this further measures are in place to prevent re-identification; examples of which include controls around date of birth (which is always replaced by pre-calculated age, age band or year/month of birth), controls around geographic identifiers, masking of practitioner codes, aggregation/suppression of certain variables and limiting number of variables provided.
- When releasing tabular data the HBAS will ensure that cell counts are not so small as to risk breaching patient confidentiality through the direct or indirect identification of an individual. If associated data allows the cell to be split then the HBAS will aggregate the data to the highest level consistent with the need to explain the results.

Further restrictions will also be placed on the release of any variable considered to be sensitive. These include variables relating to small numbers of people in Northern Ireland (i.e. local-area geographic identifiers, certain drug items etc.). It should be noted that selection criteria used in extracting data such as sex and age may be disclosive when used in conjunction with other variables.

If the HBAS considers that data may be disclosive they will bring this to the attention of the Honest Broker Governance Board who will decide on the procedure to follow. In most cases this will require further aggregation of the data.

The disclosure control protocol for researchers submitting outputs for clearance includes:

- Individual service user information will not be released.
- The Threshold Rule for all clearances is 10 so no individual cell within a tabular output should contain less than 10 unweighted units.
- Zeroes should not be submitted for release unless they are zeroes by definition (for example, the number of males who gave birth).
- Maximum and minimum values should not be submitted for release.
- The Threshold Rule also applies to outputs from statistical modelling, for example, regression analysis. Any output based on less than 10 observations should not be submitted for clearance. **To allow the HBAS to check these outputs the input data for the model must be provided alongside the output.**

Researchers' obligations

The Honest Broker Service is publicly funded to facilitate research and therefore has a responsibility to the health service as well as the Northern Ireland public to show value in this investment. Feedback is an essential part of the service both for our funders and stakeholders and also in building up the public trust in the use and value of health data for research. So it is paramount for the findings of all HBS research projects to be accessible within the public domain.

To enable this all project teams must submit a lay summary of their project including key findings to the HBAS at the conclusion of their project. This will be published on the HBS website.

As a condition for accessing data via the Honest Broker Service researchers must agree to acknowledge the HBS in any presentations, reports or other publications using the following wording:

“The authors would like to acknowledge the help provided by the staff of the Honest Broker Service (HBS) within the Business Services Organisation Northern Ireland (BSO). The HBS is funded by the BSO and the Department of Health (DoH). The authors alone are responsible for the interpretation of the data and any views or opinions presented are solely those of the author and do not necessarily represent those of the BSO.”

The Honest Broker Service logo should also be included in any acknowledgements within presentations, posters etc. The logo is included at the top of this document.

If you need to describe the HBS the following points can be used as guidance:

- The HSC Honest Broker Service is the main Trusted Research Environment for accessing Healthcare Related Service User Data for Analysis in Northern Ireland. The Honest Broker Service provides access to de-identified data via a safe setting for approved health and social care related research.
- The HBS provides de-identified or aggregated data from the Regional Data Warehouse, held within Business Services Organisation (BSO).
- All HBS processes are in line with UK General Data Protection Regulation (UK GDPR), confidentiality requirements and the ICO's Codes of Practice.
- All direct real-world identifiers are removed from the information and the potential identifiability of the remaining information is limited as far as is practical or appropriate. A legally binding contract is signed by all researchers to prevent re-identification of individual personal data.
- HBS is a safe and secure environment in which the data are processed and, in some cases, linked to other data before being provided in an approved format to the research team. Data can only be accessed via the HBS secure research environment (or 'safe haven') which is based in Business Services Organisation (BSO) in Franklin Street, Belfast or remotely via the UK Secure e-Research Platform (SeRP).
- Where more than one data source is required, datasets are linked in the HBS secure environment using the Health and Care Number (HCN) as the unique identifier. This, and any other potentially identifiable service user data, is removed from the dataset before it is provided to the research team in the agreed safe environment.

- All HBS outputs are subject to statistical disclosure control to protect patient confidentiality.

Neither the results displayed in outputs nor discussion concerning them must raise confidentiality or disclosure issues. This also includes any possibility of differencing between tables within an article. There must be a health and social care aspect to all of the research results.

If the project uses COVID-19 Genomics UK (COG-UK) data then this must be referenced in line with their specific requirements i.e. 'The COG-UK Consortium' must be listed as an author if a publication is primarily about viral genomics otherwise they should be noted as the source of the genomics data in the acknowledgements.

If the project accesses the infrastructure and data made available by the Data and Connectivity National Core Study then one of the following statements should be included to acknowledge funding in any papers or research outputs.

For research which commenced between **1st October 2020 – 31st March 2021**:

This research used data assets made available as part of the Data and Connectivity National Core Study, led by Health Data Research UK in partnership with the Office for National Statistics and funded by UK Research and Innovation (grant ref MC_PC_20029).

For research which commenced between **1st April 2021 -30th September 2022**:

This research used data assets made available as part of the Data and Connectivity National Core Study, led by Health Data Research UK in partnership with the Office for National Statistics and funded by UK Research and Innovation (grant ref MC_PC_20058)

Submission

It is a requirement that copies of publications (abstracts, papers and posters etc.) using data from HBS must be sent to HBAS on acceptance for publication. Publications should be submitted to:

honestbrokerservice@hscni.net