

MEMORANDUM OF UNDERSTANDING (MOU) FOR AN HONEST BROKER SERVICE FOR HEALTH & SOCIAL CARE INFORMATION

Agreed and signed off: September 2013

Last updated: April 2018

Review date: May 2018

MEMORANDUM OF UNDERSTANDING (MOU) FOR AN HONEST BROKER SERVICE FOR HEALTH & SOCIAL CARE INFORMATION

1. This Memorandum of Understanding (MOU) is established for the purposes of informing the development of an Honest Broker Service for Health and Social Care (HSC). The Honest Broker service enables the provision of anonymised, aggregated and in some cases pseudonymised data from the Regional Data Warehouse, (held within Business Services Organisation BSO), to the Department of Health (DoH) and HSC organisations (listed below). It also provides a service to researchers carrying out approved health and social care related research (*see section 14*).
2. The MOU should be reviewed and kept up to date by the Honest Broker Advice Service (HBAS) in conjunction with the Honest Broker Governance Board (HBGB).
3. A definitions document is provided at Appendix 6.

4. This MOU has been agreed and signed off by:

- Health and Social Care Board (HSCB)
- Business Services Organisation (BSO)
- Belfast Health and Social Care Trust
- Northern Health and Social Care Trust
- Southern Health and Social Care Trust
- South Eastern Health and Social Care Trust
- Western Health and Social Care Trust
- The Department of Health (DoH)
- Public Health Agency (PHA)
- Northern Ireland Ambulance Service Health and Social Care Trust (NIAS)
- Northern Ireland Blood Transfusion Service (NIBTS)
- NI Guardian Ad Litem Agency (NIGALA)
- NI Medical & Dental Training Agency (NIMDTA)
- Northern Ireland Practice & Education Council for Nursing and Midwifery (NIPEC)
- NI Fire & Rescue Service (NIFRS)
- Health & Social Care Regulation and Quality Improvement Authority (RQIA)
- NI Social Care Council (NISCC)
- Patient and Client Council (PCC)

(*See section 15- MOU Sign Off*).

5. Assumptions

The Honest Broker Service will only provide data in anonymised, aggregated and, where necessary, pseudonymised formats, in line with Data Protection, confidentiality requirements and the ICO's Codes of Practice.

Organisations subject to the MOU should ensure that their Privacy Notices or Fair Processing Notices make service users aware of the uses of their data, including secondary uses¹.

The Honest Broker Service has been developed in line with the ICO's Anonymisation: Managing Data Protection Risk Code of Practice² and Data Sharing Code of Practice³.

6. Scope

The MOU covers the provision of an Honest Broker Service to fulfil 2 purposes:

- 1) The provision of (or access to) anonymised/ pseudonymised data from the Regional Data Warehouse to other organisations within the HSC family, including DoH (see Appendix 3)
- 2) The provision of anonymised data from the Regional Data Warehouse for approved HSC related research (see Appendix 4).

This MOU does not cover the sharing of patient identifiable information.⁴

While this is the initial scope for the service which is to be provided by the Honest Broker, the service should be reviewed following a period of time after its establishment, to assess its value and to consider potential development of the service.

7. Purpose of an Honest Broker Service

Currently the HSC Trusts (Belfast Trust, Northern Trust, Southern Trust, South Eastern Trust and Western Trust) hold information within the Regional Data Warehouse. This information is used by the individual Trusts, but is not shared across Trusts. The Department, the Health and Social Care Board (HSCB) and PHA require access to data for various purposes including planning, commissioning of services, performance management and public health monitoring.

An Honest Broker Service can help to ensure that this data is shared, within the HSC family, including DoH, in anonymised or pseudonymised formats, thus strengthening the protection of health and social care data and patient confidentiality, whilst maximising the uses and health service benefits which can be gained from sharing this information safely.

Previously information was not provided from the Regional Data Warehouse to researchers. The Honest Broker Service enables the safe and secure provision of anonymised data to researchers for approved health and social care related research, which is in the overall interest of public health and the development of health and social care related policy.

¹ See the ICO's Privacy Notices Code of Practice

- <https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/>

² ICO's Anonymisation: Managing Data Protection Risk Code of Practice-

<https://ico.org.uk/media/1061/anonymisation-code.pdf>

³ ICO's Data Sharing Code of Practice - https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf

⁴ The sharing of patient identifiable information must be managed in accordance to the 'Code of Practice on Protecting the Confidentiality of Service User Information' and the 'DHSSPS & HSC Protocol for Sharing Service User Information for Secondary Purposes', which are available from the Department's website <https://www.health-ni.gov.uk/publications/doh-hsc-protocol-sharing-service-user-information-secondary-purposes>

8. Benefits of Providing an Honest Broker Service

The Honest Broker Service provides:

- streamlined, secure processes for data sharing for the HSC and the Department, creating efficiencies and ensuring full benefits of data sharing for the benefit of public health and well being
- Trusts and others who feed into the Regional Data Warehouse with assurances that the data for which they are responsible will only be made available in an anonymised format in a secure environment to accredited⁵ researchers for formally approved purposes
- data to researchers, which could contribute to improved health and social care outcomes and practices and associated benefits for health and social care policy development
- better data security and less data travel
- dedicated research co-ordinators, who are located at BSO offices, to assist researchers with projects and provide advice and support
- statistical disclosure control to protect patient confidentiality.

The Honest Broker Service enables the BSO to maximise data security in the Regional Data Warehouse, while removing the need for excessive procedures across the HSC for access to anonymised/pseudonymised data. Agreement for the Honest Broker Service, via this MOU, should reduce the need for the current number of Data Access Agreements across the HSC, where anonymised and pseudonymised information is required. It provides greater protection of service user information, by increasing the use of anonymised and pseudonymised service user information, whilst supporting the needs of secondary users.

9. Role of BSO & the Department (DoH)

As the Regional Data Warehouse resides within BSO, the Honest Broker Service has been established within BSO, with some resource being provided by the Department for the research support role. In providing the Honest Broker service BSO perform the role of 'data processor', acting on behalf of each of the signatory organisations, (data controllers), who feed data into the Regional Data Warehouse. They carry out the service of taking the data and anonymising or pseudonymising it before providing it to researchers, HSC organisations or the Department.

BSO do not make independent decisions about the further processing of personal data outside of the terms of their engagement under this MOU. If any queries or activity arise which are not included in the instructions under which BSO operate within this MOU, BSO must contact the relevant data controller and seek instructions on how to proceed.

In fulfilling the data processor role, BSO agree to comply with the obligations, equivalent to those imposed on all of the data controllers, by the seventh principle of the Data Protection Act (DPA).

Therefore they must ensure that,

"Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data".

BSO ensure that when processing personal data on behalf of the signatory organisations, all of the security considerations of the seventh principle of the Data Protection Act (DPA) are met.

In providing an Honest Broker service, BSO will:

⁵ Researchers will be considered as accredited once they have completed the Honest Broker Safe Researcher Training.

- Implement systems and processes for ensuring that the data outputs are appropriately anonymised.
- Where pseudonymisation techniques are used, BSO as Honest Broker must ensure appropriate disclosure control to protect the identity of individuals and must ensure that any codes or algorithms used to pseudonymise data are appropriately security controlled and accessed only by the authorised staff. Routine and regular audits should be carried out to ensure this is the case.
- Ensure that data is held and used in a secure manner and is only accessible by authorised personnel.
- Ensure that appropriate vetting and training methods are implemented for staff.
- Ensure that all requests for access to health and social care data are documented and monitored appropriately.
- Remind recipients of their obligations under the law before they access the data.

In supporting the Honest Broker Service, the Department may provide information/statistical expertise to:

- Ensure that recipients of data have the necessary support to handle and understand the data.

10. How the Honest Broker Service Works

BSO, which currently hosts the Regional Data Warehouse on behalf of the Trusts (and the Board), provides a service to process requests for health and social care data which are submitted from within the HSC family (which includes all HSC organisations and the Department). Separately from this they also manage a process for dealing with requests for anonymised data from researchers.

In the majority of cases the outputs provided by BSO are anonymised health and social care data from the Regional Data Warehouse and this will always be the case for research requests.

The Honest Broker Service provides a safe and secure environment in which the service user data can be processed (and in some cases linked to other data), before being provided in an approved format to the requestor.

Appendix 2 provides a diagrammatic overview of how the Honest Broker Service works.

11. Provision of Pseudonymised data

On occasion the BSO are required to provide the Department and HSC organisations with pseudonymised health and social care data where this is justified, (for example where there is a need to track trends, which would require a unique identifier).

The pseudonymised identifier must be unique to each individual patient/service user. The method of applying the pseudonymised identifier is via re-coding techniques which are applied to the current Health and Care Number (HCN).

The unique identifier must:

- Remain consistent throughout the life care of an individual patient.
- Consistently be applied across all systems to enable patients to be tracked across all elements of their care and throughout the lifetime of their care.
- Be meaningless to any person outside of the approved staff within the Honest Broker Service and the original Data Controller. The Data Controller may need to link the unique identifier to the HCN and associated data in order to deal with validation queries from organisations using the unique identifier, such

as the Department and HSCB. This will ensure that identification of patients and service users outside of the Honest Broker Service or beyond the original Data Controller is prevented.

12. Requests for data from within the HSC or by the Department

- The process for 'Internal' requests received from HSC organisations and the Department is mapped at Appendix 3.
- These are submitted and handled through one point of contact within the Honest Broker Service (within BSO).
- Requests are submitted using the HSC/DoH Application for Data form.
- The Honest Broker ensures that all requests are valid requests (i.e. needed for legitimate purposes) and are for anonymised data.
- If a request is made for pseudonymised data the Honest Broker ensures that appropriate justification has been given for the need for a unique identifier; otherwise the data is provided in anonymised format.
- The Honest Broker has the responsibility of gathering the relevant data and anonymising or pseudonymising that data appropriately.
- Checks are made before the data is shared to ensure that it has been appropriately and correctly anonymised or pseudonymised to ensure that no individual may be identified. (An appropriate checking and approvals process has been implemented by BSO).
- The Honest Broker ensures that only authorised and trained staff access the data and that these staff are fully aware and compliant with data protection and confidentiality obligations. Staff are made aware of disciplinary actions which will be taken as a result of a breach of the terms of the Honest Broker Service, data protection, confidentiality and security.

13. HSC & DoH User Responsibilities

As users of the Honest Broker Service, organisations to which this MOU applies will:

- Ensure they request the minimal amount of data required for the purpose.
- Provide adequate justification when pseudonymised data is required.
- Apply appropriate retention and disposal to the information they receive.
- Will not attempt to identify individuals from the data they are provided, either by using the data they already hold within their organisations, or by linking that data to data received as part of separate requests to the Honest Broker Service.

14. Research and Development Uses

One of the objectives of the Honest Broker Service is to facilitate scientifically sound research through the appropriate use of health and social care data. By providing data for these purposes in anonymised format, the rights of individuals will be respected with adequate privacy protection.

Researchers will only have access to anonymised data and be subject to an obligation not to attempt to re-identify individuals; this and other obligations are outlined in a Research Access Agreement and Disclosure Policy Agreement which researchers must sign before gaining access.

- The Honest Broker process for handling research requests is mapped at Appendix 4.

- Completed applications must provide clear evidence of the value of proposed study to health and social care related research and policies.
- Any decisions taken in relation to unsuccessful applications are fully documented.
- The Honest Broker provides an appeals process for unsuccessful applications.
- Before the data is gathered researchers are asked to sign off an Access Agreement which stipulates the terms and conditions of their use of the anonymised data, including sanctions for misuse, to ensure they will use the data only for the purposes intended and outlined in their application. This must be signed by all researchers involved. An Institutional Signatory is also required by a representative for the organisation with ultimate responsibility for research team members.
- The data is gathered by the Honest Broker and anonymised before it is provided to the researcher in a project specific dataset. The dataset is checked and approved before the researcher is given access. A safe setting/ 'safe haven' will be used for provision of the anonymised data.
- A member of staff from the Department's Information Analysis Directorate may on occasion be appointed to act as a research support contact for the researcher. Their role will be to help guide the researcher in navigating, using and understanding the data provided to them and in ensuring the researcher interprets the data accurately before it is published.
- Outputs from these analyses will normally be released once cleared by the research support contact and by an appointed contact within BSO.
- All research outputs will be checked by the research support contact and an appointed contact within BSO before they are released.
- The Honest Broker Governance Board is responsible for overseeing the Research Approvals process. Details of the composition of the HBGB and its roles and responsibilities are provided in the HBGB Terms of Reference at Appendix 5.

15. MOU Sign Off

The MOU has been signed off by the Chief Executives, or equivalent, within each organisation and by the Permanent Secretary of the Department of Health.

In signing the MOU, organisations agree to the establishment of an Honest Broker Service under the terms set out in this MOU. Organisations also agree to abide by the expectations set out for them in relation to their use of the Honest Broker Service and how they handle the data they receive.

The MOU and associated arrangements should be reviewed annually by the Honest Broker Advice Service, in consultation with the organisations included in the MOU.

The MOU Sign Off page is provided at Appendix 1.

This document will be reviewed in March 2018.

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INFORMATION**

SIGN OFF

I (print Name), Chief Executive/ Chief Officer for (print Name of Organisation) agree to the establishment of an Honest Broker Service under the terms of this MOU. In signing this declaration, as accountable officer for my organisation, I agree that my organisation will abide by the terms of the MOU. I agree that my organisation will handle the data it receives from the Honest Broker Service in line with the requirements set out by the MOU. I will ensure that staff within my organisation who use the Honest Broker Service, or data from the Honest Broker Service, are aware of their responsibilities and that they are provided with relevant training and awareness to enable them to comply with the MOU.

As users of the Honest Broker Service, my organisation and staff will:

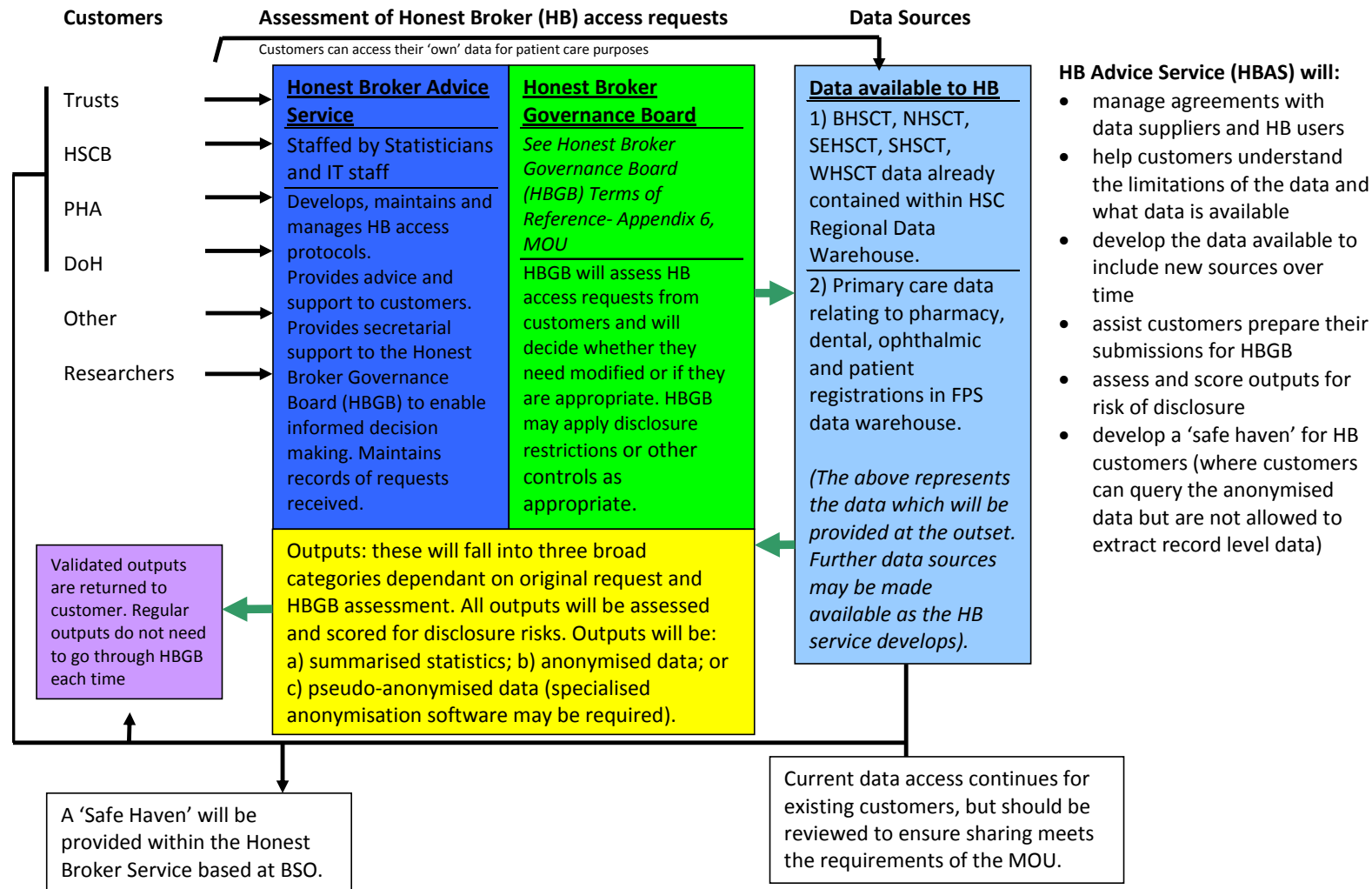
- Ensure they request the minimal amount of data required for the purpose.
- Provide adequate justification when pseudonymised data is required.
- Apply appropriate retention and disposal to the information they receive.
- Will not attempt to identify individuals from the data they are provided, either by using the data they already hold, or by linking that data to data received as part of separate requests to the Honest Broker Service.

I will ensure that staff are made aware that disciplinary action will be taken as a result of any breach of this MOU and that where breaches occur relevant action is taken.

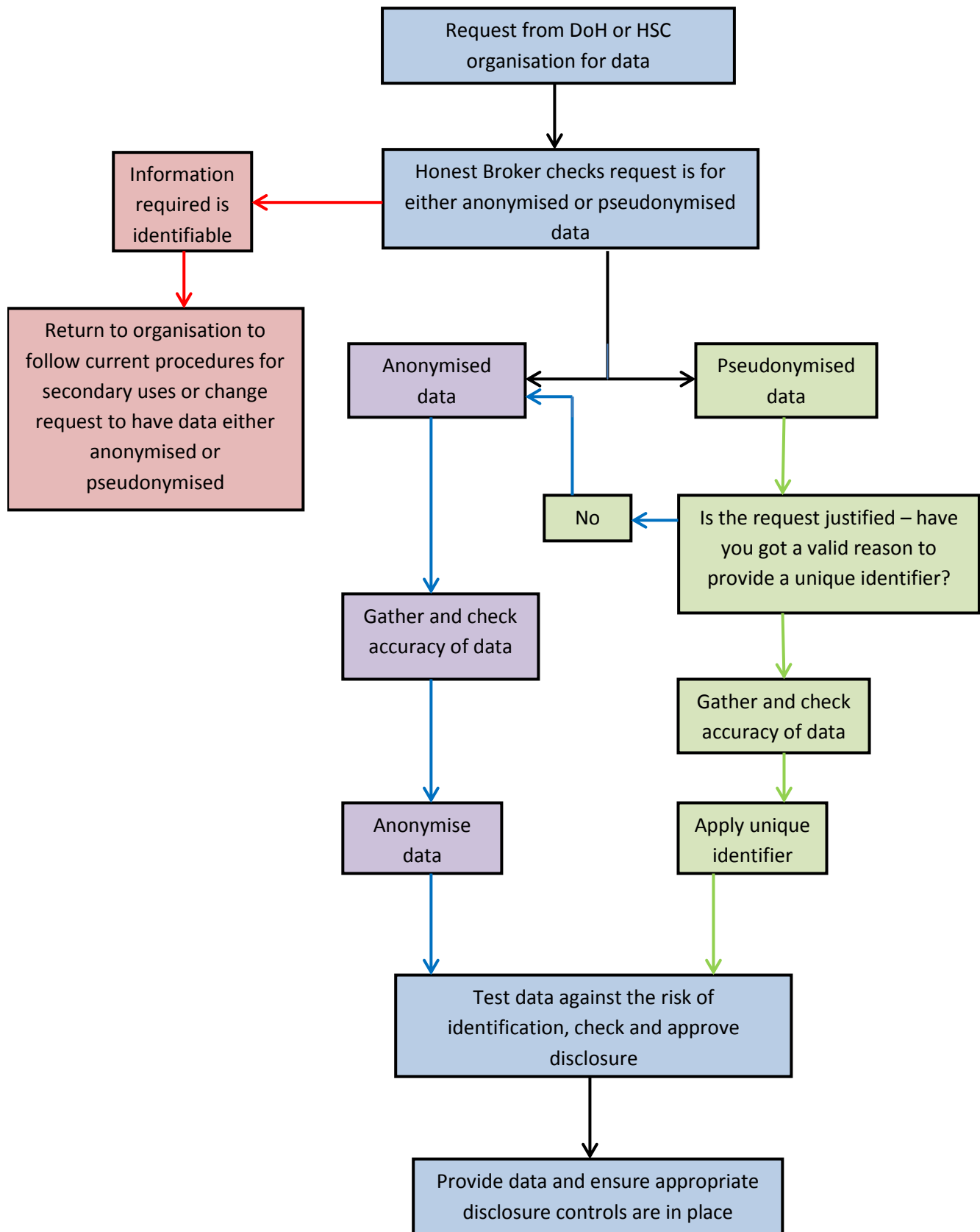
If I have any concerns over the processing of my organisation's data by BSO, I can request BSO to cease processing the data. I can also request that BSO provide information about their processes for anonymising and pseudonymising the data provided by my organisation.

Signature: _____ Date: _____

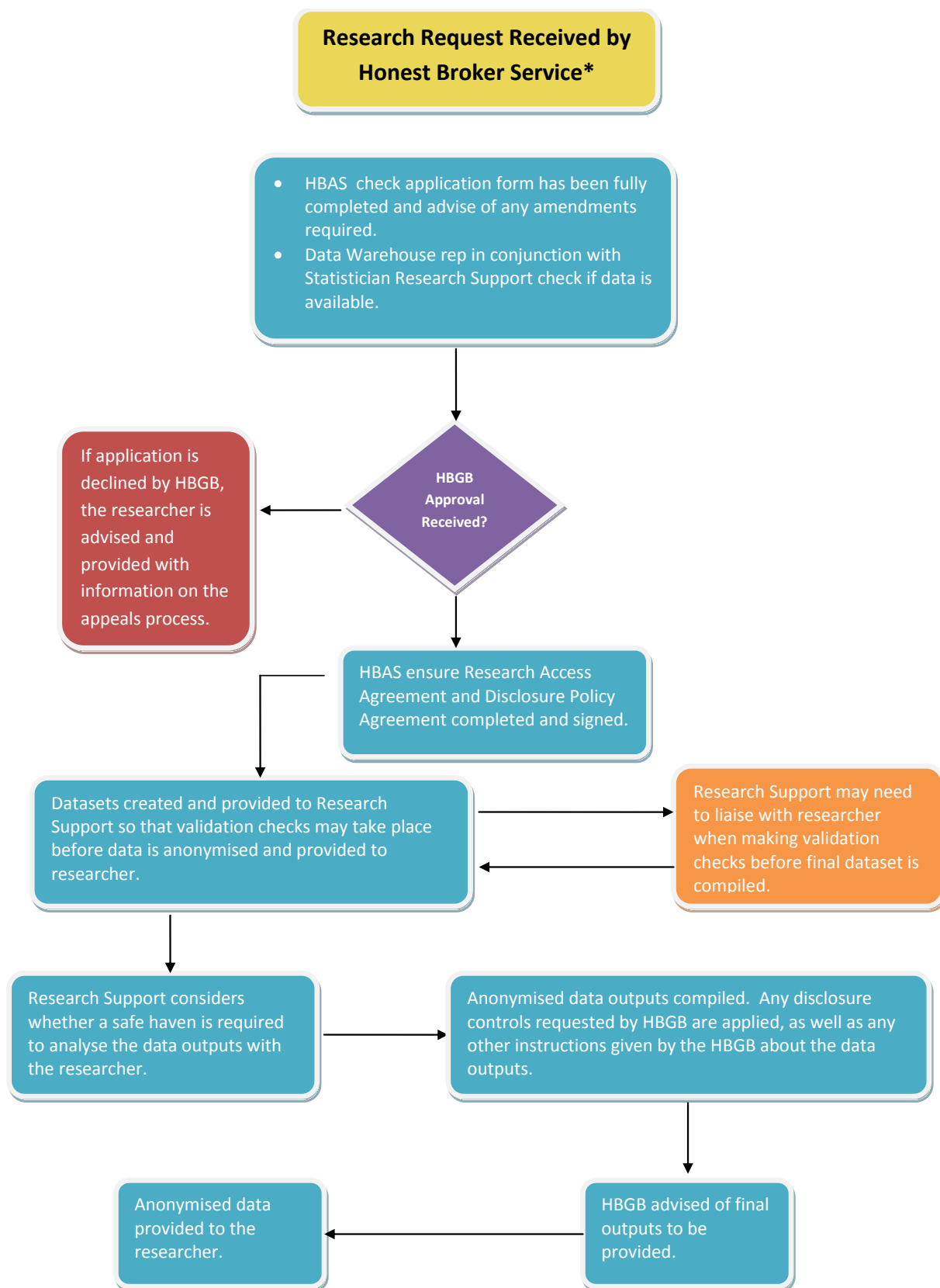
Appendix 2 – How the Honest Broker Service Works



Appendix 3 – Internal HSC/ DoH Request Process



Appendix 4 – Research Request Process



***If the request is a non-research request from within the HSC family they should follow the internal process for making non-research requests to the HBS (see Appendix 3 of the Honest Broker MOU).**

Honest Broker Governance Board - Terms of Reference

Membership

The Honest Broker Governance Board will require representation from the Data Controllers of the data held within the Regional Data Warehouse, as well as representation from the main users of the data from within the HSC family. It is recommended that membership should be as follows:

- A representative from each of the 5 Trusts, 1 of who should be an Information Governance lead within 1 of the Trusts. A Representative from the Business Services Organisation, which will be delivering the Honest Broker Service.
- A Representative from the Department's Information Analysis Directorate (IAD), which will deliver part of the research support service and will be a key user of the service from within the HSC family.
- A Representative from the HSC Board, which will be a key user of the service from within the HSC family.
- A Representative from the Public Health Agency, which will represent researchers and others using the service within the HSC family.
- A Representative from the Patient and Client Council, which will represent patients and clients whose data is held within the Regional Data Warehouse.
- A Clinician (whose role shall be to input her/his clinical expertise).
- A Personal Data Guardian Representative. It is recommended that this person should also be the Chair of the HBGB.
- An Operations Research Manager from the Trusts.
- A representative from the Office for Research Ethics Committees Northern Ireland (ORECNI).
- At least one lay representative.

Secretariat:

Honest Broker Advice Service.

Roles & Responsibilities

- Discuss and consider the risk, cost and feasibility of health and social care related research projects which are submitted to the Honest Broker service, for pre-existing data held within the Regional Data Warehouse.
- Approval of data extraction and provision in appropriate format.
- Communicate decisions in relation to the research applications back to the applicants, including conditions of access, disclosure controls, or information about why any application has been declined.
- Provide advice to researchers of any modifications which need to be made to their application.
- Ensure meetings of the HBGB are minuted by the HBAS and that records of all decisions are maintained.
- To be assured that the management of Honest Broker data for a researcher is compliant with best practice.
- To maintain oversight of the working of the Honest broker service (HBS) and review relevant performance metrics.

Appeals

Any appeals by researchers will be referred to the Honest Broker Research Appeals Panel (HBRAP), which will make a final decision.

Meetings

Meetings of the HBGB will be organised by the HBAS when research project applications have been received by the HBAS. When it is not possible to arrange a meeting within a reasonable timeframe – the approvals process will be completed by correspondence. The HBGB should aim to meet at least twice a year.

Quorum of membership

A meeting of the Honest Broker Governance Board cannot take place unless there is present at minimum, the Chair/Deputy Chair, 1 HSC Trust voting member (or her/his nominated Deputy) and 3 other voting members (or their nominated Deputies).

For the purpose of review and approval of a Honest Broker Research Application Submission, a meeting consisting of at least the Chair/Deputy Chair, 1 HSC Trust voting member (or his/her nominated Deputy) and 1 other voting member (or her/his nominated Deputy) must be convened. This meeting may happen physically, by teleconference or by email correspondence.

Modifications to Existing Projects

The HBAS will, on behalf of the HBGB, process Project Modification requests submitted by researchers. This will enable HBAS staff to amend existing project datasets and/or project end dates, where appropriate. The HBGB will be informed of any Project Modification requests.

Reporting and Documentation

The Research Approvals principles used to assess a project will be provided as an annex to the Research Application Form and will be made available to researchers as part of the application process. Documentation of decisions, actions and the minutes of meetings will be provided by the HBAS. Details of all approved projects will be made available on the BSO website.

Appendix 6 – Definitions

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| Anonymisation | The process of rendering data into a form which does not identify individuals. |
| Pseudonymisation | The process of distinguishing Individuals in a dataset by using a unique identifier which does not reveal their 'real world' identity. |
| Data Processor | Any person (other than an employee of the data controller) who processes the data on behalf of the data controller. |
| Data Controller | A person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed. |
| Data Protection Act (DPA) | The main UK legislation which governs the handling and protection of information relating to living people. |
| Personal Data | Data which relate to a living individual who can be identified- (a) From those data, or (b) From those data and other information which is in the possession of, or is likely to come into the possession of, the data controller, and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual. |
| Processing of Data | In relation to information or data, means obtaining, recording or holding the information or data or carrying out any operation or set of operations on the information or data, including— (a) organisation, adaptation or alteration of the information or data, (b) retrieval, consultation or use of the information or data, (c) disclosure of the information or data by transmission, dissemination or otherwise making available, or (d) alignment, combination, blocking, erasure or destruction of the information or data. |
| Re-identification | The process of analysing data or combining it with other data with the result that individuals become identifiable. |